Steven M Brown's SUPPORT Testimony Letter on HB 3412

April 17, 2017

Representative Margaret Doherty, Chair
House Committee on Health Care
Oregon State Legislature
900 Court Street NE
Salem, OR 97301

Dear Representative Doherty, and the Members of the House Committee on Education,

Over 186,000 Oregonians are living with hearing loss. Hearing loss is an "invisible" disability. It is easily overlooked, and underserved. Oregonians with hearing loss are underserved. For years, they have been unable to receive direct communication access and education from state agencies, non-profit organizations, and businesses because those agencies do not provide the necessary cultural and linguistic competency services, nor can existing budgets of governmental programs begin to accommodate those services. Oregonians with hearing loss encounter daily discrimination, oppression, and barriers to employment and recreation. House Bill 3412 will begin to remove those barriers.

House Bill 3412 will provide an opportunity for Oregon Department of Education (ODE) to investigate and make recommendations for the Deaf, Deaf-Blind, and Hard of Hearing children to receive the best quality of K-12 education in Oregon. The task force will provide information, education, and training, and will serve as the state authority on Deaf, Deaf-Blind, and Hard of Hearing children. It will address the entire range of needs of its clients, a range of needs that spans from the birth to the grave. It will begin to provide the functional equivalency for employment, recreation, and life that these citizens deserve.

Thank you for your time to read and consider my request for your **DO PASS** recommendations.

Best regards,

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Community-Based Needs Assessment of Oregon's Deaf and Hard of Hearing Communities:
Final Report

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Western Oregon University
Regional Resource Center on Deafness

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Every one of you has helped to move mountains.

Executive Summary

Senate Bill 449 was introduced at the 78th Oregon Legislative Assembly during the 2015 Regular Session for the purpose of creating a Commission for Deaf, Deaf-Blind, and Hard of Hearing Services in the Department of Human Services (DHS). This Office would provide a centralized location for members of the public as well as state agencies to obtain assistance to ensure access for individuals who are Deaf, Deaf-Blind, and Hard of Hearing. The Ways and Means committee concluded from the revised SB 449a that a community needs assessment was needed to identify the social, health, and educational disparities experienced by the Deaf and Hard of Hearing Communities, and $200,000 in General Funds was granted to the Department of Human Services to support this effort. Western Oregon University's (WOU) Regional Resource Center on Deafness (RRCD) was awarded the contract as of May 1, 2016; with the final report due eight months later on December 30, 2016. The contract required the use of surveys, focus groups, and key informant interviews to collect data in nine domains across the state in a culturally appropriate and fully accessible manner. The purpose of this project was to identify for DHS and the Legislature the barriers that make it difficult for members of the Deaf, Deaf-Blind and Hard of Hearing communities to successfully engage in social, educational, and health services and to make recommendations for closing any gaps.

This study's findings support the recommendation that a Commission, such as the one proposed in Senate Bill 449a be funded. Options include expanding the current Oregon Deaf and Hard of Hearing Services providing interpreter referrals into a program with administrator and employees. Another option might be to fund a Commission through the Governor's Office using funding from the taxes on telephone subscribers as other states have done. Either way, the entity could begin the process of addressing the needs of the diverse populations of Oregonians with hearing loss.

The ability to communicate, to understand and to be understood, is the cornerstone of all areas of human development. It may look different from person to person, but without it, everything else is lost. Unfortunately, the general public's perception of hearing loss is not well informed given that untreated hearing loss has recently been discovered to be a public health crisis. The public's view of hearing loss is that it is something that one must just deal with, or is not that big of a deal (people should just try harder), or that hearing aids and cochlear implants will completely alleviate the problem prevents implementation of best practices. It is ill-advised to accept this status quo as a) at some point much of the general public will also become individuals with hearing loss, and b) the general public holds positions as gatekeepers to services, creating a number of access problems for Deaf and hard of hearing individuals. Untreated hearing loss has recently been deemed to be a public health crisis by the National Academy of Sciences (2016). The following is a summary of the findings from surveys, key informant interviews, and focus groups that lead us to this conclusion:

1. The needs of individuals who are Deaf, hard of hearing, deaf-blind, or who have additional disabilities are met in very different ways. The general public and service providers alike often do not recognize this, resulting in a "one size should fit all" mindset. This creates frustration and blame between consumers and service providers. When gatekeepers do not respect the individual's communication needs, discrimination follows.

2. Throughout their lives, literally starting at birth, policies, legislation, enforcement, and gatekeepers (or the lack thereof) impact whether or not Deaf and hard of hearing Oregonians will have the opportunity to participate in their lives to their full potential. Some examples of this include:
    a. **Infant screening:** many children are identified at birth with hearing loss because of this important legislation, yet parents still struggle with decisions about the best path for their child. Many do not feel they are provided the information they need regarding communication options or how those needs may change along the way. Indeed, they often must fight to get their children's communication needs met, no matter what the communication preference is.
    b. **Later detection:** After birth, identifying hearing loss is much more difficult. It often goes undetected for the years of the birth-to-five window of opportunity for maximal language development. Hearing losses are often mistakenly diagnosed as an attention deficit, developmental delay, or even purposeful bad behavior on the part of the child.
    c. **Personal device coverage:** Oregon law requires that if an insurance company will cover a single cochlear implant for a child, it must cover bilateral implantation if so advised. There is no similar requirement for hearing aids, which are extremely costly, often from $5000-$7000 per pair.
    d. **Foster care:** Oregon Child Welfare guidelines detail multiethnic placement, but do not have a priority or policy for placing Deaf or hard of hearing children in signing or otherwise hearing-loss aware families, further stressing the child and creating an additional negative impact on the child's development.
    e. **Educational structure:** The separate structures of Oregon's educational system for Deaf and hard of hearing children means that when a need for change in the child's educational delivery is recognized, it is slow to be implemented and further precious time is lost. Other states, such as Arizona, offer multiple options in a single location so that children move fluidly between programs as the need arises. This eliminates the need for the child to fail in one system before being able to try another, as well as the resulting toll this takes on the child and the family.
    f. **Options presented:** The Oregon School for the Deaf is often presented to parents as a 'last resort,' ignoring the value of Deaf and hard of hearing role models and peers for developing children, and the expertise of the personnel there.
    g. **Preschool policies:** Legislation prevents the Oregon School for the Deaf from holding preschool there (they are only able to serve ages 5 and older). Besides providing needed educational intervention, this is a missed opportunity for children and parents to interact with other families living with similar experiences.
    h. **Impact of Language delays:** Language delays caused by these issues will follow the individual throughout their lives, reducing educational opportunities, their ability to get and keep jobs, and their earning potentials.
3. Acquired hearing loss, in older children and adults, presents its own challenges. Many people begin their lives with 'normal' hearing, and at some point either gradually or suddenly lose it. It is commonly believed that hearing loss is simply something people

must accept, that there is nothing that can be done for it. They withdraw from friends, family, and other social stimulation that is vital to quality of life and maintaining mental health. For others, it is not acceptance but a fact of life as they cannot afford hearing aids and other technology that could help them stay involved and be thriving members of society. That many people with hearing loss, even though they have seen medical professionals about it, are unaware of the array of assistive listening, telecommunication, and alerting devices that keep them active in their lives is unconscionable. Identifying this population in order to inform them of the options available, such as the Public UC's Telecommunications Device Access Program and OVRS services can help them maintain autonomy and quality of life.

4. Deaf and hard of hearing individuals with other disabilities, such as vision loss, cerebral palsy, or other physical or health issues (i.e., DeafPlus) challenge systems that are set up for consumers without hearing loss. Whether it is in a child or an adult service system, most people do not have the training required to facilitate communication with these individuals. Besides a (hearing) interpreter, an additional certified Deaf interpreter may be required. Service providers need to understand basic orientation and mobility issues, have insight into what the individual does and does not have access to through his or her senses and how to accommodate this, and maintain respect for personal choice. While most people do not have these skills, support services providers (SSPs) provide this function as needed for individuals with hearing and vision loss or those who have additional disabilities. They interpret, provide environmental and communication information through touch, and help the individual stay connected and fully functioning in their environment. In addition, they provide basic services like shopping assistance and transportation. The state of Oregon must find a way to fund SSP services for these individuals as this is a population that is least able to purchase this service for themselves.
5. Access to mental health services practitioners who understand the cultural and communication issues involved for all aspects of the Deaf and Hard of Hearing Communities, and who can communicate directly with those consumers, is at a crisis level. Whether it is for crisis counseling, everyday issues, or a psychiatric disability, Oregon does not have the capacity to serve its Deaf and hard of hearing citizens who need these services.
6. Many Deaf and hard of hearing individuals in Oregon who have lived with hearing loss for majority of their lives earn less in wages or are unemployed. Financial barriers to purchasing necessary equipment such as fire alarms with flashing lights is a significant safety issue. High-speed internet or cell phones are critical to reach 9-1-1 emergency services. The state of Oregon must find a way to fund safety related equipment and telecommunication options for individuals with financial barriers.

American Sign Language, interpreters, an array of assistive technology, personal devices such as hearing aids and cochlear implants, captioners and support service providers are key to access for members of the Deaf, hard of hearing, deaf-blind, and DeafPlus communities. As the above list of issues reveals, the challenges these individuals present to service providers who are not familiar with their communication needs or culture are as complex as the solutions are empowering.

Background of Needs Assessment

Senate Bill 449 was introduced at the 78th Oregon Legislative Assembly during the 2015 Regular Session, led by the Oregon Association of the Deaf. It was sponsored by Senator Laurie Monnes Anderson and Representative David Gomberg (Chief Sponsors), and Senators Brian Boquist and Elizabeth Steiner Hayward; and Representatives Lew Frederick and Barbara Smith Warner (Regular Sponsors).

The bill would create an Office of Deaf, Deaf-Blind, and Hard of Hearing Services in the Department of Human Services (DHS). The purpose of this Office would be to provide a centralized location for members of the public and state agencies to obtain assistance to ensure access for individuals who are Deaf, Deaf-Blind, DeafPlus, Hard of Hearing, and persons with hearing loss. After some language changes, the Senate subcommittee hearing passed Senate Bill 449a, but it was held in the Ways and Means committee. The Ways and Means committee concluded that a community needs assessment was needed to identify the social, health, and educational disparities experienced by the Deaf and Hard of Hearing Communities. The Legislature granted $200,000 in General Funds to the DHS Aging and People with Disabilities Advocacy and Development Office to support a project to collect data via a statewide Community-based Needs Assessment (CNA).

DHS published the Request for Proposals (RFP) in January 2016. The RFP specified that the CNA data would be gathered via surveys, focus groups, and interviews with Oregon’s Deaf and Hard of Hearing Communities, and that innovative, solutions-based responses were requested. Proposals were due Feb 22. Western Oregon University’s (WOU) Regional Resource Center on Deafness (RRCD) submitted a proposal and later progressed to Round 2, held in March. RRCD’s proposal was funded as of May 1, 2016; with the final report due eight months later on December 30, 2016. Funding for the project ends April 30, 2017. The total amount of the contract was $199,993.

Study Requirements

The RFP included requirements related to research procedures and data to be collected. This section reviews those requirements briefly.

Methods of Collecting and Reviewing Data

Definition of Population: The RFP section 2.2.2.5 defines the term Deaf Community as “the entire diverse Deaf population, including people who are culturally D/deaf, DeafBlind, Deaf Plus, Hard of Hearing, Late-deafened, hearing aid or cochlear implant users, and those experiencing hearing loss”. However, this is not how the term is used in the field of Deaf Studies; rather, the term ‘Deaf Community’ refers only to those individuals who identify as culturally Deaf. This report then uses the term ‘Deaf and Hard of Hearing Communities’ in recognition of the distinct needs, preferences, and perspectives of these groups, and uses procedures to ensure that the voices of all groups are equally represented.

Survey or Questionnaire: The RFP requires the use of surveys or questionnaires to collect information from the diverse community across the state. It does not specify the medium (e.g., paper, on-line).

Focus Groups: The RFP required that the contract recipient conduct a number of focus group meetings to ensure data are collected from across the state from constituents of the Deaf and Hard of Hearing Communities. The contract recipient was to "make every effort to identify individuals from specific parts of the Deaf Community who may be disenfranchised and to reach these low incidence populations to include their voice in the service needs."

Key Informant Interviews**:** The goal of these interviews is to determine the challenges public entities face and their satisfaction with the services the entities have been able to provide. Key informant interviews complement the focus groups. Specifically key informant interviews will be conducted with 1) members of the Deaf and Hard of Hearing Communities who are not well represented in the focus groups, and 2) state, county, city, and other personnel involved in the following service domains: Employment, health, mental health, alcohol and drug services, education, housing, transportation, police, fire, courts/legal, and other state, county, or city services.

Community Advisory Board: The RFP requires the contract recipient to develop and work with a Community Advisory Board (CAB), made up of diverse representatives of the Deaf and Hard of Hearing Communities to inform qualitative data analysis; to assist in interpretation and evaluation of data; and to review the processes to ensure the Deaf and Hard of Hearing Communities are being well sampled. The cost for providing accommodations is included in the budget proposal.

Domains: Nine domains or settings are identified in the RFP. For the purposes of this report, these domains are grouped by: 1) Education, 2) Employment, 3) Socioeconomic identifiers (i.e., Household Income, Safe Housing, Transportation), 4) Access to services (i.e., State, County, City Services; Emergency Responders; the Legal System), and 5) Quality of Life (i.e., health and mental health services, abuse, alcohol and drug treatment).

Cultural Competence: Finally, the RFP required that the recipient of this contract must exhibit cultural competence in the way the data are collected and reported. As it relates to hearing loss, cultural competence begins with understanding the different contingents included in the RFP definition. People who identify as Deaf, deaf, or hard of hearing do so because they hold different perspectives about hearing loss and communication preferences. The term Deaf-blind includes individuals who are totally deaf and blind, as well as individuals who are hard of hearing and experience vision loss, and every combination in between. They, too, vary in their perspectives and communication preferences, and may use spoken English, amplification (or cochlear implants), ASL, Braille, or large print. Support service providers (SSPs) are vital for many people who experience hearing loss and vision loss or additional disabilities to maintain their independence and autonomy, yet the only service provider most people are aware of is 'interpreter.'

Researchers without in-depth knowledge of the Deaf and Hard of Hearing Communities likely do not even realize the misinformation they function under. This leads to people who are hard of hearing being offered interpreters as an accommodation, culturally Deaf individuals being thought of as less intelligent because they do not use their voices or because their English is imperfect, and questions about barriers created due to one's hearing impairment, a term that riles many in the Deaf and Hard of Hearing Communities. To complicate matters more, many people with hearing loss do not claim an associated identity. They do not see themselves as having a disability (i.e., hearing loss), but rather think of themselves as simply not hearing very well. This makes them a difficult group to reach out to.

Areas of Focus

Demographics: The RFP defined demographics as (a) age, (b) county of residence, (c) race, (d) gender, (e) education level completed, (f) socioeconomic status, g) preferred identification within the Deaf and Hard of Hearing Communities, and h) primary or preferred means of communication. They required that data on demographics represent a valid sample size of the entire Deaf and Hard of Hearing Communities as listed in the Deaf Community definition. It was required that demographic results be categorized by the description listed in the Demographics definition. The on-line survey was used to collect these data.

Communication Access to Public Services: DHS also required information on the current availability and access to communication in public services, using the following: (1) Qualified or certified interpreters; (2) Computer Assisted Real Time systems; and (3) Assistive Communication Devices. Note: A number of emergency responders were listed in this section of the RFP. In this report they are covered in the section on access to public services. Information here was collected by the on-line survey of the Deaf and Hard of Hearing Communities, key informant interviews of the service providers, and focus groups of community members using these services.

Barriers and Strategies: The purpose of this project was to identify for DHS and the Legislature the barriers that make it difficult for the Deaf and Hard of Hearing Communities to successfully engage in social, educational, and health services and to make recommendations for closing any gaps. The nine domains specified were: (a) graduating from high school or obtaining a General Education Diploma (GED); (b) entering and completing college, or other higher education or vocational training; (c) earning a livable competitive wage; (d) obtaining health and mental health services; (e) keeping safe from abuse; (f) acquiring transportation services; (g) obtaining appropriate, affordable and accessible housing; and (h) accessing government services. In addition, information on accessing a variety of emergency responders services is included in this section. Information here was collected by the on-line survey of the Deaf and Hard of Hearing Communities, key informant interviews of the service providers, and focus groups of community members.

Communication Access: DHS also sought to ensure that the contract recipient used the applicable communication access services when conducting any activities to accommodate the different modes of communication used by members of the Deaf and Hard of Hearing Communities, including: (a) English (spoken) and English (written); (b) tactile or close vision signing; (c) signed English; (d) American Sign Language (ASL); (e) Pidgin Signed English (PSE); (f) non-standard or home sign language; (g) Spanish (spoken) and Spanish (written); and (h) other spoken and signed languages.

Methods

Overview

Once funding was awarded, the research team had eight months to complete the project from start to finish. Three survey protocols first had to be developed along with informed consent forms in order to complete the University’s Institutional Review Board (IRB) Protection of Human

Subjects Protocol. The academic year ends in mid-June, and the IRB does not generally meet over the summer. This step had to be completed before the project would be able to move forward.

The three surveys were developed (i.e., the on-line survey for members of the Deaf and Hard of Hearing Communities), and the interview protocols for the focus groups and the key informant interviews). The development of the survey for the Deaf and Hard of Hearing Communities was a lengthy process for this project due to the need for a version in American Sign Language (ASL) and Spanish as well as written English. To reach community members across the state, the community survey was to be conducted on-line. The protocols for the focus groups and the key informant interviews were less involved because they were communicated one-on-one and live.

Simultaneously, CAB members and participants had to be recruited. This meant holding town hall meetings, attending events, and developing public relations materials for advertising. It was important to have the CAB established early to get their assistance in recruiting participants and providing recommendations for key informants. Focus group participants were recruited through an additional questionnaire after completing the on-line community survey. It was programmed so that the information it collected was completely separate from the survey responses.

Human Subjects Protections: During June 2016, Western Oregon University's Institutional Review Board (IRB) reviewed and approved the study protocol prior to data collection. The function of the IRB is to ensure that Dr. Thew Hackett (principal investigator) and all other members of the research team protect the privacy of participants. This includes destroying videotapes after they have been transcribed and redacting identifying information from transcripts.

The principal investigator of this proposal, Dr. Denise Thew Hackett, ensured that key informants understand their rights as research participants. In order to protect the privacy of those participating in the Community Needs Assessment (CNA), facilitators of the focus groups or key informant interviews and anyone involved with coding and analysis of data were required to complete the Human Subject Certificate program through the Collaborative Institutional Training Incentives (CITI) Program prior to any review or data analysis. Both the principal investigator and the co-investigators have completed this training.

Providing Communication Access: On-line surveys were developed in several modalities, including American Sign Language, written English, and written Spanish. In some cases, group administrations were used to allow community members without computers and those who are not familiar with computers an opportunity to complete the survey. This also allowed anyone who needed one-on-one support (e.g., with a Deaf interpreter or other service provider) an opportunity to participate.

Key informant and focus group participants were identified in advance to allow for setting up the appropriate accommodations. By nature, the communication modes within focus groups were somewhat homogenous; but requests for other accommodations were honored. All accommodation costs were built into the budget proposal.

Accommodations served the dual purpose of providing access and transcripts for data review. Interviews were audio-recorded, videotaped, and/or transcribed live. CART was provided for all hard of hearing focus groups. Transcripts from the CART output provided data for the study.

Videos of ASL focus groups and interviews, and tape recordings of spoken interviews were all transcribed. Transcription of the ASL videos required the services of transcribers who knew ASL.

Ensuring Participation from All Groups: The research team's process relied on established networks and CAB members to identify and connect with individuals who were members of the different target populations of this study. Specifically, the recruitment strategy focused on reaching individuals from the diverse Deaf and Hard of Hearing Communities (including parents), providers and agencies providing services to members of the Deaf and Hard of Hearing Communities, first responders, and communication access providers.

Key Data Collection/Data Checking Components

Community Advisory Board (CAB): CAB members were recruited from each population described in section 2.2.2.5 of the RFP, and include representatives who are cochlear implant users, veterans, parents of deaf and hard of hearing children, deaf and hard of hearing transition students, and senior citizens. Leaders were recruited from consumer and advocacy organizations with members of the Deaf and Hard of Hearing Communities, as well as communication service providers (CART, interpreters, ACDs, ALDs), first responders (e.g. police, fire, emergency medical technicians), and personnel from government agencies and other places of public access. Interested CAB members who completed the CITI training also assisted in some aspects of data analysis.

***Online Survey Development*:** The 135-item survey was developed based on the nine domains specified by the RFP. Survey items, response options, and skip patterns were all programmed into an online survey platform. On-line responses were captured using Qualtrics. Next, the ASL models taped two versions of the items, one that is simply an interpretation of the English, and another that provides additional explanation to incorporate many of the linguistic contexts that are critical to understanding for many ASL users. The video clips were then edited to be included in the questionnaire. After this point, it would not have been feasible to make any changes to the written survey as changing the signed version would have required extensive time and effort, and additional IRB approval. Finally, the survey was translated into Spanish text. Thus, users had the option of viewing the questions in English, Spanish, American Sign Language (ASL), and ASL with additional explanation. These processes were conducted in June and July. Several CAB members reviewed the survey and provided feedback. A final revision of the survey was submitted to the IRB for approval before the survey was launched August 1, 2016. It was available until September 15.

Focus Groups: Once someone completed the on-line survey, they were provided an opportunity to volunteer to participate in a focus group. As the person finished the survey, a screen appeared asking if the respondent would like to participate in a focus group. If the person responded yes, then a separate screen (with data kept separate from the survey) asked for their contact information, along with some demographic information to identify which demographic group they would participate in. Dr. Thew Hackett then sorted the responses by city and category, set up dates in the area, and let people know the focus group logistics. She then waited to hear who was available on the dates to attend. A number of possible participants were lost because they were on vacation on the scheduled days in their areas.

A discussion guide, checklist of topics, and expected order was used to direct the discussion. This discussion guide was developed by Dr. Thew Hackett and reviewed by the CAB. The moderator guided conversation gently through each topic until the discussion appeared to become repetitive. It allowed participants to raise important issues and nuances that researchers often do not foresee. In a focus group, relatively homogeneous groups of participants have the opportunity to stimulate, support, and build on each other’s ideas on the topic. Participants discuss the topic in their own framework and terms. As they become more sensitized to the topic and to each other, participants fuel each other to take the discussion beyond the rhetorical or habitual.

Key Informant Interviews: Simultaneous to the focus groups, key informant interviews were conducted by phone with service providers. These service providers included access providers, state agencies, and first responders. All interviews were recorded and transcribed. A Deaf team member conducted many of the key informant interviews over the phone with an interpreter. The interpreter and the speaker were audiotaped for transcription for later review.

Most focus groups included CART service for hard of hearing individuals, and transcripts from these were used for data analysis. Focus groups for American Sign Language (ASL) users were videotaped and transcribed by a company employing individuals who use ASL.

Recruitment: The Oregon Association of the Deaf held several town hall meetings in Eugene, Medford, and Bend in late spring and early summer, and invited Dr. Thew Hackett to participate to explain the project. At least 15 individuals attended each of these town hall meetings. During one meeting in Bend, an individual who is an Accessibility Manager attended and provided valuable contact information for key informants in the Bend and Central Oregon region. Drs. Thew Hackett and Davis presented at the Salem Chapter of the Hearing Loss Association-Oregon meeting held at Capital Manor Retirement Center June 29. Approximately 60 people were in attendance. Plans were made with Capital Manor to hold a Community Survey Event there to assist individuals to complete the survey. Capital Manor has approximately 450 residents with some degree of hearing loss.

As the development of the on-line survey neared completion, activities around ensuring we recruited respondents from all of the demographics ramped up. Individuals, organizations, and news outlets were solicited at both the Information Meeting for the CNA and from the CAB members. Drs. Thew Hackett and Davis reviewed the list for additions. A Graduate Assistant looked up contact information for any that were missing this information. A press release was developed by WOU Public Relations to ensure the information was available to statewide news outlets. At the same time, a website posting updates of the process and announcements was created. The press release and the email announcement included information on how to participate in the survey and the need for focus group and key informant interview participation. We received two requests for radio interviews (one from Lebanon, and one from Coos Bay), which were completed, and are aware of the story being published in several papers. The Oregon Association of the Deaf, the Hearing Loss Association of Oregon, and the Oregon Deaf-Blind Services Task Force assisted the project in sharing announcements through their listservs. Information was also shared through the listservs for the Oregon Association on Higher Education and Disability, public school regional programs, the Oregon Public Utilities Commission Telecommunications for the Deaf Access Program (TDAP) mailing list (which includes over 5000 emails statewide) and numerous others. These organizations also published articles in their newsletters. The announcements were shared extensively through social media. Finally, as word spread, we reached out to school programs to ensure that we included parents of children with hearing loss. The Early Hearing Detection and Intervention (EHDI) program was instrumental in assisting us in recruiting for these groups.

Results

Community Advisory Board

An informational meeting was held in Salem on May 6, 2016. Because of time constraints and the need to have the meeting as quickly as possible, notice was disseminated by email and social media through organizations, including but not limited to the Hearing Loss Association-Oregon, Oregon Association of the Deaf, PUC Telecommunications Device Access Program recipients, Oregon Deaf-Blind Services Task Force, Oregon Association on Higher Education and Disability, Oregon School for the Deaf, and Tucker-Maxon Oral School. Even with the short notice, the meeting was attended by 40 individuals representing the diversity of the Deaf, hard of hearing, and hearing loss communities in Oregon. This meeting provided an overview of the process that brought the CNA to fruition, a description of the planned research project, and information about the CAB and the application process. American Sign Language (ASL) interpreters, certified Deaf interpreters (CDI), computer assisted real-time translation (CART), and assistive listening equipment were provided. The individuals attending represented parents of Deaf and hard of hearing children; teachers of the Deaf; Deaf and hard of hearing individuals, including cochlear implant users; individuals who are DeafBlind and deaf-blind; individuals who are deaf and have additional disabilities; senior citizens; and veterans with hearing loss. Attendees came from the Oregon Coast, Bend, Eugene, and Medford, along with the Portland and Salem areas. Information was collected from these individuals regarding their interest in applying to the CAB, and organizations/institutions to include in our outreach efforts.

An application form along with informational materials about the responsibilities of CAB members was developed by Dr. Thew Hackett. Information was disseminated to attendees of the informational meeting, along with the other listservs and social media outlets described above. Twenty applications were received and reviewed for representativeness of the diversity of the community, geographic area, ability to commit to the process, and ability to contribute to the process. Fifteen initial members were selected, although we continued to accept applications. The members included five individuals from the Portland area, five individuals from the Salem area, one from Eugene, two from Medford, and two from Bend. Each member potentially represented multiple target groups, including eight Deaf, six hard of hearing, five cochlear implant users, one veteran, five senior citizens, one DeafBlind, one deaf-blind, one Deaf plus, one late-deafened, one youth, and two parents.

American Sign Language (ASL) interpreters, certified Deaf interpreters (CDI), computer assisted realtime translation (CART), and assistive listening equipment were provided for each CAB meeting. CAB meeting locations rotated to ensure participation from the most distant members.

CAB meetings were held in June, August, and November. CAB members assisted in identifying locales or demographics where numbers were weaker, and provided suggestions for spreading the word. At the November CAB meeting, members reviewed a data set of all items by identity. The process involved review of output, brainstorming of research questions, evaluation of limitations, and identifying areas of interest or concern. Because of the confidentiality of the data, participants were not allowed to take the printouts with them after the meeting.

Focus Groups

The project held a total of 12 focus groups with hard of hearing participants, with a total of 16 participants (1-2 per group); and 15 focus groups with 35 Deaf participants (1-5 per group). Six additional hard of hearing focus groups were held where the scheduled participants did not show up. Focus groups were held in Salem, Eugene, Roseburg, Klamath Falls, Medford, Bend, and Portland. Three of the one-on-one interviews were conducted over the telephone due to geographic distance (Northern Coast and outside of Central Oregon).

The short timelines of this project required that data be collected over the summer with the fall to analyze it and write up the results. Summer is a challenging time to recruit people to participate in something like a focus group. The Deaf community is well organized around this, and indeed sees it as an opportunity to interact with others who are similarly Deaf. Hard of hearing individuals are not typically eager to discuss their hearing losses. This can be seen in the number of people attending the focus groups.

Multiple attempts were made to host focus groups in Eastern Oregon and Coastal Regions, for both face-to face and tele-meeting (e.g. phone, Skype, videophone) with only two participants willing to participate.

We also found that we needed to alter the way we collected data from parents of children with hearing loss. The Early Hearing Detection and Intervention (EHDI) organization contacted us with feedback saying that they were hearing the survey questions were for the most part not a good fit for children’s experiences. Indeed, most items addressed services that would most likely be accessed by adults. As a result, we scheduled five focus groups for the purpose of collecting data from parents and their children.

Key Informant Interviews

A total of 19 key informant interviews were completed, including emergency personnel, legal services for the state of Oregon, disability services providers in higher education, personnel in elder care, and vocational rehabilitation services providers. Key informant interviews were done utilizing the semi-structured interview guides with a focus on systemic issues as a provider or service.

On-line Survey

A total of 1,140 survey responses were collected. During database preparation, 168 responses were deleted as they did not qualify for the survey. An additional 89 responses were deleted as the respondents answered only a few preliminary questions. The final database contains 883 responses. Most respondents took the English version (n=773), another 110 took the on-line ASL version, and an additional 2 took the Spanish version.

Survey support labs were held in multiple locations to assist people who do not have access to computers or who may have disabilities that would impact their ability to respond to the survey.

These labs were held in Salem, Eugene, Roseburg, Klamath Falls, Medford, Bend, and Portland, alongside focus group meetings. There were two to twenty participants in each lab.

There were a few unexpected events during the data collection. First, Google abruptly took the ASL videos down and would not reinstate them. They provided no explanation. One of our editors worked tirelessly to get the videos reformatted and transferred to another system, and the survey was up and running again after a day and a half.

In the process of working with people in completing the surveys during the survey support labs, project staff discovered an interesting interpretation of one of the questions meant to screen out people who were not eligible. The item was: “Do you have a hearing loss?” Senior citizens, sometimes with mild losses, sometimes more severe, often interpreted the question as “Have you lost your hearing?” They reasoned that they still had some hearing, so they would answer “no.” This would immediately exit them from the survey. Although it is impossible to know exactly how many people outside of the labs may have exited the survey because of this interpretation of the question, 99 respondents were exited because they responded ‘no’ to this item. This quirk of interpretation is a perfect example of the challenges of conducting research on a population that often does not embrace a label.

Demographics

Residency

In addition to experiencing hearing loss, in order to participate in the survey, respondents also had to live, work, or use services in Oregon. Nearly all respondents (98.0%; N=865) live in Oregon; 60.2% (N=532) also seek services in Oregon. Seven out of 10 respondents from outside of Oregon (N=18) live in Washington State; one participant was from Idaho, and four live in California.

Not unexpectedly, Marion county and Multnomah county provided larger portions of respondents than other counties (15.5%; N=134 and 19.5%; N=169, respectively).

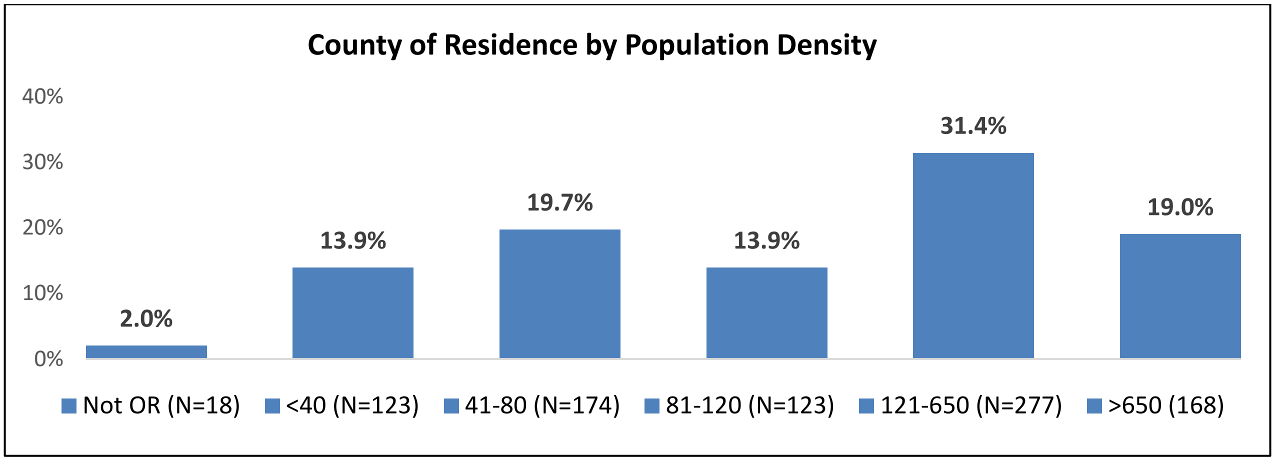
Table 1: County Density and Response Rate for each County

Oregon County Residency (Base: Lives in Oregon) (N=865)	Density	Percent	Count
Multnomah	>650	19.40%	168
Marion	121-650	15.50%	134
Washington	121-650	8.90%	77
Polk	81-120	8.50%	74
Clackamas	121-650	7.60%	66
Lane	41-80	7.40%	64
Jackson	41-80	6.50%	56
Deschutes	<40	6.50%	56
Benton	81-120	4.00%	35
Linn	41-80	2.40%	21
Douglas	<40	2.20%	19
Josephine	41-80	1.80%	16

Yamhill	81-120	1.60%	14
Klamath	<40	1.00%	9
Columbia	41-80	0.90%	8
Lincoln	41-80	0.70%	6
Coos	<40	0.70%	6
Tillamook	<40	0.70%	6
Crook	<40	0.60%	5
Wasco	<40	0.50%	4
Clatsop	41-80	0.30%	3
Hood River	<40	0.30%	3
Lake	<40	0.30%	3
Umatilla	<40	0.30%	3
Baker	<40	0.20%	2
Grant	<40	0.20%	2
Jefferson	<40	0.20%	2
Malheur	<40	0.10%	1
Union	<40	0.10%	1
Wallowa	<40	0.10%	1

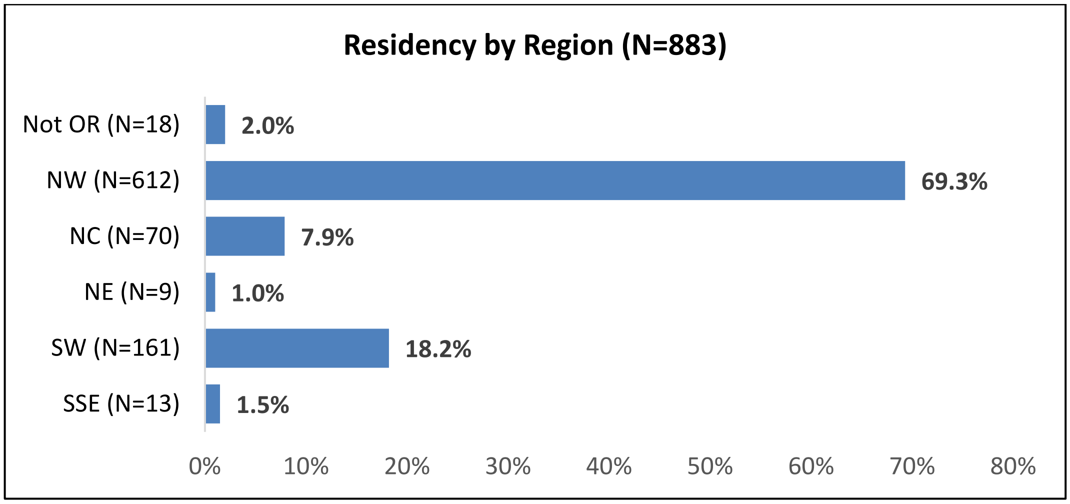
The population density (number of people per square mile) for each county is listed in the above table. Figure 1 indicates the number of residents in each population zone. Nearly one in three respondents (31.4%; N =277) live in counties with a population density of 121-650 residents. It is also notable that almost 50% of the population lives in areas with 120 persons or less per square mile.

Figure 1: County of Residence by Population Density



By far, the largest proportion of respondents live in the northwest region (69.3%; N= 612). The southwest region is represented by 18.2% (N=161) of respondents, mimicking the state's population distribution. A correlation of .92 was found between the number of respondents in each county and the county population. This provides further evidence that the survey sampled the state well.

Figure 2: Residence by Region



Race/Ethnicity

Almost 85% of respondents self-identify as White (83.9%; N=736). This is identical to the ethnic makeup of Oregon (i.e., 83% https://suburbanstats.org/population/how-many-people-live-in-oregon). Because the counts were low in the individual categories of all other racial and ethnic identities, they were combined into 'Other' (16.1%; N=141). The largest portion of this category is Hispanic or Latino/a (N=52). The next largest were American Indian or Alaska Native and Black or African American (N=25 and 22 respectively). The other racial and ethnic identity categories had fewer than 20 respondents each.

While the majority (72.0%; N=636) say neither themselves nor their parents were born outside the U.S., a sizable portion (13.7%; N=120) of respondents were. Likewise, 19.4% (N=168) have at least one parent born outside the U.S., while 6.7% (N=59) say both themselves and their parents were born on foreign soil.

Table 2: Citizenry of Parents and Children

Born Outside the U.S. (N=877)	**Percent**	**Count**
Yes	13.7%	120
One or Both Parents Born Outside of the U.S (N=867)		
Both parents	10.7%	93
One parent	8.7%	75
Respondent/Parents Born Outside the U.S. (N=883)		
Neither	72.0%	636
Parent(s) only	12.3%	109
Respondent only	6.9%	61
Both respondent and parent(s)	6.7%	59
Information incomplete	2.0	18

Gender

Less than half of respondents (40.1%; N=318) are men; a few (0.8%; N=6) identify as transgender, and 1.1% (N=9) prefer not to provide gender information.

Table 3: Gender

Gender (N=793)	Percent	Count
Female	57.8%	458
Male	40.1%	318
Prefer not to answer	1.1%	9
Transgender	0.8%	6
Other	0.3%	2

Age

Almost 34% of respondents (N=298) are age 65 and above. Respondents under 18 years of age account for 8.2% (N=71) of the respondents. While this may seem unbalanced compared to ages of individuals in Oregon, it does follow national trends in hearing loss, with 30% or more over the age of 65 experiencing enough of a loss that it interferes with their lives. Although not shown specifically in Table 4, seven children (.8%) were under the age of 5 at the time of the study. Parent comments were collected in focus groups.

Looking at the age groups in extremely general terms, there were 71 (8.1%) respondents under 18 (non-working), 87 (9.9%) in their early working years (18-34), 173 (19.6%) in their middle working years (35-49), 252 (28.7%) in their later working years (50-64), and 298 (33.9%) of retirement age (65 and older).

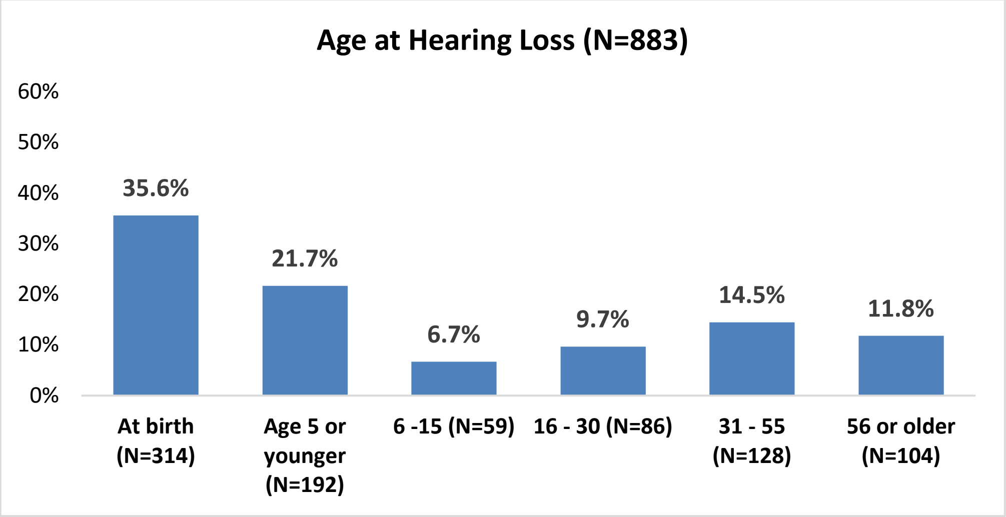
Table 4: Age of Respondents at the Time of the Survey

Age (N=879)	Percent	Count
Under 18	8.1%	71
18-24	4.2%	37
25-29	3.0%	26
30-34	2.7%	24
35-39	7.1%	62
40-44	4.8%	42
45-49	7.6%	67
50-54	8.4%	74
55-59	9.9%	87
60-64	10.4%	91
65-74	16.5%	145
75+	17.4%	153
Net 65+	***33.9%***	***298***

Age at Hearing Loss

Figure 3 indicates over one in three (35.6%; N=314) were born with hearing loss or deafness; and another one in five (21.7%; N=192) lost their hearing after birth but before the age of 5. This is significant because birth to age 5 is considered to be the prime ‘window of opportunity’ for language development. Over one third of respondents (36.8%; N=314) described their hearing loss as progressive. As the figure below indicates, over 90% of individuals in this study have or will experience hearing loss through their prime education and work years.

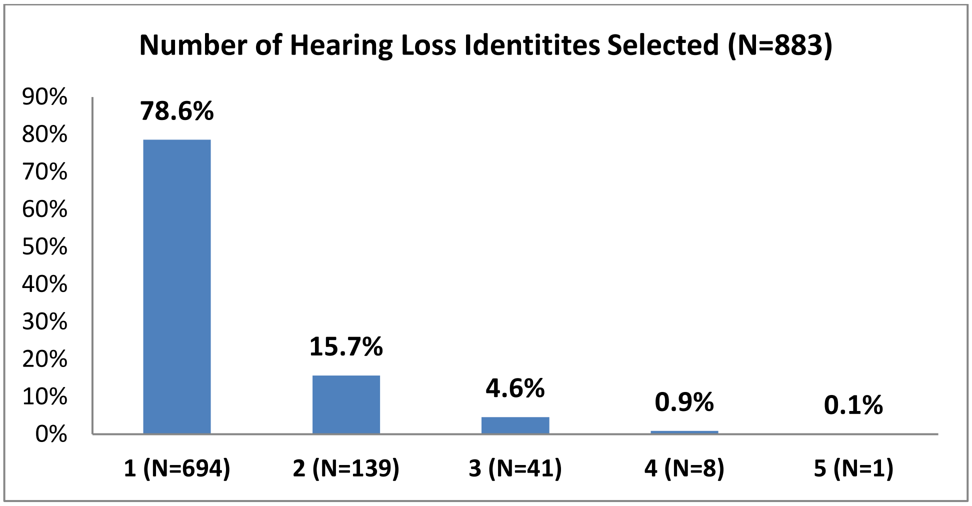
Figure 3: Age at the Time of Hearing Loss



Hearing Loss Identity

Respondents were asked how they identified themselves with regard to their hearing loss. Multiple options were provided; indeed, the RFP listed nine different identifiers. Clearly, the majority of respondents (78.6%; N=694) identify with one label, but 22% selected more than one label.

Figure 4: Identities Selected by Respondents to Describe their Hearing Loss



Nearly 37.9% (N=335) identify as hard of hearing. One in four (25.9%; N=229) identify as hearing impaired, and almost 30% (N=262) identify as culturally Deaf. The long list of options was included in an effort to capture as many ways people identify as possible, and as requested in the definitions in the RFP. Clearly, though, labels and identities do not always align as the definitions would predict. At least three individuals indicated in open-ended responses that they also had severe vision losses, even though they did not identify themselves as Deaf-Blind or DeafBlind. Several people identified as both culturally Deaf and hearing impaired. This is unusual because most people who describe themselves as culturally Deaf shun the label hearing impaired. This speaks to the diversity of beliefs and attitudes in the community and may also indicate that some people are not familiar with all of these labels. (See Appendix A for explanations of the labels in Table 5.)

Table 5: Chosen Identity with Regard to Hearing Loss

Identity with Regard to Hearing Loss (Multiple Response) (N=883)	Percent	Count
Hard of hearing	38%	335
Culturally Deaf	30%	262
Hearing Impaired	26%	229
Deaf (not culturally)	14%	119
Oral Deaf	6%	53
Late-deafened	5%	44
I don’t label myself as somebody with a hearing loss	3%	27
Deaf Plus	3%	23
DeafBlind	2%	15
Deaf-Blind	1%	12
Other	1%	10

Communication Preference

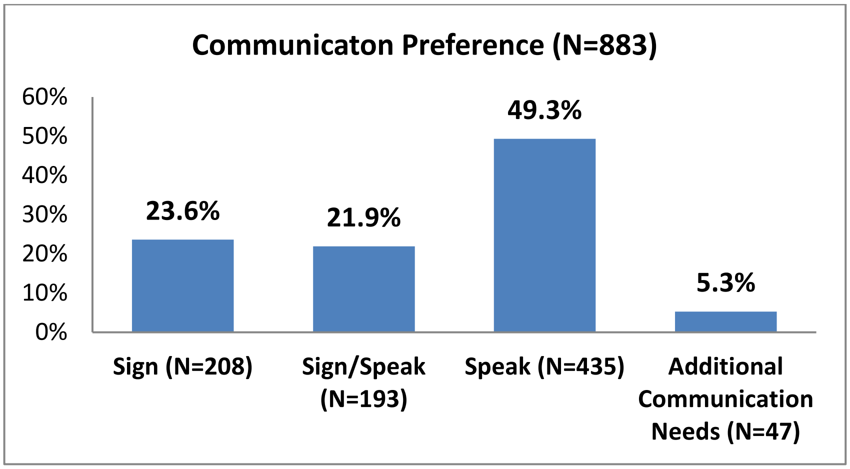
Spoken English (both speech and lip-reading) is the preferred communication mode for two-thirds of respondents (67.7%; N=594), followed by American Sign Language (35.3%; N=310). Both writing (28.4%; N=249) and texting (28.5%; N=250) are used by over one in four respondents. Total communication or Sim-Com (14.4%; N=126) or PSE (Pidgin Signed English) (12.6%; N=126) round off the most widely used communication modes. (See Appendix A for explanations of the labels in Table 6.)

Table 6: Communication Modes used by Respondents

Communication Modes Used (Multiple Response) (N=878)	**Percent**	**Count**
Spoken English (speech and lip-reading)	67.70%	594
American Sign Language (ASL) only	35.30%	310
Texting	28.50%	250
Writing	28.40%	249
Total communication or Sim-Com (using both sign and speech at the same time)	14.40%	126
PSE - Pidgin Signed English (Some ASL signs with English sentence structure)	12.60%	111
Other spoken language (speech and lip-reading)	1.70%	15
Tactile ASL or other tactile sign language	1.30%	12
Other	1.30%	11
Cued Speech	1.10%	10
Braille	0.70%	6

By evaluating response options of those who had requested interpreters and those who provided information about their communication preferences in other items, participants were reassigned to one of four groups: People using mainly spoken language, those mainly using sign language (without speech), those mainly using a combination of sign and speech, and those with additional communication needs (i.e., individuals with hearing and vision loss, and those with additional disabilities). Half of respondents (49.3%; N=435) prefer speech as their communication mode. Over one in five (23.6%; N=208) prefer to sign; another 21.9% (N=193) prefer a combination of sign and speech.

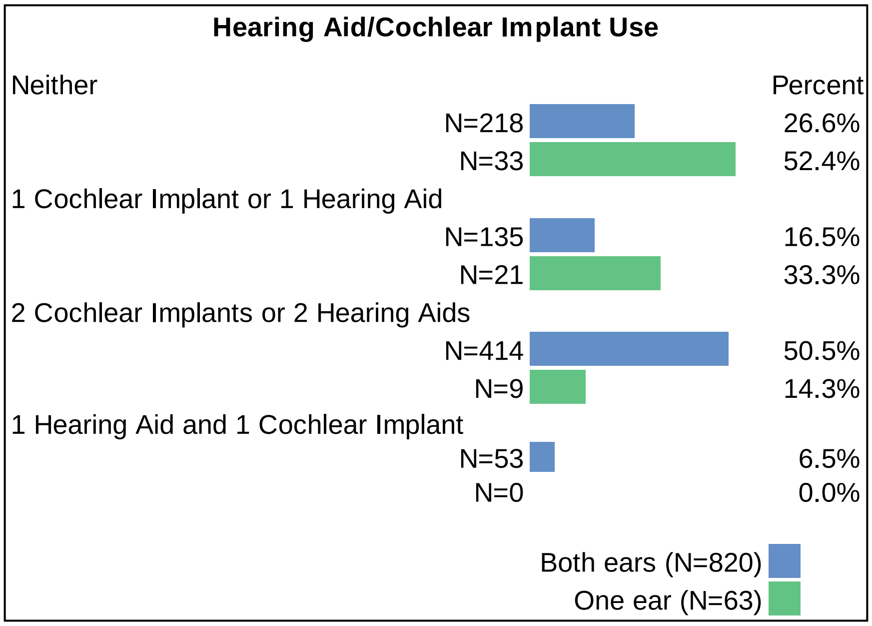
Figure 5: Communication Preference



Hearing Aid and Cochlear Implant Use

Among those respondents who indicated they use cochlear implants, three in four (76.3%; N=106) have one (unilateral) implant only. Respondents with hearing aids were more likely to aid each ear (70.5%; N=383). While 93% of respondents (N=820) experience hearing loss in both ears, only half (N=414) aid both ears. Fewer than half with a loss in one ear aid it. Three individuals with cochlear implants indicated they do not use them, as well as 11 individuals with hearing aids. The most common reasons for no longer using hearing aids was that they need new ones and could not afford them.

Figure 6: Use of Hearing Aids and Cochlear Implants by Loss in One or Both Ears



More respondents who use cochlear implants are extremely or very satisfied with their devices than hearing aid users (57.4% vs. 38.2%). Another 16.2% (N=22) are dissatisfied to some degree with their cochlear implants, and 19.7% (N=105) are dissatisfied with their hearing aids. People who were dissatisfied with their cochlear implants were mainly dissatisfied because they did not have the speech perception they desired and still had to rely on speech reading. Although no one listed expense as an issue with cochlear implants, 22 respondents did in the follow-up question related to hearing aids. (Expense is also brought up in several other places in the survey, and in focus group sessions.) Eighteen mentioned problems with hearing in background noise, but 62% (N=186 out of 296) were dissatisfied because of their lack of ability to perceive speech with them. Many use this as a rationale not to replace them as they are perceived to be not worth the expense.

Figure 7: Comparison of Satisfaction with Hearing Aids and Cochlear Implants

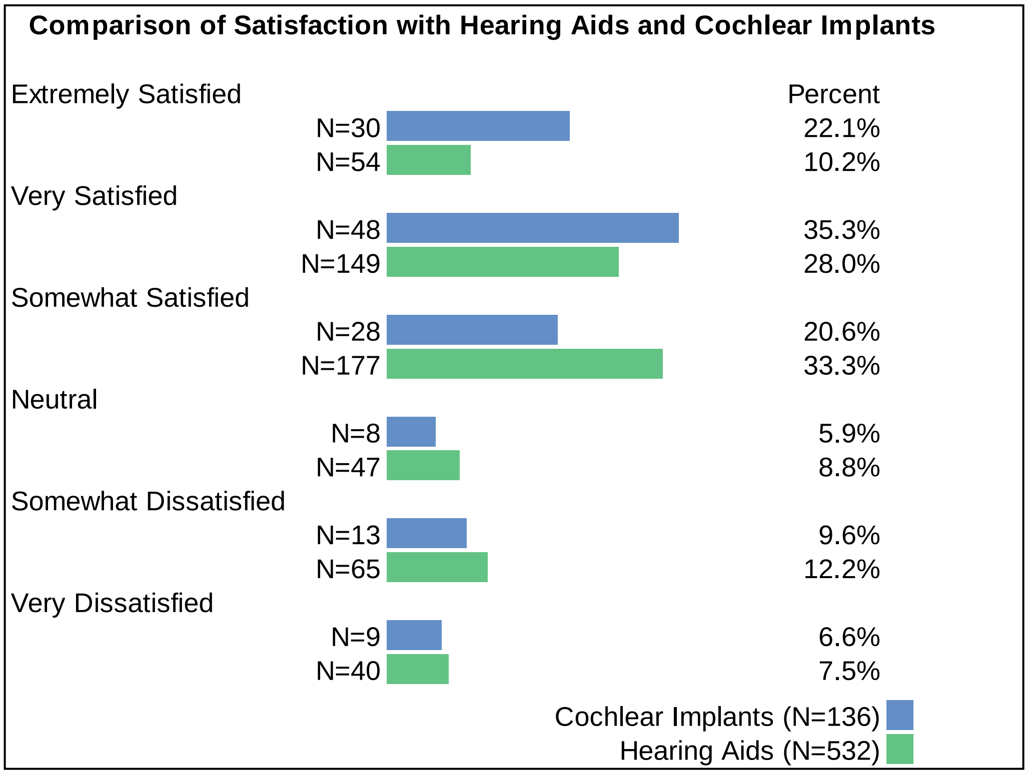
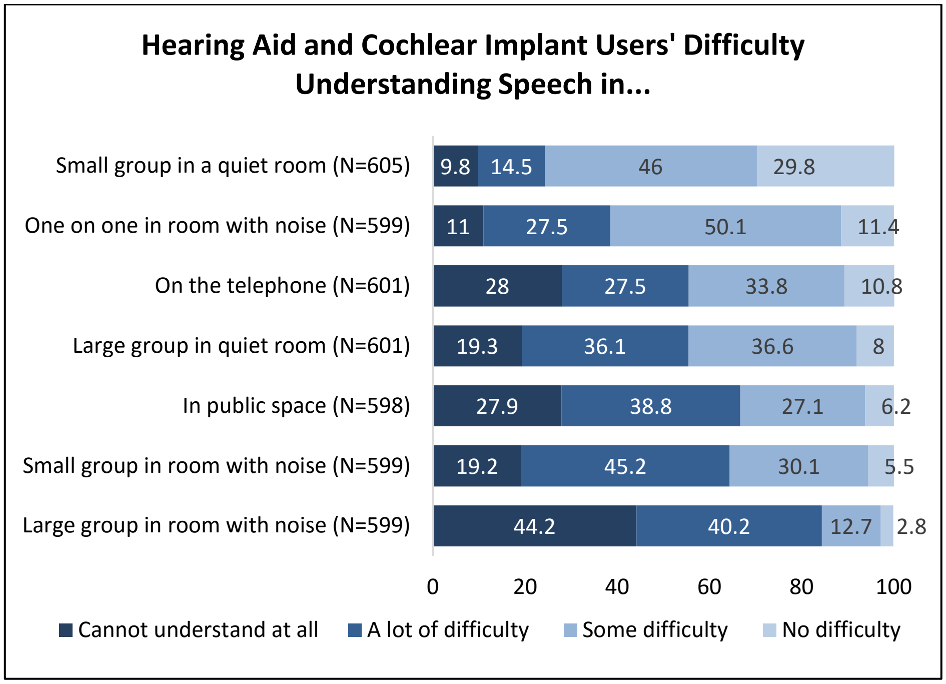


Figure 8 is a revealing glimpse into the communication challenges faced by individuals with hearing loss. Limited to those who are using hearing aids or cochlear implants, respondents were asked about the difficulty of understanding speech and environmental noises in settings with and without background noise. For one on one in a room with noise or on the telephone, close to nine in ten have some level of difficulty understanding either speech or environmental sounds.

Respondents experience difficulty understanding speech in many settings. In most situations, about ninety percent or more experience difficulties understanding. Even in a small group in a quiet room, understanding speech presents difficulties for seven in ten respondents (70.2%; N=425).

A large group in a room with noise means no understanding of speech at all for 44.2% of the respondents (N=265), even using hearing aids or cochlear implants. Over one in four cannot understand speech on the phone (28.0%; N=168) or in public spaces (27.9%; N=167).

Figure 8: Hearing Aid and Cochlear Implant Users' Ratings of their Speech Perception



> A male senior citizen with progressive hearing loss who identifies as hard of hearing and relies on spoken language shared his positive experience with an audiologist who had proper training and shared critical information that he wished many other hearing aid users would benefit from knowing. *"One huge help for me was some information that decreased my expectations. And that they said was to aim for 80 percent of normal hearing because if they do it louder, the ambient noise blocks your understanding [of speech and environment sounds]. So you don't get 20/20 hearing the way you get 20/20 eyesight with glasses. That has been a huge help. I didn't expect to have normal hearing. I'm just very grateful that it's better."*

ASL interpreters are most widely used in hearing environments by over two in five respondents (44.8%; N=380). Caption is used by three in ten (31.7%; N=269). Seven percent of respondents use nothing in a hearing environment (7.1%; N=60).

Hearing aids (62.6%; N=550) are the most commonly used devices, with 19% (N=161) using only a hearing aid or a cochlear implant. While many people are not aware of the various assistive technologies (see Appendix A for explanations of the labels in Table 7), some people short-change themselves, as demonstrated by this female hard of hearing participant:

> *"I have not asked for CART. I figure these are nonprofit organizations with limited budgets. If I was—I'm not contributing enough for them to be able to afford that. That's my own personal decision."*

Table 7: Assistive Technology (including Interpreters) in Any Hearing Environment

Use of Any In Hearing Environment (Multiple Response) (N=848)	Percent	Count
ASL interpreter	44.8%	380
Caption	31.7%	269
Only hearing aid or cochlear implant	19.0%	161
Assistive listening device (FM system, loop)	16.6%	141
Mobile Apps for smartphones and tablets	15.1%	133
CART	11.8%	100
Certified Deaf interpreter	8.1%	69
I do not use anything	7.1%	60
Support Service Provider (SSP)	3.4%	29
Brailler, CCTV, other vision loss equipment	3.1%	27
Captel/vp	3.1%	27
Ask someone to help (family, friends, etc.)	2.2%	19
Close vision interpreter	1.5%	13
Other (doorbell signals, hearing dog)	1.5%	13
Intervenor	1.2%	10
Haptics	0.8%	7
Protactile	0.7%	6

A hard of hearing female from Central Oregon shared a common reaction related to technology, *"I think for some people – it is sort of frightening to use technology. So again, somebody to walk them through it, get them comfortable with technology would help."*

Accommodations in Public Settings

The common theme of accommodations arose several times among focus groups. A hard of hearing female summarized, *"CART not only eases the burden of those for people like myself, it allows us to recruit more people who have hearing loss into the field. In fact we find foreign visitors or attendees whose mother tongue is not English are actually using the CART system because they gain a lot out of it too. If it's good for a particular disability population, it's actually good for everybody, not just that one particular population. So the complaint is it's too expensive or too difficult. I think people [running businesses] are not aware of the positive impact of making these particular accommodations. And I think the legislature needs to understand the positive impact that is far beyond the community in question, it will have an impact."*

A cochlear implant user who uses primarily spoken language discussed his recent event at the Moda Center, *"The customer service staff was not aware that FM systems were available and it was not until I insisted that I speak to supervisor that it was possible and made available. It made my whole night but that's the kind of thing where the event planners are not being educated. They don't educate them or their and volunteers or workforce to know what is truly available. …Sometimes when you request FM systems [anywhere] and they don't work or have missing parts."*

A Southern Oregon male with progressive hearing loss, as well as many other hard of hearing participants, reported on the value of CapTel (a telephone displaying a text screen).

Financial Barriers Related to Hearing Aids

A young hard of hearing woman who uses both ASL and spoken language in her employment setting reported wanting to buy an FM system to help block out unwanted environment noises but was told "*money is not available right now*." This same person had to keep her hearing aids for 12 years because of financial barriers said, "*I have to wait for 12 years to buy new hearing aids. 12 years I have had my old hearing aids because they are expensive. Then I finally got insurance coverage with hearing aids, but it was covered like 20% - the insurance benefit was $1500 while the cost of hearing aids was $5000, so I had to save about $3500.00."* Because of a financial barrier related to hearing aid cost she took many necessary steps to protect her new hearing aids from damage until, "*I was running recently, the sweat was going into the hearing aids and broke the hearing aids. I bought the hearing aids 2 years ago with Kaiser Insurance but now because I don't have that insurance anymore [because of a job change], I can't go there for repairs. The warranty is not good anymore*."

A male cochlear implant user who works in medical setting and primarily uses spoken language reported, "*I really do think the people, the population of people who benefit from hearing aids would have a greater use of hearing aids if there was some sort of mandates for insurance coverage for hearing aids and it's not happening yet and not happening nationwide. The state of Oregon is a health leader in the nation and that would really improve the situation for those who would be willing to use hearing aids, if they didn't have to pay out-of-pocket for them all of the time."*

Education

Although one in ten (9.8%; N=84) respondents indicated they did not finish high school, 61 of these individuals are under 18, and another 7 fall into the 18-24 category, and thus may be in the process of completing; another 12.7% (N=108) did finish their education with a high school diploma. Forty-two percent (N=319) graduated from an Oregon high school.

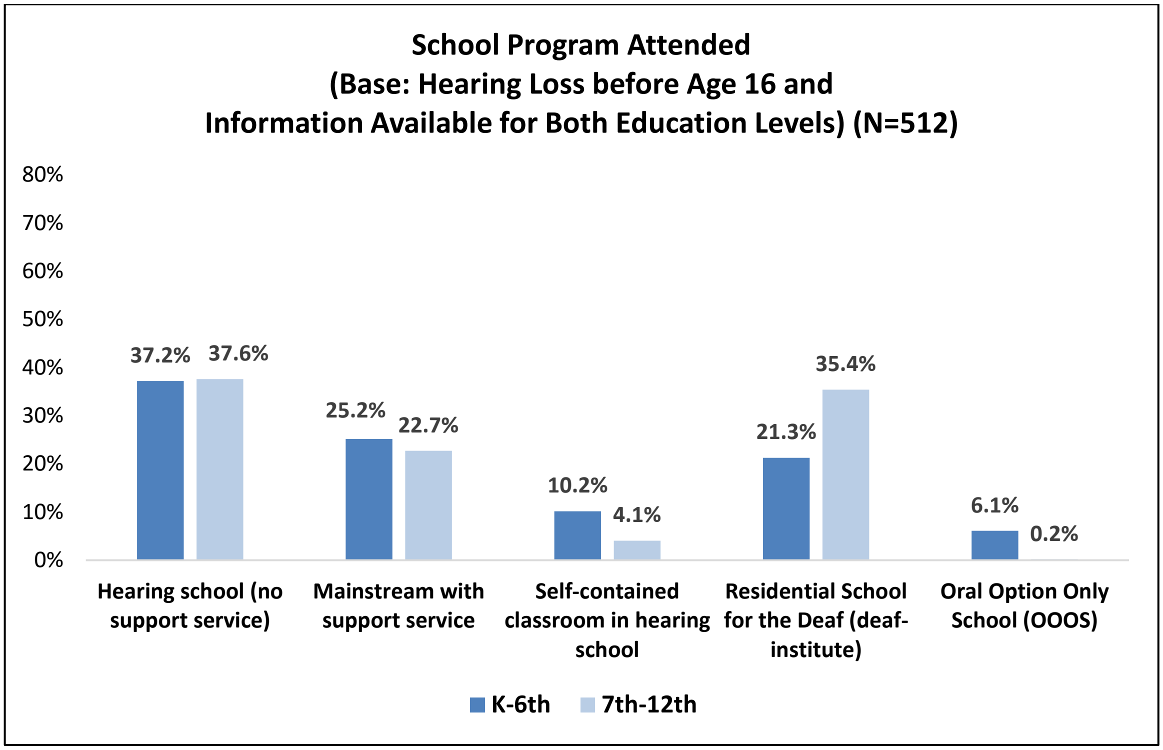
Nearly half (48.2%; N=411) achieved a 4-year or higher college degree. Among respondents who attended college, three-fourths (74.0%; N=490) completed their training/degree.

Table 8: Highest Level of Education

What is your highest level of education? (N=853)	Percent	Count
Currently in high school	7.0%	61
Did not complete high school	3.0%	23
Completed high school	12.7%	108
Currently in college	6.0%	49
Completed some college but not degree	14.0%	122
AA/AS or trade degree	9.3%	79
BA/BS (4 year college)	20.2%	172
MA/MS (Graduate)	22.2%	189
Terminal degree (e.g., Ed.D, Ph.D., JD, MD)	5.9%	50

Over one-third of respondents attended a regular hearing school without supports for K-6th grade (37.2%; N=194) and for 7th-12th grade (37.6%; N=196). Residential schools for the Deaf saw the largest increase from elementary to high school. While 111 (21.3%) attended a residential school for the Deaf for their early schooling; the number increases by 14% or 72 students for 7th-12th grade (35.4%; N=183). Of these students, 34 moved from mainstream programs with support, 23 moved from regular schools without support, 16 from self-contained classrooms, 8 from oral programs, and 2 from 'Other.' Only 8 students left residential programs, 7 moving to regular hearing programs and 1 moving to a self-contained classroom. This trend is common to the state. Oregon School for the Deaf reports their elementary program is very small, and they experience a large number of transfer students in the higher grades.

Figure 9: School Program Attended



Education Barriers Related to Learning Needs Accommodations

A hard of hearing adult with a mild hearing loss who attended University of Oregon recalled the significant barrier to her education, *"Most barriers [I experienced] are related to education barriers because I used ASL interpreters growing up but many people think that I do not need ASL interpreters because I can speak well."*

She further recalled her experience on how the Disability Service Center at the University took away her autonomy in determining her learning needs, "*Being able to speak doesn't mean how well you can hear. So, some can speak well, but still cannot hear well. For me, in classrooms, if there were noise in the background, I can't follow the instructor's voice or if the instructor talks and a student made a comment in the background, I would turn around and see who was talking and I* *would miss information and then need to catch up. Or if I want to write notes and I am looking down as I write notes and then I would look up and miss something or when I am writing notes and I would miss comments from a student in the background. So, an ASL interpreter will help me not miss as much information. Then they said no you do not need it. You should try closed caption services from distance [caption via remote].”* Then they offered different services such as CART, *“it was harder with CART to follow the conversation in the classroom. An ASL interpreter would be able to point out the people who is talking back and forth and I can understand who said this and that allows me to follow the conversation better.”*

She continued to fight for two semesters to advocate for her needs, “*When they finally provided interpreter, the interpreter they provided was hard of hearing and I thought that was strange. It seemed like that the interpreter was missing information as well, so I approached the interpreter and said, ‘Do you know that you are not interpreting everything that they are saying?’ She said, ‘Oh I am hard of hearing and I must have missed.’…That did not make sense to me so I went back to the disability services. That was before the certification for ASL interpreters, so they did not have any certified interpreters. They just found somebody who was a parent who could sign and happened to be hard of hearing to interpret my 300 level English Course!”*

A young woman who identifies as both Deaf and Hard of Hearing shared her excitement related to starting college this fall in Oregon but experienced a familiar battle as many other Deaf and hard of hearing students related to advocating for their learning needs, *“I will start at OSU this fall, so right now, I’m meeting with the disability services on campus and I requested different accommodations for me to succeed in class. I asked for interpreters, extended test times, FM access in the classroom. The woman worked in that department for 20 years with Deaf students. When I asked for the extended time in class, she said, ‘Why?’ I explained, but she still didn’t understand why I needed that. Yeah, so the college doesn’t really understand why I need all these different accommodations in classes.”*

Barriers Related to Education Options and Information

A teacher who uses both ASL and spoken language remarked, *“The key is communication in ASL. This access will improve communication, jobs, and education. The key is communication. They can communicate and speak, and write, and then in school they can understand. And then that will lead to future job opportunities. That will improve jobs, and the key is language. Where is the language? It’s missing [in this equation]. Hearing people are pushing it aside, and making it all about the ear. They say, ‘Speech will help,’ but no, no, they forget that the eyes come first for visual access. For example, if you give an apple and an orange to a blind person, either deaf-blind or blind, they’ll feel it and won’t be able to tell which fruit is which. You’d have to tell them, or they could smell the orange or taste it, yes. But with visual access, you immediately know which is the apple and which is the orange. Why shut out our visual access? It’s the same for Deaf and blind people. Visual access, signing. Deaf-blind people are more experienced in how to communicate using this system, which is known as ProTactile. That impressed me. The answer is right there. Why stop that access and remove it?”*

The parent of a 6 year old oral child shared her frustration related to lack of options, *“I want to get it there [in records] that Portland Public Schools does not have a truly oral option. They have total communication option and sign language option, they don’t have an oral education option, I find* *that to be breaking the law for Deaf and hard of hearing students where they don't have fully oral option if that is the communication mode that parent has chosen for that child."*

A parent of 8 year old child asks: *"In Portland Public School it is $25,000 per kid which is why they don't want to release that money [to pay for other options]. They want to keep it in the school and they feel that they can use the IEP and spend the money that way. I use that in quotation marks but 15 minutes of speech a week for an investment of $25,000 for ten months of the school year, what's my ROI?"*

A parent of 8 year old daughter who goes to Oregon School for the Deaf expressed her struggle with the system at the school district, *"There's no real happy medium. …She can't go into two different programs or go half day to one school [OSD] and another half day at another [mainstream at hearing school], or different ways of combining them. At that young age, there is no way the parents are going to know what the best fit is yet for their child."*

"We see a lot of Deaf children being very isolated. So they're in the neighborhood school but they're not really integrated into the community because of the language barrier and we're seeing a lot of mental health problems in the Deaf community because of their isolation," expressed a parent of a Deaf child who is also a teacher.

Many more concerns were expressed by parents of Deaf children, *"There is a lot of training for hearing teachers. I don't know if you know that concept of 'you have to be Deaf to get it.' Takes one to know one kind of thing. As a Deaf person, I know what the Deaf experience is like and the same thing goes for any deaf teachers. So they understand what a Deaf child is experiencing…their world view and their world experience. It's so nuanced. It's so different from interaction with non-deaf people. And it's so easy for someone who is not Deaf to miss these very small subtle aspects in facial expression and body movements that are so meaningful."*

An interesting point made by parents of Deaf children, *"You know, we have all these policy makers, almost all of them are hearing and so they're making decisions that greatly impact Deaf people's lives without understanding their Deaf world and the Deaf experience."*

"The way the system is currently designed forces parents to choose that school or this school, this whole idea of placement options. And parents have to gamble. Sometimes they just take a guess, pick a school randomly because they have no idea what's going to be best for their children yet. They haven't experienced any of these or certainly not all of them. It's like playing a game. It's taking a gamble with them. Resources and tools are not provided all in one place for a diversity of needs. And so a child gets pulled out of one school and thrown into another the next year. Instead of all these different approaches being allowed to be provided in one place."

The parent of an adopted 7 year old hard of hearing child with progressive vision loss in Southern Oregon shared, *"My child was originally put in a program for children with severe delays or disability. I pulled him out after 2 days because he is not autistic and didn't fit in the category as a Deaf individual. The classroom was full of stimulation [meaning lots of adults and children talking at the same time] going on and the Deaf child will miss out all the information because the information is not being communicated to him directly."* He was eventually put into a different school with self-contained classroom but did not have an audiologist coming in until the parent fought with the district, *"He was receiving speech therapy via a computer which was obviously ineffective. After a lot* *of negotiating and pushing and pulling and documenting, I finally got a speech therapist to come in once a week to work with him at the school. I felt we like we lost six to eight weeks because of this. I also feel like here in this county I have to fight for everything. As a result, he doesn't know how to interact with hearing children because of his delay and isolation is a struggle. He's not able to do things that other kids get to do, like go to camp. Because they won't have an interpreter. Even doing Boys Scouts, you know, not having an interpreter for Boy Scouts [they have asked for one multiple times]…He watched his older brother [hearing] going to camps and Boys Scout all summer and it hurts."*

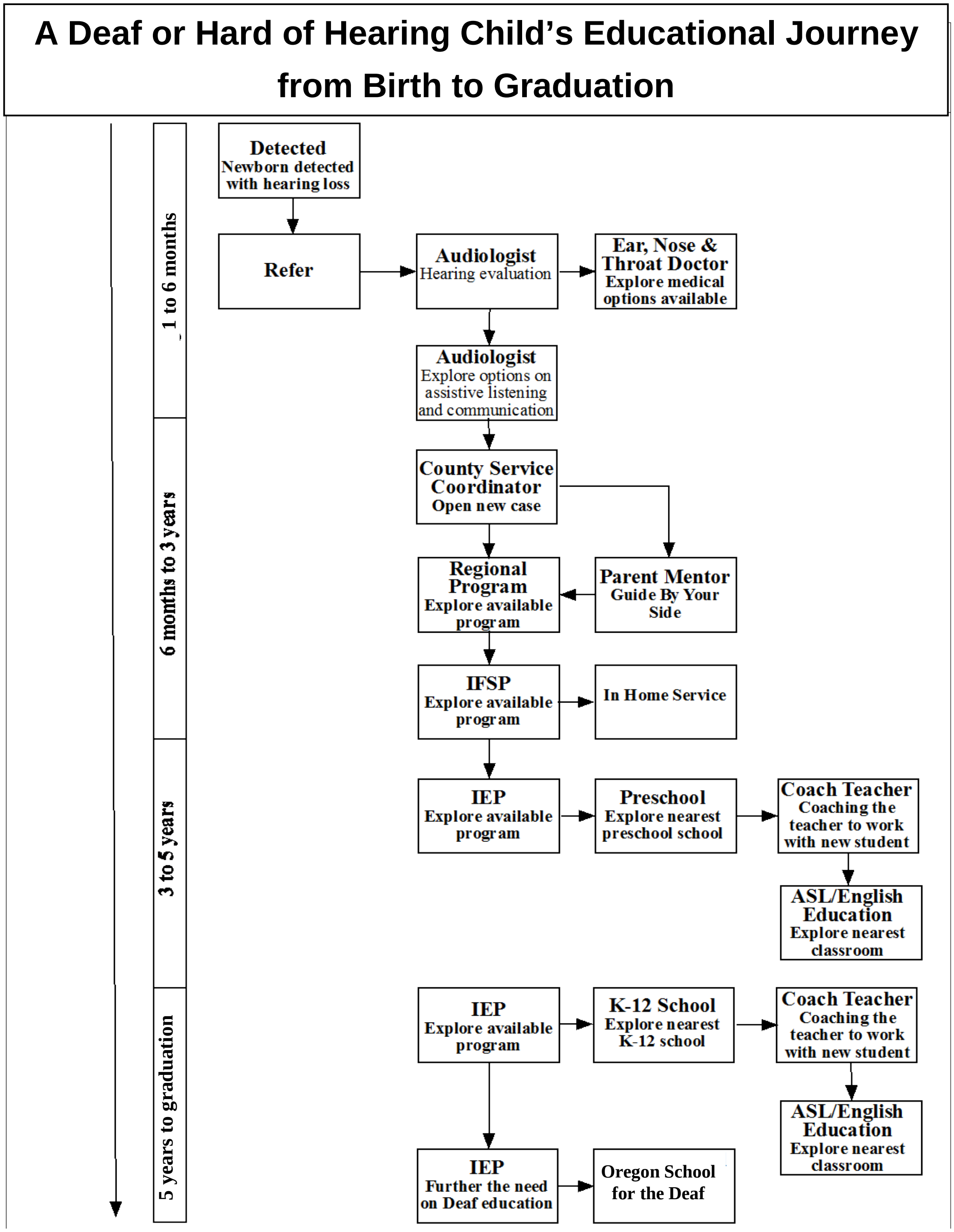
A parent of 7 month old baby expressed her frustration with an early intervention program on communication*, "The early intervention preschool right now, the only preschool I could get a hold of that had any sign support and with a hearing specialist, doesn't get it."*

Another parent with a Deaf child who uses both ASL and spoken language who is involved with the Hand and Voice expressed frustration with a recent incident in Central Oregon, *"I hear and see a lot of really, really confused parents. And depending where you are in the state, I'm so sad to hear, early intervention tells parents there [in central Oregon] they need to sit on their hands and not sign to their babies because their babies will never speak if they do that. And that's coming from early intervention and it's still happening. So part of the issue there is there are no certified Deaf and hard of hearing specialists in the early intervention program in many of the rural parts of the state. Huge barriers. So what we're talking about is these children growing up many times very frustrated."*

The parent of an adult hard of hearing child who uses both ASL and spoken language shared, *"There's this window in there, there's this problem where kids aren't getting language. And I'm not talking about sounds. Because what I'm seeing is they're not getting language. And when they finally get [the hearing aids] on, they're being told to not sign. And so there's just this big gap and for me that's a huge barrier as children go forward and I would just like to see, you know, the system to be able to support whatever it is that parents are dreaming of and wanting for their children. I'd like to see babies with lots of language."* Another parent of a 5 year old hard of hearing child continued, *"That sounds so crazy to me that they're not encouraging signing because even for kids without hearing loss now it's like baby signing, baby signing. They can communicate what they want to you instead of crying. It seems very odd that anyone would advocate the opposite."*

The following flowchart and description was developed based on data from several Focus Group interviews with Parents of Deaf, deaf, and hard of hearing children. Comments from parents and teachers are interwoven in the description and italicized.

Figure 10: Flow Chart of Services Involved in Child's Education Path



In Oregon, when a baby is born, a hearing screening takes place to determine if the newborn experiences any range of hearing loss. Once it is determined the baby potentially has a hearing loss, the newborn is referred to an audiologist for further testing. After an audiologist confirms the hearing loss, the audiologist will discuss assistive listening devices and communication options available to the newborn baby. Typically, families may choose to explore options that involve surgery, for example, cochlear implants, although this would not occur until the baby is older.

After the personal devices (e.g., hearing aids and cochlear implants) and communication options are considered for the baby, the family will be referred to the County Service Coordinator to open a new case. They will work with the family to explore the appropriateness of the nearest regional school program.

Many parents expressed frustration with limited information on communication options from ENTs and other professionals; as one parent of a 7 year old deaf boy who relies on an oral approach stated, *"When you go to the doctor and the doctor tells you your child is deaf, you don't hear anything about the next step, which is to choose a communication method. And the idea that there is an entire method that is oral wasn't actually presented…I was presented with cued speech, which is dead. I mean nobody uses cued speech and there is nobody to even teach you that and I spent months and months researching cued speech on my own until I found other options."*

At age 6 months to 3 years, the family with a toddler living with hearing loss will work with a representative from the Regional School Program to determine the nearest possible program available to this family. If the parents wish to have a Parent Mentor to work with them, the County Service Coordinator will make another referral to a Parent Mentor through the program Guide By Your Side via Hands and Voices of Oregon. The parents will attend the Individual Family Service Plan (IFSP) meeting through the Regional Program. The IFSP is a plan for special service for young children with disabilities from birth to age three. After the age of three, an Individualized Education Program (IEP) is put into place. The IFSP plan is often carried out at the Deaf or hard of hearing child's home.

An annual meeting for IFSP is hosted with the Regional School Program and the parents to discuss the education path. This IFSP evolves into an IEP once the child turns three until graduation or it is no longer needed. Parents expressed frustrations for not being provided the entire range of options related to education for the Deaf and hard of hearing individuals. For example, in the Metro Portland area during the child's time at age of three to five years old, the Regional School Program allegedly withheld the information that there is a classroom for Deaf or hard of hearing students. Many parents reported not being aware of a Deaf classroom or other options for their child.

The parent of a 1 year old son who uses both ASL and spoken language observed: *"There seems to be a rift down the middle; one is oral and one is ASL, and they are very much against one another but I want him to be able to speak and so he can hear and speak to other people, but I want him to be with his Deaf roots and be able to do sign language. I want him to be multifaceted. Why can't we do that?"*

The parent of a 5 year old Deaf boy complained: "*When my son was diagnosed as Deaf, they [the early intervention team] looked at us and said ASL or oral, you need to pick one and you can't do both. They said we will confuse him if we do both ASL and oral. You look at people who have hearing infants and they say teach them sign language for teaching them to eat and sleep but they are telling me I can't do that with my Deaf child. You don't know where to get information, but you feel like you are forced to have to make a decision for your child at that stage."*

The Regional School Program provides placement in a classroom. The placement includes coaching the teacher who works with the child in mainstreamed classrooms (i.e., the Deaf or hard of hearing child is placed in a hearing classroom with supports). The County Service Coordinator leads the meeting and makes the recommendation to place the child in a special class or mainstreamed program. (Note: if a child needs additional supports, classes for children with developmental disabilities or behavioral challenges are often not prepared to support a Deaf or hard of hearing child.) Many parents reported that they did not know about the possibility of an ASL and English classroom until much later in the child's education.

It is standard to have a Parent Mentor through Guide By Your Side to accommodate parents at every meeting that involves a County Service Coordinator and Regional School Programs. The Parent Mentor can advocate and ensure that parents of a Deaf or hard of hearing child receives all kinds of information, options, and resources that are made available to them.

Some parents expressed frustration that their child had to fail in other settings before the option of Oregon School for the Deaf was presented. This puts Deaf and hard of hearing child at risk for persistent language deprivation, and the lack of academic growth can be pronounced and severe in comparison to their hearing peers.

According to parents, the Oregon School for the Deaf is perceived as the last resource to work with the Deaf child over other academic programs. This results in information about this option being withheld until much later in the child's life.

> A parent who is involved with the Hands and Voice organization with an adult Deaf child who uses both ASL and spoken language shared, *"Even if you're getting the language in [auditorily], there are still holes. Even if you have really good hearing aids, it's that Swiss cheese effect. You're not always getting perfect language. Our kids are still going to need lots and lots of visual support as well. So these are barriers throughout their whole life."*
>
> Another parent of an adult hard of hearing student added, *"I always hear the phrase hearing aids are not like eyeglasses. You know, they don't give you 20/20 hearing. Are you finding that the people you work with understand that? Do their teachers understand that? Even now, we still have to educate school districts on this. They [mainstream programs] do not understand. They don't get it. They still think that the [Deaf or hard of hearing] kids just don't listen. They're the ones not listening."*

Financial Barriers to Education

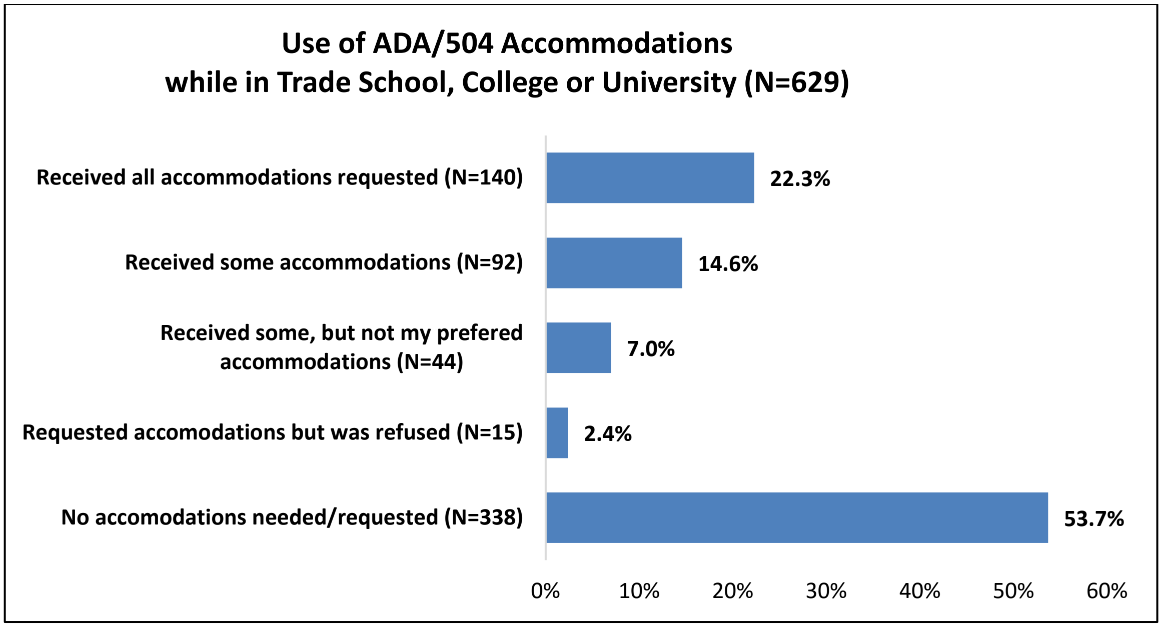
> A parent of 5 year old deaf daughter who choose the oral only option at Tucker-Maxon stated, "*I live in Portland. Oregon City is paying for students who go to Tucker-Maxon. My daughter comes here. Portland Public Schools never paid, so I am out of luck. I had to apply for scholarships and go through this huge process to find a financial help."*
>
> Another parent of a Tucker-Maxon student*, "That's why I came to this focus group. I want Portland Public to pay tuition as an option because I have seen what they do with children in Portland Public Schools system. Put all the deaf kids in one room and they 'integrate them at lunch.'"* This parent reported she refinanced her house in order to pay for the tuition.

> Another angry parent of a Deaf child stated, *"I think that Portland Public Schools wants my daughter to fail and fail badly before I could look at another option before they were pushed hard enough to move."*
>
> An angry parent requested to have this on record, *"Tuition is $17,000 a year at Tucker-Maxon, 10 months and if you are a full time working parent, which you have to be to pay for that it's another $400-600 a month, so it's insane. We need support [reference to financial support]."*

Postsecondary Educational Settings

The requirements of postsecondary settings are very different from secondary settings. In the public school system, children with disabilities are identified, have individualized education plans developed, and are provided accommodations based on this. In postsecondary settings, it is up to the individual to request an accommodation, which also entails knowing what accommodations might be most useful in this new setting and how to use them effectively. Students also must provide documentation of the need for the requested accommodation. Nearly half (46.3%; N=291) of respondents have requested ADA/504 accommodations while in school. Of these, just 22.3% (N=140) received all requested accommodations. Fewer received only some accommodations (14.6%; N= 92) or not their preferred ones (7.0%; N=44).

Figure 11: Use of Accommodations in Postsecondary Settings



ASL interpreters (68.8%; N=185) and note takers (69.1%; N=186) are the most widely used accommodations in trade school or college by respondents who received accommodations. Note: The number of people who did not request accommodations is inflated by the number of people who lost their hearing post-college. Because we do not know at what age participants attended college, we did not remove any respondent age categories from this analysis.

Table 9: Accommodations used in Postsecondary Education Settings

Accommodations Used (Multiple Response) (N=269)	Percent	Count
Note takers	69.1%	186
ASL interpreters	68.8%	185
CART or other caption service	21.2%	57
Other (please specify)	19.0%	51
Personal listening devices (e.g. FM system)	13.8%	37
Oral interpreter	3.7%	10

Among those respondents who used accommodations while in school (N=269), a sizable portion state that these accommodations were not sufficient for their education or training (15.2%; N=41) or were unsure it helped them (13.8%); N=37). Thus, almost one-third of those attending postsecondary education programs felt they could have had more effective accommodations than they received.

Employment

Respondents were asked several questions about their employment status, if they were seeking work, and if they believed hearing loss has had any impact on their ability to get, keep, or be promoted on the job. Over one-third (36.0%; N=302) were employed for wages at the time of the study; with another 7.5% (N=63) self-employed. Eleven percent (N=95) were out of work at the time of the study. Nearly two in five (38.5%; N=323) were retired.

Table 10: Employment Status

Are you currently… (Multiple Response) (N=838)	Percent	Count
Employed for wages	36.0%	302
Self-employed	7.5%	63
Out of work for a year or more	8.6%	72
Out of work for less than a year	2.7%	23
A homemaker	5.7%	48
A student	13.1%	110
Retired	38.5%	323

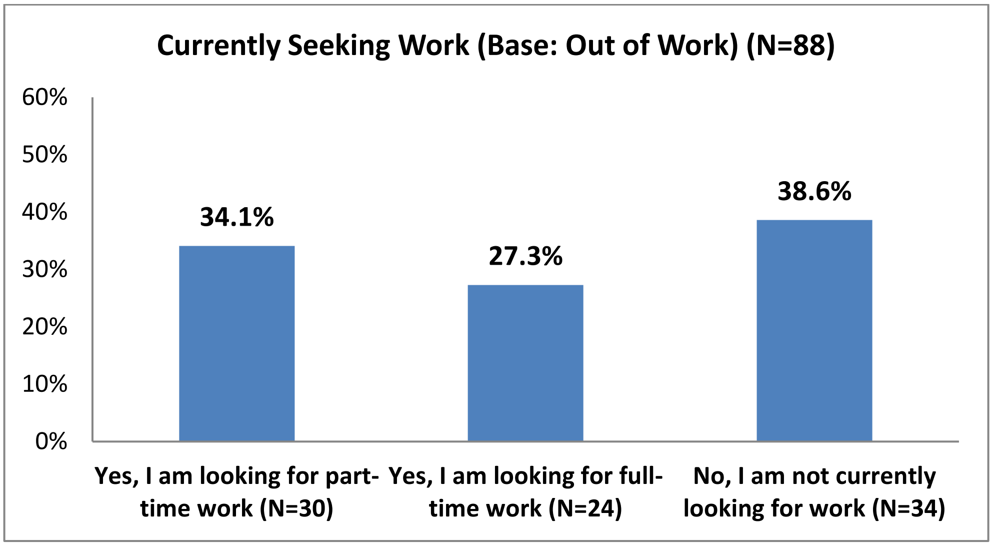
Four in ten (40.0%; N=342) were employed at the time of the survey. Another one in ten (10.0%; N=84) were out of work. Half (50.1%; N=428) were out of the labor market.

Table 11: Employment Status

Employment Status (N=854)	Percent	Count
Employed	40.0%	342
Out of work/looking	6.3%	54
Out of work/not looking	3.3%	28
Out of work/unspecified	0.2%	2
Out of labor market (e.g., retired, student, underage)	50.1%	428

Among respondents who are currently seeking work, just over one-fourth (27.3%; N=34) want a full-time position. Thirty-nine percent (N=34) are not looking for work at the moment.

Figure 12: Currently seeking work



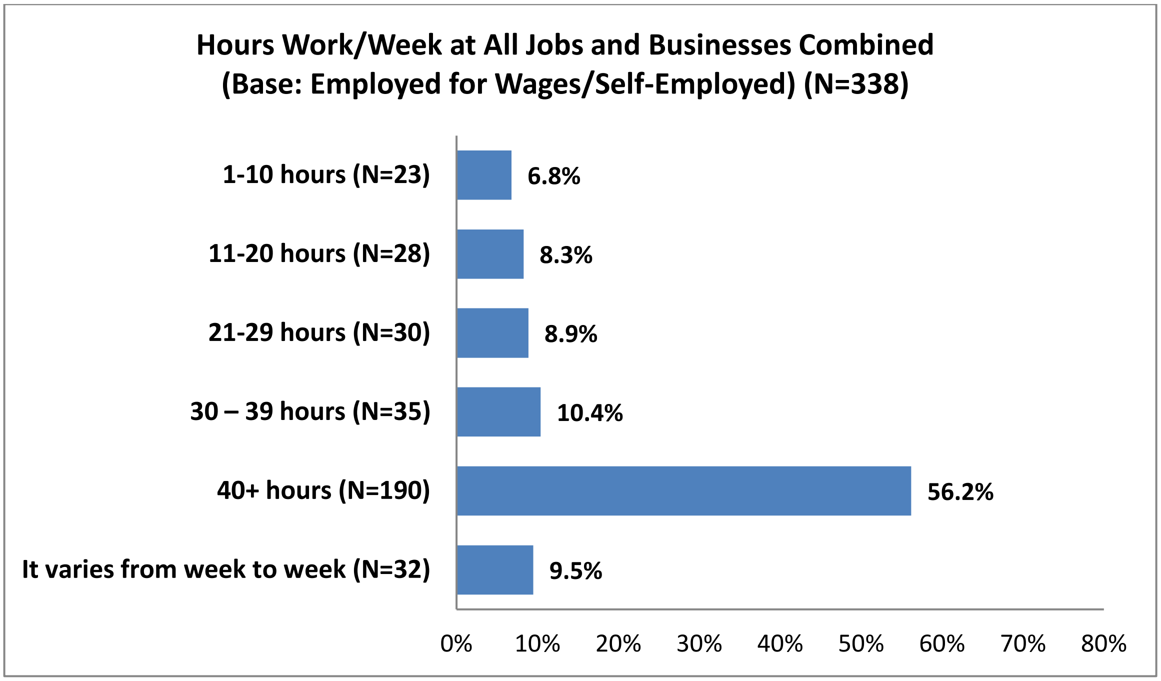
Employment, household income, and housing are all closely related. Respondents who indicate they live alone are significantly more likely than others to report an annual income from all sources below $35,000.

Table 12: Annual Household Income by Number in Household

Annual Household Income from All Sources (N=769)	Live Alone (N=188)	Others in Household
Under $25,000	43.1% (81)	25.0% (145)
$25,000 - $34,999	20.7% (39)	11.0% (64)
$35,000 - $49,999	10.1% (19)	11.6% (67)
$50,000 - $74,999	12.8% (24)	19.5% (113)
$75,000 - $99,999	8.5% (16)	12.8% (74)
$100,000 - $149,999	3.2% (6)	13.6% (79)
$150,000+	1.6% (3)	6.6% (38)

Over half of respondents who are currently employed for wages or self-employed work 40 or more hours per week (56.2%; N=190). A smaller portion (15.1%; N=51) works 20 or fewer hours, while about one in ten work a variable schedule (9.5%; N=32).

Figure 13: Hours Worked per Week at all Jobs



Half (49.4%; N=165) of employed respondents are hourly workers, while two in five (41.6%; N=139) are salaried. The remaining 9% are paid on commission or some other way.

Fully one in five respondents (21.5%; N=176) report that they have left employment previously because of their hearing loss. Among those, 17.8% (N=31) say they felt strongly encouraged to take early retirement due to their hearing loss. An equal portion (17.2%; N=138) of all respondents feel that they were previously laid off or fired due to their hearing loss.

Table 13: Perceived Impact of Hearing Loss on Employment

Impact of Hearing Loss on Employment	Percent	Count
Believe they were ever laid off/fired due to their hearing loss (N=803)	17.2%	138
Left employment because of Hearing Loss (N=819)	21.5%	176
Felt strongly encouraged to take early retirement due to their hearing loss *(Base: left employment due to hearing loss)* (N=176)	17.8%	31

Among those respondents who are currently out of a job (N = 91), 16.5% (N=15) have turned down a job in the past 12 months. While they included a number of reasons for this, five respondents cited reasons centered on their hearing loss, such as their inability to hear or the lack of accommodations at the job site.

Misconceptions about what Deaf and hard of hearing people can do is by far the most commonly cited reason for not finding a job among respondents (31.3%; N= 198). Another 21.3% (N=135) think it is because of their hearing loss.

Table 14: Causes for Not Finding Job

Reasons Experienced Why Cannot Find Job (Multiple Response)(N=633)	**Percent**	**Count**
Other	44.2%	280
Misconceptions about what Deaf and hard of hearing people can do	31.3%	198
I think it is because of my hearing loss	21.3%	135
There are not many jobs that I am qualified for in my area	20.1%	127
I do not have enough education for many jobs	18.0%	114
I think it is because cost of interpreters or captioning	14.5%	92
I need qualified ASL or other interpreters and cannot get one	13.0%	82
Most jobs do not pay enough	12.6%	80
A need for employer provided equipment	7.7%	49
I have restricted hours for work	7.0%	44
A need for support person at work	6.5%	41
A need for ongoing supervision or assistance	5.2%	33

Workplace situations can be difficult for people who are Deaf or hard of hearing. About three in five say department/staff meetings (62.3%; N=442) or socializing with co-workers (58.9%; N=418) can be difficult due to their hearing loss. In-service-training (47.6%; N=338) or working/ communicating with the public (57.0%; N=405) are also viewed as difficult situations. Lack of ability to satisfy social norms are significant even if a person is doing their job well. It has a negative impact on the individual’s self-esteem and on coworkers’ desires to engage with the person on projects.

Table 15: Difficult Communication Situations in the Workplace

Difficult Workplace Situations (Multiple Response) (N=710)	**Percent**	**Count**
Department/staff meetings	62.3%	442
Socializing with co-workers	58.9%	418
Working with and/or communicating with the public	57.0%	405
Work related social functions	50.1%	356
In-service/training	47.6%	338
Receiving instruction and supervision	33.8%	240
Other	20.7%	147
Performance evaluation	20.1%	143

Treatment at Work

A hard of hearing woman shared her common frustration while at work during large meetings where she relies on induction loops or FM systems for communication access, "*People don't want to use the microphone…They can holler all they want but if it doesn't come into the microphone you're not going to hear it. So it's either one or the other, and they'll go, 'I can talk loud enough', and they'll quit talking in the microphone."*

A hard of hearing male reported he quit working at a health care organization before anticipated, "*Because it was difficult for me to hear under most circumstances, like in a conference room, and I could not get accommodations that worked for me*." He continued to share a common dilemma that many Deaf and hard of hearing individuals experience at the workplace, "*I don't know of any other organizations other than the Hearing Loss Association that can provide that sort of comprehensive information to individuals that are hard of hearing in terms of employers. But I think mostly it takes self-advocacy to get it happen and a lot of people are afraid to confront an employer and say I need special phone, I need this, I need that. Because they are afraid they're going to get canned*."

Barriers Related to Employment

A hard of hearing woman who lives in the Northern Coast region, who relies solely on spoken language, shared her significant employment barriers, "*The hearing aids that I bought in my late 30's and early 40's were getting more helpful. But I still had a lot of problems working. …I have my Bachelor's Degree in Sociology and my Master's in Library Science, and I did fine in school. But to try to find a job was something else entirely. And I knew that I'm not going to be able to hear well, I'm not going to be able to answer the phone, because I wouldn't be able to get even just phone numbers right or names spelled right. Just a simple message like that. And a couple of jobs I had, I had to fill in for the receptionist, but I couldn't do it. I just fell apart. And so they, so they modified the job for me, but I still had problems. I used the services of rehabilitation, and my counselor thought to put me in a secretary job. And I didn't do well at all. I worked about twice as hard as I had to, but the supervisor still told me that my performance is pretty bad.*" Then, after she received her Library degree, she thought she had a new employment opportunity but continued to struggle, "*I thought, well I can't be sitting at the reference desk and saying, 'What? What? What?' or any kind of front desk. So they modified the job for me, like that, but I still, I just didn't, I had a lot of problems. They had modified the job so much that they decided it just isn't going to work out. I interviewed well, and so I could get jobs. But I couldn't keep them*." As a result she took an early retirement at age of 47, "*because I couldn't take it anymore."*

A young Deaf ASL user shared her employment barrier in Southern Oregon, *"I had a job interview with the Oregon Department of Transportation in Medford. They contacted me a week and half later before asking if I was still interested. Sure, so for the interview, I let them know I was Deaf. They hesitated; I asked for an interpreter to make everything more fluent for everyone. They said, 'Okay.' They actually asked if I could bring someone, like my friend or family, and I told them it wasn't professional, and that my family and friends weren't certified. I wanted to keep my personal and business lives separate. Their response was, 'oh…'."* Upon her arrival, there was not an interpreter present, so she offered to communicate by typing on her iPad. She stated this was not as effective but the only option at that time. This person was not offered the job and experienced similar incidents with other State level jobs. Ultimately she was hired with the US Forest Department in Oregon, a Federal level job.

A Deaf engineer reported a barrier related to lack of qualified interpreters in employment setting, *"I'm an engineer and I need someone who knows the jargon because that could cost me my job. If they are incompetent, they can make me look bad and people won't realize that [it's really the interpreter's problem]."*

A deaf-blind male with Usher syndrome who relies on spoken language shared his struggle on employment, *"Because I made aggressive use of the assistive devices, I was able to complete my education and even get some employment, although it was very difficult getting employment."* He had a stable job until he had to retire early due to his hearing and vision difficulties, *"I retired early because of my hearing and vision loss… it was definitely getting harder for me to read literature thoroughly and this slowed down my productivity, which I didn't want to continue."*

Socioeconomic Indicators

Although this project was not able to collect data to construct a true socioeconomic status (SES) value for each respondent, information was collected on the number in the household and the household income. In addition, because they are closely related to SES, information on ability to obtain safe, affordable housing and transportation are included in this section.

Number in Household

Nearly one-fourth of respondents (23.9%; N=199) live alone. Over one in three (36.8%; N=306) have one other person in the household.

Table 16: Number Living in Household

Number in Household(N=831)	Percent	Count
Lives alone	23.9%	199
1	36.8%	306
2	16.2%	135
3	11.0%	91
4	4.8%	40
5 or more	7.2%	60

Household Income

Three in ten (29.4%; N=226) reported an annual household income from all sources of under $25,000. This category also had the largest proportion of respondents regardless of how many members there are in the household. Over half (54.0%; N=415) have an income under $50,000.

Table 17: Annual Household Income from All Sources

Annual Household Income from All Sources (N=769)	Percent	Count
Under $25,000	29.4%	226
$25,000 - $34,999	13.4%	103
$35,000 - $49,999	11.2%	86
$50,000 - $74,999	17.8%	137
$75,000 - $99,999	11.8%	91
$100,000 - $149,999	11.1%	85
$150,000+	5.3%	41

Another way of looking at this data is to compare the household income with how many people are living in the house. While only 7% (n=55) of those reporting their income are possibly living at the federal poverty level (our data are reported in ranges), fully 30% are earning under $25,000/year, many with three or more people in the household.

Table 18: Household Income by Number Living in Home

Number in home	Under $25K	$25-34.9K	$35-49.9K	$50-74.9k	$75-99.9k	$100-149.9k	$150k or more	Total
Self	81	39	19	24	16	6	3	**188**
1	61	38	35	64	26	37	21	**282**
2	39	8	12	22	17	17	4	**119**
3	18	6	10	13	14	17	8	**86**
4	11	2	4	4	7	5	4	**37**
5 or more	16	10	6	10	10	3	1	**56**
Total	**226**	**103**	**86**	**137**	**90**	**85**	**41**	**768**

Housing

About half of respondents stated that they owned the home they live in (51.8%; N=423). Another 22.7% (N=185) rent their current home. One in seven (14.3%; N=117) live with family members.

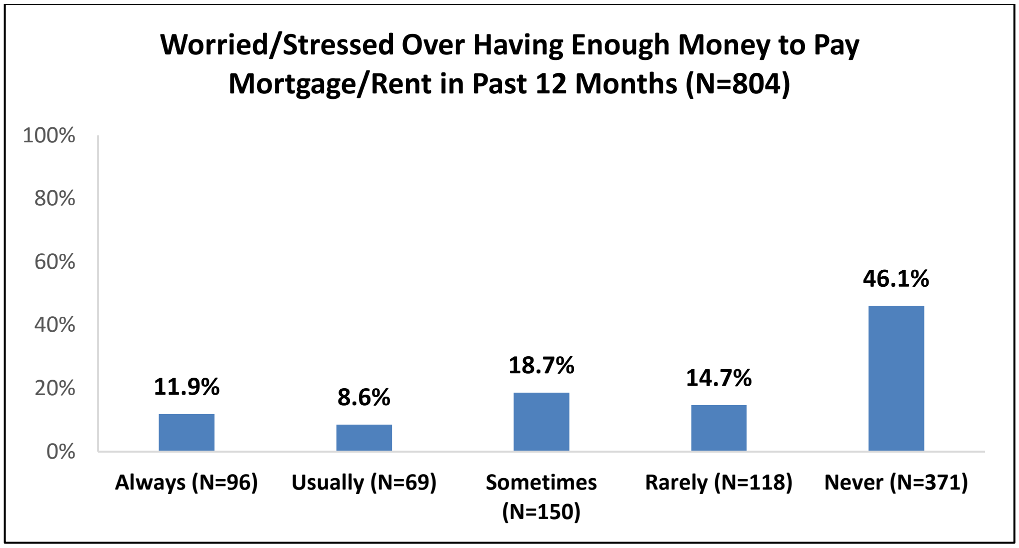
Table 19: Current Living Situation

Living Situation (N=816)	Percent	Count
I own the home I live in	51.80%	423
I rent the home I live in	22.70%	185
I live with other family members	14.30%	117
Other	7.10%	58
I live with roommates (not friends or family)	2.70%	22
I live with friends	0.90%	7
I sleep on sofa or floor at someone’s house	0.20%	2
Transient (moving around often)	0.10%	1
Homeless	0.10%	1
Migrant	0.00%	0

The majority of respondents have not moved in the past year (78.4%; N=633), and 13.5% (N=109) have moved once. A small portion 5.2% (N=42) has moved three or more times in the last year, indicating instability in their home lives.

While over two in five say they never worry or stress about having enough money to pay their rent or mortgage (46.15; N=371), a sizable portion (20.5%; N=165) say they worry or stress always or usually.

Figure 14: Concerned about Ability to Pay Mortgage/Rent in last 12 months



Forty-six respondents (5.6%) indicated they do not feel safe where they live. Safe affordable housing is out of reach for many as they are not employed (16.3%; N=87) or they do not get paid enough (24.7%; N=132). Another 22.6% (N=121) have too many debts or a bad credit score (16.3%; N=87). Even with low incomes, many say they do not qualify for affordable housing (20.6%; N=110).

Table 20: Difficulties in Obtaining Safe, Affordable Housing

Challenges to Safe Affordable Housing (N=535)	Percent	Count
Costs too much, my job does not pay enough	24.7%	132
I have a lot of debts (loans, credit card, etc.)	22.6%	121
I don’t qualify for affordable housing program	20.6%	110
Costs too much as I don’t have a job	16.3%	87
I have a bad credit score	16.3%	87
Long waiting list for affordable housing	13.1%	70
Other	10.5%	56
I don’t understand the application procedure for affordable housing program	5.6%	30
I don’t have references	4.7%	25

Other Barriers Faced in Housing

A Deaf ASL user who has fostered Deaf and Hard of Hearing children shared, *"With my foster kid, the DHS took care of the interpreting process. They're [DHS] very strict [about regulations], which is good. We had one smoke alarm that wasn't acceptable because we're Deaf. She was right; it would just beep and we wouldn't know if there were a fire, you know what I mean? So I had to change it to a visual alarm, so I was glad she knew that. The alarm also had to be with a carbon monoxide detector. It had to have a light. So, it's sad that a regular smoke alarm is maybe $20, but for Deaf people, the detector is $179. Wow. I had to pay for that and we need several of these in the house. Luckily, our costs were covered [by DHS] so that helped us do it sooner, but that was interesting. I know this will be a financial barrier for many Deaf and hard of hearing people."*

A young hard of hearing male who wears hearing aids and uses ASL expressed his frustration, *"I'm renting an apartment, and when I started the lease two years ago, I requested visual alerts for the doorbell and fire alarm. They said they'd provide it for me, but then the management said I had to pay for it myself. I thought they were obligated to provide it, but they said I had to pay for it."*

A Deaf parent relayed this about the cost of equipment: *"I'm looking for a motion-sensing system for my child to alert us if needed during middle of the night. We might not know if he gets up during the night, so I've been looking for a motion-sensing thing, but there doesn't seem to be one with a flashing light. If you buy something, you can connect it and transfer it to the clock, but it's a small thing for sensing motion. And it's costly, so it's a long process. We're not able to find that. There's one company, Weitbrecht Communications, that has a kit for anything for your apartment like alarms, doorbells, everything. It's $700!"*

A deaf-blind male senior citizen shared his barrier as a homeowner, *"I passionately love my yard. I work in my yard as much as I can but it is very hard doing that. And I can barely afford the amount of extra help that I pay for."*

Then he shared his frustration over a recent home repair. *"When I had the ceiling repaired, it was a huge controversy. It was a huge battle with contractors 'cause the contractors said, 'Well, we think we fixed it good enough.' And so I asked the neighbor and the neighbor said, 'I don't think that's good enough. I couldn't look and decide for myself [because of significant vision loss]. So, eventually I hired another contractor and he basically said, 'It's good enough. I think I can just put one coat of paint on it.' There's a big repair in the area and it could have certainly been done better but I can't see it well enough. So it puts a lot of stress on me to know who to trust."* This same area leaked again during a recent downpour.

Transportation

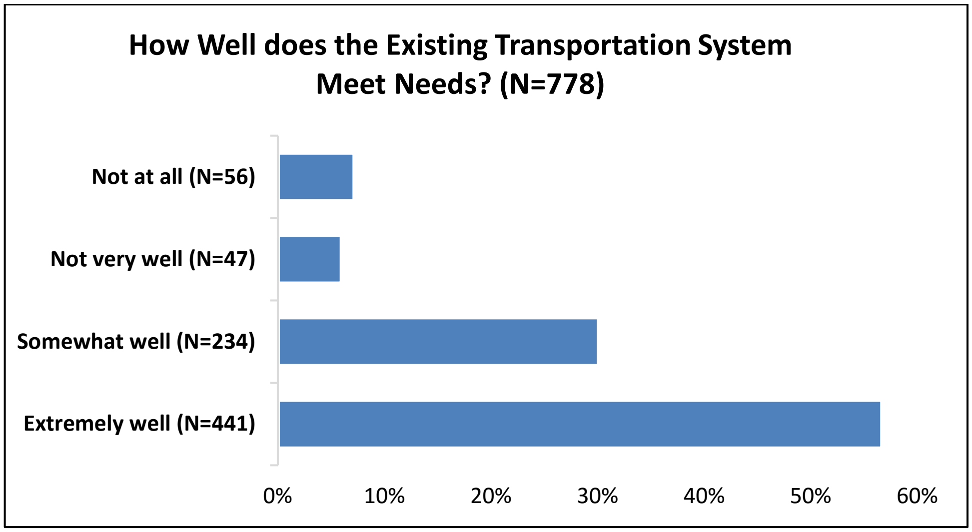
By far, respondents rely mostly on cars for their transportation needs (74.0%; N=81). One in ten (10.0%; N=81) relies on friends or families for their needs.

Table 21: Transportation Most Frequently Used

Most often used Transportation (N=814)	Percent	Count
Car or other motorized vehicle	74.0%	602
Friend/Family	10.0%	81
Public Transportation – BUS	6.1%	50
Public Transportation – Light Rail	3.1%	25
Walking	2.6%	21
Bicycle	1.6%	13
Paid support service provider	1.6%	13
Public Transportation – Other	1.1%	9

The existing transportation system, including transit, bikes, or highway, seems to meet over half of respondents' needs extremely well (56.7%; N=441). A sizeable proportion (13.2%; N=103), however, does not get their needs met at all or not very well.

Figure 15: Does Transportation Meet Needs?



Among those who use public transportation (bus, light rail, or other) (N=83), just over two in four (43.4%; N=36) say the system serves them extremely well; with another 45.8% (N=38) stating it serves them somewhat well. Another 10.8% (N=9) do not believe the existing transportation system serves them adequately. Most responses about issues with transportation relate to being in a rural area where there is no public transportation or only limited times and stops, and not being able to get to the stops.

Transportation Barriers

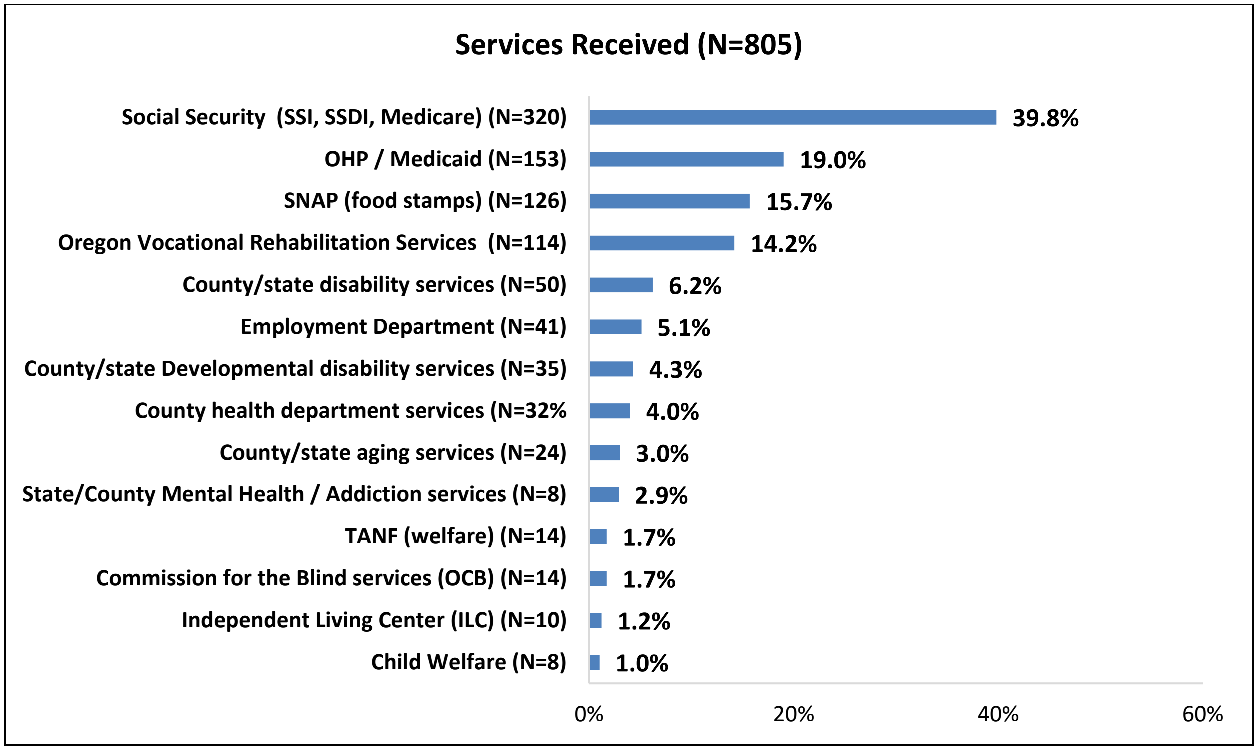
> A DeafBlind person shared her significant barrier in transportation living in a rural town, *"Because of my hearing loss and my vision loss, my biggest barrier is transportation. I love this town and I would like to settle here if I can but the biggest problem is transportation. If I want to go food*

> *shopping, I have to find a friend who would be willing to drive me to the grocery store or hire a SSP to drive me."* She also discussed significant social isolation because of a transportation barrier by depending on the person's schedule in order to plan any activities*. "If I had an awful day or feel overwhelmed, I can't [just] go out."* Limited bus schedule is a barrier for many who rely on public transportation and often feel isolated during evenings and weekends, *"There is a bus but it is very, very limited. It only works Monday through Friday and for a limited time period per day. The last bus to [the bigger town] is 5:30PM. The first bus is in the morning and it runs every 50 minutes."*

Public Services

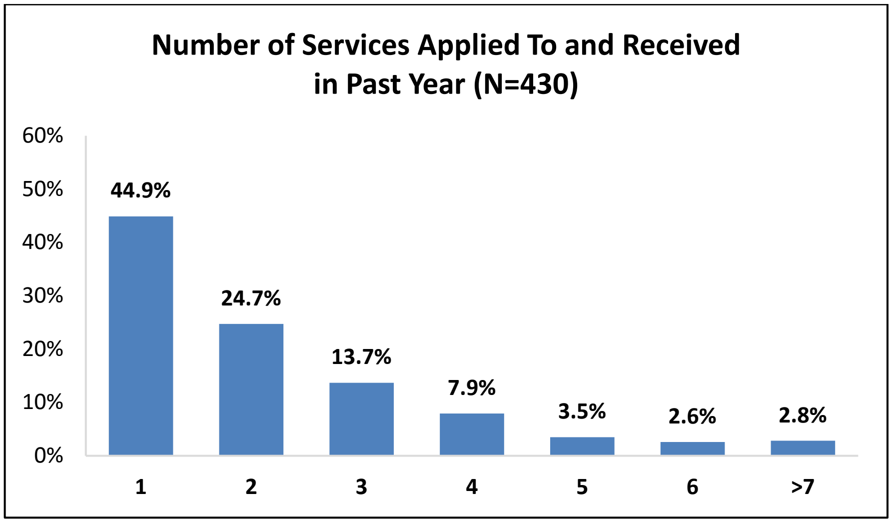
Respondents were asked about their use of 14 different public services over the past year. Overall, 39.8% (N=320) received services through social security, and another 19.0% (N=153) received services through OHP/Medicaid.

Figure 16. Services Received



Of the 805 respondents who answered the questions about which of 14 public services they have applied to in the past year, 42.7% (N=344) did not apply to any service. Among the 430 respondents who did receive services, 44.9% (N=193) applied to and received one service. The average number of services received is 2.24.

Figure 17. Number of Services Applied to and Received in the Past Year



Respondents were asked if they had applied for any of these services in the past year only, in order to ensure responses and any concerns that were brought up were current and relevant. In the chart below, the bars on the left indicate the percent who did not apply in the past year, and the bars to the right indicate the percent who did apply for the service in the past year. Note: they may already be using the service from an application in a previous year.

Figure 18. Overall Agency Usage

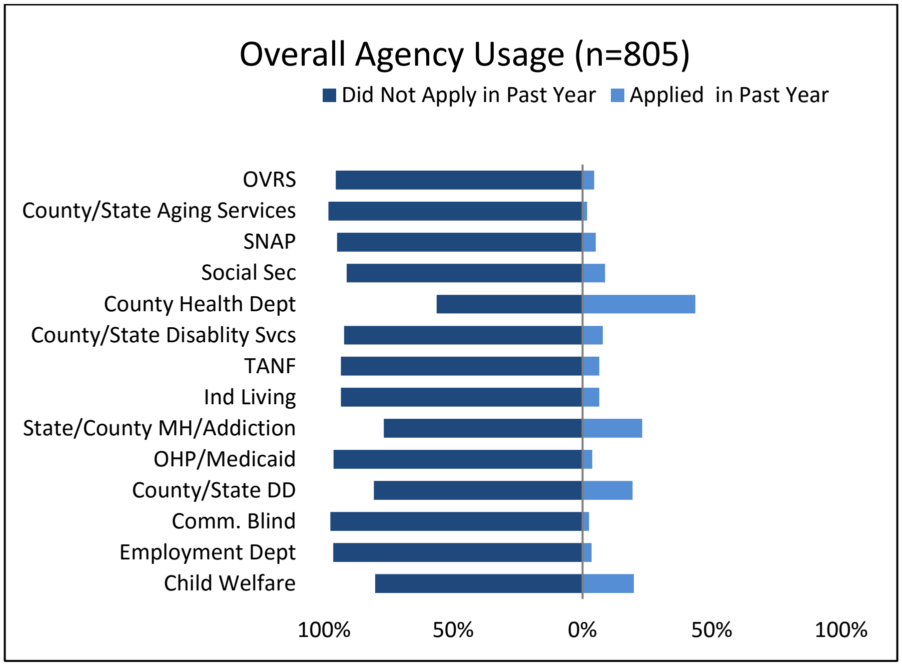


Figure 19 breaks down those who applied for services and what their current application status was. The darkest color on the far left are those waiting for a response, the middle segments are those who have applied and did not receive services, and the far right segments are those who applied and were approved for services. Note the N, listed next to the agency, varies greatly for each program.

Figure 19. Agency Application Status

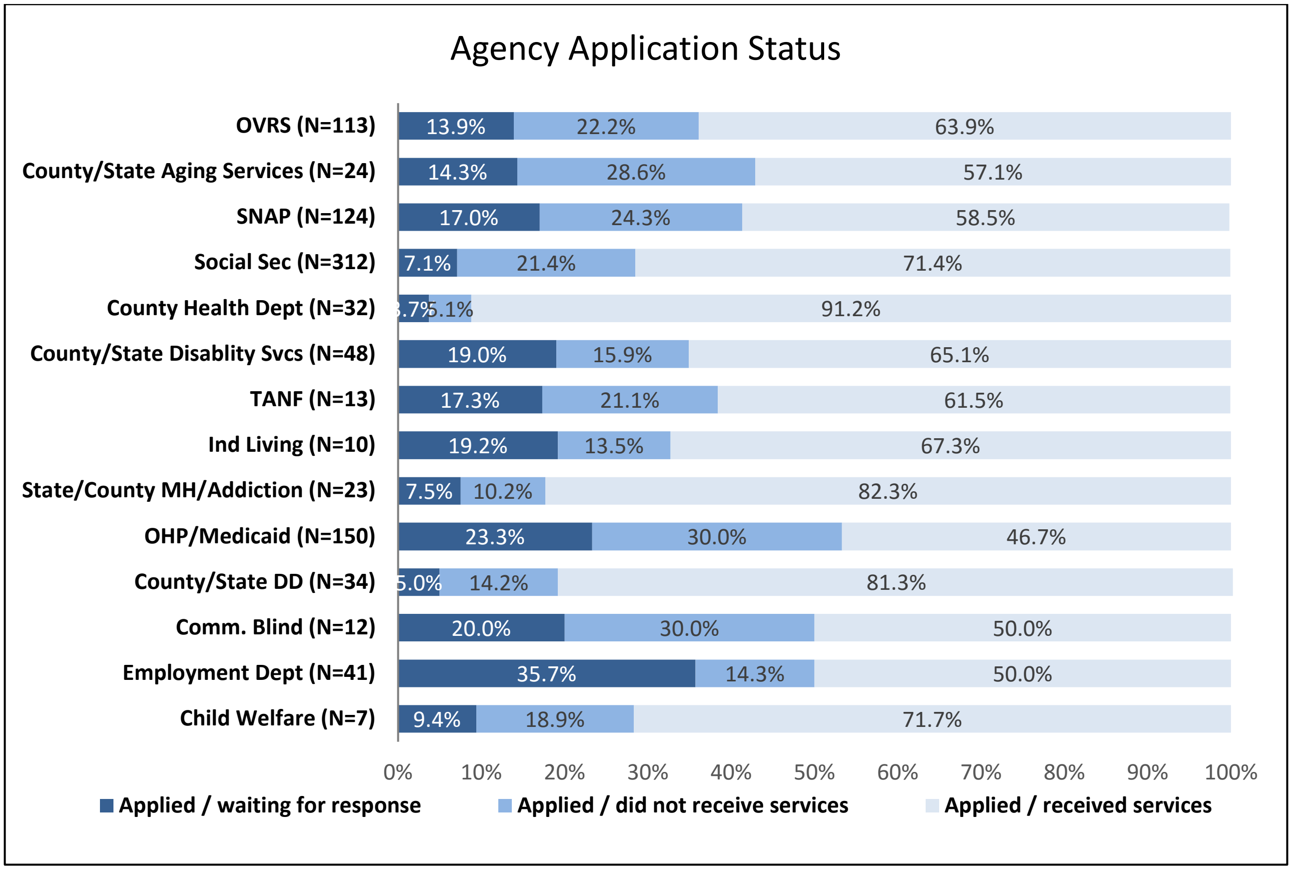
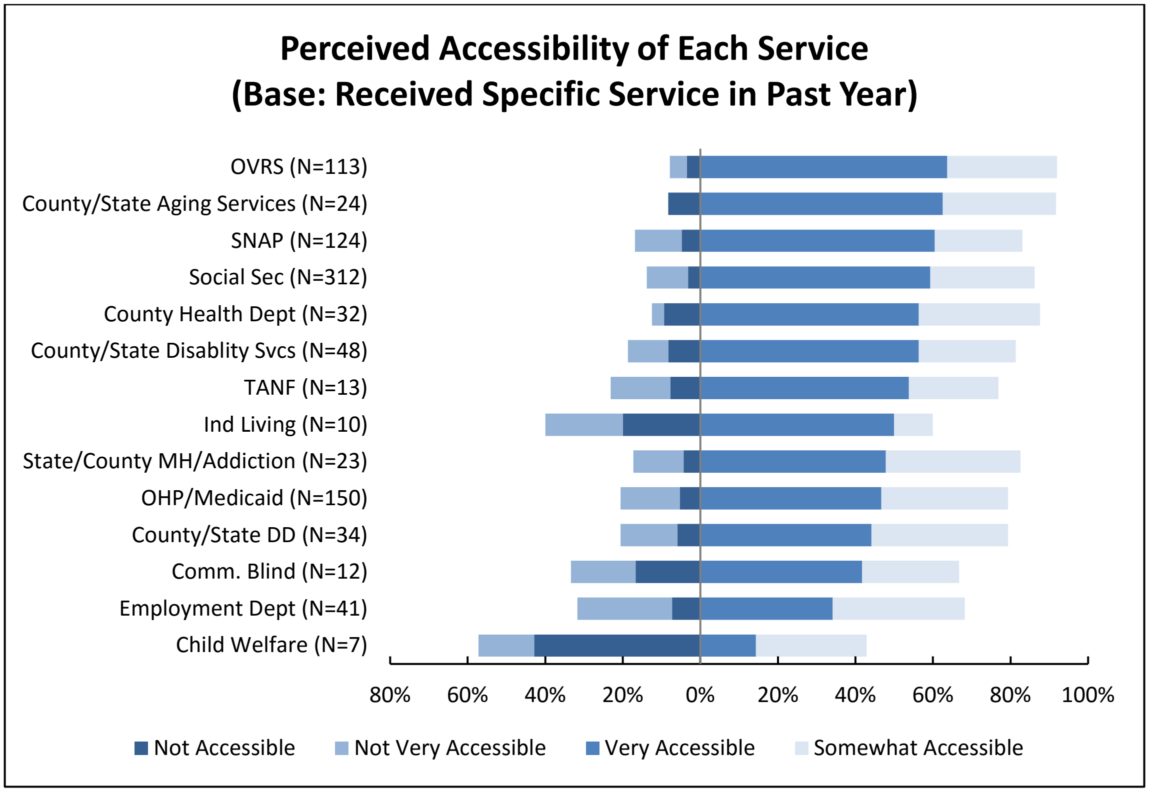


Figure 20 reflects how accessible consumers of state and county services perceived them to be. To the right of the midline are the Very Accessible and Somewhat Accessible responses, and to the left are Not Accessible and Not Very Accessible responses. The baseline for this question is limited to individuals who received services from the agency, thus the N's vary widely. Total N's are listed next to the agency. Among respondents who received specific services, the Oregon Vocational Rehabilitation Services were seen as most accessible (92.0%; N=104). Least likely to be viewed as accessible was the Child Welfare office (42.9%; N=3).

Figure 20. Perceived Accessibility of Each Service



One-third (34.8%: N=247) of the total respondents to this item report having no difficulties when accessing public services. Of those who did face challenges, people impatient with communication (45.7%; N=196) or the lack of available interpreters (40.3%; N=173) are among the main reasons that make access to public services difficult for respondents.

Table 22: Difficulties in Accessing Public Services in the Past 12 Months

Difficulties in Accessing Public Services –Past 12 months (Multiple Response) (N=429)	**Percent**	**Count**
Person impatient with communication	45.7%	196
No interpreter available	40.3%	173
System too complicated/procedures and rules too confusing	31.0%	133
Interpreter not qualified	25.6%	110
Automated phone system not accessible	21.7%	93
No CART or caption services available	17.9%	77
Requests for accommodations ignored/denied	14.2%	101
No FM/Loop/Personal assistive listening system	11.4%	49
No certified Deaf Interpreter	9.6%	41
Other	1.7%	12
Another person does all communication and work for me	1.4%	10
Space/facility not accessible	1.1%	8

Vocational Rehabilitation Services

Oregon Vocational Rehabilitation Services provides services to Oregonians with disabilities to obtain and maintain employment. The only exceptions are legal or total blindness or deaf-blindness. Deaf-blind individuals are served by the Oregon Commission for the Blind. OVRS currently has Rehabilitation Counselors who have Masters Degrees in rehabilitation counseling with a focus on Deaf and hard of hearing services in 8 out of 30 offices. It is reported that FM systems are available in each of the 30 offices located in Oregon. They reported they provide accommodations when requested by the Deaf and hard of hearing individuals for meetings, but pointed out challenges related to finding qualified interpreters.

When asked about what desired changes they would like to see in OVRS, one Rehabilitation Counselor for the Deaf stated, *“I'm hoping to be able to expand and do some targeted things with the Deaf students that are not necessarily in the school for the Deaf. We've got a really strong program for the Oregon School for the Deaf kids. But once they get out into the mainstream system we tend to lose them.”*

She continued, “Finding qualified partners to provide services at all is a challenge in most of the state, but for providing accommodations generally it's finding qualified interpreters. Generally for us, policy wise, that means certified. We want RID [Registry of Interpreters for the Deaf] certification or any certification. There's specific levels of certification that we consider acceptable. We do on occasion stray from that -- especially if the consumer says, ‘I want this interpreter because this interpreter is the best match for my communication style.’ We do not allow friends or family members to be interpreters -- that's just not okay. We work with clients when they are saying, ‘Well, so and so could just interpret.’ It's like, ‘No. And here's why’ and this is an opportunity to educate the Deaf or hard of hearing consumer who may not be aware of the issues or potential harm.”

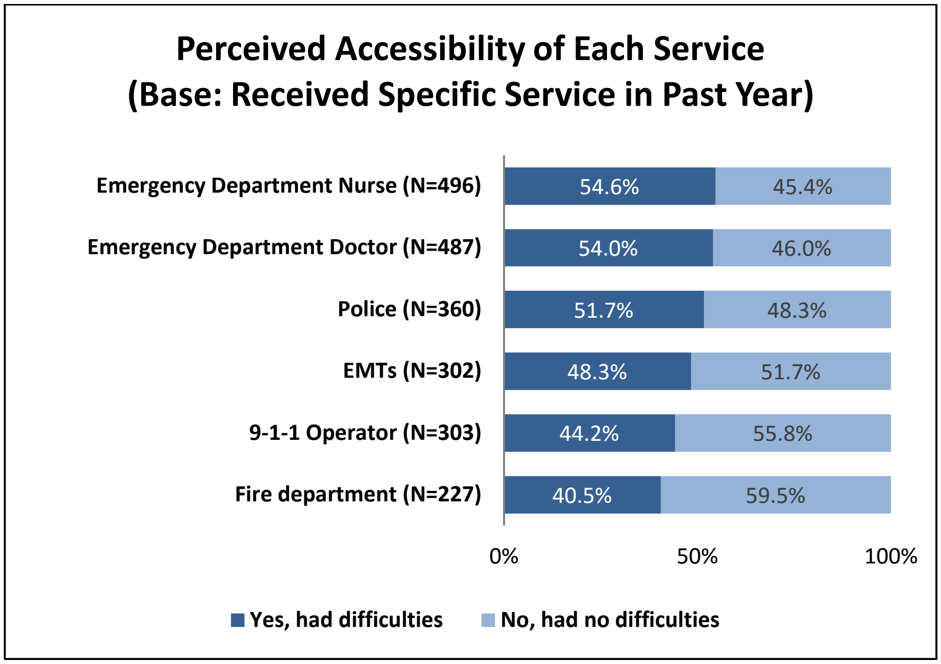
Barriers Related to Public Service Agencies

An organization that works closely with the DHS to provide services to the DeafPlus population shared both success stories and barriers related to accommodations and information access for their staff who are Deaf and hard of hearing: *“Much of our training is very discriminatory against folks who are Deaf. Oregon Developmental Disabled Services contracts with a company called OTAC. Oregon Technical Advisory Committee or something like that. They do all our training. …They provide specific training on autism or other characteristics, other developmental disabilities. They have a very comprehensive training program that they provide in English. They have webinars all the time. And they have refused [to make them accessible]. They have been asked in writing, verbally, we've asked them if there was any way to change that. We've tried to go through DHS to get some kind of accommodation [like the interpreter in the ‘picture in picture’ option on your webinar. Hey, at least have closed captioning--although that's really not the way to go because that's still English. And they have refused. So, I go to the training [because I am hearing] or I send my [hearing] assistant. We learn all the trainings and then we have to teach it to our [Deaf] staff.”* This requires additional resources and time for the organization.

First Responders

Respondents also experienced difficulties communicating with or receiving assistance from first responders in an emergency situation. Responses varied slightly from 806 to 821. The greatest number of respondents had interactions with emergency department doctors and nurses (60%). Respondents had the fewest interactions with fire departments (28%). Among those who used any of the services, over two in five stated they found it difficult to receive assistance from or communicate with first responders. Especially troubling are the percentages for situations involving emergency departments where over half had difficulties with either the doctors (54.0%; N=263) or the nurses (54.6%; N=271).

Figure 21. Difficulties Communicating with Emergency Responders



Text to 9-1-1

Several participants mentioned some incidents related to text to 9-1-1: *"The truth of the matter is any Deaf person will tell you that when they try to call 9-1-1, and this is something that we're currently changing and you may be very well aware of. But if you try to call 9-1-1 on TTY it hangs up on you. It hangs up on you again and again and again and again. Just because there's the delay. They think that there's nobody there anymore. So, text is the way to go. Talk to text. Text to talk is the way to go. Just within the last couple of weeks, Multnomah County, the north end of Oregon, and the southern end of Washington began a text to 9-1-1 system just within the last couple of weeks. We've been talking with both the city and the county for a very long time about text to 9-1-1. And as soon as I heard that they were doing it up there, I contacted Lane County here and they're waiting to see how it goes up there. But we really need it down here. It's just unbelievable that they don't have it. Not only for my Deaf staff. I have Deaf staff in the community. When an emergency happens -- we have smart phones for when we go out in the community and there's Sorenson on* *that phone so that they can make a videophone call from the cell phone. But that's still not as good as text to 9-1-1. So, we're looking forward to it."*

A lieutenant paramedic who was interviewed stated, "*Another thing that will help on the 9-1-1 side is direct texting with 9-1-1 for emergency calls rather than going through video relay. I think that would really speed up the emergency response, which I believe some counties are doing, texting 9-1-1, but not all of them."*

A website was developed to share information related to the text to 9-1-1 call in Oregon: www.nwtext911.info. Several videos with closed captions are posted on this website, as well as an ASL version (with subtitles). In addition, NG9-1-1 (next generation 9-1-1) is coming, and should be explored for Oregon. It will have options that will provide multiple ways to contact 9-1-1 that will help people with a variety of disabilities.

Fire Alarm Devices

A Deputy Fire Marshal from Central Oregon was interviewed related to accommodations for the Deaf and hard of hearing. This Fire Marshal initiated a program in 2005 to provide smoke alarms with flashing lights to Deaf and hard of hearing individuals. During the past year, 10 devices were provided to Deaf and hard of hearing individuals in the region.

A lieutenant paramedic from the Lower Willamette Valley was interviewed and mentioned that his department provided the smoke detector with a flashing light for the Deaf and hard of hearing population few years ago, but it was just a one-time opportunity.

During 2016, Portland Fire and Rescue Service (PF&R) received a $95,239 grant from the Federal Emergency Management Administration (FEMA) and then PF&R contributed additional $4,761 to make the total project amount to $100,000 to purchase and install specialized smoke alarms for the city's Deaf and hard of hearing residents. (More information can be found at: https://www.portlandoregon.gov/fire/article/570048.)

Emergency Management

Several emergency management individuals were interviewed in Oregon. Many confirmed that they were not sure if the videos related to emergency were captioned, nor could they confirm if any videos were provided in ASL for individuals who rely on visual language.

Foster System Barriers

Although not specifically listed in the state agencies list, several focus group participants shared stories related to the current foster system:

A Deaf woman in her late thirties who uses ASL *stated, **"**I have a barrier not for me, but for my foster child [who is Deaf]. We got a foster child who is six years old last June. We are his sixth family — he was with a different family each year. The number one barrier is probably communication. It's frustrating. He is Deaf and has a cochlear implant, but hasn't had an opportunity to learn how to use it. He doesn't know how. He's only six. With us, my husband was certified in 2012 [to take in foster children], and we specifically asked about Deaf children around Oregon. They said there was no way they could know if a child was Deaf, that they couldn't disclose that* *information. That means his life was almost ruined because he hopped from hearing family to hearing family who couldn't communicate with him. We're fortunate. Oh my God, I have a broken heart seeing what he's gone through and how he's become a product of that, his hopping from family to family. So we have a really tough time with him. He's signing, but he's making up signs that aren't decipherable. We can't understand him, and he makes faces in frustration, because he's trying so hard to speak and sign. — The point is, his barriers. Why didn't he get a Deaf family? I did ask the case worker if there were any other Deaf people interested in this, and she said there were three families: one hearing, a Deaf woman and hearing husband, and then a woman. The first family wasn't qualified because of the housing situation not fitting that child in terms of safety. So is it possible that your research [referring to this CNA report] could find a way through DHS to make sure that we in the Deaf community can know if Deaf foster kids are available out there. We could be the first to take those kids — often there aren't enough Deaf families, foster Deaf families."*

A young woman in her early twenties who uses both ASL and spoken language, and uses a cochlear implant, shared her personal story as a foster child for almost three years with four different families, **"***I went through the foster system, when I was a young kid. My mother was arrested, so the police had a few hours to place me and my brother, so they found the first family who was all hearing and didn't know sign. I didn't know how to communicate with them and all that. They couldn't find someone who knew sign, then a week later, they placed me with another family — it was two ladies, a mother and daughter. They didn't know sign. The daughter knew some signs, but it was still hard for me to communicate. We have a need for more qualified people who can sign in foster care. My barrier was that I didn't know what was going on in my case."* She was eventually placed with her relatives who did not sign and communicated mostly by writing. "*I want to see more foster care parents who can sign, or they could be Deaf, either way*."

A hearing mother who uses both ASL and spoken language in Southern Oregon adopted a Deaf son from the foster system, "*DHS never explained what happened [child's history]. When he came to me [at age of 3], he couldn't eat, he didn't know how to play, he couldn't hold his body yet. He was like a newborn baby…He had no body strength at all. Even when I would hold him, he'd just flop… I suspected he was in a crib for two years and was severely neglected. He did not have any language."*

Barriers to Housing Services for Individuals who Need Additional Services

People needing specialized housing for the Deaf who also have intellectual developmental disabilities expressed several frustrations with many barriers experienced in the state: *"They [Deaf residents] live in group homes with speaking staff and speaking roommates and they're isolated. They either get frustrated or fight and then they get ostracized for fighting or they isolate themselves and hide. The service we provide is opening up the world to them in their own language. I guess the best way to put this is that if you can imagine a situation where someone spoke French or Portuguese and they were in a house that only spoke English. That makes no sense. Well, it makes no sense to have somebody that uses American Sign Language to be in a house that speaks English. It's useless. You can't provide services to them at the same level as the speaking peers.*

"It's really a discrimination issue. Truly. There's no regulation or mandate for any of the providers to provide to folks who are developmentally disabled and deaf in their own language. They

continue to only hire speaking folks and who don't know ASL. There are some exceptions to that where there's a person here and a person there knows some sign language.

"And it goes beyond that because Deaf culture is very different than the speaking culture. So, having Deaf-to-Deaf is really important. It also makes sense because a Deaf person can learn how to be a direct support person in three to four months and be pretty good at it. But if you have a speaking person who's going to learn ASL, it's going to take four to six years. But even then, that's better than nothing. There's no funding for these.

"Here at this site, we pay for it ourselves and we have interpreters for everything that they do. Medical places, doctors and dentists and things like that, through us, have learned that they need to have interpreters and we mandate that they have interpreters because that's all disabilities access. It's the law.

"I can tell you, for sure, that other agencies do not. DHS does not. ODDS does not. I have a case manager that comes into this house every few months to do monitoring. For either behavioral stuff or medical stuff or whatever and they don't bring an interpreter with them.

"I actually saw a case manager, now they call them service coordinators, but I've seen a case manager come and when I have a new resident move into my house, she had the paperwork for him to sign. She didn't show up with an interpreter. She didn't want me to interpret. She spoke to the Deaf gentleman in English and pointed at things for him to sign where there's no way he could understand. It's just absolutely frustrating and wrong. You know, I get angry."

A 70 year old Deaf female who lives in Central Oregon who suffered from a stroke on her right side, expressed frustration with the Department of Human Services and believes that a lack of qualified DHS staff and ASL interpreter has been making it difficult for her to acquire an available bed at Chestnut Lane (a senior citizen housing that serves Deaf, hard of hearing, and deaf-blind in Gresham, OR*), "DHS won't let me go to Chestnut Lane. They [DHS] rejected me. They came to my home and evaluated me. Then they said I can't go to Chestnut. I was shocked. I need it because I have many health issues and I must live in assisted living. Right now I live at home by myself. I fall a lot and no one can help me. DHS say no to everything I asked for. For example, I asked for a caregiver and a [fall alert button]. I said I needed it and they [DHS] said I didn't need one. What?! I live by myself but they said sorry, if you want one, you can rent one. That was an insult. They knew I can't afford it. I barely can walk to bathroom. I cannot feel anything on my right side from the stroke, and I'm also half-blind from macular degeneration."*

She continued her story and shared a recent incident when she fell and struggled to call for help, *"A female manager of [the fire] department installed the alarm. She showed me how to use it. It was outstanding. She also put a lockbox outside that could store my house key. No one can access it except for the fire department in case of fire. That way they can use it if I'm inside and can't open the door. This is because I fell one time and had to use videophone. The video interpreter couldn't see my face but could see my hands. I said that I had fallen and needed someone to come to help me, but to not break in because it isn't my house. They said okay, but how do we come in? They asked if I could crawl to the door. I hurt my knee, but I did crawl to the door. I was hopeful I could reach the doorknob, and I did open it to the two men outside. They lifted me to a chair. I hurt my knee and they wanted me to go to the hospital, but I didn't want to because I had my dog in the*

> *house. I couldn't just leave the dog stuck in the house, so I insisted on staying. They thought I broke my knee. It's still tender today. This is why I need to live at Chestnut Lane."*

The Court System

Respondents were asked about their ability to complete legal forms (such as contracts) on their own, and were asked about their experiences (if any) with the court system. A small portion of respondents (16.0%; N=120) say they have trouble completing legal forms; with another 15.6% (N=117) not sure that they can complete forms on their own. Of the 778 responding to this item, 22.2% (N=169) indicated they were involved in the court system within the past five years.

While over one-third (37.3%) of respondents who were involved with the court system were invited to jury duty in the past five years, almost one quarter (23.1%) appeared as defendants.

Table 23: Reasons Involved in Court System

What are the reasons you were in court? (Multiple Response) (N=169)	**Percent**	**Count**
I was invited to do jury duty	37.3%	63
I was a witness	14.8%	25
I was a defendant	23.1%	39
Other	50.3%	85

Other reasons for court involvement involved traffic court (9.5%; N=16), divorce (9.5%; N=16) or child custody or support (4.1%; N=7), and financial issues (4.7%; N=8) of various types. Nine (5.3%) went to support family members who had court dates.

Out of the 63 respondents who were invited to serve on a jury, 23.8% (N=15) served, while the majority (76.2%; N=48) were excused. Among these, one in three (34.0%; N=18) believe they were excused because they had requested accommodations for their hearing loss.

Half (49.0%; N=75) of the respondents indicated they had no accommodations provided while in court. Certified American Sign Language interpreters are the most widely available accommodation.

Table 24: Accommodations used in Court Settings

Did you have any of the Following Available when in Court? (Multiple Response) (N=153)	**Percent**	**Count**
No accommodations were requested	49.0%	75
American Sign Language Interpreter (certified)	36.6%	56
Assistive Listening Devices (e.g., FM or Loop Systems)	8.5%	13
American Sign Language Interpreter (not certified)	5.2%	8
Video remote interpreter (VRI)	5.2%	8
CART/caption software	4.6%	7
Certified Deaf Interpreter	2.0%	3

Even though the above requests were provided, they did not always work as they should have. Four of the thirteen using assistive listening systems in the courtroom complained they were provided but did not work. Among those respondents (N=8) who had a video remote interpreter (VRI) available in the court, the experience was mostly perceived as negative (N=6), with the monitor too far away to see or the image freezing.

Respondents are noticeably unsure about the policies and availability of interpreters and assistive technology in the court system in their county of residence. Respondents were asked if their counties have policies regarding how courts notify people about the availability of interpreters or accommodations like CART, FM system, loop; if they've been encouraged to bring their own interpreters or assistive technology to court; if they understand the need for interpreters and assistive technology; if there is a designated person to contact for access; if the county court has a courtroom that is looped; and if information about accommodations is posted in public spaces. Between 62 and 82% of respondents who had been in the court system and had requested accommodations responded they were not sure if their counties had these policies or requirements.

ADA in Court System

Court ADA coordinators were interviewed throughout the state. The current training model involves statewide ADA training once every four months for new employee orientation. ADA coordinators at each of the courts in the state are responsible to provide ADA accommodations for all individual with disabilities who submit a request. Currently there are approximately 40 State ADA coordinators in Oregon*. “We have some information available. Website accessibility, accessibility, ADA. It describes on our internet page how to request an accommodation. Our policies aren't attached to this page, specifically. It guides them to how to request an accommodation, how to contact the ADA coordinator for each court and office of the State Court Administrator's office. And there's a request for an accommodation to use website information. And then we also provide an ADA complaint form and a court language access complaint form.”*

Barriers Related to Legal System

A Deaf woman who uses ASL shared her frustration related to meeting with a lawyer in Willamette Valley, *“I'll share one topic, that I'm not sure about the lawyer knowing the ADA law. That law means you provide interpreters for any situation regardless of factors —court, everything, the lawyer provides it. So I met with a lawyer. I have two lawyers, and I met with one to discuss something, and I wasn't billed for the interpreter even though it was kind of a hidden fee. So I paid [the bill]. Everything was okay and worked out. But the different lawyer, I was asked if I needed an interpreter, and I said yes. They said they'd provide one, so I went ahead and met with him for a consultation. Later, I got the bill and saw that I had to pay for the interpreter! Hey! He gets the write-off, but I have to pay? I went to argue with the lawyer, but he said it wasn't in his hands, and I ended up having to pay. So what's really the law? It's supposed to be that we ask for interpreters and get them, without paying for them? That's my question.”*

A Deaf woman in her forties who uses ASL shared her experience with the police when her sense of agency was lost, *“Two years ago, I was in a serious car accident, where the car was totaled. So at the site of the accident, the police showed up. Me and my best friend are both Deaf, so we didn't know what was going on. We requested an interpreter, but the cop said, ‘No, well, sorry,* *we can't do that.' And it was hard for me to read his illegible handwriting, so we had to wait for my best friend's [hearing] parents to show up to be able to help by talking with the police and exchange information."*

A Deaf mental health professional shared a concern related to incidents where Deaf individuals are not being properly evaluated for competency related to the court system, "*There are a lot of barriers related to the legal and mental health system. You have to be 100% competent [to stand trial]. Because [culturally] Deaf people are one percent of the population, we should have that percentage [to evaluate]. But, if you think about it, a lot of the things causing deafness cause other things, so we should have* more *Deaf people showing up. They don't really understand the language or the court process, and things that cause deafness often cause mental health or other problems. We should have at least 1% but we don't. That means we know there are people out there in the world who are not identified and not competent to go to court. They're being swept under the rug in the system. …Some Deaf people are a bit more complicated [to evaluate] because [their language dysfluencies are mistaken for] mental health issues. Sometimes we can be creative with labeling them, like saying 'communication disorders' if we need to help the person develop competency. But sometimes the lawyer doesn't realize that the Deaf person does not understand. Deaf people often will fake it, nodding and pretending, when in reality they're not understanding of what is happening. We need a proper specialist to evaluate their competency."*

He continued: "So there are Deaf people who are breaking the law, and their lawyers either don't notice or don't understand that the Deaf person isn't competent for court. Basically, these Deaf people do not meet the requirement for legal proceedings without some help. Many are in prison, but should have been sent to the OSH. They do not have access to communication in prison."

A former inmate who is hard of hearing and relies on ASL for communication shared his incident at the Washington County jail, *"I often attend classes and treatment in jail such as Alcoholics Anonymous (but I was never diagnosed with alcohol abuse). They wouldn't provide an interpreter. I just sit there and am lost because I was required to attend this 90 day in-patient treatment when I didn't have alcohol issue."* His partner also shared stories of where she became his advocate because of the barriers he experienced while in jail, *"I was a college student at that time. I remember how burned out I was, driving back and forth, fighting for him, taking care of my baby. I had no time for myself. I had postpartum depression, which deeply impacted me that summer. I couldn't take care of myself. I had to focus on the system, on him, fighting for him. The point is they didn't provide him with services he needed. They kept bluffing, and saying they couldn't give him a TTY but they would use him to interpret for other Deaf inmates. I was so pissed off. I got his hearing aids, he can't live without his hearing aids. There are current legal actions with the jail system in Oregon for similar issue."*

A DeafBlind male with tunnel vision who relies on ASL from Southern Oregon shared his recent incident with a police officer, *"The police came and arrested me July 2, and wrote me a citation, and I went to court. My communication barrier came when the police showed up. The police parked, and I told them I couldn't hear. I informed them I was Deaf, but the police kept commanding me to get down on the ground. I cooperated and put my hands behind me. They handcuffed me, and as I was on the ground, the police began asking me questions. I couldn't talk! I just shrugged and tried to verbalize that I'm Deaf, I'm Deaf, I'm Deaf. The police then asked, 'Can you read lips?' I shook my head no. They asked me questions on paper, and I shrugged because I couldn't write with*

> *my hands in handcuffs! They put me in the car and drove to the police station. They put me in a room, not a cell, but a room, where they removed the cuffs and explained what happened. They let me go with a citation. They also didn't read my Miranda rights."*

Quality of Life

The final set of variables were grouped into the category 'Quality of Life.' This category includes questions related to health, mental health, bullying and harassment, freedom from abuse, and alcohol and drug use.

Overall Indicators

Three quarters of respondents describe their physical and mental health, as well as the quality of their life, as either excellent or good. Quality of life especially is seen as excellent or good by 79.0% (N=622), while 70.6% (N=558) feel their mental health is excellent or good. Just a small percentage feel that either their health or quality of life is poor or even grave.

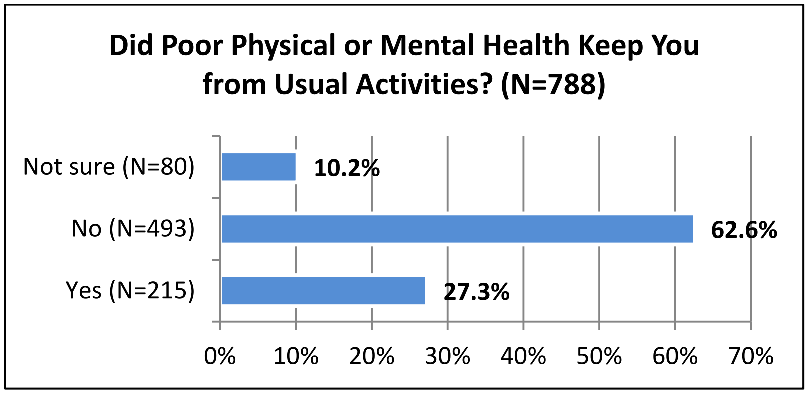
Table 25: Overall Quality of Life Indicators

Description of Overall Health and Quality of Life	**Excellent/ Good**	**Fair**	**Poor/ Grave**
Your overall physical health (N=791)	76.4% (604)	19.3% (153)	4.3% (34)
Your overall mental health (N=790)	70.6% (558)	22.8% (180)	6.6% (52)
Overall quality of life (N=787)	79.0% (622)	17.7% (139)	3.3% (26)

Health

Over one in four (27.3%; N= 215) respondents say their poor physical or mental health kept them from doing their usual activities, such as self-care, work, or recreation. Another 80 (10.2%) were unsure of the impact of their health or mental health on their usual daily activities.

Figure 22: Physical or Mental Health Interference with Usual Activities



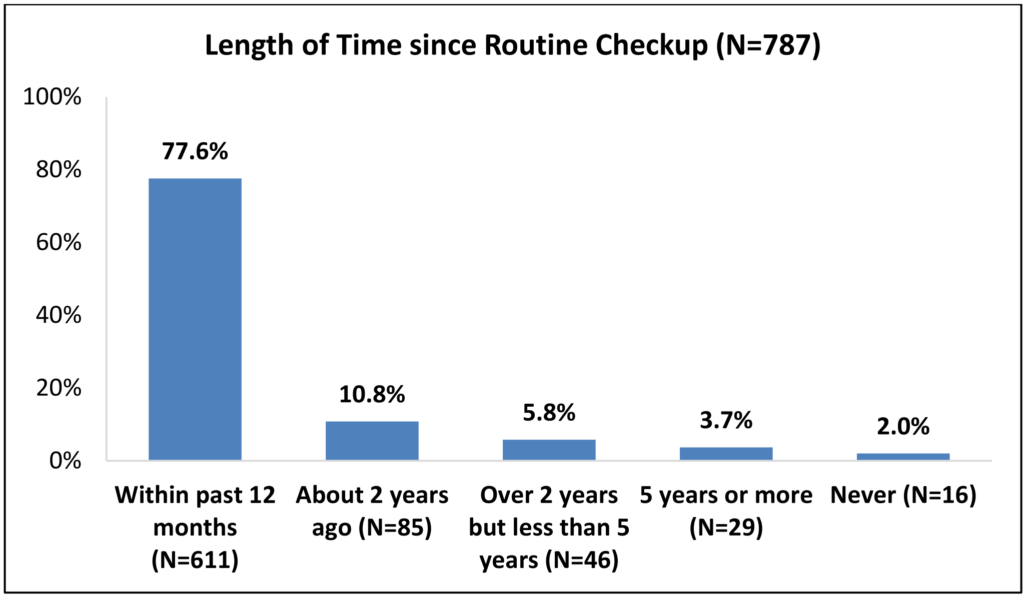
While the majority of respondents have medical coverage through Medicare (49.2%; N=3.83) or Medicaid (15.8%; N=123), over one-fourth (27.7%; N=216) buy their plan themselves or through a family member. One in five (21.2%; N=165) receive health insurance through their employer. Only 2.8% have no coverage.

Table 26: Type of Medical Coverage

Type of Medical Coverage (N=779)	Percent	Count
Medicare	49.20%	383
An individually purchased plan	27.70%	216
Plan through employment	21.20%	165
Medicaid / Oregon Health Plan	15.80%	123
Military/VA	6.70%	52
Affordable Care Act (ACA)	2.80%	22
No coverage	2.80%	22
Other	0.80%	6
Alaska Native, Indian or Tribal Health	0.50%	4

Even with insurance, out of 786 respondents, one in five (20.9%; N=164) delayed a doctor's visit at least once in the past twelve months because they could not afford the costs. Three-fourths (77.6%; N=611) have received a routine physical checkup within the past 12 months. However, a small portion have not received a checkup in over two years (9.5%; N=75), with 2.0% (N=16) stating they have never gone for a routine physical exam.

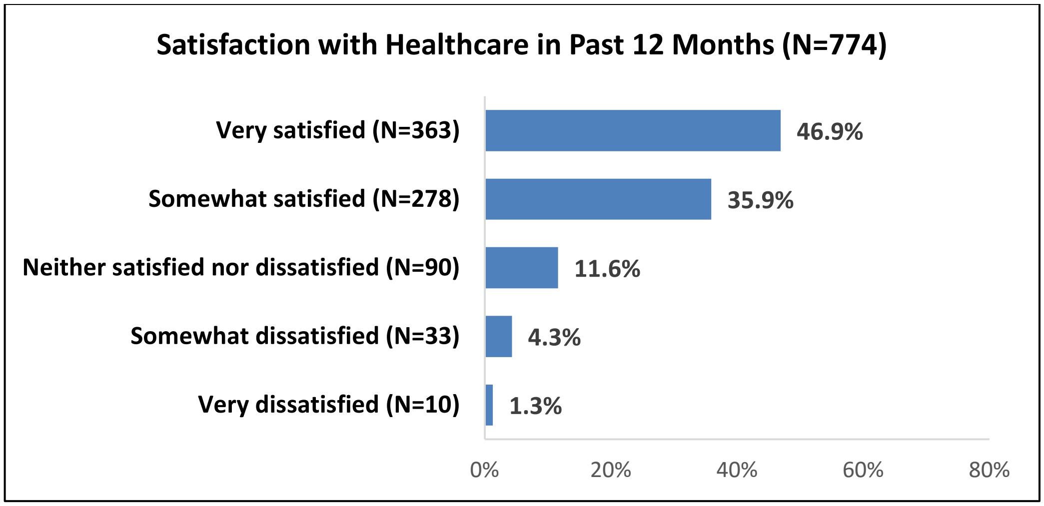
Figure 23. Length of time Since Routine Checkup



Respondents were also asked if they had experienced delays in medical treatment. While untimely appointments are the main reasons medical care was delayed (17.3%; N=121), respondents also mentioned interpreter availability or doctors not sensitive to their communication needs as reasons to not seek needed care (16.4%; N=115). Fifty-nine percent (N=413) did not experience delays in medical care or did not need any care.

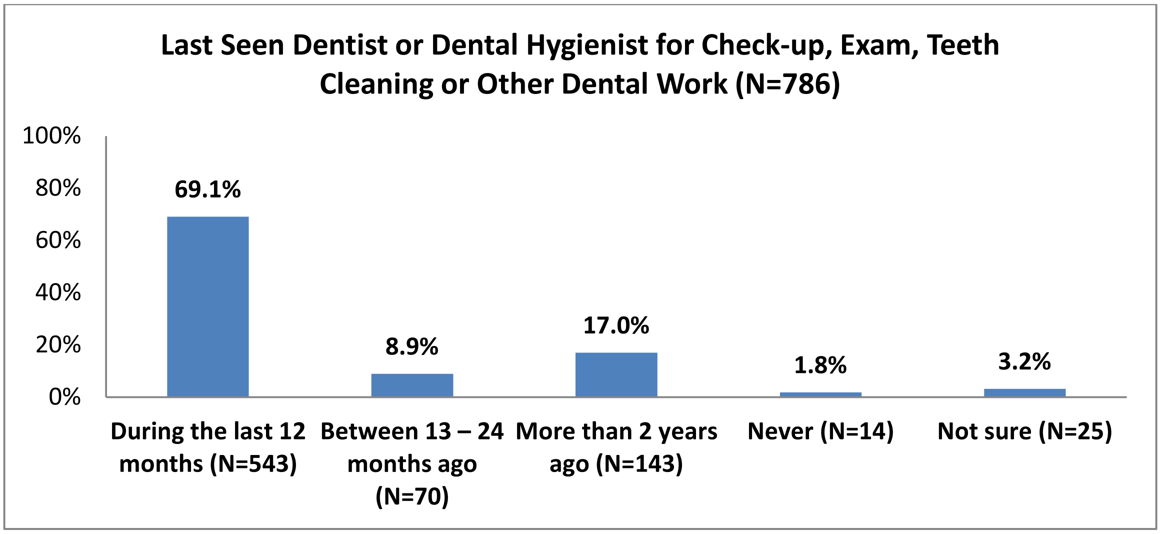
Almost half (46.9%; N=363) are very satisfied with the healthcare they have received in the past 12 months. Few (5.6%; N=43) express dissatisfaction overall.

Figure 24. Satisfaction with Healthcare in Past 12 Months



While seven in ten (69.1%; N=543) respondents have visited a dentist in the past 12 months, a smaller portion has not done so in over two years (17.0%; N=143). A few (1.8%; N=14) have never visited a dental office for a checkup, cleaning, or other dental work.

Figure 25. Timeframe of Seeing Dentist



Respondents are nearly split when it comes to their healthcare treatment and their hearing loss: While 9.1% (N=70) feel they were treated worse than others due to their hearing loss when they sought health care, nearly as many (6.9%; N=53) feel they were treated better. Overall, the majority feels they are treated the same as others (84.0%; N=646).

Table 27: Treatment in Healthcare Settings

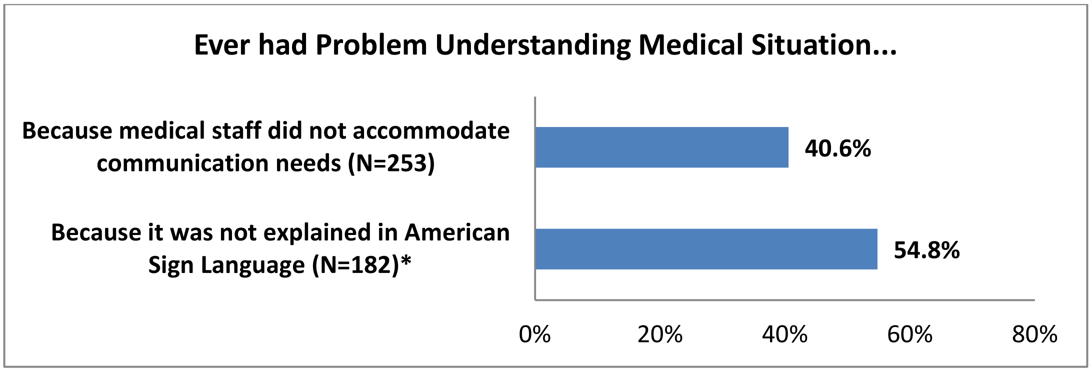
Within the past 12 months, when seeking healthcare, do you feel you were treated worse than, the same as, or better than other people without hearing loss? (N=769)	**Percent**	**Count**
Worse than others	9.1%	70
The same as others	84.0%	646
Better than others	6.9%	53

It is unclear on what the participants based this valuation. They did not seem to relate it to communication. Of the respondents who use ASL, tactile ASL, or SimCom (N=334), only half (N=170) report their doctor provides an ASL interpreter. Another 2.4% (N=8) report direct communication with their doctors (i.e., their doctor uses ASL him or herself). In the open-ended responses (N=579), 124 (21.4%) take a family member or friend with them to assist in communication. The majority of these respondents are people who would identify as hard of hearing and who do not use ASL for communication. Only 5 (.9%) indicated they used assistive listening technology in the doctor’s office, while 30 (5.2%) indicated they use writing.

Overall, two in five (40.6%; N=253) report they had a problem understanding a medical situation because the medical staff did not accommodate their communication needs. Among those who use ASL (N=332), over half (54.8%; N=182) had a problem because the situation was not explained in ASL.

A sizable portion of all respondents also state their doctor has asked them to bring their own interpreter or a family member to help with their communication needs (17.0%; N=130). Nearly three in four (72.6%; N=599) say their doctor accommodates them by speaking slower or making sure he or she speaks directly to them face to face.

Figure 26. Problem Understanding Medical Situation

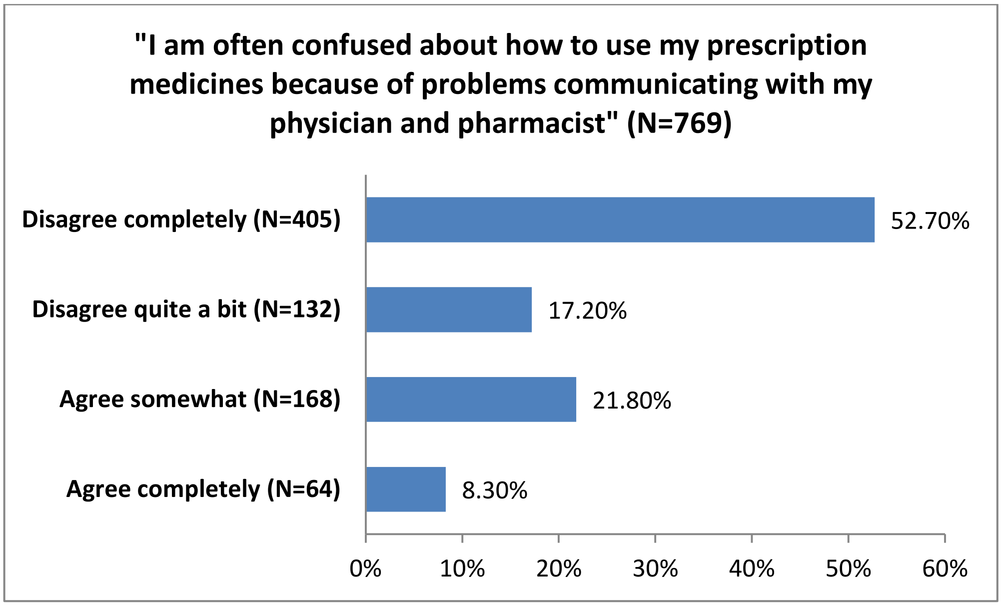


**Note: the base for the top item is people who mainly use spoken English (N=623) and the base for the lower item is respondents who communicate via American Sign Language, Total Communication, or Tactile American Sign Language (N=332)*

A hard of hearing male in his sixties shared his frustration and negative experience with the medical profession*, "The medical profession is really not good at providing assistive listening devices. We [HLAA] worked heavily with medical health and got them at least in the hospital to make some things available to hard of hearing people. But if you go to see a doctor and he's talking about what he's going to prescribe for you or what you should do for this condition or that condition and you don't understand but you think you've understood, it can be dangerous. They don't provide assistive devices."*

Further, when asked if they have experienced confusion about the use of prescription medicines, one-third (N=232) agree that they have been confused about how to use a prescription because of communication problems with their doctor or the pharmacist. In addition, 9.1% (N=71) say they have gotten sick or had a bad reaction to a prescription medicine because they did not understand the instructions.

Figure 27. Confusion about Prescriptions because of Communication



Communication Barriers in Medical Settings

A Deaf ASL user who grew up oral [spoken language methodology] and currently lives in Southern Oregon shared a situation that happened to her frequently when attending doctor's appointments, "*I call ahead of time and request for sign language interpreter. 'Sure, okay, we'll get one' and then I say 'Thank you.' Then I would show up [at the doctor's office] and ask 'Where is the interpreter? And they would respond, 'Oh there is no interpreter.' They act like they didn't know anything about my request but they do. They've seen me from before but they also know that I can talk. 'You can talk. You don't need an interpreter.' I would tell them that my mouth is not broken but my ears are*."

This same woman shared her frustration related to her speaking ability, "*People have told me that my speaking ability is awesome and is like a hearing person's ability and I say 'thank you' but really, it is a curse because they don't give me an interpreter because I've been told many times that I speak fine, and that I don't need an interpreter. My mouth does not need an interpreter, my ears do!"*

A senior citizen ASL user in Willamette Valley shared her medical setting barrier, *"I had a doctor perform surgery on my foot. I asked for an interpreter, and was told they would take care of everything. I showed up, and there was no interpreter. The nurse said, 'Oh, we don't need to. We can write back and forth.' The woman knew a bit of sign, and I was caught off guard. It was okay, better than nothing. …But for more details, she couldn't understand. I had to repeat myself over and over. I didn't like that, no. I wanted to emphasize certain things, and she couldn't understand. I preferred an interpreter, but they said we didn't need one. I wonder if they were trying to save money by using this woman who worked at the doctor's clinic."*

Several participants expressed their struggle using Video Remote Interpreting (VRI). A few expressed that this can be a helpful resource when a live interpreter is not available, however, it should not be used in many medical settings. Several stories were shared:

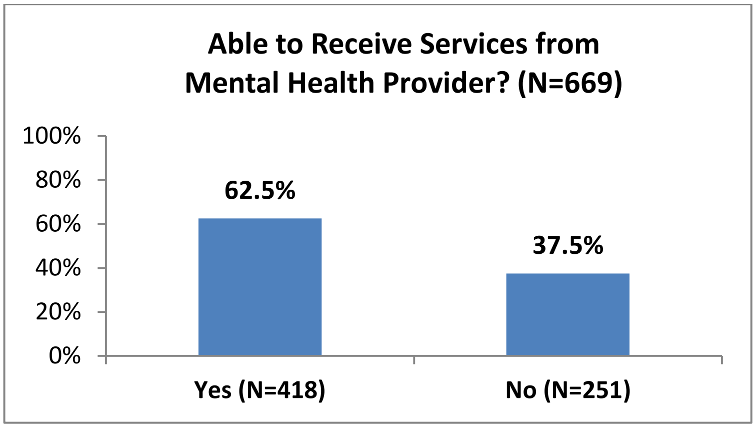
> A Deaf woman who uses ASL from Southern Oregon shared situations where the doctor's office uses the VRI equipment for Spanish-language users and reported that Spanish-speaking patients often get priority: *"I went in [doctor's reception] and signed in. I asked where the interpreter was. The interpreter should have arrived by now. 'Oh, we didn't get one.' I told her, 'I called in advance and requested one.' The person goes to speak to someone else then comes back and says, 'We don't, ah, we have to wait until you're in the back. We can get you VRI from the back, not from the front.' I said, 'Well, you gave me a lot of paperwork to fill out.' And she said, 'You can do that here in the waiting room.' Well, there were a lot of questions on these papers. I go ahead and fill out the paperwork but didn't get it all done in time. Then I go in to the back and there is no VRI. They said, 'We couldn't get it. There is another Spanish family using it.' I notice with VRI, they use it a lot with Spanish families…Spanish-speaking patients…than with Deaf. They get priority over Deaf people. I notice that has happened a number of times. And even in the middle of my using the VRI, someone came in and took away the device saying, 'We have to use this for a Spanish-speaking patient.' They took it away from me. I was left feeling helpless. It has happened to me several times."*
>
> A Deaf woman from Southern Oregon who uses ASL wanted to share her story on VRI barriers*: "My primary doctor was wonderful. I had her for many years. She used to allow live interpreters. Awesome. Until one year ago, Asante made the decision that they would no longer use live interpreters for Deaf patients. Only VRI. Which is hard because sometimes VRI freezes, freezes, freezes. And, sometimes, it's not available which means having to cancel appointments. [A friend told me] this story: They brought the VRI into the room and told the Deaf person to hold the monitor close to his face. They passed it around and then told the Deaf person to hold it. They did not include the stand to hold the monitor. It was a laptop. So, the Deaf person had to struggle with holding the laptop in one hand and signing using the other one hand. It was so ridiculous!"*
>
> Another ASL user reported her struggle with using VRI in an emergency room, *"We need live interpreters. An example is in the ER. I know VRI is a backup for the ER. We need it. That's fine when no live interpreters are available. But, sometimes, it is not convenient. Like, one time, two or three months ago, I went to the ER. I was hit with a terrible migraine. It was a mini-stroke. At that time, I was bent over with my fists clenched. I could not use VRI. I wish at that time, I had a live interpreter to be able to get down to my eye level and sign to me. It would have been perfect. But it was impossible. There were no interpreters."*
>
> A Deaf person shared an emotional story related to her frustration at the hospital with her family member who is Deaf with vision loss issues*. "My Deaf mother was in hospital and the hospital staff said the VRI must stay at the end of the bed. My mom was sitting up in bed with her legs outstretched. They wanted to put the VRI at the end of the bed just past her feet. She can't see. She can't see. She is blind in her left eye. Her right eye was blurry. She'd just had a stroke. That is why she was in the hospital. My dad…my dad's Deaf. So he told them to adjust the VRI so that it was facing him so that he could sign and could talk for my mom. They said 'No. No.' They said my dad could not touch the screen. They said he would have to direct his comments to my mom. My dad then yelled and said. 'SHE CAN'T SEE! She can't — she's relying on me!' They ignored him and started speaking. The interpreter on the screen is continuing to sign. My dad becomes frustrated. My*

> *mom was just sitting there staring at the screen blankly. It just so happened my sister — she's from the area — she came in and saw what was going on. She started telling them how it needed to be done, that the screen needed to be turned to face my dad. They said, 'We can't. It's our policy. We can't turn the screen for others to see. The screen must be facing the patient only.' My dad — oh, he was so angry. We had to appease my dad and tell him, 'We're in the hospital, calm down, calm down.' Then we turned to my mom: 'You need to watch the screen. Do you understand?' Then my hearing sister just started interpreting. She basically just took over."*

Mental Health

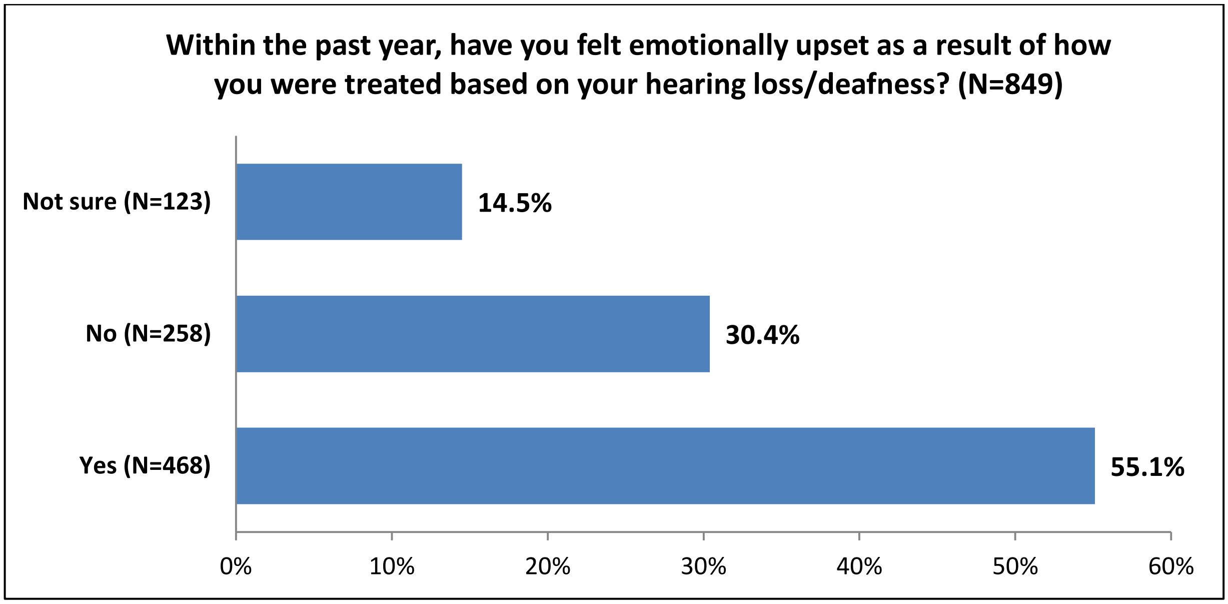
Respondents were asked several questions about their mental health and their use of mental health service providers. Over one-third (37.5%; N=251) of respondents say they were not able to receive services with a mental health provider to help them deal with stress or mental health issues. Among those who were able to (62.5%, N=418), just 60% (N=233) say their provider accommodates their communication needs.

Figure 28. Able to Receive Mental Health Services



Over half of respondents (55.1%; N=468) say they have felt emotionally upset over their treatment due to their hearing loss or deafness in the past year. Another 14.5% (N=123) are unsure if they have felt upset for this reason.

Figure 29. Felt Emotionally Upset over Treatment Based on Hearing Loss/Deafness



Over half (55.8%; N=467) think about their hearing loss or deafness at least daily. Only 17.3% (N=145) say they never think about it. Nearly as many (16.7%; N=140) say they constantly think about their hearing loss.

Table 28: How Much Thought given to Hearing Loss

How Often Think about Hearing Loss or Deafness (N=836)	**Percent**	**Count**
Never	17.3%	145
Once a year	8.3%	69
Once a month	8.6%	72
Once a week	9.9%	83
Once a day	11.4%	95
More than once a day	24.5%	205
Once an hour	3.2%	27
Constantly	16.7%	140
Net: weekly or more	***65.8%***	***550***

Availability of Mental Health Services

A state employer reported, "*The mental health services here in the state are abysmal. There literally are four private practice counselors that I know of who are either CODA's [children of Deaf adults] or Deaf themselves, culturally Deaf themselves and, most of those, you know, are full up or they only serve a certain part of the state or they can't take insurance or they don't take Oregon Health Plan which is the insurance that most folks who are receiving social security are on. Addiction treatment is nonexistent accessibly. There's still frustrations with employers and even some training*

> *institutions not being willing to provide interpreters because they think it's an undue hardship, which generally it's not, but they -- they don't want to provide the interpreters because of the cost."*

Isolation as a Mental Health Issue

> A deaf-blind male who relies on spoken language expressed grave concern related to research that indicated individuals with combination of hearing and vision loss are considered at a higher risk for depression, *"I can definitely understand that now…The loss of independence."*
>
> A hard of hearing female who lives in the North Coast region expressed her social isolation like this: "*Trying to make friends with people…nobody understood me, or they just didn't want to bond with me. …going to a movie and not being able to make out what they're saying or what the movie is about. Sometimes announcements in public places, I couldn't make them out. Lectures, if I go to anything like that, I couldn't hear anything they're saying. Maybe if I sit way in the front. That's how I got through school, just sitting in the front and studying. But I wasn't developing social skills, which I didn't realize until much, much later in my life. Because I kind of stayed away from people, and they stayed away from me. I missed out on social opportunities, business opportunities, and professional opportunities. Opportunities to have fun, like going to a movie. Hearing loss affects my whole life. It isolates you. Hearing loss is very isolating."*
>
> A hard of hearing senior citizen with a unilateral hearing loss [hearing loss in one ear] who lives in urban setting stated, "*The mental health system [is where most barriers exist] primarily because most mental health professionals are not used to working with individuals with hearing loss, and the impact of hearing loss or whatever the mental health issue is. One obvious one is that hearing loss itself is causing isolation and depression because of the lack of human contact, or the person is being isolated for another reason and hearing loss is making it worse because they don't know how to reach out."*
>
> A male cochlear implant user who uses primarily spoken language explained, *"Self-advocacy is really important. Effective self-advocacy is very much dependent on self-confidence. Having a disability or just generally not fitting in any way erodes self-confidence and make it so much harder to be able to participate fully in society."*
>
> A Southern Oregon male in his forties with progressive hearing loss echoed a familiar statement, "*Hard of hearing people have a tendency to withdraw and isolate themselves*," mainly to avoid stress, "*When my wife wants to go to something and I know I'm not going to understand it, I drag my feet if I am not able to get myself out of the situation*."

Mental Health System Barriers

Currently there is a significant shortage of mental health providers with specialized training to work with the Deaf and hard of hearing population, and who are considered fluent in ASL.

> A Deaf professional with mental health training discussed the current significant shortage of mental health providers who specialize in working with the Deaf and hard of hearing population, *"Compared with other providers of living and training, services here are nonexistent. We have three licensed mental health providers here in Oregon, and one doesn't really do clinical work anymore. One provides services [to Deaf and hard of hearing individuals] who receive Medicaid, but the other*

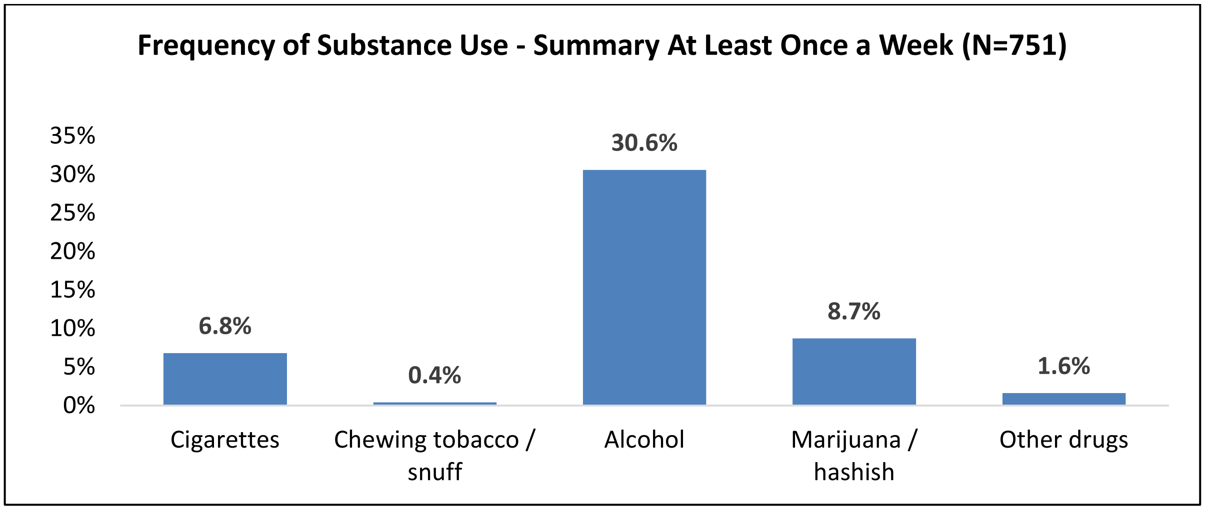
> *two cannot because of not being set up for Medicaid with Oregon Health Plan. With the current establishment here, private employers can't work with that system unless they want to provide services for free."*
>
> A Deaf woman who lives in an urban setting and uses ASL expressed anger with the shortage of Deaf counselors or mental health workers who uses ASL. *"A serious barrier for me is not being able to get the mental health services I need because of insurance limitations. I don't want to see a hearing counselor."*

Substance Use and Treatment

Respondents were asked to indicate which substances they had used and how often they used them, ranging from 'never' to 'daily.' With the exception of alcohol, the majority of respondents indicated they had never used the listed substances (e.g., 96.3% never use 'other drugs').

Nearly one in three (30.6%; N=230) use alcohol at least once a week; 6.8% (N=51) smoke at least once a week; and 8.7% (N=65) use marijuana/hashish at least once a week.

Figure 30. Frequency of Substance Use (at least once a week)



Among respondents who indicated any substance use and replied to the follow-up questions (N = 469), 6.2% (N=29) have considered treatment services or have been counseled to do so. Among these respondents, 59.4% (N=19) have used treatment services for alcohol or drug issues.

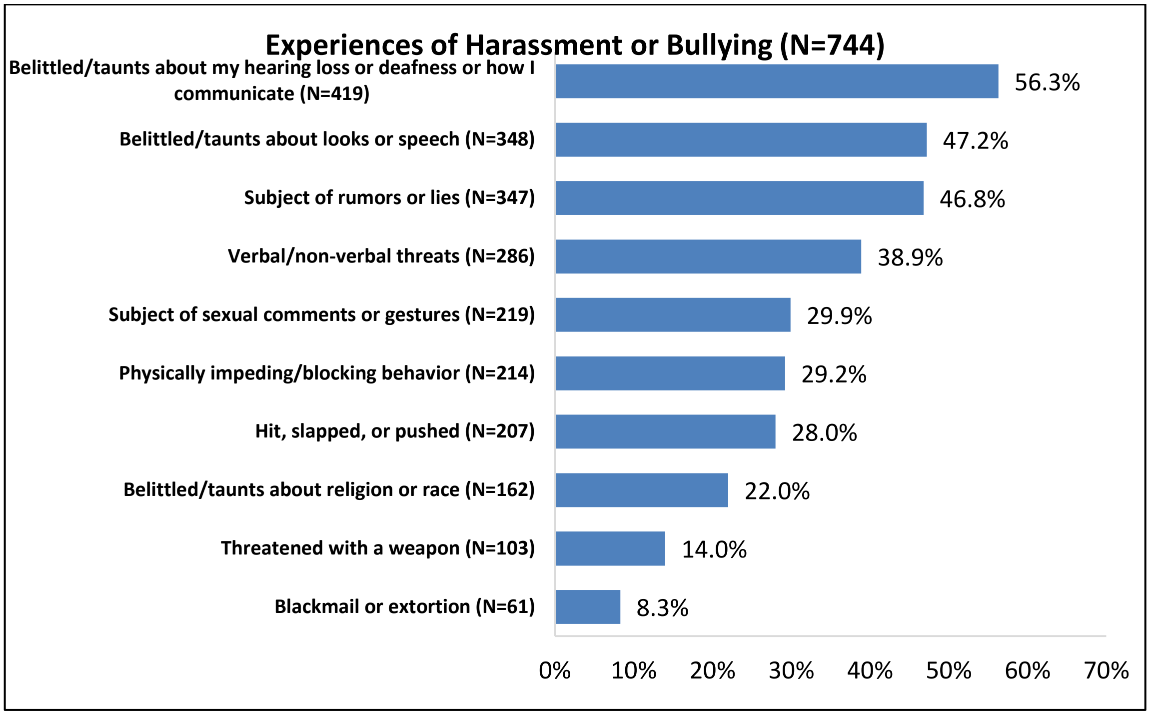
Of those 19 respondents who have used treatment services for their alcohol or drug issues, half (52.9%: N=9) received interpreters or other communication accommodations. The majority received ASL interpreters.

Harassment, Bullying, and Abuse

Participants were next asked a series of questions regarding harassment and bullying they had experienced, including where it had occurred, if they had contacted the police, and if they had received mental health services after the experience. Ten different harassment and bullying situations were described. Thirty percent (N=224) of respondents (N=750) indicate that they have never experienced harassment or bullying, and 35.8% (N=316) have experienced it in the past year. Twenty-two (3.0%) indicated that they had experienced all 10 at some point in their lives.

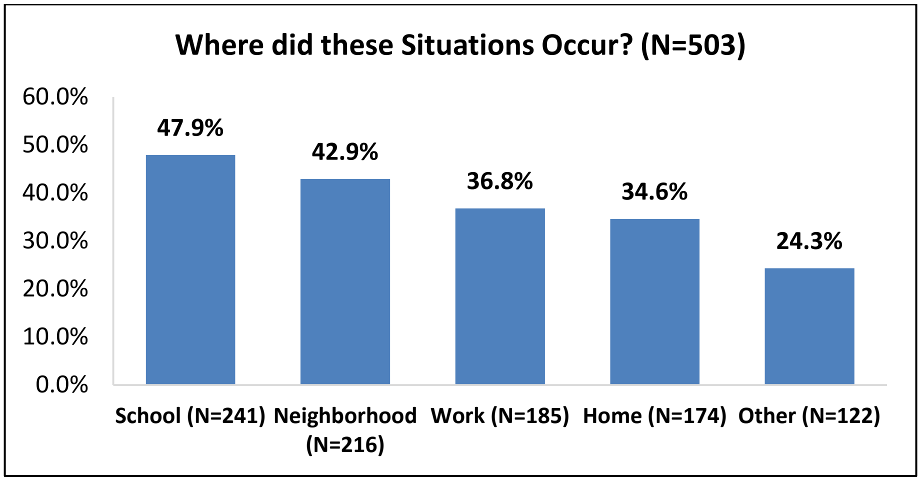
Over half (56.3%; N=419) of respondents have experienced taunts about their hearing loss or how they communicate during their lives. Nearly half (47.2%; N=348) have been belittled or taunted over their looks or speech. Another 46.8% (N=347) have been the subject of rumors or lies.

Figure 31. Experiences of Harassment or Bullying



Nearly half of 503 respondents (47.9%; N=241) have experienced situations involving harassment or taunts at school. Forty-three percent (N=216) also experienced such events in their own neighborhood.

Figure 32. Where Harassment/Bullying Occurred



Among respondents who have experienced harassment or bullying about their hearing loss or the way they communicate (N=419), 47.3% (N=198) said the harassment occurred at school, while 44.2% (N=185) stated it happened in their neighborhood.

Among those respondents who attended a mainstream school (with or without support) during K-6th grade and who have experienced harassment or bullying about their hearing loss or the way they communicate (N=243), 47.3% (N=115) said it occurred at school, while 43.6% (N=106) stated it happened in their neighborhood.

Respondents were also asked about their experiences of being harmed, threatened or abused. Forty-four respondents indicated they had contacted the police for assistance because of this. Thirty-seven people (84%) responded to the follow-up question asking if the communication experience with the police was positive or negative. Of these, 21 indicated positive experiences and 16 indicated negative experiences. The experiences tended to be described as positive when interpreters were provided, officers were understanding and made the effort to communicate, and were respectful. The negative experiences can be summed up by these three comments: *"I struggled to understand what they were saying." "They seemed irritated with the communication issues, and I was treated very dismissively." "They talked to the hearing people instead of me!"*

While 2.0% (N=15) say they have been physically forced to have sexual activity when they did not want to, 5.7% (N=43) responded they did not want to answer this question. Another 2.2% (N=17) were intentionally hit or physically hurt by their spouse/partner during the past 12 months; of these, only one person was encouraged to go to a shelter as a consequence. When these experiences are added to those that resulted in the respondent contacting the police, a total of 61 unduplicated responses related to harm, abuse, and threats were reported.

Among those who had been forced into sexual activity or who have been hit or physically hurt by their spouse/partner, just 48.4% (N=15) say they are able to receive services with a mental health provider to help them with violence, harassment, or abuse. Among these, 80.0% (N=12) say their mental health provider accommodates their communication preferences. Among those without access, a lack of insurance coverage or lack of interpreters are cited as reasons.

Limitations of the Study

While several excellent outcomes were a product of this research, the extremely short time frame impacted the project in several ways:

- In the development of the survey, the cognitive interview step was skipped. If time had allowed the inclusion of this step, some of the questions that caused people confusion could have been avoided. These were discussed in the report.
- The CAB had limited opportunity to review surveys and data. Many of them were also on vacations over the summer. This was mostly handled by requesting assistance from individual CAB members through email.
- Because it was summer, it was difficult to recruit individuals for focus groups, especially related to school programs. Even consumer organizations reduce the number of meetings they have over the summer.
- While social media was used heavily, which leaves out those without computers, large segments of the population were still reached through setting up community meetings.
- Building community trust takes time. For weeks after the survey had closed and focus groups were completed, people continued to request the opportunity to participate.
- The language level of the training program to educate researchers about protecting human rights (CITI) was challenging for most CAB members who do not use English as their first language. Although a graduate student was in the process of translating the materials into ASL, the project was not completed in time for this study.
- Because of the scope of the project and the timelines, there was insufficient time to compare data with secondary data sets, which would be helpful to the interpretation.

Findings and Recommendations

The Regional Resource Center on Deafness has appreciated the opportunity to conduct this important needs assessment for the State of Oregon. After reviewing the data, the research staff summarized a number of findings that led to recommendations for the State's consideration to improve services to Oregon's Deaf and Hard of Hearing Communities.

1. **Newborn infant hearing screening has made a huge impact on the lives of children with hearing loss.**
    a. Information for parents about services is not consistently provided.
    b. Language input from birth is vital. Oral and ASL methods used together will help the child develop Theory of Mind, agency, and understanding consequences, among others.
    c. Oregon requires insurance companies to cover bilateral cochlear implants for children if they qualify for them.
    d. Insurance companies do not cover hearing aids in the same way. As children grow, they need their hearing aids to grow with them. This is extremely expensive for parents, at a time when language input to children will have the most impact on the trajectory of their lives.
2. **Education of Deaf and hard of hearing children is complicated by both historical issues and state policy and law.**
    a. Until recently, there was no law on the books requiring teachers of the Deaf to be fluent in ASL.
    b. Oregon has just one program training teachers of the Deaf, and there is a severe shortage of qualified teachers in the state.
    c. Oregon has numerous public high school programs to teach ASL, but no requirements for those teachers to demonstrate mastery as other world languages do. College ASL programs often find incoming students have learned individual signs to match with English, but not the grammatical features of ASL.
    d. Finding skilled educational interpreters is a challenge for mainstream programs, especially in rural areas.
    e. Deaf and hard of hearing role models are vital to the child's identity development.
    f. The Oregon School for the Deaf is prevented by law from holding a preschool program there, something that is vital to Deaf and hard of hearing children's development.
    g. Although there is screening at birth, there may be complications to delivering early intervention services, sometimes because the services are not available, and sometimes because parents do not have the resources to follow through.
3. **Identity, critical mass, and access to community are challenges individuals and communities face.**
    a. Deaf, hard of hearing, deaf-blind, and deaf with additional disabilities adult role models can provide children a better understanding of how they might naturally approach the world with a visual or tactile mindset.
    b. Deaf, hard of hearing, deaf-blind, and deaf with additional disabilities adult role models can provide hearing teachers a better understanding of how to teach children taking advantage of their visual or tactile mindsets.

   c. Because deafness, deaf-blindness, and hearing loss with additional conditions are low-incidence disabilities, it is a challenge for many families to find peer groups for their children.
   d. Parents find it difficult to find ASL classes, to afford them when they are available, and to fit them into their schedules, especially if they have multiple children or jobs that don't allow flexible schedules.
   e. Although mainstream programs are popular and a good fit for some children, they are not the best fit for all children. Notably, many children move from mainstream settings to residential settings between elementary and high school. Better systems need to be in place to either improve support for children in mainstream settings or to identify at the earliest point possible when the setting is not a good fit so the child does not lose valuable educational years.
   f. Many children do not find their way to a Deaf community (referring to a culturally defined community) until after high school. This is often when they learn sign language and begin to develop a Deaf identity. This also applies to many children coming out of oral only programs.
   g. As one teacher of the Deaf pointed out, *"Apparently teaching hearing babies ASL improves their cognitive development, but parents are warned against teaching their Deaf or hard of hearing babies ASL. It's obscene, really."* Reviews of research show that children are not less likely to learn to speak if they also use sign language.

4. **Hearing aids, cochlear implants, and assistive technology can be extremely helpful or extremely confusing and frustrating.**
   a. If there isn't audibility, there is not a good fit. If the audiologist hasn't tested audibility, there is no proof that it has been achieved through the hearing aids. This means the hearing aids are not providing the benefit they could, the individual is not hearing as well as they could, and that thousands of dollars have been wasted.
   b. Hearing aids and cochlear implants cannot overcome noisy environments alone. Other (additional) assistive technology can be extremely helpful in these situations.
   c. The general public, including those with hearing loss, often do not recognize the benefits and limitations of hearing aids and cochlear implants. There is a pervasive attitude of 'there's not much that can be done' to improve the individual's situation.
   d. Hearing aids, cochlear implants, and other assistive technology can be very expensive, especially recognizing the equipment may need to be replaced every five years. Individuals with hearing loss need assistance in locating support for purchasing this equipment.
   e. The vast majority of individuals with hearing loss are not aware of other types of assistive technology which can be used with or without hearing aids and cochlear implants. The one specialist that individuals with hearing loss may see (e.g., hearing aid dispenser; audiologist; ear, nose, and throat specialists) are typically not providing information about other assistive listening equipment. This information is found through consumer groups and internet searches.
   f. Video remote interpreting (VRI) can be a powerful tool, but it is not appropriate for all settings. It is often difficult to see the screen, the screen is smaller than having a live person there, and the image may freeze, causing communication interruptions. In legal settings, disrupting the flow of the courtroom causes some judges to pull the accommodation. In healthcare, even when it is working properly, it is a challenge for a patient laying in a bed to see or focus on the screen, much less hold the screen in a

position where it is viewable. Additionally, holding the screen would interfere with the Deaf patient responding. This is not necessarily as much of an issue if the patient is able to sit up and if the screen is on a stand.

5. **Access to higher education is often at risk because of early years of experimentation with educational settings and communication modes.**
    a. The early education merry-go-round of seeking the right educational environment for a child often means that they end up having challenges obtaining a regular diploma. English language skills may be below grade level and places students at risk of not completing.
    b. Entrance exams that have not been standardized on this population (or on any other minority population) can prevent capable students from entering bachelors and masters level program, thus limiting their ability to earn a living and become the role models for other Deaf, hard of hearing, deaf-blind, and individuals who have additional disabilities.
6. **Access to the labor market is often at risk as it is more difficult for Deaf and Hard of Hearing Communities members to get the education they need for some jobs, as well as employment training and on-the-job training.**
    a. Numerous transition programs have indicated the importance of work experience in high school as a gateway to early adult employment opportunities and later earning ability.
    b. Many members of the Deaf and Hard of Hearing Communities face the limiting stereotypes of the public and experience underemployment and unemployment.
    c. Hard of hearing individuals exit the labor force earlier than they would like because of challenges functioning in groups (e.g., staff meetings), using the phone, and social/interpersonal challenges. The labor market is losing talented, experienced people because of a lack of knowledge about assistive technology.
7. **Public services definitely play a major role in the lives of members of the Deaf and Hard of Hearing Communities, but they often face challenges with paperwork, legalese, complex rules, and workers who do not know how best to communicate with them.**
    a. Mental Health services are vital as isolation can cause depression. Coupled with the link between not using amplification and dementia, this sets up the population for challenges.
    b. Programs supporting substance abuse treatment, domestic violence and abuse, and mental illness are rarely accessible to members of the Deaf and Hard of Hearing Communities. Counselors who can provide treatment via direct communication or who understand the impact of disabilities on an individual are extremely rare.
8. **Impacting public attitudes is one of the most important issues that needs to be addressed.**
    a. While newborn hearing infant screening has produced impressive results for babies, hearing loss often occurs after birth, and often not until later adulthood. Adults tend to put off having their hearing tested for seven years before seeking assistance.
    b. Many participants referenced the challenges of communicating with the general public, which is especially problematic when seeking services or medical or emergency assistance.
    c. Myths the public holds regarding the ability of hearing aids or cochlear implants to restore normal hearing, that all people with hearing loss speech read, that people with

hearing loss are less intelligent or less able have a profoundly negative impact on the self-esteem, self-image, sense of agency, and the ability to successfully compete in higher education and employment.

   d. Members of the general public become members with hearing loss, hearing and vision loss, and hearing, vision, and physical function loss. They also become family members of others with these losses. The better they understand the challenges and how to deal with them, the longer they can remain active in their lives and assist other family members to remain active and connected in theirs.
   e. People who are at the front desks of many of the services members of the Deaf and Hard of Hearing Communities seek, are the gatekeepers to those services. They should be well trained to interact with members of the Deaf and Hard of Hearing Communities and ensure that their communication needs are being met.

9. **Communication access is vital to the success of individuals at home, work, school, or play.**
   a. Self-advocacy must be taught, along with what the law requires and what the responsibilities of the individual are.
   b. In order to have an educated populace, access must be provided to all.
   c. Communication access, such as open captioning and freely available assistive listening technology, benefits everyone (e.g., English language learners, people needing to search the text of a speech on video, people unfamiliar with the technology can easily try it out).
   d. Many, many focus group respondents, when asked what services could be provided to improve communication access responded: “Get them to enforce the ADA!”
10. **Individuals who are DeafBlind or deaf-blind or who have additional disabilities are in severe need of support service providers (SSPs).**
   a. Most of these individuals do not have the funding to pay for assistance to go to the grocery store or be driven to the doctor. Some states provide funding for a few hours each month, rarely enough for these individuals to lead anything close to a normal life.
   b. Being able to go for a walk, have mail read to you, or simply not be in fear that because you are by yourself you are vulnerable to a random accident or violence is something that most of us don’t face.
   c. Oregon does not currently provide funding for SSPs. SSPs help the individual both with communication and with what is happening in the environment…the kind of feedback the rest of us take in with our eyes.
11. **Deaf children in foster care need a way to be connected to families who have the language skills to help them grow to their full potential. Time is always of the essence with children.**

The research team believes that the most efficacious way to address these findings would be a Commission for the Deaf, Hard of Hearing, and Deaf-Blind. This center (or preferably a main center with satellite centers located around the state, or some other way to reach the rural parts of the state in person) would function with an advisory board of stakeholders to inform the staff and the State of the current events in the numerous areas that impact members of the Deaf and Hard of Hearing Communities’ lives. The employees would be individuals who, for the most part, experience hearing loss themselves and who can use the variety of communication modes they will face as the

State's citizens seek assistance. The Center should be able to advocate and lobby as needed for changes in Oregon's laws and standard practices. For example:

1. Early Childhood Intervention and Education: Develop a committee comprised of teachers of the Deaf, university faculty, parents, state agencies, and consumer organizations to evaluate the laws, policies, and standard operating procedures that are interfering with getting the best services to identified children at the earliest stage. This is one of the most important actions that can have an impact on children's futures to prevent them from becoming at risk of dropping out, not completing with a regular diploma, and their future earnings abilities. Explore the LEAD-K model for Oregon (e.g., https://www.facebook.com/LANGUAGEEQUALITY/), and explore changing the law so that Oregon School for the Deaf can house preschool and early intervention programs on campus.
2. Review policies in general that impact members of the Deaf and Hard of Hearing Communities: Another example worth studying is how Deaf and hard of hearing foster children are matched with families. Currently, there does not seem to be any way to connect Deaf children with families who sign. These kinds of policies stay on the books until someone is able to recognize that a change is needed.
3. Support Families and Children: The sooner both families and children have Deaf role models in their lives, the sooner they will learn how to learn visually along with amplification. Provide a center where families can learn from experts and from each other, and children can meet peers who have the same life experiences they have.
4. Assistive Technology: Provide an assistive technology center and satellite centers where people can check out assistive technology and see what will work for them. The impact of hearing loss is different for everyone, and some devices work better than others. Because of the expense of the equipment, and some people's difficulties in learning new technology, these centers should be staffed with people who experience hearing loss and vision loss to ensure functionally relevant equipment is recommended.
5. Ensure that the ADA is enforced: There are laws in place, but there is much confusion among consumers about what their rights and responsibilities are. Technical assistance should be provided to agencies, businesses, and consumers. This center can also provide technical assistance in the labor market to ensure that employers are aware of their responsibilities under the law.
6. Ensure access to higher education and thereby the labor market: Again, a committee of stakeholders should evaluate entrance requirements at universities and community colleges to determine if their policies unfairly prevent individuals who are Deaf or hard of hearing from obtaining an advanced degree when they are otherwise qualified.
7. Ensure availability of affordable hearing aids and assistive technology for all. The impact of hearing loss can be devastating: To children because of the impact on language learning and education, to adults because it can reduce their employability and upward mobility on the job, and to seniors because a recently worsening loss can further isolate them from family and loved ones unnecessarily. In addition, recent research has shown there to be a connection between untreated hearing loss and dementia. For those who do not identify with the Deaf community and use ASL, hearing loss is not just an inconvenience, it is a health hazard.

8. Ensure the affordability and availability of support services providers to people who are deaf and have additional disabilities. This is an area where the State is behind other states in providing these life-affirming services.
9. Provide outreach to positively impact public perceptions on living with hearing loss and to help people understand the options that are available.
10. Provide a community center where people can come to learn sign language, and other supports can be provided, such as reading mail to individuals with low vision. The community center can showcase Deaf adult role models, and in general, provide a gathering place where people can come to feel a part of a community of people who are like themselves.

Currently the state has a system of service providers who face a challenge providing services to this low incidence population. Because attitudes about hearing loss, especially in people who are gatekeepers to services, are a major problem for members of Oregon's Deaf and Hard of Hearing Communities, the State faces a challenge keeping everyone trained who will interface with a Deaf, hard of hearing, or deaf-blind person infrequently. And because of communication challenges, the State may not even know how many people have given up before they even try to obtain services.

The final recommendation is for the State to review The National Association of the State Agencies for the Deaf and Hard of Hearing's (NASADHH) most recent survey of state agencies for the Deaf and hard of hearing. Here it can find out how other states have funded such centers, how other states are combining services into these centers (e.g., telecommunications device access programs, grants for assistive technology libraries, interpreter referral and certification). This report is included here in Appendix B. There are a myriad of community partners, such as Western Oregon University, EHDI, Hands and Voices, RSPF, OVRS (to name just a few) who could help make this happen and who could assist in providing innovative services that would make Oregon a model for providing services and preventing its Deaf and Hard of Hearing Communities from falling into any of the possible at-risk outcomes they face.

Biographies

Cheryl D. Davis, Ph.D., Grant oversight: Dr. Cheryl Davis has been the Director of the Regional Resource Center on Deafness since 2003, and in 2004 received the Special Friend of Hard of Hearing People award from the Hearing Loss Association of America (then Self Help for the Hard of Hearing) for her work in educating consumers and service providers across the country on hearing assistance technology. She was the co-investigator in the development, standardization, and psychometric testing of the Transition Competence Battery for Deaf Adolescents and Young Adults, a project that explored Deaf adolescents' employment and independent living skills. She has published articles in both trade and consumer journals regarding access, accommodations, and self-advocacy. Dr. Davis was responsible for ensuring that the tasks were carried out on time and within budget, and served as a reviewer of the research methods as the study was carried out.

Denise Thew Hackett, Ph.D., MSCI, Principal Investigator: Dr. Denise Thew Hackett is bilingually fluent in American Sign Language (ASL) and written English. She identifies as Deaf and has worked as a psychologist and researcher in the marginalized community for most of her professional career to address mental health and health disparities faced among Deaf and hard of hearing individuals. She is currently an Assistant Professor at Western Oregon University in the Rehabilitation and Mental Health Counseling (RMHC) program in DSPS.

Dr. Thew Hackett is uniquely qualified to be conducting this project. Her previous hands-on experience in developing American Sign Language survey with the National Center on Deaf Health Research trained her in the crucial framework of incorporating necessary culturally sensitive components when working with marginalized communities who have historically been excluded from many traditional surveys. Dr. Thew Hackett experienced working with the Community Based Participatory Research (CBPR) model during her 7-year career at the University of Rochester Medical Center, which included her 3-year Postdoctoral Training in Preventive Cardiology. She co-authored peer-reviewed articles on CBPR and ethical issues.

Relevant to research experiences in mixed methods framework with marginalized communities, Dr. Thew Hackett was an assistant to the PI in a NIH-funded project “Informed Consent for the Deaf and Hard of Hearing Population” (quantitative method) and a CDC-funded project “Factors Influencing Partner Violence Perpetration Affecting Deaf Individuals” (mixed methods using KII, FG and survey). During her Postdoctoral training, Dr. Thew Hackett led the “Tailoring a Healthy Living Intervention to Deaf Adults: Sociocultural Data from the Target Group.” She also conducted numerous KII and focus groups (FG) with her colleagues, and mentored interns on this framework. Additional experiences are outlined in the vita included in this proposal. Dr. Thew Hackett believes in incorporating diversity qualities among the Deaf and hard of hearing communities in every step of the project.

Evaluator, Sybille Guy, Ph.D. Team, The Research Institute: Dr. Guy is the Director of TRI's Center on Research, Evaluation & Analysis (CREA), and has an extensive background in team leadership and project management. Dr. Guy received her Ph.D. from the University of California at Los Angeles (UCLA) in Quantitative Psychology. As Data Analyst for the project she participated in quantitative and qualitative research instrument development and analysis.

Appendix A: Definitions

Note: Definitions with numbers in front of them are from RFP# DHS-4131-16: Community-based Needs Assessment (CNA).

2.2.2.1 “Assistive Communication Devices (ACD)” means technology that allows people experiencing communication barriers to communicate with the public at large.

2.2.2.2 “Assistive Listening Devices (ALD)” means a system of using amplifiers that bring sound directly into the ear via hearing aid telecoils or personal amplifying units.

2.2.2.3 “Computer Assisted Real-Time (CART)” means a form of instant translation of the spoken word into English text using a stenotype machine, computer, and real-time software which can be produced and delivered in-person or over the Internet.

2.2.2.4 “Culturally Competent” or “Cultural Competence” means the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, abilities, religions, genders, sexual orientations and other diverse backgrounds in a manner that recognizes, affirms and values the worth of individuals, families and communities, while protecting and preserving the dignity of each. Operationally defined, it is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes that create cultural settings in which quality of services produce better outcomes.

2.2.2.5 “Deaf Community”, for purposes of this RFP, means the entire diverse Deaf population, including people who are culturally D/deaf, DeafBlind, Deaf Plus, Hard of Hearing, Late-deafened, hearing aid or cochlear implant users and those experiencing hearing loss. This term may be used throughout the RFP for the purpose of brevity rather than restating each category and is not intended to exclude any group or population within the Deaf Community.

2.2.2.6 “Demographics” means age, county of residence, race, gender, education level completed, socioeconomic status, preferred identification within the Deaf Community, and primary or preferred means of communication.

2.2.2.7 “Focus Group” means a component of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a product, service, concept, advertisement or idea.

2.2.2.8 “Interpretive services” means services provided by a qualified individual or firm to provide communication access to individuals belonging to the Deaf Community via assistive technology including, but not limited to ALDs, CART, and qualified sign language interpreters.

2.2.2.9 “Qualified interpreter”, for purposes of this RFP, means “someone who is able to interpret effectively, accurately, and impartially, both receptively and expressively, using any specialized vocabulary.” (RID) will serve as documentation of qualification. Interpreters lacking NAD or RID certification may be deemed qualified if they have other certification (i.e., certification from another state or Educational Interpreter Performance Assessment (EIPA) for school settings).

American Sign Language (ASL): American Sign Language (ASL) is a visual language. With signing, the brain processes linguistic information through the eyes. The shape, placement, and movement of the hands, as well as facial expressions and body movements, all play important parts in conveying information. Like any spoken language, ASL is a language with its own unique rules of grammar and syntax. Source: https://nad.org/issues/american-sign-language/what-is-asl

ASL Interpreter: A sign language interpreter is a person trained in transferring meaning between a spoken and a signed language. This usually means someone who interprets what is being said and signs it for someone who can't hear, but understands sign.

Assistive listening device: a term applied to devices that transmit, process, and amplify sound. They may be used in conjunction with hearing aids, cochlear implants, or simply headphones or ear buds. The term is not used to refer to hearing aids or cochlear implants.

Braille: a form of written language for blind people, in which characters are represented by patterns of raised dots that are felt with the fingertips. Source: http://www.dictionary.com/browse/braille

Captel: CapTel is a captioned phone. It looks like a regular desk phone, but has a large digital readout so the individual can read what the other party says. A CapTel operator, automatically patched into the phone call on outgoing calls and (if you've got two phone lines) can be automatically patched into the call on incoming calls, too, creates the captions in real time. http://www.nchearingloss.org/captel.htm?fromncshhh.

Certified Deaf Interpreter: A Deaf Interpreter is a specialist who provides interpreting, translation, and transliteration services in American Sign Language and other visual and tactual communication forms used by individuals who are Deaf, hard-of-hearing, and Deaf-Blind. Source: http://www.interpretereducation.org/specialization/deaf-interpreter/

Close vision interpreter: used by deaf-blind individuals with low vision or tunnel vision. The interpreter works within the deaf-blind individual’s range of vision, usually from a distance of about five feet or less.

Cochlear Implant: an electronic device that partially restores hearing in people who have severe hearing loss due to damage of the inner ear and who receive limited benefit from hearing aids. Source: http://www.mayoclinic.org/tests-procedures/cochlear-implants/basics/definition/prc-20021470

Cued Speech: a visual mode of communication that uses handshapes and placements in combination with the mouth movements of speech to make the phonemes of a spoken language look different from each other. Source: http://www.cuedspeech.org/cued-speech-definition.php

Culturally Deaf: refers to an individual with little or no functional hearing, who uses American Sign Language to communicate, and considers themselves to be members of the Deaf Culture. Source: https://www.deaftec.org/content/deaf-definitions.

Deaf and Hard of Hearing Communities: the term used in this report over Deaf Community (see 2.2.2.5 above) to refer the entire diverse population with hearing loss, including people who are culturally Deaf, deaf, deaf-blind, DeafBlind, Deaf Plus, Hard of Hearing, Late-deafened, hearing aid or cochlear implant users and those experiencing hearing loss.

deaf (not culturally): "small d" deaf do not tend to associate with members of the Deaf ccommunity, identify themselves more as hearing, and tend to regard their hearing loss in medical terms. Source: https://www.verywell.com/deaf-culture-big-d-small-d-1046233

Deaf-Blind (with hyphen): is a combination of vision and hearing loss.

DeafBlind (without hyphen): DeafBlind people identify themselves as culturally Deaf and blind, and have a strong Deaf identity.

DeafPlus: refers to the individual hearing status combined with additional conditions. (idea borrowed from http://www.handsandvoices.org/comcon/articles/deafplus.htm)

Haptics: developed in Norway during the early 90’s in an effort to standardize a method of communication that was already evolving organically within the deaf-blind community. Haptic communication is a fixed set of signals performed in a specific way and in a defined order to provide visual and environmental information as well as social feedback to an individual who is deaf-blind. https://nationaldb.org/library/page/2588

Hard of Hearing: refers to an individual who has a hearing loss who may only use oral aural language and amplification, and may or may not use sign language. Source: https://www.deaftec.org/content/deaf-definitions

Hearing Impaired: used to describe an individual with any degree of hearing loss, is a term offensive to many Deaf and hard-of-hearing individuals. Source: https://www.deaftec.org/content/deaf-definitions

Late deafened: usually means deafness that happened postlingually, any time after the development of speech and language. Often it means after the age of adolescence (13 and above). Source: http://www.michdhh.org/deaf_hard_of_hearing/late_deafened.html

Oral deaf: a deaf individual utilizing the Oral method is a method for communication by using only the spoken language, lip reading, and voice training. Source: http://www.lifeprint.com/asl101/topics/communicatingwithdeaf.htm

Pidgin Signed English: a combination of American Sign Language (ASL) and English. ASL is a distinct language, and (like most other languages) it does not map perfectly to English. Source: http://www.nchearingloss.org/pse.htm

ProTactile this philosophy: supports the idea of providing social feedback through back channeling via touch. https://nationaldb.org/library/page/2588

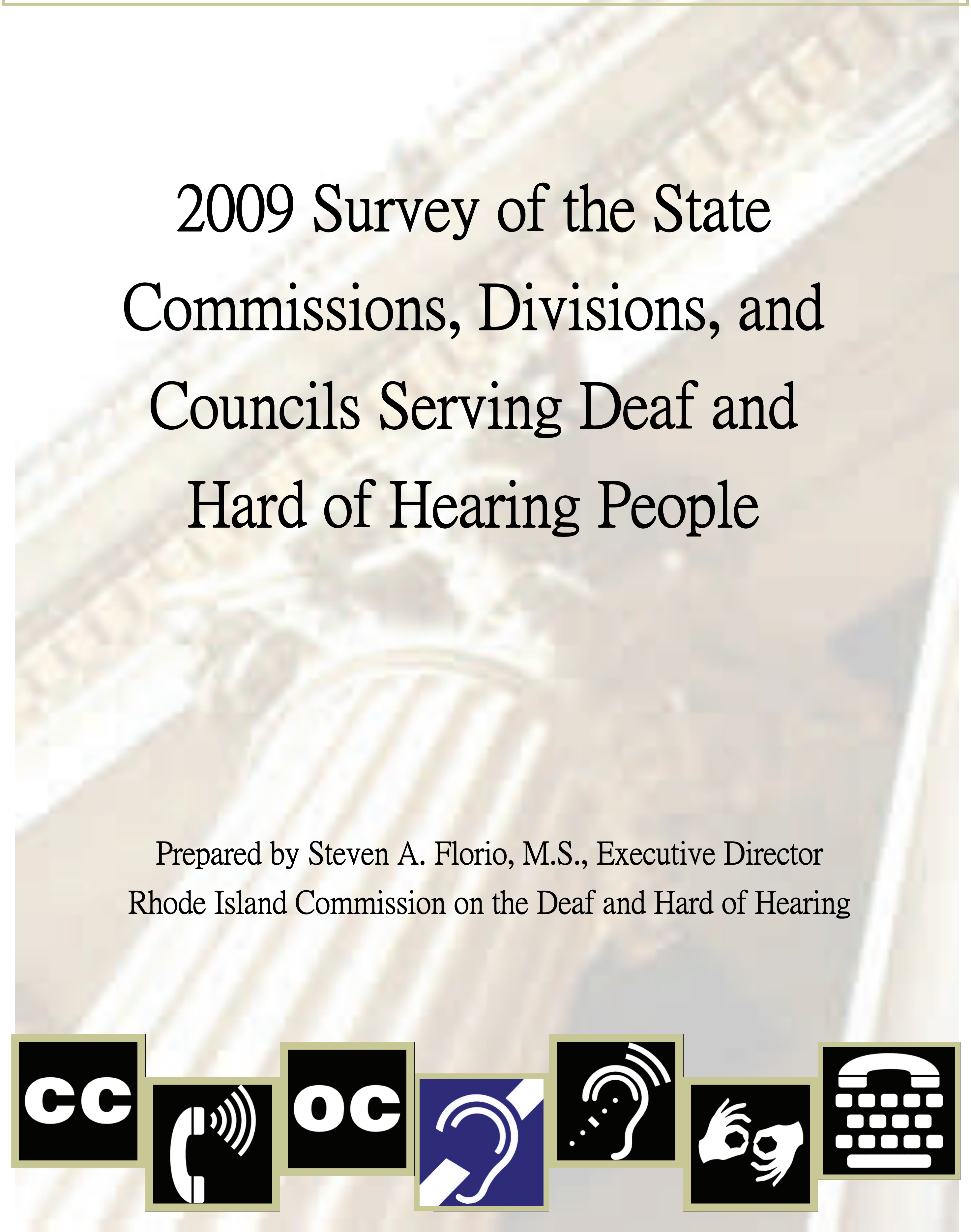
Support Service Provider (SSP): A support service provider can be any person, volunteer or professional, trained to act as a link between persons who are deaf-blind and their environment. They typically work with a single individual, and act as a guide and communication facilitator. The SSP serves as the eyes and ears of the person who is deaf-blind. Source: http://www.aadb.org/information/ssp/white_paper_ssp.html#history

Tactile ASL: a common means of communication used by people with both a sight and hearing impairment where the signer signs into the receiver’s hands.

Total Communication or Sim-Com: is an approach to Deaf education that aims to make use of a number of modes of communication such as signed, oral, auditory, written and visual aids, depending on the particular needs and abilities of the child. Source: https://en.wikipedia.org/wiki/Total_Communication

VideoPhone: A videophone is a telephone with a video display, capable of simultaneous video and audio for communication between people in real-time. A Deaf individual might use this to sign directly with another person or with the relay service, a hard of hearing person may use it to assist with speech reading. Source: https://en.wikipedia.org/wiki/Videophone

Appendix B: NASADHH 2009 Survey of State Commissions, Divisions, and Councils Serving Deaf and Hard of Hearing People



2009 Survey of the State Commissions, Divisions, and Councils Serving Deaf and Hard of Hearing People

Prepared by Steven A. Florio, M.S., Executive Director

Rhode Island Commission on the Deaf and Hard of Hearing

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I. Purpose and Method

The purpose of this survey is to report the current functions, budget, staffing, demographic, and services of state agencies serving deaf and hard of hearing people in the United States. This will help agency administrators and their board members to gain understanding of how each commission, division, and council are structured as well as how their services and programs are delivered within their statutes and means in their respective states.

The Michigan Division on Deaf and Hard of Hearing volunteered to gather information and put it into a report back in 2002 and 2004. The last survey conducted was done in 2004. The Rhode Island Commission on the Deaf and Hard of Hearing stepped up and volunteered to gather information for this 2009 Survey Report. This report is developed primarily for the agency administrators and board members only.

A questionnaire was copied from the 2004 Survey Report with revisions including a section on demographics and a question on agency's change added. The 2009 Survey was created online through www.surveymonkey.com so everyone would be able to participate and respond more quickly and conveniently. The e-mail with url links to surveymoney.com was sent to 39 known states (including 2 in Minnesota) that have a commission, division, council, or office serving Deaf and Hard of Hearing persons. The respondents were asked to fill the questionnaire if they meet the definition below.

> *Definition of State Agency: A state government agency established and funded by the state legislature to serve deaf and hard of hearing people exclusively. Staff members are employees of the state civil service. This agency provides statewide services including but not limited to, information and referral, interpreter referral, interpreter classification or qualification or licensing, advocacy, and technical assistance. This state agency may have a commission, council, or board of appointees to give guidance to the agency.*

The questionnaire asked for at least 85 informational items. Microsoft Excel 2003 was used to tabulate the responses. The tables were created to give the readers a clear picture of selected topics and a clear comparison eliminating the need for a lengthy written report. These responses were put together into a Microsoft Publisher 2003 format to create a final 2009 Survey Report. Frequent reminders were sent to the respondents after the deadline through e-mails and videophones (direct or via video relay service).

This 2009 Survey Report is distributed only to the agency administrators and/or board chairpersons of known states that are listed in the report electronically.

I. Purpose and Method (continued)

I am truly pleased to report that 100% participation in the 2009 survey has occurred and I want to thank all respondents for taking their time to participate in the survey. I am confident that anyone who reads this report will find the 2009 Survey Report informative and useful.

Please do not hesitate to contact me if you have questions or concerns about the 2009 Survey Report, I can be reached at 401-354-7651 either via point-to-point or video relay service or by e-mailing to me at SFlorio@cdhh.ri.gov.

Steven A. Florio, M.S., Executive Director
Rhode Island Commission on the Deaf and Hard of Hearing
One Capitol Hill, Ground Floor
Providence, RI 02908

II. Executive Summary

The findings of the survey are summarized as follows:

1) **Number of Respondents:** All 39 state agencies including 2 in Minnesota responded to the questionnaire. This represents 100% participation of known state agencies or 76% of the states in United States of America.

2) **Deaf and Hard of Hearing Terms:** 85% of the agency names including the theme, "Deaf and Hard of Hearing" .

3) **Communication:** 100% of the agencies who participated have a website on the internet. (Only 88% in 2004). 79% of the agencies now have videophone access. (No source back in 2004 but we can safely assume it was under 50% in 2004.)

4) **Administrator:** 39% of the administrator positions are state civil service classified and 26% of the positions are Governor-appointed. 59% of the administrators are either deaf or hard of hearing.

5) **Administrator Salary:** The salaries of the agency administrators in the survey range from $35,000 to $85,000 per year. 59% of the administrators are in the vicinity of $45,000 to $85,000, and 26% are $85,000 and up.

6) **Department:** 28% (11) of the agencies are independent, followed by 23% (9) under Rehabilitative Services, Two 13% (5 each of two) fall under Human Rights/Services and Social/Health Services.

7) **Board Composition:** The size of respondents′ boards range from 7 to 27 members. Four (4) respondents do not have a board. The board members in 28 (72%) states are appointed by the Governor. Board terms vary from 2 to 4 years. An overwhelming majority of the boards meet at least 4 times a year. 19 (49%) state commissions have a law requiring a majority of deaf and hard of hearing persons on the board. 100% of the state boards reimburse their members travel expenses, only one with a certain criteria (reimbursed if more than 50 miles travelled.).

8) **Fiscal Year:** All but five (5) states follow the July 1 through June 30 fiscal year.

9) **Authorized Budget:** Virginia has the largest budget (2004: North Carolina) and New Mexico has the highest dollar amount per capita (2004: North Carolina). Total of all 39 state agencies' budgets is **$86,992,065.00.**

10) **Staff Size:** The number of employees on staff range from 1 to 72. (2004: 55) The average number of agency employees is 13 (2004: 12)

II. Executive Summary (Continued)

11) **Services:** The most common services that the agencies provide are Information and Referral (95%), Advocacy (90%), Deaf Awareness/Orientation (79%), Technical Assistance (77%), and Interpreter Referral (72%). Over half (1/2) of the agencies provide Assistive Technology, Interpreter Directory, CART Referral, Services to Hard of Hearing, Client Assistance, and Adult/Community Education. 13% (N = 5) of the state commissions provide or manage the telecommunication relay services.

12) **Interpreter Services:** 72% of the state agencies provide the Interpreter Referral service. 41% (N = 16) of the state commissions qualify or license interpreters within their state. The data sources used to compute the figures of Deaf and Hard of Hearing population among the state agencies are varied.

13) **Demographic:** California has a large general and deaf/hard of hearing population. The average percentage used to compute the Deaf and Hard of Hearing figures against the data source is 10%.

14) **Agencies Affected since 2004:** The most significant changes or impacts on the state agencies occurred in Texas (2004) and Washington (2009). Two newly established state agencies since 2004 are Florida (2004) and New York (2008). And since the 2004 survey, Vermont has been eliminated (2009).

1.0 AGENCY

1.1 Survey Participation

Thirty nine (39) state commissions, divisions, councils, and offices serving Deaf and Hard of Hearing persons from thirty eight (38) states responded to the questionnaire. That is fantastic because this is 100% participation. This is the first time that the report includes all state commissions, divisions, councils, and offices. There are a few states that do not have state agencies including commission, divisions, councils, and offices that can be founded under 1.2 List of States that do not have an agency serving Deaf and Hard of Hearing persons. (Table 1.1)

	State	Agency Name
1	Arizona	Arizona Commission for the Deaf and Hard of Hearing
2	California*	California Office of Deaf Access
3	Colorado	Colorado Commission for the Deaf and Hard of Hearing
4	Connecticut	Connecticut Commission on the Deaf and Hearing Impaired
5	Delaware	Delaware Office for the Deaf and Hard of Hearing
6	Florida	Florida Coordinating Council for the Deaf and Hard of Hearing
7	Hawaii	Hawaii Disability and Communication Access Board
8	Idaho	Idaho Council for the Deaf and Hard of Hearing
9	Illinois	Illinois Deaf and Hard of Hearing Commission
10	Indiana	State of Indiana, Deaf and Hard of Hearing, Employment and Innovations
11	Iowa	Deaf Services Commission of Iowa
12	Kansas	Kansas Commission for the Deaf and Hard of Hearing
13	Kentucky	Kentucky Commission on the Deaf and Hard of Hearing
14	Louisiana	Louisiana Commission for the Deaf
15	Maine	Maine Division for the Deaf, Hard of Hearing, and Late Deafened
16	Maryland	Maryland Governor's Office of the Deaf and Hard of Hearing
17	Massachusetts	Massachusetts Commission for the Deaf and Hard of Hearing
18	Michigan	Michigan Division on Deaf and Hard of Hearing
19	Minnesota (Commission)	Commission of Deaf, DeafBlind, and Hard of Hearing Minnesotans
20	Minnesota (DHHSD)	Minnesota Deaf and Hard of Hearing Services Division
21	Mississippi	Mississippi Office on Deaf and Hard of Hearing
22	Missouri	Missouri Commission for the Deaf and Hard of Hearing
23	Nebraska	Nebraska Commission for the Deaf and Hard of Hearing
24	Nevada*	Nevada, Aging & Disability Services Division - Disabilities Unit
25	New Hampshire	New Hampshire Office of the Deaf and Hard of Hearing
26	New Mexico	New Mexico Commission for the Deaf and Hard of Hearing Persons
27	New Jersey	New Jersey Division of the Deaf and Hard of Hearing
28	New York	New York State Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-Blind, or Hard of Hearing
29	North Carolina	North Carolina Division of Services for the Deaf and Hard of Hearing
30	Oregon	Oregon Department of Human Services - Deaf and Hard of Hearing Services Program
31	Pennsylvania	Pennsylvania Office for the Deaf and Hard of Hearing
32	Rhode Island	Rhode Island Commission on the Deaf and Hard of Hearing
33	Tennessee	Tennessee Council for the Deaf and Hard of Hearing
34	Texas	Texas, Office for Deaf and Hard of Hearing Services
35	Utah	Utah Division of Services for the Deaf and Hard of Hearing
36	Virginia	Virginia Department for the Deaf and Hard of Hearing
37	Washington	Washington Office of the Deaf and Hard of Hearing
38	West Virginia	West Virginia Commission for the Deaf and Hard of Hearing
39	Wisconsin	Wisconsin Office for the Deaf and Hard of Hearing

* = Agency overseeing grants that are awarded to the organizations serving the Deaf and Hard of Hearing persons.

1.2 List of States that do not have a state agency serving Deaf and Hard of Hearing persons.

Table 1.2

	State	Comments
1	Arkansas	
2	Alabama	
3	Alaska	
4	Georgia	a nonprofit organization receiving state contract in providing statewide services for deaf and hard of hearing.
5	Montana	
6	North Dakota	
7	Ohio	
8	Oklahoma	
9	South Carolina	
10	South Dakota	
11	Vermont	Position eliminated effective June 2009.
12	Wyoming	

1.3 Communication and Technology

This section indicates how the public to contact representatives at the agency for any reason on any questions they may have. TTY was eliminated because it is clearly on the decline. However, the videophone has dramatically increased since 2004. As you can see, seventy-nine percent (79%) of all agencies have videophone available for the public to use to reach the agency. Also, in 2004, only 88% (n=26) of agencies have their websites available for the public. Today, 100% of state agencies have websites.

Table 1.3

N	Website	Toll Free	Videophone	Agency Email	Administrator Email
39	39	21	31	20	39
100%	100%	54%	79%	51%	100%

1.4 State Commissions, Councils, Divisions, and Offices Established

Michigan was the 1st state to pass legislation to create a state program or a state service for the Deaf and Hard of Hearing on October 29, 1937. The only time they were inactive was 1975 to 1979. Virginia was the first state to establish an independent state department (commission, council, division, and office) serving the Deaf and Hard of Hearing.

As of January 2010

State	Year	Anniversary
Michigan	29-Oct-1937	72
Virginia	1-Jul-1972	37
Texas	1973	37
Connecticut	1974	36
Iowa	1975	35
New Jersey	31-Jul-1977	32
Rhode Island	1977	32
Arizona	1978	32
Tennessee	1-Jul-1978	31
Minnesota (DHHSD)	1979	31
Washington	1979	31
Nebraska	Spring 1979	30
California	1980	30
Louisiana	1980	30
Wisconsin	1981	29
Kentucky	1982	28
New Hampshire	1-May-1981	28
Kansas	1-Jul-1982	27
Utah	1983	27
Oregon	1983	27
Maine	1-Jul-1983	26
Minnesota (Comm.)	1985	25
Pennsylvania	1986	24
Massachusetts	1-Jul-1986	23
Indiana	1988	22
Missouri	1988	22
North Carolina	1989	21
West Virginia	1989	21
Nevada	1990	20
Idaho	1-Jul-1991	18
New Mexico	26-Jul-1991	18
Delaware	1-Mar-1993	16
Illinois	1-Jan-1997	13
Mississippi	1-Jul-1998	11
Hawaii	1-Jan-2000	10
Maryland	2001	9
Colorado	1-Jul-2001	8
Florida	1-Jul-2004	5
New York	2007	3

1.4 State Commissions, Councils, Divisions, and Offices Established (Continued)

Additional comments about their establishments

Indiana - Legislation was passed in 1988. The office opened in 1989.

Nevada - Relay and equipment distribution started in 1990. The advocacy component was added in 2002.

New York - Legislation was passed in July 2007. New York State Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-Blind, or Hard of Hearing was officially established on January 1, 2008.

Pennsylvania - Legislation was passed in 1986. The office opened in 1988.

Rhode Island - Legislation was passed in 1977. The office opened on May 9, 1978. It was restructured on July 13, 1992 with its current name, RI CDHH.

Wisconsin - Legislation was passed in 1939 to set a state appropriation for Wisconsin Association of the Deaf (WAD)'s Service Bureau of the Deaf. According to the March 1979 final report of the Governor's Committee on Problems of Deaf & Hard of Hearing People, the Service Bureau initially was a private non-profit agency (unconfirmed) operated by the WAD. Apparently as a result of the final report, which had a list of recommendations, the Bureau became a state entity---by 1981, under the auspices of the then-named Department of Health and Social Services. The agency was formerly called, the Bureau of the Hearing Impaired.

1.5 History of the First State Agency Established in the United States of America.

Michigan's Act 72 of 1937 was passed to establish the Division on Deafness on October 29, 1937. The original language of the bill is below:

DIVISION ON DEAFNESS ACT

Act 72 of 1937

AN ACT to establish the division on deafness and the advisory council on deafness within the department of labor; to prescribe the powers and duties of the department, the division, the council, and certain state officers; to establish a fund and provide for expenditures from that fund; and to provide for an appropriation.

History: 1937, ACT 72, Eff. Oct. 29, 1937.

Additional history milestones of the Division on Deaf and Hard of Hearing (Current name of the State Agency in Michigan) are as follows:

HISTORY/MILESTONES

- 1921 - Michigan Association of the Deaf (MAD) began first effort to establish the Division of Deaf and Deafened (DDD).
- 1937 - The legislature passed P.A. 72 that established the DDD in the Department of Labor and Industry to assist deaf persons with employment.
- 1938 - First deaf person was hired as the first director.
- 1958 - DDD was transferred to Michigan Employment Security Commission.
- 1975 - DDD ceased activity after the director resigned.
- 1979 - DDD was revitalized by Governor William Milliken and transferred to Michigan Department of Labor, Bureau of Commission on Handicapper Concerns.
- 1980 - DDD reopened its doors with Christopher Hunter as its director. It has new services: advocacy, information and referral, interpreter referral, and technical assistance. It has staff of 4 persons: State Interpreter Coordinator, Rights Representative and Secretary.
- 1988 - The legislature amended the law (P.A. 434), changing name to Division on Deafness and revising responsibilities to protect and assist all hearing impaired persons, with special emphasis on deaf persons" , forming 13 member Governor appointed Advisory Council.
- 1993 - Hard of Hearing Specialist position was added to serve hard of hearing Michigan citizens.
- 1996 - DDD and Michigan Commission on Disability Concerns were eventually transferred to the Michigan Independence Agency after the Department of Labor was abolished.
- 1997 - Hard of Hearing Specialist position was eliminated through the department downsizing affected by the early retirement program.
- 1998 - Hard of Hearing Specialist position was restored through public contacts to the legislature and department. Today DOD has four staff members: Director, State Interpreter Coordinator, Hard of Hearing Specialist, and Secretary.
- 2002 - Executive Order #2002-10 DOD renamed Division on Deaf and Hard of Hearing (DODHH)

1.6 Has Your Agency Changed Since 2004?

California - Our Deaf Access Program has undergone budget cuts since 2004.

Colorado - 3.3 FTEs added in February 2010.

Connecticut - In 2005, the agency's Business/Human Resources Department was transferred to the Department of Administrative Services. This was done through legislation, 23 agency's Business/HR Departments were merged. This has been positive for the agency, more resources are available especially with the tight fiscal constraints. It has not increased restrictions or had an effect on the challenges that confront the agency.

Indiana - Yes, we are more connected to Vocational Rehabilitation Services and Bureau of Blind and Visually Impaired. Some ways, it has helped working closer with the Rehabilitation Counselors for the Deaf but it has become more challenging too as not everyone understands the challenges faced by deafness.

Kansas - Downsized by losing one part-time support staff. Our agency is now 100% State General Funds.

Maryland - No - there were legislative attempts to merge us with the Department of Disabilities but they did not pass.

Massachusetts - Through interagency agreements, we administer, coordinate, and provide communication access to other agencies; funding for providing these services increased from $300K to over $900K. Budget reductions have reduced funding for both administrative support and direct services. We shared Information Technology, Human Services, and Legal Counsel staff with other agencies within EOHHS in effort to stretch resources.

Minnesota (Comm.) - No, in fact, our budget has gone from $95,000 in 2004 to $600,000 this year.

Minnesota (DHHSD) - The agency has gradually reduced level of services over the past few years due to budget reduction/ unallotment decisions.

Missouri - In FY2010, the commission received an 18% budget reduction in Personnel money. This resulted in the loss of 1 full-time position, and reduced a second position to part-time.

Nebraska - Downsized one staff due to budget cuts. Minimal impact.

Nevada - Under DHHS, we were an offshoot of the Departments' Director's. Last year, the Legislature decided to merge us with Aging Services changing the name. Our prior agency was The Office of Disability Services.

Has your agency changed since 2004? (Continued)

New York - Legislation was passed in July 2007. New York State Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-Blind, or Hard of Hearing was officially established on January 1, 2008. This is part of New York State Commission on Quality of Care and Advocacy for Persons with Disabilities. NYS Commission on Quality of Care and Advocacy for Persons with Disabilities was originally established on January 1, 1978 under different name and is with its current name starting on April 15, 2005. In 2005, the Commission on Quality Care of the Mentally Disabled and the Office of Advocate for Persons with Disabilities merged by statute to avoid duplication and to improve service delivery and advocacy for persons with disabilities.

North Carolina - In SFY2008-2009, the Governor and the NC General Assembly, in two separate actions, transferred a total of $9.5M from the Telecommunications Trust Fund into the General Fund to address NC's budgetary shortfall. Legislative action mandated that DSDHH's Community Resources Program (seven regional centers) be funded by the Telecommunications Relay Service receipts instead of general appropriations, giving the State of NC $2M per year. Due to the large cash balance in the Telecommunications Trust Fund, these actions did not significantly impact DSDHH's programs and services. However, DSDHH must comply with certain restrictions on travel and expenditures in order to ensure a balanced budget at the end of SFY2010.

Oregon - In 2005, our program was moved from the Oregon Disabilities Commission and placed within the Department of Human Services. The effect was to downsize this program while we are under a hiring freeze.

Rhode Island - In 2007, the Legislature attempted to consolidate RICDHH into a Department of Advocacy with 4 of the small agencies but failed. In 2008, Governor attempted to consolidate RICDHH into the Department of Elderly Affairs with two other small agencies in response to the legislature's request but failed.

Texas - In 2004 the state legislature undertook a major reorganization by consolidating 3 agencies into 4 new departments. The former Texas Commission for the Deaf and Hard of Hearing is now the Office for Deaf and Hard of Hearing Services (DHHS) under the Dept of Assistive and Rehabilitative Services. All staff and programs have remained intact and services remain unchanged but with increased funds. In the organization DHHS is under the Division of Vocational Rehabilitation and thus able to use agency funds for matching purposes to draw down federal funds. This has resulted in roughly $1.2 million increase in service funds which has a very positive impact. A troublesome restriction is that we cannot be involved with the legislature. Much more policy and paperwork are involved with the new structure and we have not gotten additional staff to handle the paperwork. Overall the changes have been helpful.

Has your agency changed since 2004? (Continued)

Utah - No but we have had to lay off a few employees that has affected the services we provide.

Washington - The previous and current Secretary has reorganized and retained ODHH reporting to the Office of the Secretary. This reorganization is at the discretion of Secretary, not law or executive order. This is positive as ODHH visibility is heightened, opportunities to access executive management is available, etc..

West Virginia - In 2004 the positions of Staff Interpreter and Deputy Director were consolidated into one position - Deputy Director (who is also an interpreter). This has not had a significant impact other than in amount of manpower to complete projects.

2.0 Administration

2.1 Position Title and Type

Of 39 state agencies, 38% (N = 15) of positions is called, Director and 36% (N = 14) of positions is called, Executive Director. 38% (N = 15) of positions are identified as state civil service classified and 25% (N = 10) of positions are identified as Governor Appointee.

Table 2.1 Title

Title	N
Director	15
Executive Director	14
Administrator	2
Deputy Director	1
Office Public Information Officer	1
Program Assistant	1
Manager	1
Commissioner	1
Social Services Program Specialist II	1
State Coordinator	1
Public Policy and Government Relations Director	1
Total	39

Table 2.2 Type

Type	N
Civil Service Class	15
Governor Appointee	10
Report to the governing board	5
Appointed by the Department	4
Report directly to Governor	3
State Administrative, exempt	1
Report directly to OVR Director	1
Total	39

2.2 Hearing Status of Administrators

Of 39 State Agencies, 59% (N = 23) of state agency administrators identified themselves deaf or hard of hearing. Only 1% increase since 2004. The majority, if not all, of administrators who identified themselves as hearing know Sign Language. (Based on conversations between the administrators and Steven Florio of Rhode Island while conducting the 2009 Survey.)

Table 2.3 Hearing Status

	2009		2004	
Hearing Status	States	%	States	%
Deaf	17	44%	13	50%
Hard of Hearing	6	15%	2	8%
Hearing	16	41%	7	27%
No response	0	0%	4	15%
Total	39	100%	26	100%

2.3 Salary Range of Administrators

Of 39 State Agencies, 26% of salary ranges is $85,000 and over. The rest of salary ranges are pretty even. The possible factors are the size of agency's annual budget, administrators' longevity among the administrators, base salary range, college education, and other incentives.

Table 2.4 Salary Range of Administrators

	2009		2004	
Salary Range	**N**	**%**	**N**	**%**
$0 - $25,000	0	0%	0	0%
$25,001 - $35,000	0	0%	0	0%
$35,001 - $45,000	4	10%	2	8%
$45,001 - $55,000	5	13%	7	28%
$55,001 - $65,000	7	18%	3	12%
$65,001 - $75,000	5	13%	7	28%
$75,001 - $85,000	6	15%	5	20%
$85,001 and higher	10	26%	1	4%
No Response	2	5%	0	0%
Total	39	100%	25	100%

2.4 List of Administrators

Table 2.4 - Administrators

State	Administrator	Title
Arizona	Sherri Collins	Executive Director
California	Tom Lee	Deputy Director
Colorado	Cliff Moers	Administrator
Connecticut	Stacie J. Mawson	Executive Director
Delaware	Loretta Sarro	Public Information Officer
Florida	Mary Grace Tavel	Program Assistant
Hawaii	Francine Wai	Executive Director
Idaho	Steven Snow	Executive Director
Illinois	John Miller	Director
Indiana	Rhonda Marcum	Manager
Iowa	Kathryn Baumann-Reese	Administrator
Kansas	Rebecca J. Rosenthal	Executive Director
Kentucky	Virginia L. Moore	Executive Director
Louisiana	Naomi DeDual	Executive Director
Maine	John G. Shattuck	Division Director
Maryland	Lisa H. Kornberg	Director
Massachusetts	Heidi L. Reed	Commissioner
Michigan	Sheryl Emery	Director
Minnesota (Comm.)	Mary Hartnett	Executive Director
Minnesota (DHHSD)	Bruce Hodek	Division Director
Mississippi	Benjamin Wagenknecht	Director
Missouri	Barry Critchfield	Executive Director
Nebraska	Peter J. Seiler, Ed.D.	Executive Director
Nevada	Betty Hammond	Social Svcs Pgm Specialist II
New Hampshire	H. Dee Clanton	State Coordinator
New Mexico	Barbara "BJ" Wood	Executive Director
New Jersey	David Alexander	Director
New York	Rosemary Lamb	Director
North Carolina	Jan Withers	Director
Oregon	Patricia O'Sullivan	Public Policy/Gov't Rel. Director
Pennsylvania	Sharon Behun	Director
Rhode Island	Steven A. Florio	Executive Director
Tennessee	Thom Roberts	Executive Director
Texas	David W. Myers	Director
Utah	Marilyn Call	Division Director
Virginia	Ronald L. Lanier	Director
Washington	Eric Raff	Director
West Virginia	Marissa Johnson	Executive Director
Wisconsin	Linda Huffer	Director

3.0 Location of the Agency

Department	N	State
Independent or Executive Office	**11**	Arizona, Connecticut, Idaho, Illinois, Maryland, Minnesota (Commission), Nebraska, New Mexico, New York, Rhode Island, and Virginia
Social and/or Health Services	**5**	
Department of Social Services		California
Department of Health		Florida
Department of Social and Health Services		Washington
Department of Health Services		Wisconsin
Department of Health		Hawaii
Human Rights or Services	**5**	
Within the Division of Boards and Commissions under the Dept. of Human Services		Colorado
Department of Human Rights		Iowa
Department of Human Services		Minnesota (DHHSD)
Department of Human Services		New Jersey
Department of Human Services		Oregon
Health and Human Services	**4**	
Executive Office of Health and Human Services		Massachusetts
Department of Health and Human Services, Aging and Disability Services Division		Nevada
Department of Health and Human Resources		West Virginia
Department of Health and Human Services		North Carolina
Rehabilitation Services	**9**	
Division of Vocational Rehab under Dept of Labor		Delaware
Bureau of Rehabilitative Services under Dept of Family and Social Service		Indiana
Social Rehabilitation Service within the Kansas Rehabilitation Services		Kansas
Department of Social Service within the LA Rehabilitation Services		Louisiana
Bureau of Rehabilitation under Department of Labor		Maine
Department of Rehabilitation Services		Mississippi
Division of Vocational Rehab under Dept of Human Services		Tennessee
Department of Assistive and Rehabilitative Services		Texas
Department of Rehabilitation under Dept of Education		Utah
Labor	**2**	
Department of Labor, Energy and Economic Growth		Michigan
Department of Labor and Industry		Pennsylvania
Education	**3**	
Education and Workforce Development Cabinet		Kentucky
Department of Elementary and Secondary Education		Missouri
Department of Education, Division of Career Technology and Adult Learning		New Hampshire

4.0 Board Composition

4.1 Size

For the purpose of this section, the term, "board" is defined as a board, commission, or advisory council. Only 4 state agencies (California, Delaware, Texas, and Washington) do not have a board/advisory function. Washington's Advisory Committee was abolished by the Governor's Executive Order this year (2009).

The largest number of seats is 27 in North Carolina and the smallest number of seats is 7 in 4 states (Colorado, Indiana, Iowa, and New Mexico).

49% (N = 19) of State Agencies have a law requiring a majority of deaf and hard of hearing persons on the board.

Table 4.1—Size of Board Composition

State	N	Majority D/HH Required
North Carolina	27	No
Maine	26	No
Connecticut	21	No
Massachusetts	12-20	Yes
Florida	17	No
Hawaii	17	No
Kansas	17	No
Louisiana	17	No
New Hampshire	17	No
Pennsylvania	17	No
West Virginia	17	No
Maryland	16	Yes
Minnesota (Comm.)	15	Yes
Utah	15	Yes
New York	15	Yes
Arizona	14	Yes
New Jersey	14	Yes
Kentucky	13	Yes
Michigan	13	Yes
Rhode Island	13	Yes

State	N	Majority D/HH Required
Oregon	12	Yes
Illinois	11	Yes
Nevada	11	No
Tennessee	11	No
Idaho	9	No
Mississippi	9	No
Missouri	9	Yes
Nebraska	9	Yes
Virginia	9	No
Wisconsin	9	Yes
Minnesota (DHHSD)	8	Yes
Colorado	7	No
Indiana	7	Yes
Iowa	7	Yes
New Mexico	7	Yes
California	N/A	N/A
Delaware	N/A	N/A
Texas	N/A	N/A
Washington	N/A	N/A

4.2 Seats of the Board

72% (N = 28) of State Agencies' board members are appointed by the Governor.

Table 4.2—Seats of the Board

State	One Term equals to a number of	Appointed by:	The Travel Expense reimbursed?
New Mexico	6	Governor	Yes
Missouri	4	Governor	Yes
Virginia	4	Governor	Yes
Wisconsin	4	Governor	Yes
Florida	4	Governor	Yes
Pennsylvania	4	Governor	Yes
North Carolina	4	Mixed of Governor, Department Administrator, and selected by membership	Yes
Kentucky	2 to 4	Governor and selected by the membership for some slots	Yes
Hawaii	2 to 4	Governor	Yes
Iowa	3	Governor	Yes
Minnesota (DHHSD)	3	Department Administrator	Yes
Illinois	3	Governor	Yes
Nevada	3	Department Administrator	Yes
Tennessee	3	Governor	Yes
Michigan	3	Governor	Yes
New Jersey	3	Governor	Yes
Minnesota (Comm.)	3	Governor	Yes
Maryland	3	Governor	Yes if they requested.
Kansas	3	Governor	Yes
Louisiana	3	Governor	Yes
New Hampshire	3	Department Administrator	Yes
West Virginia	3	Governor	Yes
Indiana	2 to 3	Department Administrator	Yes
Colorado	2	Governor	Yes
Mississippi	2	Department of Rehab Services' Executive Director	Yes
Nebraska	2	Governor	Yes
Oregon	2	Department Administrator	Yes
Rhode Island	2	Governor	Yes if they requested.
Arizona	2	Governor	Yes
Utah	2	Board of Education	Yes if they live more than 50 miles away.
Maine	2	Governor	Yes
Massachusetts	2	Governor	Yes
Connecticut	Coterminous with Governor	Governor	Yes
Idaho	Vary depending on each seat	Governor	Yes
New York	Staggered	4 by Governor and 4 by legislative leaders	Yes
California	N/A	N/A	N/A
Delaware	N/A	N/A	N/A
Texas	N/A	N/A	N/A
Washington	N/A	N/A	N/A

4.3 Representatives on the Board

Almost all state agencies have a law requiring both Deaf and Hard of Hearing to serve on the board. Parents are second after Deaf and Hard of Hearing.

Table 4.3 Representatives

Representative	N
Deaf	31
Hard of Hearing	30
Parent	20
State Government Official	16
Deaf Organization	15
Educator	12
Interpreter Organization	11
General Public	9
Audiologist	8
Hard of Hearing Organization	7
Local Rep. (each island county incl'd)	7
Late Deafened Organization	5
Physician including otolaryngolsist	4
Hearing	3
Early Intervention Provider	3
Not Required	3
Psychologist	2
No Response	2

Table 4.4 Other Representatives

Other Representatives	N
Professionals	7
State Agency Representatives	4
Community Representative (D/HH)	3
Late-Deafened	2
Interpreter	2
Hearing Aid Specialist/Dispenser	2
Supt of School for the Deaf/School Rep	2
Deaf-Blind organization	2
Government Representatives-ex officers	1
Elders	1
Children and Families	1
Business Community	1
Local Public School	1
Speech Disabled	1
Director of Vocational Rehabilitation	1
Black-Deaf organization	1
Persons with Disabilities	1
Service Providers	1

4.4 Meeting

74% (N = 29) of the state boards are required to meet at least 4 times a year. Utah is required to meet at least 10 times a year. Massachusetts is required to meet at least 8 times a year. Only two states (Mississippi and New York) are required to meet at least 3 times. Also, only two states (Oregon and Nevada) do not have any law requiring a certain number of meetings a year. Utah allows the members to participate in the meeting by video conferencing.

4.5 Communication Access at the Meeting.

All State Agencies' boards arranged various communication access services for their meetings without requiring a request of communication access in advance.

Interpreters - - -	100%
CART - - -	90%
Assistive Listening Devices -	28%
Assistive Listening System -	14%
Oral Interpreter - - -	5%
Tactile Interpreters for Deaf-Blind -	5%

5.0 Funding

5.1 Fiscal Year

Only 5 states have different fiscal years than the rest of state agencies. 33 states follow the July 1st through June 30th fiscal year. 3 of 5 states (Michigan, New Hampshire, and Wisconsin) start their fiscal year on October 1st and end on September 30th, similar to the Federal Government′s fiscal year. One of 5 states, Texas, starts on September 1st and ends on August 31st. And one of 5 states, New York, starts on April 1st and ends on March 31st.

5.2 Authorized Budget

The respondents were asked for their total authorized annual budget for their agencies. It is difficult to compare state budgets when no two state agencies providing the same services and programs. Some states manage or provide telecommunications relay service (TRS) and/or Telecommunication Distribution and others do not. TRS and Telecommunication Distribution services account for a large portion of the budgets.

For your own assessment needs, various data formats are provided as follows:

1) Budget by Per Capita
2) Annual Gross Amount
3) Rank by State Funds
4) Rank by “Surcharge” Funds
5) Rank by General Population including Gross Amount and State Funds

By per capita, New Mexico is leading in per capita, $2.07 per person, to provide services for the Deaf and Hard of Hearing. Florida is the lowest with $0.01 per capita based on 18,881,445 people living in Florida and are used to services provided for Deaf and Hard of Hearing people by the Florida government. New York is the 2nd lowest with $0.02 per capita. Please see Table 5.1 for per capita of all states next page.

Table 5.1 Budget by Per Capita

	State	Per Capita	Gross	Population
1	New Mexico	$ 2.07	$ 4,100,000.00	1,984,356.00
2	Virginia	$ 2.04	$ 15,859,138.00	7,769,089.00
3	North Carolina	$ 1.44	$ 13,000,000.00	9,000,000.00
4	Minnesota (DHHSD)	$ 1.36	$ 6,800,000.00	5,000,000.00
5	Hawaii	$ 1.09	$ 1,400,000.00	1,288,198.00
6	Utah	$ 0.91	$ 2,021,891.00	2,233,169.00
7	Washington	$ 0.89	$ 5,624,971.00	6,287,759.00
8	Massachusetts	$ 0.87	$ 5,500,000.00	6,349,097.00
9	Arizona	$ 0.84	$ 5,441,100.00	6,500,000.00
10	Nevada	$ 0.68	$ 1,646,018.00	2,414,807.00
11	Louisiana	$ 0.64	$ 2,800,000.00	4,400,000.00
12	Nebraska	$ 0.48	$ 858,400.00	1,783,432.00
13	Connecticut	$ 0.44	$ 1,529,248.00	3,501,252.00
14	Maine	$ 0.43	$ 560,508.00	1,300,000.00
15	Rhode Island	$ 0.37	$ 370,146.00	1,011,960.00
16	Colorado	$ 0.21	$ 954,040.00	4,550,688.00
17	Tennessee	$ 0.19	$ 1,020,000.00	5,464,458.00
18	Texas	$ 0.19	$ 3,900,500.00	21,000,000.00
19	New Hampshire	$ 0.18	$ 313,721.00	1,700,000.00
20	Delaware	$ 0.15	$ 133,900.00	873,092.00
21	West Virginia	$ 0.15	$ 268,000.00	1,800,000.00
22	Kentucky	$ 0.14	$ 860,000.00	6,000,000.00
23	California	$ 0.14	$ 5,200,000.00	36,700,000.00
24	Iowa	$ 0.13	$ 378,792.00	2,926,324.00
25	Kansas	$ 0.11	$ 290,000.00	2,700,000.00
26	Wisconsin	$ 0.10	$ 500,000.00	5,000,000.00
27	Michigan	$ 0.10	$ 1,000,000.00	10,003,422.00
28	Minnesota (Comm.)	$ 0.10	$ 495,000.00	5,000,000.00
29	Idaho	$ 0.09	$ 150,600.00	1,600,000.00
30	New Jersey	$ 0.09	$ 807,000.00	8,682,661.00
31	Missouri	$ 0.07	$ 403,792.00	5,800,310.00
32	Illinois	$ 0.07	$ 808,800.00	12,419,293.00
33	Oregon	$ 0.06	$ 240,000.00	3,790,060.00
34	Maryland	$ 0.05	$ 301,000.00	5,633,597.00
35	Indiana	$ 0.05	$ 325,000.00	6,195,643.00
36	Pennsylvania	$ 0.04	$ 460,000.00	12,448,279.00
37	Mississippi	$ 0.04	$ 104,500.00	2,921,088.00
38	New York*	$ 0.02	$ 316,000.00	19,460,297.00
39	Florida	$ 0.01	$ 250,000.00	18,881,445.00

** = $316,000 was appropriated by the General Assembly when the Interagency Coordinating Council for the Deaf and Hard of Hearing was first established. $316,000 and additional adjustments annually are now part of the overall agency's budget, NYS Commission on Quality of Care and Advocacy for Persons with Disabilities, ($17.6m)*

Table 5.2 Rank by Annual Gross Amount

	State	Gross
1	Virginia	$ 15,859,138.00
2	North Carolina	$ 13,000,000.00
3	Minnesota (DHHSD)	$ 6,800,000.00
4	Washington	$ 5,624,971.00
5	Massachusetts	$ 5,500,000.00
6	Arizona	$ 5,441,100.00
7	California	$ 5,200,000.00
8	New Mexico	$ 4,100,000.00
9	Texas	$ 3,900,500.00
10	Louisiana	$ 2,800,000.00
11	Utah	$ 2,021,891.00
12	Nevada	$ 1,646,018.00
13	Connecticut	$ 1,529,248.00
14	Hawaii	$ 1,400,000.00
15	Tennessee	$ 1,020,000.00
16	Michigan	$ 1,000,000.00
17	Colorado	$ 954,040.00
18	Kentucky	$ 860,000.00
19	Nebraska	$ 858,400.00
20	Illinois	$ 808,800.00
21	New Jersey	$ 807,000.00
22	Maine	$ 560,508.00
23	Wisconsin	$ 500,000.00
24	Minnesota (Comm.)	$ 495,000.00
25	Pennsylvania	$ 460,000.00
26	Missouri	$ 403,792.00
27	Iowa	$ 378,792.00
28	Rhode Island	$ 370,146.00
29	Indiana	$ 325,000.00
30	New York*	$ 316,000.00
31	New Hampshire	$ 313,721.00
32	Maryland	$ 301,000.00
33	Kansas	$ 290,000.00
34	West Virginia	$ 268,000.00
35	Florida	$ 250,000.00
36	Oregon	$ 240,000.00
37	Idaho	$ 150,600.00
38	Delaware	$ 133,900.00
39	Mississippi	$ 104,500.00

** = $316,000 was appropriated by the General Assembly when the Interagency Coordinating Council for the Deaf and Hard of Hearing was first established. $316,000 and additional adjustments annually are now part of the overall agency's budget, NYS Commission on Quality of Care and Advocacy for Persons with Disabilities.($17.6m)*

Table 5.3 Rank by State Funds

The funding source of the state agencies varies. State agencies that received at least 85% from the surcharge fund (excise tax or other names) are excluded from this list. To be included, state agencies receive state funds appropriated by the state legislature and/or Memo of Understanding (MOU)/Grants through other state agencies/departments.

	State	State Funds
1	Massachusetts	$ 5,280,000.00
2	Minnesota (DHHSD)	$ 5,168,000.00
3	California	$ 2,860,000.00
4	Louisiana	$ 2,800,000.00
5	Utah	$ 2,021,891.00
6	Connecticut	$ 1,529,248.00
7	Hawaii	$ 1,400,000.00
8	Texas	$ 1,189,652.50
9	Tennessee	$ 1,020,000.00
10	Michigan	$ 1,000,000.00
11	Kentucky	$ 860,000.00
12	Nebraska	$ 858,400.00
13	Illinois	$ 808,800.00
14	New Jersey	$ 807,000.00
15	Wisconsin	$ 500,000.00
16	Minnesota (Comm.)	$ 495,000.00

	State	State Funds
17	Pennsylvania	$ 460,000.00
18	Missouri	$ 403,792.00
19	Iowa	$ 378,792.00
20	Rhode Island	$ 370,146.00
21	Indiana	$ 325,000.00
22	Maine	$ 319,489.56
23	New York*	$ 316,000.00
24	Maryland	$ 301,000.00
25	Kansas	$ 290,000.00
26	West Virginia	$ 268,000.00
27	Florida	$ 250,000.00
28	Oregon	$ 240,000.00
29	Idaho	$ 150,600.00
30	Delaware	$ 133,900.00
31	Mississippi	$ 104,500.00
32	New Hampshire	$ -

* = Please check the footnotes in the previous page of Annual Gross Amount for information on NY.

Table 5.4 Rank by "Surcharge" Funds

The definition, "Surcharge", refers to a charge against the telephone on landlines, wireless, and internet known as VOIP paid by the consumers in these respective states to cover various services and programs provided. Some states have different names for it such as Disabled Telephone Users Fund, Excise Tax, Universal Service Fund, and TRS fund. Most of them are set up by the State Public Utilities Commission or the similar.

	State	Funding	From other sources
1	Virginia	$ 14,431,815.58	99% from Communications Tax for Relay
2	North Carolina	$ 12,900,000.00	99% from surcharge on landlines and wireless.
3	Washington	$ 5,624,971.00	100% from Excise Tax from Telephone subscribers TRS surcharges.
4	Arizona	$ 5,441,100.00	100% - Excise Tax (telephone landline only)
5	New Mexico	$ 4,100,000.00	100% from Telephone Relay service surcharges
6	Nevada	$ 1,646,018.00	100% from PUC's telecommunication fund
7	Minnesota (DHHSD)	$ 1,632,000.00	24% from telephone surcharge for TEDP
8	Colorado	$ 820,474.40	86% from Disabled Telephone Users Fund
9	Maine	$ 140,127.00	25% from Universal Service Fund.

Table 5.5 Rank by General Population including Gross Amount and State levels.

	State	Population	Gross Amount	State Fund	Other sources
1	California	36,700,000.00	$ 5,200,000.00	$ 2,860,000.00	$ 2,340,000.00
2	Texas	21,000,000.00	$ 3,900,500.00	$ 1,189,652.50	$ 2,710,847.50
3	New York*	19,490,297.00	$ 316,000.00	$ 316,000.00	$ -
4	Florida	18,881,445.00	$ 250,000.00	$ 250,000.00	$ -
5	Pennsylvania	12,448,279.00	$ 460,000.00	$ 460,000.00	$ -
6	Illinois	12,419,293.00	$ 808,800.00	$ 808,800.00	$ -
7	Michigan	10,003,422.00	$ 1,000,000.00	$ 1,000,000.00	
8	North Carolina	9,000,000.00	$ 13,000,000.00	$ 13,000,000.00	$ -
9	New Jersey	8,682,661.00	$ 807,000.00	$ 807,000.00	$ -
10	Virginia	7,769,089.00	$ 15,859,138.00	$ 1,427,322.42	$14,431,815.58
11	Arizona	6,500,000.00	$ 5,441,100.00	$ 5,441,100.00	$ -
12	Massachusetts	6,349,097.00	$ 5,500,000.00	$ 5,280,000.00	$ 220,000.00
13	Washington	6,287,759.00	$ 5,624,971.00	$ 5,624,971.00	$ -
14	Indiana	6,195,643.00	$ 325,000.00	$ 325,000.00	$ -
15	Kentucky	6,000,000.00	$ 860,000.00	$ 860,000.00	$ -
16	Missouri	5,800,310.00	$ 403,792.00	$ 234,692.00	$ 169,100.00
17	Maryland	5,633,597.00	$ 301,000.00	$ 301,000.00	$ -
18	Tennessee	5,464,458.00	$ 1,020,000.00	$ 1,020,000.00	$ -
19	Minnesota (Comm.)	5,000,000.00	$ 495,000.00	$ 495,000.00	$ -
20	Minnesota (DHHSD)	5,000,000.00	$ 6,800,000.00	$ 6,800,000.00	$ -
21	Wisconsin	5,000,000.00	$ 500,000.00	$ 500,000.00	$ -
22	Colorado	4,550,688.00	$ 954,040.00	$ 954,040.00	$ -
23	Louisiana	4,400,000.00	$ 2,800,000.00	$ 2,800,000.00	$ -
24	Oregon	3,790,060.00	$ 240,000.00	$ 240,000.00	$ -
25	Connecticut	3,501,252.00	$ 1,529,248.00	$ 1,092,320.00	$ 436,928.00
26	Iowa	2,926,324.00	$ 378,792.00	$ 378,792.00	$ -
27	Mississippi	2,921,088.00	$ 104,500.00	$ 104,500.00	$ -
28	Kansas	2,700,000.00	$ 290,000.00	$ 290,000.00	$ -
29	Nevada	2,414,807.00	$ 1,646,018.00	$ 1,646,018.00	$ -
30	Utah	2,233,169.00	$ 2,021,891.00	$ 1,821,891.00	$ 200,000.00
31	New Mexico	1,984,356.00	$ 4,100,000.00	$ 4,100,000.00	$ -
32	West Virginia	1,800,000.00	$ 268,000.00	$ 268,000.00	$ -
33	Nebraska	1,783,432.00	$ 858,400.00	$ 832,648.00	$ 25,752.00
34	New Hampshire	1,700,000.00	$ 313,721.00	$ -	$ 313,721.00
35	Idaho	1,600,000.00	$ 150,600.00	$ 143,070.00	$ 7,530.00
36	Maine	1,300,000.00	$ 560,508.00	$ 462,399.00	$ 98,109.00
37	Hawaii	1,288,198.00	$ 1,400,000.00	$ 1,400,000.00	$ -
38	Rhode Island	1,011,960.00	$ 370,146.00	$ 370,146.00	$ -
39	Delaware	873,092.00	$ 133,900.00	$ 133,900.00	$ -

** = $316,000 was appropriated by the General Assembly when the Interagency Coordinating Council for the Deaf and Hard of Hearing was first established. $316,000 and additional adjustments annually are now part of the overall agency's budget, NYS Commission on Quality of Care and Advocacy for Persons with Disabilities.($17.6m)*

6.0 Staffing

6.1 Full-time and Part-time Count

3 States, North Carolina, Minnesota, and Massachusetts, have the largest number of full-time employees on their staff. Connecticut has a large number of part-time employees on their staff. The average of full-time employees among 39 state agencies is 11 employees. For part-time employees, the average is 2 employees.

Table 6.1 Rank by Total Staff

	State	FTE	Part-Time	Total
1	North Carolina	71	1	72
2	Massachusetts	51.66	13	64.66
3	Minnesota (DHHSD)	53	0	53
4	Connecticut	9	40	49
5	Indiana *	3	21	24
6	Utah	20	2	22
7	Texas	18	0	18
8	Washington	17	0	17
9	Hawaii	16	0.5	16.5
10	New Mexico	16	0	16
11	Arizona	15	0	15
12	Kentucky	13	0	13
13	Nebraska	12	1	13
14	Virginia	9	2	11
15	Nevada	9.56	0	9.56
16	New Jersey	9	0	9
17	Wisconsin	8	1	9
18	Illinois	8	0	8
19	Colorado**	6.1	0	6.1
20	Minnesota (Comm.)	5	0	5
21	Pennsylvania	5	0	5
22	Iowa	4	1	5
23	Missouri	4	1	5
24	New York***	5	0	5
25	California	4	0	4
26	Louisiana	4	0	4
27	Michigan	4	0	4
28	Maryland	3	0	3
29	Mississippi	3	0	3
30	Rhode Island	3	0	3
31	West Virginia	3	0	3
32	Kansas	2	1	3
33	Maine	2	1	3
34	Oregon	1	2	3
35	Delaware	2	0	2
36	Idaho	2	0	2
37	New Hampshire	2	0	2
38	Tennessee	2	0	2
39	Florida	1	0.6	1.6

* 21 RCDs as part-time included.

** effective on February 2010

*** NYS CQCAPD - Overall 103 FTEs. For D/HH Council, 5 FTEs sharing responsibilities with other councils.

6.2 Staff Hearing Status

Top five (5) state agencies that have best percentage of Deaf and Hard of Hearing employees hired are Tennessee, Mississippi, Rhode Island, Nevada, and Colorado. The majority of employees have normal hearing.

Table 6.2 Rank by percentage of all Deaf, Hard of Hearing, Late Deafened, DeafBlind, and D/HH plus Disabilities.

	State	Deaf	%	HoH	%	Late-Deafened	%	HL + DA	%	ALL D/ HH/LD/ HD	%	Hear-ing	%
1	Tennessee	1	50%	1	50%	0	0%	0	0%	2	100%	0	0%
2	Rhode Island	2	67%	0	0%	0	0%	0	0%	2	67%	1	33%
3	Mississippi	1	33%	0	0%	0	0%	1	33%	2	67%	1	33%
4	Nevada	5	47%	1	9%	1	9%	0	0%	7	66%	3.56	34%
5	Colorado*	2	33%	0	0%	0	0%	2	33%	4	66%	2	33%
6	Pennsylvania	3	60%	0	0%	0	0%	0	0%	3	60%	2	40%
7	Minnesota (Comm.)	2	40%	0	0%	0	0%	1	20%	3	60%	2	40%
8	Utah	9	41%	2	9%	1	5%	1	5%	13	59%	9	41%
9	New Mexico	5	36%	3	21%	0	0%	0	0%	8	57%	6	43%
10	Indiana**	7	29%	6	25%	0	0%	0	0%	13	54%	11	46%
11	Kentucky	5	38%	1	8%	1	8%	0	0%	7	54%	6	46%
12	New Hampshire	1	50%	0	0%	0	0%	0	0%	1	50%	1	50%
13	Kansas	1	50%	0	0%	0	0%	0	0%	1	50%	1	50%
14	Idaho	1	50%	0	0%	0	0%	0	0%	1	50%	1	50%
15	Delaware	1	50%	0	0%	0	0%	0	0%	1	50%	1	50%
16	Michigan	1	25%	1	25%	0	0%	0	0%	2	50%	2	50%
17	Iowa	2	44%	0	0%	0	0%	0	0%	2	44%	2.5	56%
18	Wisconsin	2	22%	0	0%	2	22%	0	0%	4	44%	5	56%
19	Illinois	3	43%	0	0%	0	0%	0	0%	3	43%	4	57%
20	Arizona	4	33%	1	8%	0	0%	0	0%	5	42%	7	58%
21	Washington	6	35%	0	0%	0	0%	1	6%	7	41%	10	59%
22	Missouri	1	20%	1	20%	0	0%	0	0%	2	40%	3	60%
23	Massachusetts	14	24%	7	12%	2	3%	0	0%	23	39%	36	61%
24	Texas	6	33%	1	6%	0	0%	0	0%	7	39%	11	61%
25	North Carolina	19	30%	4	6%	0	0%	1	2%	24	38%	39	62%
26	Florida	0	0%	0	0%	0.6	38%	0	0%	0.6	38%	1	63%
27	Nebraska	3	27%	1	9%	0	0%	0	0%	4	36%	7	64%
28	Maryland	0	0%	1	33%	0	0%	0	0%	1	33%	2	67%
29	Minnesota (DHHSD)	17	32%	0	0%	0	0%	0	0%	17	32%	36	68%
30	New York ***	0	0%	1	25%	0	0%	0	0%	1	25%	4	100%
31	California	1	25%	0	0%	0	0%	0	0%	1	25%	3	75%
32	New Jersey	2	22%	0	0%	0	0%	0	0%	2	22%	7	78%
33	Virginia	1	9%	1	9%	1	9%	0	0%	3	17%	8	73%
34	Hawaii	1	6%	1	6%	0	0%	0	0%	2	13%	14.5	91%
35	West Virginia	0	0%	0	0%	0	0%	0	0%	0	0%	3	100%
36	Oregon	0	0%	0	0%	0	0%	0	0%	0	0%	3	100%
37	Maine	0	0%	0	0%	0	0%	0	0%	0	0%	3	100%
38	Louisiana	0	0%	0	0%	0	0%	0	0%	0	0%	4	100%
39	Connecticut	0	0%	0	0%	0	0%	0	0%	0	0%	49	100%
								Total		178.6	37%	311.56	63%

* effective on February 2010
** 21 RCDs as part-time included.
*** NYS CQCAPD - Overall 103 FTEs. For D/HH Council, 5 FTEs sharing responsibilities with other councils

6.3 Staff Position Titles Other Than Administrator

State	Staff Position Titles Other Than Administrator
Arizona	Deputy Director, Assistant to the Executive Director, Business Manager, Special Project Specialist, Administrative Assistant, Deaf Specialist, Hard of Hearing Specialist, Licensing/ Certificate Coordinator, Account Payable, Information Assessment Coordinator, AZTEDP Program Planner, and Public Relations Coordinator.
California	Deputy Director, Staff Services Manager, Staff Services Analyst, and Associate Governmental Program Analyst
Colorado	Legal Auxiliary Services Manager, Telecommunications Equipment Distribution Program Coordinator, Sign Language Interpreter, Technical Assistance Specialists (2), and Legal Auxiliary Services Coordinator
Delaware	Public Information Officer and Administrative Support Specialist
Florida	Program Assistant and Outreach and Education Coordinator.
Hawaii	Program and Policy Development Coordinator, Program Specialists (3), Communication Access Specialist, Communication Access Technician, Facility Access Specialists (4.5), Planner, Secretary, Clerk, Coordinator, and Assistant Coordinator
Idaho	Administrative Assistant
Illinois	Assistant Director, Personnel Manager, Legal Counsel, Program Coordinator, Project Coordinator, Interpreter Coordinator, and Executive Secretary.
Indiana	Program Director, Program Consultants, Counselors and Secretaries
Iowa	Secretary, Disability Consultants (3)
Kansas	Interpreter QA Coordinator, and Information Referral Specialist
Kentucky	Executive Staff Assistant, Internal Policy Analyst, Interpreter Referral Specialist, Information Coordinators (2), Executive Secretary, Executive Interpreter, Interpreter II, Network Analyst, Document Processing Specialist, Administrative Specialist, and Information Office Supervisor.
Louisiana	Program Coordinator, Program Specialist, and Administrative Program Specialist
Maine	Administrative Assistant and Central Office Consultant
Maryland	Assistant Director, and Special Assistant
Massachusetts	Deputy Commissioner of Program and Policy, Deputy Commissioner of Administration and Finance, Administrative Assistant, Case Manager, Staff Interpreter, Interpreter/CART Specialist, Department Supervisor, Director of Interpreting Services, Director of Case Management, Project Coordinator, Program Coordinator, Human Resources Liaison, Accountant, Accounting Clerk, Business Manager, Contract Manager, Communication Access Outreach Training Specialist, and Screening and Evaluation Coordinator
Michigan	Interpreter, Interpreter Coordinator, and Hard of Hearing Specialist
Minnesota (Comm.)	Public Policy Coordinator, Education Outreach Director, Technology Access Specialist, and Office Coordinator
Minnesota (DHHSD)	Assistant Director, Regional Managers, Mental Health Director, Program Development Supervisor, Telephone Equipment Administrator, Program Planner, Staff Interpreters, Administrative Assistants, Program Consultants, TED Specialists, Deaf-Blind Specialist, Office Liaison, and Mental Health Specialists.
Mississippi	Assistant Administrative II and full-time interpreter
Missouri	Interpreter Certification Coordinator, Workshop/Training Specialist, Information Specialist/Staff Interpreter, and Executive Secretary
Nebraska	Field Representatives, Mental Health Specialist, Business Manager, Staff Assistants, and Administrative Assistant
Nevada	Management Staff (.24 FTE), Support Staff (.32 FTE), Program Administration, Office Manager, Regional Supervisor, Case Manager Specialists, and Communication Support Staff
New Hampshire	Secretary

6.3 Staff Position Titles Other Than Administrator (continued)

State	Staff Position Titles Other Than Administrator
New Mexico	Chief Financial Officer, Service Coordinator, Las Cruces Office Coordinator, Service Coordinators (2), Director of Special Projects, Director of Public Policy and Advocacy, Director of Telecommunication and Technical Assistance, Director of Communication Access and Development, Office Administrative Assistant, Telephone Distribution Program Specialist, Information and Referral Specialist, Public Education and Outreach Specialist, Financial Coordinator, and Business Operations Specialist.
New Jersey	Executive Assistant, Secretarial, Deaf and Hard of Hearing Specialists
New York	Attorneys, social workers, policy analysts, nurses, fiscal analysts, division directors, administrative officer, personnel administrator, mail clerks, administrative assistants, and agency director.
North Carolina	Office Assistant, Program Assistant, Technology Resource Coordinator, Emergency Preparedness Coordinator, Planner/Evaluator, Business Manager, Communication Access Manager, Human Resources Manager, Information Technology Specialist, Hard of Hearing Services Manager, Community Resource Program Manager, Telecommunication Resources Program Manager, Equipment Distribution Service Coordinator, Staff Interpreter, Director's Interpreter, Regional Center Manager, Deaf Services Specialist, Hard of Hearing Services Specialists, Deaf-Blind Services Specialist, Interpreter Services Specialist, Telecommunication Consultant, and Community Accessibility Consultant.
Oregon	Program Coordinator, part-time back-up/support for coordinator, manager, and trainer.
Pennsylvania	Administrative Assistant, Representatives (3)
Rhode Island	Program Manager and Interpreter/CART Referral Specialist
Tennessee	Secretary
Texas	Financial Services Liaison, Interpreter, BEI Program Administrator, Interpreter Certification Administrative Technicians (2), Communication Access Administrative Technician, Communication Access Specialist, Direct Services Program Specialist, Hard of Hearing Specialist, Outreach Development Specialist, STAP.Office Administrator, STAP Program Specialists (2), and STAP Administrative Technicians (5)
Utah	Secretaries, deaf facilities supervisor, interpreters, interpreter certification manager, counselors, case managers, outreach position, deaf program specialists, hard of hearing program specialists, certified deaf interpreter, language mentors for interpreter, and Training Technology specialist.
Virginia	Administration & Policy Manager, Relay & Technology Manager, Business Manager, Outreach Manager, Technology Programs Specialist, VQAS Programs Specialist, Outreach Specialist, Program Support Technician, ISP Coordinator, and CapTel Specialist.
Washington	Assistant Director, Fiscal Officer, Executive Assistants (6), Program Managers (2), Program Support, Information Technology (IT) Manager, IT Network Specialist, IT Database Specialist, Office Assistant, and Customer Service Representative.
West Virginia	Deputy Director and Secretary
Wisconsin	Human Services Program Coordinator, Regional Coordinator, Administrative Assistant, and Interpreter.

7.0 Services

7.1 General Services

The top five (5) services provided by among 39 state agencies are Information and Referral (95%), Advocacy (90%), Deaf Awareness/Orientation/Training (79%), Technical Assistance (77%), and Interpreter Referral (77%).

Table 7.1 - General Services

	Services	N	%
1	Information and Referral	37	95%
2	Advocacy	35	90%
3	Deaf Awareness/Orientation/Training	31	79%
4	Technical Assistance	30	77%
5	Interpreter Referral	28	72%
6	Assistive Technology	27	69%
7	Interpreter Directory	25	64%
8	CART Referral	25	64%
9	Services to Hard of Hearing	24	62%
10	Client Assistance	24	62%
11	Adult/Community Education	20	51%
12	Lending Library	19	49%
14	Interpreter Training and Workshop	18	46%
15	Newsletter	18	46%
16	Equipment Loan	18	46%
17	Interpreter Qualifying and Licensing	16	41%
18	Telecommunication Distribution Program	16	41%
19	Senior Citizens Services	15	38%
20	Emergency needs	14	36%
21	Deaf-Blind Services	13	33%
22	Interpreter Services (direct)	12	31%
23	Research	12	31%
24	Deaf Festival	10	26%
25	Sign Language Instructions/Classes	8	21%
26	Counseling	7	18%
27	Relay Service	5	13%
28	Job Development and Placement	5	13%
29	Video Remote Interpreting Service	4	10%
30	Legislation affecting community- direct lobbing	3	8%
31	Community Outreach	3	8%
32	Remote CART Service	2	5%
33	Accessibility to State Agencies	2	5%
34	Equipment Program contracted by Division	1	3%
35	Case Management Services for Adults	1	3%
36	Children's Specialists	1	3%
37	Communication Access Technology and Training Services	1	3%
38	Deaf and Hard of Hearing Independent Living Services	1	3%
39	Communication Services	1	3%
40	Quality Assurance Screening	1	3%

7.2 Relay Services

The State Agencies identified are responsible to oversee the State Relay Service in various forms.

Table 7.2 - Overseeing State Relay Services

Relay Services
Arizona
New Mexico
North Carolina
Virginia
Washington

7.3 State Telecommunication Distribution Program

The State Agencies identified are in charge of Telecommunication Distribution Program.

Table 7.3 - Telecommunication Distribution

Telecommunication Distribution Program
Arizona
Colorado
Kentucky
Louisiana
Maine
Minnesota (DHHSD)
Nebraska
Nevada
New Mexico
New Jersey
North Carolina
Tennessee
Texas
Virginia
Washington
Wisconsin

7.4 Legislative Actions by the State Agencies

The State Agencies identified are allowed by the statutes to initiate, create, and lobby the legislation at the General Assembly.

Table 7.4 - State Agencies Allowed to lobby the legislations

Legislative Actions
Kentucky
Minnesota (Commission)
Rhode Island

7.5 Interpreter Referral

The State Agencies identified provide the interpreter referral services in various ways. Some provide regular interpreter referral services. Some provide interpreter referrals to State departments/agencies only, some provide for state courts only, some maintain a list of interpreters for distribution purposes, some are responsible to handle registrations of interpreters who work in the state.

Table 7.5 - Interpreter Referral

Interpreter Referral
Arizona
California
Colorado
Connecticut
Idaho
Illinois
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota (DHHSD)
Mississippi
Nebraska
Nevada
New Hampshire
New Mexico
New Jersey
North Carolina
Pennsylvania
Rhode Island
Tennessee
Texas
Utah
Virginia

7.6 Interpret Qualifying and Licensing

The State Agencies identified have programs that issue certificates, licenses, and/or qualify interpreters in their respective states.

Table 7.6 - Interpreter Qualifying and Licensing

Interpreter Qualifying and Licensing
Arizona
Colorado
Illinois
Kansas
Kentucky
Louisiana
Massachusetts
Michigan
Missouri
Nebraska
New Hampshire
New Mexico
Pennsylvania
Texas
Utah
West Virginia

8.0 Demographic Information

81 Demographic—Deaf and Hard of Hearing Population

The information below with both percentages and data sources varies from state to state. All 39 state agencies need to agree on percentage for each category (Deaf, Hard of Hearing, and Deaf Blind) and which source they will use to compute the figure in their respective states. They need consistency as to how to compute the figures.

Table 9.1 - Rank by Deaf and Hard of Hearing Population

	State	**General Population**	**Deaf and Hard of Hearing**	**Percentage of Deaf/HoH**	**Percentage of Deaf Only**	**Percentage of HoH Only**	**Percentage of Deaf-Blind**
1	California	36,700,000.00	3,800,000.00	2.0%	N/A	N/A	N/A
2	Texas	21,000,000.00	3,800,000.00	8.8%	2.3%	6.5%	N/A
3	Florida	18,881,445.00	3,021,031.00	16.0%	N/A	N/A	N/A
4	New York	19,490,297.00	1,500,000.00	N/A	N/A	N/A	N/A
5	Michigan	10,003,422.00	1,400,000.00	10.0%	N/A	N/A	N/A
6	Illinois	12,419,293.00	1,068,059.00	8.6%	N/A	N/A	N/A
7	North Carolina	9,000,000.00	1,000,000.00	15.3%	N/A	N/A	N/A
8	Maryland	5,633,597.00	957,711.00	17.0%	N/A	N/A	N/A
9	Washington	6,287,759.00	880,286.00	N/A	N/A	N/A	N/A
10	New Jersey	8,682,661.00	800,000.00	8.6%	N/A	N/A	N/A
11	Tennessee	5,464,458.00	780,373.00	7.0%	18%	N/A	N/A
12	Arizona	6,500,000.00	704,000.00	11.0%	N/A	N/A	N/A
13	Virginia	7,769,089.00	675,910.00	8.7%	1%	N/A	N/A
14	Kentucky	6,000,000.00	645,000.00	11.0%	N/A	N/A	N/A
15	Pennsylvania	12,448,279.00	624,061.00	N/A	N/A	N/A	N/A
16	Missouri	5,800,310.00	580,000.00	10.0%	1%	9%	N/A
17	Massachusetts	6,349,097.00	546,022.00	8.6%	0.23%	N/A	N/A
18	Minnesota (Comm.)	5,000,000.00	500,000.00	10.0%	N/A	N/A	N/A
19	Wisconsin	5,000,000.00	500,000.00	10.0%	N/A	N/A	N/A
20	Minnesota (DHHSD)	5,000,000.00	497,229.00	10.0%	1%	9%	N/A
21	Indiana	6,195,643.00	495,651.00	N/A	N/A	N/A	N/A
22	Colorado	4,550,688.00	418,000.00	8.6%	0.9%	7.7%	N/A
23	Louisiana	4,400,000.00	400,000.00	10.0%	1%	N/A	N/A
24	New Mexico	1,984,356.00	337,340.00	16.0%	2%	14%	N/A
25	Kansas	2,700,000.00	270,000.00	12.0%	10%	N/A	N/A
26	Iowa	2,926,324.00	229,131.00	8.0%	0.9%	7.1%	N/A
27	Connecticut	3,501,252.00	208,000.00	8.0%	6%	2%	N/A
28	Utah	2,233,169.00	199,822.00	10.0%	1.7%	8.8%	N/A
29	Nevada	2,414,807.00	193,184.56	8.0%	N/A	N/A	N/A
30	Oregon	3,790,060.00	179,000.00	N/A	N/A	N/A	N/A
31	Idaho	1,600,000.00	137,000.00	8.6%	1.6%	7%	N/A
32	Maine	1,300,000.00	105,000.00	10.0%	N/A	N/A	N/A
33	New Hampshire	1,700,000.00	101,000.00	10.0%	N/A	N/A	N/A
34	Rhode Island	1,011,960.00	87,028.00	8.6%	N/A	N/A	N/A
35	Hawaii	1,288,198.00	47,817.00	N/A	N/A	N/A	N/A
36	Delaware	873,092.00	31,000.00	N/A	N/A	N/A	N/A
37	Mississippi	2,921,088.00	20,000.00	N/A	N/A	N/A	N/A
38	Nebraska	1,783,432.00	11,630.00	N/A	N/A	N/A	N/A
39	West Virginia	1,800,000.00	Unknown	N/A	N/A	N/A	N/A
			Average:	**10.0%**	**3%**	**8%**	**0%**

8.2 Demographic— Data Sources to be Used for Deaf and Hard of Hearing Population

Table 9.2 - Data Sources Used by States

State	Data Sources
Arizona	U.S. Census Bureau
California	State Department of Finance Estimates - 1990 and U.S. Census - 2008
Colorado	U.S. Department of Health and Human Services - July 2007
Connecticut	General Population from CT Dept of Health - 2008
Delaware	US Census Sensory Data - 2006 and US Census Bureau - July 2008
Florida	Florida Legislature Economic and Development Resource.
Hawaii	D/HH population from Gallaudet University Library FAQ - June 2004
Idaho	Formula set-forth by Gallaudet Research Institute (GRI)
Illinois	United States Department of Health and Human Services at 8.6%, Gallaudet University Research Institute, the Centers for Disease Control and Prevention, and National Center for Health Statistics.
Indiana	2003 US Census Bureau
Iowa	US Census
Kansas	Gallaudet Research Institute
Kentucky	US Census, University Research as of 2007
Louisiana	US Census - 07/08
Maine	National Institute on Deafness and Communication Disorder 2002
Maryland	US Census estimates for 2008
Massachusetts	US Department of Commerce, Bureau of the Census, 2000 Census- March 2001, National Center for Health Statistics
Michigan	Contracted State Survey
Minnesota (Comm.)	National Center for Health Statistics - 2006
Minnesota (DHHSD)	Gallaudet Research Institute
Mississippi	US Census Bureau & Gallaudet University Research Institute
Missouri	US Census Bureau - 2007, 10% inaccurate, CDC indicates better % is 14% including institutionalized persons
Nebraska	General Population from US Census 2008. D/HH population based on a number of registrations for various programs that Nebraska Commission offered in the past.
Nevada	
New Hampshire	US Census Bureau - 2000
New Mexico	
New Jersey	US Center for Health Statistics - 1994
New York	US Census - 2008 and NYSCQCAPD's website
North Carolina	15.32% for age 18 and up only. US Census Bureau and 2008 Series 10 report data from www.cdc.gov/nchs/nhis.htm
Oregon	US Census
Pennsylvania	US Census - 2000 and US Census 1990

8.2 Demographic— Data Sources to be Used for Deaf and Hard of Hearing Population (Continued)

Table 9.2 - Data Sources Used by States (continued)

State	Data Sources
Rhode Island	US Census 2001, Nat'l Center for Health Statistics- Nat'l Health Interview Survey-1994
Tennessee	1990 Census (figures were taken from the Tennessee Statistical Abstract 1994/1995)
Texas	2005 Census and 2005 National Health Interview Survey
Utah	US Census Bureau 2000
Virginia	National Center for Health Statistics - 2005
Washington	US Census - general population, Gallaudet Research Institute 2005 on D/HH
West Virginia	US Census Bureau
Wisconsin	US Census

9.0 Agency Website and E-Mail Addresses

9.1 Agency Website Addresses

Table 8.1 - Agency Website Addresses

State	Website
Arizona	www.acdhh.org
California	www.cdss.ca.gov/cdssweb/PG145.htm
Colorado	www.coloradodeafcommission.com
Connecticut	www.ct.gov/cdhi
Delaware	www.delawareworks.com/dvr/services/dodhh.shtml
Florida	www.fccdhh.org
Hawaii	www.hawaii.gov/health/dcab
Idaho	www.cdhh.idaho.gov
Illinois	www.idhhc.state.il.us
Indiana	www.dhhs.in.gov
Iowa	www.dsci.iowa.gov
Kansas	www.srskansas.org/kcdhh
Kentucky	www.kcdhh.org
Louisiana	www.dss.state.la.us
Maine	www.maine.gov/rehab/dod
Maryland	www.odhh.maryland.gov
Massachusetts	www.state.ma.us/MCDHH
Michigan	www.mcdc-dodhh.org
Minnesota (Comm.)	www.mncdhh.org
Minnesota (DHHSD)	www.dhhsd.org
Mississippi	www.odhh.org
Missouri	www.mcdhh.mo.gov
Nebraska	www.ncdhh.ne.gov
Nevada	www.dhhs.nv.gov
New Hampshire	www.ed.state.nh.us
New Mexico	www.cdhh.state.nm.us
New Jersey	www.state.nj.us/humanservices/ddhh/
New York	www.cqcapd.state.ny.us
North Carolina	www.ncdhhs.gov/dsdhh/
Oregon	www.oregon.gov/DHS/odhhs/index.shtml
Pennsylvania	www.dli.state.pa.us….Keyword: ODHH
Rhode Island	www.cdhh.ri.gov
Tennessee	www.tennessee.gov/humanserv/rehab/cc6.html
Texas	www.dars.state.tx.us/dhhs
Utah	www.deafservices.utah.gov
Virginia	www.vddhh.org
Washington	http://odhh.dshs.wa.gov
West Virginia	www.wvdhhr.org/wvcdhh
Wisconsin	http://dhs.wisconsin.gov/sensory/

9.2 Agency E-mail Addresses

These email addresses are used by the public to contact the agency. Specific individual's email address is not included.

Table 8.2 - Agency E-mail Addresses

State	Agency E-Mail Addresses
Arizona	info@acdhh.state.az.gov
California	deaf.access@dss.ca.gov
Colorado	email.ccdhh@state.co.us
Connecticut	cdhi@ct.gov
Hawaii	dcab@doh.hawaii.gov
Illinois	dhh.webmaster@illinois.gov
Iowa	dhr.dsci@iowa.gov
Kentucky	info_svcs@ky.gov
Maryland	odhh@gov.state.md.us
Massachusetts	See website for link to submit msgs
Michigan	DODHH@Michigan.gov
Minnesota (Comm.)	mncdhh.info@state.mn.us
Missouri	mcdhh@mcdhh.mo.gov
New York	webmaster@cqcapd.state.ny.us
North Carolina	DSDHH.Information@ncmail.net
Oregon	info.odhhs@state.or.us
Pennsylvania	ra-li-ovr-odhh@state.pa.us
Rhode Island	cdhh@cdhh.ri.gov
Tennessee	TCDHH.Council.DHS@tn.gov
Virginia	frontdsk@vddhh.virginia.gov
Washington	odhh@dshs.wa.gov
West Virginia	wvcdhh@wvdhhr.org

10.0 Agency Contact List

Arizona
Arizona Commission f/t D/HH
1400 W. Washington Street, Room 126
Phoenix, AZ 85007
800-352-8161 TOLL - V/TTY
602-542-3323 V/TTY
866-948-7035 VP
602-542-3380 FAX
info@acdhh.state.az.gov

California
Office of Deaf Access
744 P Street, M.S. 8-16-91
Sacramento, CA 95814
916-653-7651 TTY
916-653-8320 VOICE
916-653-4001 FAX
deaf.access@dss.ca.gov

Colorado
Colorado Commission f/t D/HH
1575 Sherman Street, 2nd Floor
Denver, Colorado 80203
303-866-4734 TTY
720-457-3679 VP
303-866-3824 VOICE
303-866-4831 FAX
email.ccdhh@state.co.us

Connecticut
Commission on the D/HI
P.O. Box 330730
67 Prospect Avenue
Hartford, CT 06133
800-708-6796 TOLL
860-231-8169 TTY
860-231-8756 VOICE
860-231-8746 FAX
cdhi@ct.gov

Delaware
Delaware Office f/t D/HH
Division of Vocational Rehabilitation
4425 North Market Street
Wilmington, DE 19802-1307
302-761-8275 TTY
302-504-4741 VP
302-761-8275 VOICE
302-761-6611 FAX
Loretta.Sarro@state.de.us

Florida
Florida Coordinating Council f/t D/HH
4052 Bald Cypress Way, Bin A06
4025 Esplanade Way, Room 235.10
Tallahassee, FL 32399-1707
866-602-3275 TOLL
850-245-4914 TTY
850-245-4913 VOICE
850-921-8138 FAX
MaryGrace_Tavel@doh.state.fl.us

Hawaii
Disability and Communication Access Board
919 Ala Moana Blvd. Room 101
Honolulu, Hawaii 96814
808-586-8121 TTY/Voice
866-552-3572 VP
808-586-8129 FAX
dcab@doh.hawaii.gov

Idaho
Idaho Council f/t D/HH
1720 Westgate Drive, Suite A
Boise, ID 83704
800-433-1323 TOLL/VOICE
800-433-1361 TTY
208-473-2122 VP
208-334-0952 FAX
snows2@dhw.idaho.gov

Illinois
Illinois D/HH Commission
1630 S. 6th Street
Springfield, IL 62703
877-455-3323 TOLL
217-557-4495 TTY
217-303-8010 VP
217-557-4495 VOICE
217-557-4492 FAX
dhh.webmaster@illinois.gov

Indiana
Indiana, D/HH, Employment and Innovation
402 W. Washington Street
IGCS – W453
Indianapolis, IN 46204
800-545-7763 TOLL
866-800-4634 VP
317-542-3325 FAX
Rhonda.Marcum@fssa.in.gov

10.0 Agency Contact List (continued)

Iowa

Deaf Services Commission of Iowa
Iowa Department of Human Rights
321 E 12th Street
Des Moines, IA 50319
888-221-3724 TOLL
515-281-3164 TTY
515-598-7327 VP
515-281-3164 VOICE
515-242-6119 FAX
dhr.dsci@iowa.gov

Kansas

Kansas Commission f/t D/HH
915 SW Harrison Street
Docking State Office Building, 9 N
Topeka, Kansas 66612
800-432-0698 TOLL
785-368-8046 TTY
785-246-5077 VP
785-368-8034 VOICE
785-368-7467 FAX

Kentucky

Kentucky Commission on the D/HH
632 Versailles Road
Frankfort, KY 40601
800-372-2907 TOLL
502-573-2604 TTY/VOICE
502-385-0544 VP
502-573-3594 FAX
Info_svcs@ky.gov

Louisiana

Louisiana Commission for the Deaf
627 North Fourth Street, 2nd Floor
P.O. Box 91297
Baton Rouge, LA 70821-9297
800-256-1523 TOLL – TTY/V
866-515-9928 VP
225-219-2949 FAX
ndedual@dss.state.la.us

Maine

Division f/t D, HH, and Late Deafened
42 Commerce Drive
Augusta, Maine 04333
888-755-0023 TTY
866-760-8430 VP
207-623-7957 VOICE
john.g.shattuck@maine.gov

Maryland

Maryland Governor's Office of the D/HH
217 E. Redwood Street
Suite 1300
Baltimore, MD 21202
410-767-7756 TTY
443-453-5954 VP
410-767-6290 VOICE
410-333-1016 FAX
odhh@gov.state.md.us

Massachusetts

Massachusetts Commission f/t D/HH
150 Mount Vernon Street, Suite 550
Dorchester, MA 02125
800-530-7570 TTY
800-882-1155 VOICE
617-740-1700 TTY
866-970-7177 VP
617-740-1600 VOICE
617-740-1810 FAX

Michigan

Division on Deaf and Hard of Hearing
201 N Washington Sq. Suite 150
Lansing, MI 48913
877-499-6232 TOLL – TTY/VOICE
517-507-5223 VP
517-335-7773 FAX
DODHH@Michigan.gov

Minnesota I

Commission of D/D-Blind/HH Minnesotans
444 Lafayette Road North
St. Paul, MN 55155-3814
888-206-2001 TTY
651-964-2060 VP
651-431-5961 VOICE
651-431-7588 FAX
mncdhh.info@state.mn.us

Minnesota II

Deaf and Hard of Hearing Services Division
Elmer Andersen Human Services Building
540 Cedar Street
St. Paul, MN 55155
888-206-6506 TTY
651-964-1452 VP
651-431-2355 VOICE
651-431-7417 FAX

10.0 Agency Contact List (continued)

Mississippi
Office on Deaf and Hard of Hearing
3895 Beasley Road
Jackson, MS 39213
601-898-7056 TTY
601-206-0228 VP
601-898-7057 VOICE
601-898-7098 FAX
benjamin.wagenknecht@mdrs.state.ms.us

Missouri
Missouri Commission f/t D/HH
1500 Southridge Drive
Suite 201
Jefferson City, MO 65109
573-526-5205 TTY/VOICE
573-526-5209 FAX
mcdhh@mcdhh.mo.gov

Nebraska
Nebraska Commission f/t D/HH
4600 Valley Road
Lincoln, NE 68510
800-545-6244 TOLL
402-471-3593 TTY/VOICE
402-471-3067 FAX

Nevada
Aging & Disability Svcs Div.– Disabilities Unit
3656 Research Way
Suite 32
Carson City, NV 89706
888-337-3839 TOLL
775-687-3388 TTY
775-687-4452 VOICE
775-687-3292 FAX
bahammond@adsd.nv.gov

New Hampshire
Office of the Deaf and Hard of Hearing
21 South Fruit Street, Suite 200
Concord, NH 03301
603-271-1483 TTY
646-863-7075 VP
603-271-3471 VOICE
603-271-7095 FAX
hdclanton@ed.state.nh.us

New Mexico
New Mexico Commission f/t D/HH Persons
2500 Louisiana Blvd.
Suite 400
Albuquerque, NM 87110
866-755-0242 TOLL
505-881-8824 TTY/VP/VOICE
505-881-8831 FAX

New Jersey
New Jersey Division of the D/HH
222 South Warren Street
Trenton, NJ 08625
609-984-7281 TTY/VOICE
609-498-7019 VP
609-633-3625 FAX

New York
NYS Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-Blind, or Hard of Hearing
NYS Commission on Quality of Care and Advocacy for Persons with Disabilities
401 State Street
Schenectady, NY 12305-2397
800-624-4143 TOLL – TTY/VOICE
518-388-0691 VOICE
518-388-3375 FAX
webmaster@cqcapd.state.ny.us

North Carolina
NC Division of Services f/t D/HH
2301 Mail Service Center
Raleigh, NC 27699-2301
800-851-6099 TOLL
919-874-2212 TTY/VP/VOICE
919-855-6872 FAX
DSDHH.Information@ncmail.net

Oregon
Dept of Human Svcs D/HH Services Pgm
500 Summer Street NE
Salem, OR 97301
800-521-9615 TOLL
503-947-5183 TTY/VOICE
503-947-5184 FAX
Info.odhhs@state.or.us

10.0 Agency Contact List (continued)

Pennsylvania

Pennsylvania Office f/t D/HH
1521 North 6th Street
Harrisburg, PA 17102
800-233-3088 TOLL – TTY/VOICE
717-783-4912 TTY/VOICE
866-572-2628 VP
717-783-4913 FAX
ra-li-ovr-odhh@state.pa.us

Rhode Island

Rhode Island Commission on the D/HH
One Capitol Hill, Ground Level
Providence, RI 02908
401-222-1205 TTY
401-256-5511 VP
401-222-1204 VOICE
401-222-5736 FAX
cdhh@cdhh.ri.gov

Tennessee

Tennessee Council f/t D/HH
Citizens Plaza Building, 14th Floor
400 Deaderick Street
Nashville, TN 37243
800-270-1349 TTY
615-313-4918 VOICE
615-532-4685 FAX
TCDHH.Council.DHS@tn.gov

Texas

Office for D/HH Services
P.O. Box 12904
Austin, TX 78711
512-407-3251 TTY
512-410-6556 VP
512-407-3250 VOICE
512-407-3299 FAX
david.myers@dars.state.tx.us

Utah

Division of Services f/t D/HH
Sanderson Community Center of the D/HH
5709 South 1500 West
Taylorsville, UT 84123
801-313-6815 TTY
801-657-5200 VP
801-263-4861 VOICE
801-263-4865 FAX
mcall@utah.gov

Virginia

Virginia Department f/t D/HH
1602 Rolling Hills Drive
Suite 203
Richmond, VA 23229-5012
800-552-7917 TOLL
804-662-9502 TTY
804-325-1290 VP
804-662-9502 VOICE
804-662-9718 FAX
frontdsk@vddhh.virginia.gov

Washington

Office of the Deaf and Hard of Hearing
P.O. Box 45301
Olympia, WA 98503-5300
800-422-7930 TOLL
360-902-8000 TTY/VOICE
360-339-7382 VP
360-902-0855 FAX
odhh@dshs.wa.gov

West Virginia

West Virginia Commission f/t D/HH
Capitol Complex
Building 6, Room 863
Charleston, WV 25305
866-461-3578 TOLL
304-558-1675 TTY/VOICE
304-205-0330 VP
304-558-0937 FAX
wvcdhh@wvdhhr.org

Wisconsin

Office for the Deaf and Hard of Hearing
1 West Wilson Street #451
Madison, WI 53703
888-701-1251 TTY
608-266-1865 VOICE

2009 Survey Questionnaire

WWW.MONKEYSURVEY.COM

Data Collection Process
October 2009-December 2009

GENERAL INFORMATION

Please fill in your State Agency contact information:

Name of Agency: ___________________________
Address: __________________________________
Address2: __________________________________
City: ______________ State: _______Zip Code: _________

Toll-free number: ( ) _____-________
Main phone number - TTY: ( ) ______-________
Main phone number - VP: ( ) ______-________
Main phone number - Voice: ( ) _____-________
Fax number: ( ) _____-________
Agency E-mail address: __________________________
Website address: ________________________
Agency founded (MM/DD/YYYY):_______/______/_______

What is location of your agency? Under what agency or department?

____

Since 2004, has your agency merged with any other agencies, expanded, downsized, or reorganized as required by law or executive order? If yes, please explain the impact on your agency in general. Positive? Increase restrictions? Challenges?

____
____
____
____

GENERAL ADMINISTRATION INFORMATION

Name of Administrator: ______________________________

What is the title of administrator's position? (Examples: Executive Director, Commissioner, Director, etc.)

Hearing Status?

- ☐ Deaf
- ☐ Hard of Hearing
- ☐ Late-Deafened
- ☐ Hearing

Which one of the following listed below best matches your Administrator’s position?

- ☐ Civil Service Classified Position
- ☐ Governor appointed position
- ☐ Report directly to Governor
- ☐ Other (please specific): ____________________

What is Annual Salary of the Administrator? Please check one. (confidential)

- ☐ $0 to $25,000
- ☐ $25,001 to $35,000
- ☐ $35,001 to $45,000
- ☐ $45,001 to $55,000
- ☐ $55,001 to $65,000
- ☐ $65,001 to $75,000
- ☐ $75,001 to $85,000
- ☐ $85,001 and higher

Administrator's contact information:

E-mail address: ____________________________________
Videophone: ______________________________________
Phone - Voice:_____________________________________
Fax number: ______________________________________

COMPOSITION OF COMMISSION, COUNCIL, OR BOARD

Number of Members serving on commission, council, or board?

____

One Term = how many year?

____

Appointed by:

- ☐ Governor
- ☐ Department Administrator
- ☐ Legislature
- ☐ Other (please specify): ______________________________

Does your law requires a majority number of deaf and hard of hearing representatives?

- ☐ Yes
- ☐ No

What representations on your commission, council, or board does your law require? (Please check all that apply.)

- ☐ not required
- ☐ hard of hearing
- ☐ psychologist
- ☐ physician, otolaryngolsist
- ☐ state government official
- ☐ deaf organization representative
- ☐ hard of hearing organization representative
- ☐ late deafened organization representative
- ☐ general public
- ☐ deaf
- ☐ audiologist
- ☐ educator
- ☐ parent
- ☐ early intervention provider
- ☐ interpreter organization

☐ hearing
☐ local(regional) representative
☐ Other (please specify): ___________________________________

Minimum number of regular meetings in a year as required by the law.

____

What communication access accommodation(s) is automatically and routinely arranged for the regular meeting? Any accommodation that would not require a special request in advance? (Please check all that apply.)

☐ Interpreter
☐ CART
☐ Assistive Listening System (ALS)
☐ Assistive Listening Device (ALD)
☐ Video Remote Interpreter (VRI)
☐ Remote CART
☐ Other (please specify): _____________________________

Are the members reimbursed for travel expenses?

☐ Yes
☐ No
☐ Other (please specify): ____

FUNDING (Fiscal Year 2010)

What is your fiscal year cycle?

☐ October 1 to September 30
☐ January 1 to December 31
☐ July 1 to June 30
☐ Other (please specify): _____________________________

Total authorized (enacted) budget for Fiscal Year 2010? (e.g.: $560,000)

____

Is your authorized (enacted) budget good for …..

☐ One year (annual)?
☐ Two years (biennial)?
☐ Other (please specify): _________________________

Funding Source(s) (Please check all that apply.):

☐ State appropriation (What % is state funded? _____%)
☐ Federal
☐ Third party contract (MOU, Agreements, etc.)
☐ Grants (state and/or federal)
☐ Fees
☐ Donations/gifts
☐ Other (please specify):
____

STAFF AT YOUR AGENCY

Please fill in:

✦ Number of full-time equivalent (FTE) staff positions (administrator included.): ___________

✦ Number of part-time positions Number of staff members who are deaf: _______________

✦ Number of staff members who are hard of hearing: __________

✦ Number of staff members who are late-deafened: ___________

✦ Number of staff members who are hearing: ____________

✦ Number of staff members who are deaf, HoH, or LateD **PLUS** other disability: _________________________

Please list staff positions that are part of your agency (please attached if you have many positions that might not fit in this section.):

____

____

Please check all that apply closely and list other services that are not on this list.

- ☐ Adult/Community Education
- ☐ Advocacy
- ☐ Assistive Technology
- ☐ Counseling
- ☐ Client Assistance
- ☐ Deaf Awareness/Orientation/Training
- ☐ Deaf Festival
- ☐ Equipment Loan
- ☐ Emergency Needs
- ☐ Information and Referral
- ☐ Interpreter Directory
- ☐ Interpreter Referral
- ☐ CART Referral
- ☐ Interpreter Services (direct)
- ☐ Interpreter Qualifying and Licensing
- ☐ Interpreter Training and Workshop
- ☐ Video Remote Interpreting Service
- ☐ Remote CART Service
- ☐ Job Development and Placement
- ☐ Lending Library
- ☐ Newsletter
- ☐ Research
- ☐ Senior Citizens Services
- ☐ Deaf Blind Services
- ☐ Services to Hard of Hearing
- ☐ Sign Language Instruction/Classes
- ☐ Technical Assistance
- ☐ Relay Service
- ☐ Telecommunication Distribution program
- ☐ Other (please specify): ___________________________________

DEMOGRAPHICS

Questions about your population in your State

✦ What is the combined deaf and hard of hearing population estimate of your state? ____

✦ What is the total general population in your state?:___________________________

✦ What data source do you use to compute the estimates? U.S. Census Bureau? U.S. Department of Health? As of WHEN? Please be specific.:

____

✦ What percentage do you use to compute the population of Deaf and Hard of Hearing?: ____

✦ Please put 'N/A' if you do not have it, what percentage do you use to compute the population of DEAF only?: ______________

✦ Please put 'N/A' if you do not have it, what percentage do you use to compute the population of Hard of Hearing only?: __________________

Please put 'N/A' if you do not have it, what percentage do you use to compute the population of Deaf-blind? : ___________

Any general comments?

____
____
____

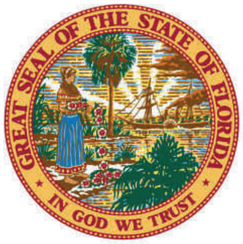

GREAT SEAL OF THE STATE OF ARIZONA
DITAT DEUS
1912

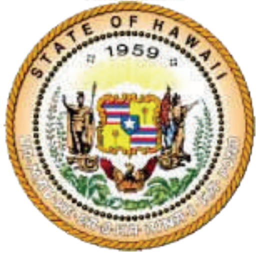

THE GREAT SEAL OF THE STATE OF CALIFORNIA
EUREKA


STATE OF COLORADO
NIL SINE NUMINE
1876


SIGILLUM REIPUBLICÆ CONNECTICUTENSIS


GREAT SEAL OF THE STATE OF DELAWARE
LIBERTY AND INDEPENDENCE
1793 · 1847 · 1907


GREAT SEAL OF THE STATE OF FLORIDA
IN GOD WE TRUST

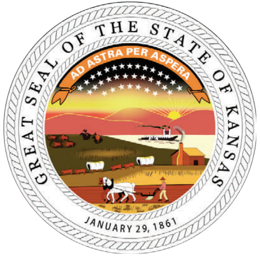

STATE OF HAWAII
1959


GREAT SEAL OF THE STATE OF IDAHO
ESTO PERPETUA


SEAL OF THE STATE OF ILLINOIS
NATIONAL UNION STATE SOVEREIGNTY
1868
1818
AUG. 26TH 1818


SEAL OF THE STATE OF INDIANA
1816

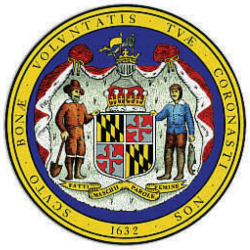

THE GREAT SEAL OF THE STATE OF IOWA
OUR LIBERTIES WE PRIZE AND OUR RIGHTS WE WILL MAINTAIN


GREAT SEAL OF THE STATE OF KANSAS
AD ASTRA PER ASPERA
JANUARY 29, 1861


COMMONWEALTH OF KENTUCKY
UNITED WE STAND
DIVIDED WE FALL

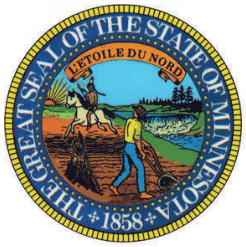

STATE OF LOUISIANA
UNION JUSTICE CONFIDENCE


DIRIGO
MAINE


SCVTO BONÆ VOLVNTATIS TVÆ CORONASTI NOS
FATTI MASCHII PAROLE FEMINE
1632

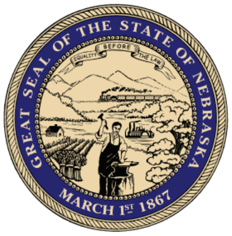

SIGILLUM REIPUBLICÆ MASSACHUSETTENSIS


THE GREAT SEAL OF THE STATE OF MICHIGAN
E PLURIBUS UNUM
TUEBOR
SI QUÆRIS PENINSULAM AMŒNAM
CIRCUMSPICE


THE GREAT SEAL OF THE STATE OF MINNESOTA
L'ETOILE DU NORD
1858

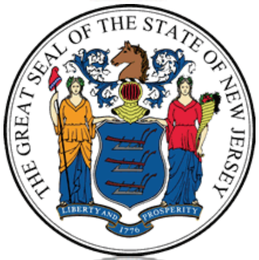

THE GREAT SEAL OF THE STATE OF MISSISSIPPI


THE GREAT SEAL OF THE STATE OF MISSOURI
UNITED WE STAND DIVIDED WE FALL
MDCCCXX

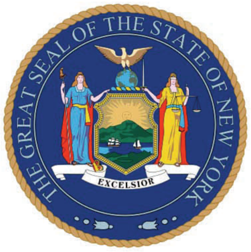

GREAT SEAL OF THE STATE OF NEBRASKA
EQUALITY BEFORE THE LAW
MARCH 1ST 1867

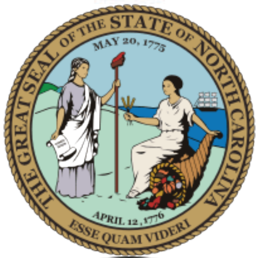

THE GREAT SEAL OF THE STATE OF NEVADA
ALL FOR OUR COUNTRY


SEAL OF THE STATE OF NEW HAMPSHIRE
1776


THE GREAT SEAL OF THE STATE OF NEW JERSEY
LIBERTY AND PROSPERITY
1776


GREAT SEAL OF THE STATE OF NEW MEXICO
Crescit Eundo
1912


THE GREAT SEAL OF THE STATE OF NEW YORK
EXCELSIOR


THE GREAT SEAL OF THE STATE OF NORTH CAROLINA
MAY 20, 1775
APRIL 12, 1776
ESSE QUAM VIDERI


STATE OF OREGON
THE UNION
1859


SEAL OF THE STATE OF PENNSYLVANIA


SEAL OF THE STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS
HOPE
1693


THE GREAT SEAL OF THE STATE OF TENNESSEE
XVI
AGRICULTURE
COMMERCE
1796


THE STATE OF TEXAS


THE GREAT SEAL OF THE STATE OF UTAH
1847
1896


VIRGINIA
SIC SEMPER TYRANNIS


THE SEAL OF THE STATE OF WASHINGTON
1889


STATE OF WEST VIRGINIA
MONTANI SEMPER LIBERI


GREAT SEAL OF THE STATE OF WISCONSIN
FORWARD

Kindergarten Readiness Assessment
Fall 2016

Comparison of the
Deaf & Hard of Hearing students
with their counterparts

Oregon Department of Education

Comparisons of results for the Deaf & Hard of Hearing students with their counterparts

Intro:

In Fall 2016, Oregon Kindergarten Readiness Assessment (KA) was administered to almost 41 thousand children entering Kindergarteners statewide.

The Oregon School for the Deaf, ask the Oregon Department of Education (ODE) to compare the KA test results for the student identified as 'Deaf & Hard of Hearing' (D&HH), with their counterparts (referenced herein as the 'main group'. 64 students were identified with hearing disabilities, 54 of whom had valid KA test scores.

Oregon's Kindergarten Readiness Assessment looks at three areas:
- Students Learning Behavior (Self-Regulation and Interpersonal Skills)
- Early Mathematics (one test)
- Early Literacy (three tests, English Letter Names and Sounds Recognition)

Findings:

The overall conclusion is that aggregate D&HH results lag the main group in all three areas.
This most cases, observed lag computes to be statistically significant (@95% confidence interval). Yet, caution is advised when assigning practical significance to the observed differences, given that:

- this is a small subgroup relative to its population (54 vs 40,716, about one-tenth of one percent). Small sized groups compromise the confidence with which we could generalize to a larger or future D&HH population.
- the numerical difference between the scores have not been qualified/aligned/normalized to any future outcomes. In other words the present or future significance of say a 2 point score difference is currently undetermined.

However even with small performance differential, few would deny that parity is desirable outcome for equity reasons. Knowing where these differences occur, should help in coming up with performance gap mitigation strategies.

Demographically speaking, this D&HH group was primarily (**92%**) composed of two ethnicity/race subgroups: Hispanic 35%; White 57%. In contrast, **86%** of the main group were Hispanic 23%; White 63%.

The gender ratio for the D&HH group was 46% female, 54% male, fairly similar to the main group ratio of approximately 48.5% female, 51.5% male.

In the Approaches To Learning assessment, the D&HH male scores were much more variable than the D&HH female scores. In contrast, the main group male and female scores were similar to each other.

In Early Mathematics, the D&HH Hispanic subgroup had lowest and most varied scores, very unlike the main group Hispanic scores. The D&HH male/female scored differently. In contrast, gender does not show differential performance in the main group.

In Early Literacy, for the **Uppercase** English Letter Name Recognition test, the D&HH Hispanic scores was *significantly* less than their main group counterparts. Similar pattern exists for the **Lowercase** English Letter Name Recognition test**.**

In Early Literacy, English Letter Sounds Recognition, the D&HH group Hispanic and males scored significantly lower than there main group counterparts.

It was interesting to note that the only instance in which a D&HH subgroup performed similar to their main group counterpart was the female subgroup and it was in the Early Literacy, English Letter Sounds Recognition test.

Kindergarten Readiness Assessment

Fall 2016

Comparisons of results for the Deaf & Hard of Hearing students with their counterparts

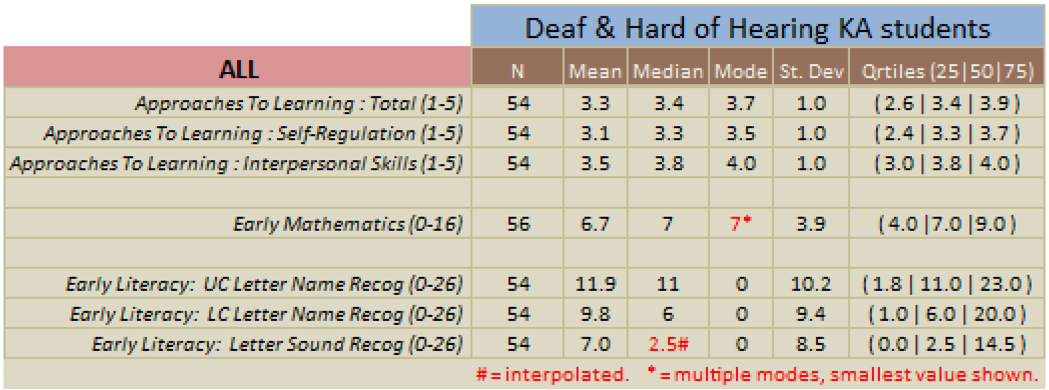
Document Contents:

The attached table and charts show the aggregate KA scores for the D&HH and main groups.
Additional breakouts for Hispanics and Whites, females and males are included.

The numerical results are presented in 10 side-by-side tables

	D&HH KA students	Other KA students
• ALL	**Table 1**	**Table 2**
• *Hispanic*	**3**	**4**
• *White*	**5**	**6**
• *Female*	**7**	**8**
• *Male*	**9**	**10**

This is the **Table 1** referenced above. It shows the aggregate statistics for the D&HH subgroup for the three Kindergarten Assessment domains.



	Deaf & Hard of Hearing KA students					
ALL	N	Mean	Median	Mode	St. Dev	Qrtiles (25|50|75)
Approaches To Learning : Total (1-5)	54	3.3	3.4	3.7	1.0	(2.6 | 3.4 | 3.9)
Approaches To Learning : Self-Regulation (1-5)	54	3.1	3.3	3.5	1.0	(2.4 | 3.3 | 3.7)
Approaches To Learning : Interpersonal Skills (1-5)	54	3.5	3.8	4.0	1.0	(3.0 | 3.8 | 4.0)
Early Mathematics (0-16)	56	6.7	7	7*	3.9	(4.0 |7.0 |9.0)
Early Literacy: UC Letter Name Recog (0-26)	54	11.9	11	0	10.2	(1.8 | 11.0 | 23.0)
Early Literacy: LC Letter Name Recog (0-26)	54	9.8	6	0	9.4	(1.0 | 6.0 | 20.0)
Early Literacy: Letter Sound Recog (0-26)	54	7.0	2.5#	0	8.5	(0.0 | 2.5 | 14.5)

= interpolated. * = multiple modes, smallest value shown.

N:	The subgroup count of students who had valid KA test scores.
Mean:	Arithmetic mean of students in that subgroup
Median:	50th percentile score.
Mode:	Most frequently observed aggregate score.
St.Dev:	Standard deviation for the Arithmetic mean.
Qrtiles:	Aggregate scores at the 1st, 2nd, and 3rd quartiles. 50% of the student had score between the low and high numbers shown.

Some Observations:

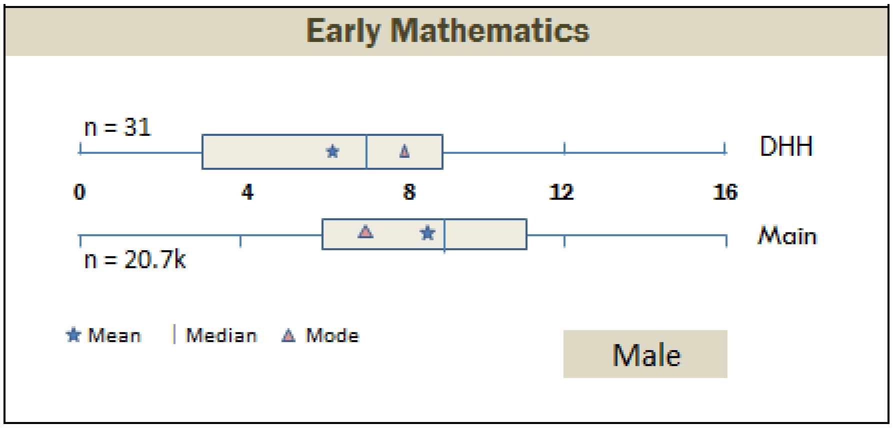
While larger group size is desirable for making comparisons, the D&HH group was further subdivided into race/ethnicity and gender categories (see tables 3 to 10).

This sub-division resulted in subgroup counts too low for much statistical confidence in any interpolation. Induced conclusions need to be corroborated with external or additional assessment.

However one can see that in Fall of 2016, virtually all **aggregated** D&HH scores lagged their counterpart scores in every assessment (see tables 3 and 10).

Charts:

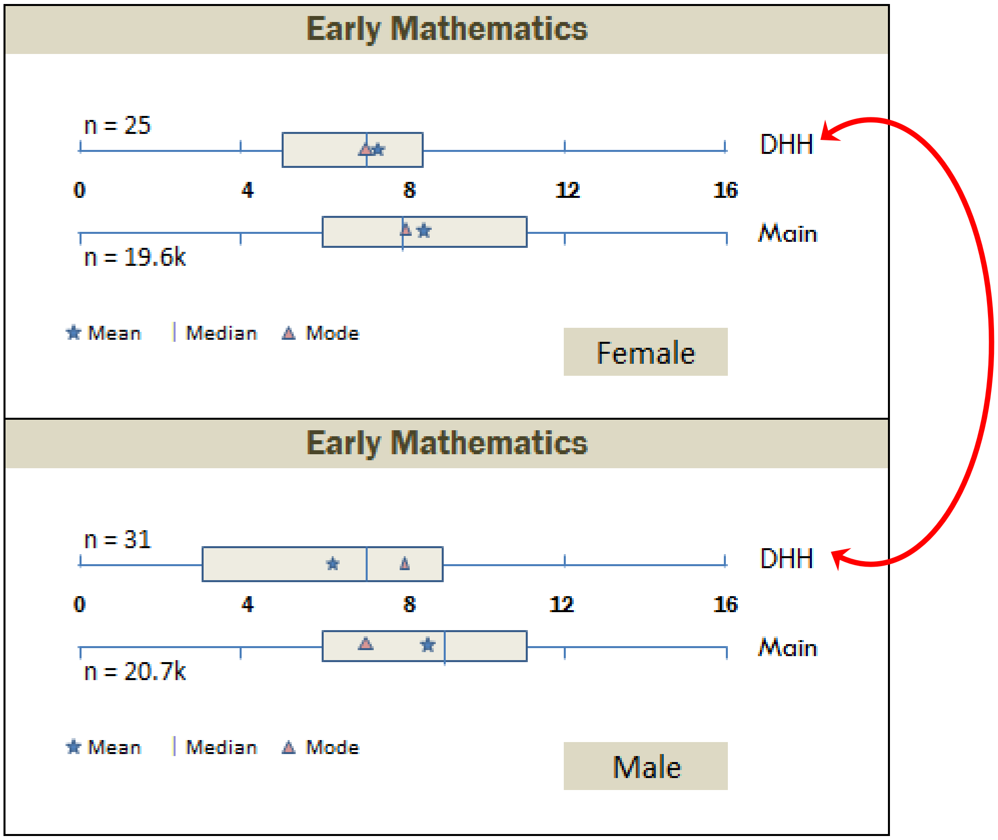
The box-plot charts help visualize the numbers in the tables.
For example, this one compares the Early Mathematics results of **Male** students of the D&HH Main groups.



The chart shows some of the commonly used measures of central tendency and also includes a shaded rectangular object to represent the distribution of the scores within the referenced group (**Males**, in this example). The rectangle depicts the Inter-Quartile (IQ) score range (middle 50% of the students). The left side of the IQ box show the 25th percentile and the right side shows the 75th percentile. The median (50th percentile) is the vertical bar somewhere in the middle of the IQ box.

If the vertical bar is not roughly in the middle of the rectangle, then the score distribution is 'skewed' towards the longer section of the box. The X-axis shows the range of scores possible for the test. The group sizes are also shown on the left side of this chart.

Intra-group performance differentials can be visualized by comparing two adjacent charts.



Intra-group compare

Compare the D&HH Female and Male box-plots. Notice the tighter cluster of scores for the D&HH females compared to the D&HH males. Also note that while both have 75th percentile scores around +8, the 25th percentile mark is significantly lower for the males, and that male score distributon is skewed left. Two-chart compares makes it easier to see that genders scored differentially in D&HH group Early Mathematic scores.

In contrast, a similar gender comparison in the Main group shows their IQ rectangles are fairly equivalent, the middle 50 percent had similar low and high scores. However note the differences in the Mode, and Median statistics for males.

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing

JOINT COMMITTEE ON INFANT HEARING, Carianne Muse, Judy Harrison, Christine Yoshinaga-Itano, Alison Grimes, Patrick E. Brookhouser, Stephen Epstein, Craig Buchman, Albert Mehl, Betty Vohr, Mary Pat Moeller, Patti Martin, Beth S. Benedict, Bobbie Scoggins, Jodee Crace, Michelle King, Alice Sette and Beth Martin

Pediatrics; originally published online March 25, 2013;
DOI: 10.1542/peds.2013-0008

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

STATEMENT OF ENDORSEMENT

Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing

PREFACE

FREE

This document is a supplement to the recommendations in the year 2007 position statement of the Joint Committee on Infant Hearing (JCIH)[1] and provides comprehensive guidelines for early hearing detection and intervention (EHDI) programs on establishing strong early intervention (EI) systems with appropriate expertise to meet the needs of children who are deaf or hard of hearing (D/HH).

EI services represent the purpose and goal of the entire EHDI process. Screening and confirmation that a child is D/HH are largely meaningless without appropriate, individualized, targeted and high-quality intervention. For the infant or young child who is D/HH to reach his or her full potential, carefully designed individualized intervention must be implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices, and proven models.

The delivery of EI services is complex and requires individualization to meet the identified needs of the child and family. Because of the diverse needs of the population of children who are D/HH and their families, well-controlled intervention studies are challenging. At this time, few comparative effectiveness studies have been conducted. Randomized controlled trials are particularly difficult for ethical reasons, making it challenging to establish causal links between interventions and outcomes. EI systems must partner with colleagues in research to document what works for children and families and to strengthen the evidence base supporting practices.

Despite limitations and gaps in the evidence, the literature does contain research studies in which all children who were D/HH had access to the same well-defined EI service. These studies indicate that positive outcomes are possible, and they provide guidance about key program components that appear to promote these outcomes. This EI services document, drafted by teams of professionals with extensive expertise in EI programs for children who are D/HH and their families, relied on literature searches, existing systematic reviews, and recent professional consensus statements in developing this set of guidelines (eg, refs 2 and 3; H.M. Schachter, T.J. Clifford, E. Fitzpatrick, S. Eatmon, M. Morag, A. Showler, J.C. Johnston, M. Sampson, and D. Moher, unpublished data, 2002).

JOINT COMMITTEE ON INFANT HEARING
Carianne Muse, MPH, Judy Harrison, MA, Christine Yoshinaga-Itano, PhD, Alison Grimes, AuD, Patrick E. Brookhouser, MD, Stephen Epstein, MD, Craig Buchman, MD, Albert Mehl, MD, Betty Vohr, MD, Mary Pat Moeller, PhD, Patti Martin, PhD, Beth S. Benedict, PhD, Bobbie Scoggins, EdD, Jodee Crace, MA, Michelle King, MS, Alice Sette, AuD, and Beth Martin, MA

KEY WORDS
hearing loss, hearing screening, hearing impairment, deafness, audiology

ABBREVIATIONS

ASL—American Sign Language
CDC—Centers for Disease Control and Prevention
D/HH—deaf or hard of hearing
EHDI—early hearing detection and intervention
EI—early intervention
IDEA—Individuals with Disabilities Education Improvement Act
IFSP—individualized family service plan
JCIH—Joint Committee on Infant Hearing

www.pediatrics.org/cgi/doi/10.1542/peds.2013-0008

doi:10.1542/peds.2013-0008

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Terminology presented a challenge throughout document development. The committee noted that many of the frequently occurring terms necessary within the supplement may not reflect the most contemporary understanding and/or could convey inaccurate meaning. Rather than add to the lack of clarity or consensus and to avoid introducing new terminology to stakeholders, the committee opted to use currently recognized terms consistently herein and will monitor the emergence and/or development of new descriptors before the next JCIH consensus statement.

For purposes of this supplement:

Language refers to all spoken and signed languages.

Early intervention (EI), according to part C of the Individuals with Disabilities Education Improvement Act (IDEA) of 2004,[4] is the process of providing services, education, and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), those who have an existing delay, or those who are at risk of developing a delay or special need that may affect their development or impede their education.[5]

Communication is used in lieu of terms such as communication options, methods, opportunities, approaches, etc.

Deaf or hard of hearing (D/HH) is intended to be inclusive of all children with congenital and acquired hearing loss, unilateral and bilateral hearing loss, all degrees of hearing loss from minimal to profound, and all types of hearing loss (sensorineural, auditory neuropathy spectrum disorder,[6] permanent conductive, and mixed).

Core knowledge and skills is used to describe the expertise needed to provide appropriate EI that will optimize the development and well-being of infants/children and their families. Core knowledge and skills will differ according to the roles of individuals within the EI system (eg, service coordinator or EI provider).

This supplement to JCIH 2007 focuses on the practices of EI providers outside of the primary medical care and specialty medical care realms, rather than including the full spectrum of necessary medical, audiologic, and educational interventions. For more information about the recommendations for medical follow-up, primary care surveillance for related medical conditions, and specialty medical care and monitoring, the reader is encouraged to reference the year 2007 position statement of the JCIH[1] as well as any subsequent revision. When an infant is confirmed to be D/HH, the importance of ongoing medical and audiologic management and surveillance both in the medical home and with the hearing health professionals, the otolaryngologist and the audiologist, cannot be overstated. A comprehensive discussion of those services is beyond the scope of this document.

INTRODUCTION

Since the first universal newborn hearing screening programs were established in the early 1990s, significant progress has occurred in the development and implementation of protocols for screening, audiologic evaluation, fitting of amplification, medical management of children who are D/HH, and support services for families. Despite this progress, provision of the highest quality EI for infants/children who are D/HH and their families remains an urgent priority. The Centers for Disease Control and Prevention (CDC) reported that over 96.9% of all newborns were screened in 2008.[7] In the United States, there is evidence that earlier identification of children who are D/HH, accompanied by timely and appropriate interventions, can result in language, communication, cognitive, and social-emotional skills that are consistent with children's cognitive abilities and chronological age.[8–10] The ultimate goal of EHDI is to optimize language, social, and literacy development for children who are D/HH.

Although the first EHDI programs in the United States were established more than 20 years ago, most states/territories are not yet able to provide documentation of outcomes resulting from EI services. Lacking such documentation, it is unclear whether state/territory systems are accomplishing the goal of preventing or minimizing communicative delays typically observed in late-identified children who are D/HH. EHDI programs are complex systems requiring a high degree of collaboration at local, state/territory, and national levels among families, birthing hospitals, audiologists, physicians, educational personnel, speech-language pathologists, state health and educational agencies, private service providers, leaders who are D/HH, and support networks. Personnel constraints, financial limitations, and the lack of existing systems have hindered attainment of some of the EHDI goals.[11] This supplement is designed to provide support for the development of accountable and appropriate EI follow-through systems. All goals stated within this document should begin with a baseline measure specific to each state/territory. The goal should be for the program to show annual improvements that lead to 90% attainment of the goal at the end of a 5-year period.

An optimal EI service team centers around the family and includes professionals with pediatric experience. The specific professionals on each team should be individualized on the basis of family needs. This list of professionals may include, but is not limited to, an audiologist, teacher of the D/HH, speech-language pathologist, service coordinator, individuals who are D/HH, and representatives of family-to-family support networks. Depending on the needs of the child, it also could include physical therapists, occupational therapists, psychologists, and educators with expertise in deaf/blind, developmental delay, and/or emotional/behavioral issues.

BEST PRACTICE GUIDELINES

This best practice document for the implementation of EI services (habilitative, rehabilitative, or educational) is intended to assist the state/territory EHDI systems in optimizing the development and well-being of infants/children and their families. Another goal of this document is to facilitate the development of systems that are capable of continuously evaluating and improving the quality of care for infants/children who are D/HH and their families. Finally, this document outlines best practices to promote quality assurance of EI programs for children from birth to age 3 years and their families.

Goal 1: All Children Who Are D/HH and Their Families Have Access to Timely and Coordinated Entry Into EI Programs Supported by a Data Management System Capable of Tracking Families and Children From Confirmation of Hearing Loss to Enrollment Into EI Services

Rationale

Screening hearing in newborns creates an opportunity but it does not guarantee optimal outcomes. Timely access to quality EI providers is a critical component of a successful system. The Colorado EDHI program is an example of a program that has been able to collect comprehensive outcome data due to the implementation of EI and a consistent EI program (eg, criteria for selection of EI providers, professional development through in-service training and mentoring, a standard protocol of developmental assessments at regular intervals). The Colorado EHDI system was established in 1992 and focused on timely and coordinated access to EI with statewide data management to ensure follow-through. Beginning in 1995 and continuing to the present, a series of articles on the Colorado system was published. These studies had over 500 different infant participants who were D/HH, who had no additional disabilities, and who had hearing parents. The studies included longitudinal data on 146 children from infancy through 7 years of age. Almost all were early-identified and had timely access to an appropriate and consistent EI system.[12] On average, these children achieved age-appropriate developmental outcomes not only in the first 3 years of life[10,13–16] but through age 7[9,17,18] (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2001). Other studies provided support for these findings,[19,20] but only the Moeller study,[8] published before establishing universal newborn hearing screening, studied children from a consistent EI services program.

Part C of the IDEA requires that infants and toddlers with disabilities receive EI services from birth to age 3 years.[5] These services are provided according to an individualized family service plan (IFSP). A barrier to the development of comprehensive systems for children who are D/HH is the lack of coordination between local and state part C programs, state EHDI programs, and existing systems for children who are D/HH. To accomplish goals for monitoring and tracking children who are D/HH, a strong partnership with part C will be necessary at the national, state/territory, and local levels. At the current time, tracking systems from universal screening to confirmation that a child is D/HH, to enrollment in EI, and to developmental outcomes are being developed in many states/territories, but there are currently only a few coordinated systems.[7]

Loss to documentation and loss to follow-up rates are threats to the effectiveness of EHDI systems. Reduction in these losses is a high priority to strengthen the development of EHDI systems. Continuously updated data reported to the CDC indicate that a significant number of referrals lack documentation of confirmatory audiologic evaluations and/or enrollment in EI. It is estimated that currently only 1 in 4 children who are D/HH are successfully tracked to an EI system.[7] Loss to documentation and ineligibility for services (eg, infants with unilateral hearing loss in some states) also may contribute to loss to follow-up rates.

Recommendations

1. Share a baseline analysis of EHDI follow-up statistics with part C to establish collaboration and to identify system gaps or needs regarding statistics to be reviewed, such as (1) confirmation/identification of children who are D/HH and (2) their enrollment in EI services.
    - Identify the referral process operating within the state/territory. Establish a timely, coordinated system of entry into EI services. Ensure that providers have the core knowledge and skills necessary to optimize the overall development and well-being of children and their families. Identify methods to report and track individual children from audiologic confirmation to

developmental outcomes. These identified methods often involve coordination between part C at the state or local levels and existing systems of EI for children who are D/HH. Delineate clear and agreed upon responsibilities for all participating agencies, including the development of specific timelines and designation of specific positions for communication and reporting responsibilities. Schedule feedback mechanisms minimally on a quarterly basis (eg, the frequency with which participating agencies will report to the state database regarding enrollment into EI). Develop a flowchart for dissemination of information/data.

- Collect, regularly analyze, and report data on compliance with the requirement for timely access to an EI system. Timely access is defined by this document as referral to part C within 2 days of audiologic confirmation and implementation of services within 45 days of referral. To accomplish this goal, first EI contact with the family should occur within a week of referral. This schedule allows for time to complete the mandated developmental assessment and IFSP within the 45-day timeline. Part C regulations established in 2011 provide for referring a child as soon as possible, but in no case more than 7 days, after the child has been identified with deafness/hearing loss.

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.
   - Determine which entity will take responsibility for the development and update of a state/territory family resource manual.
   - Monitor the development or adaptation of a family resource manual, available in different languages and diverse formats (eg, written, captioned video/DVD/Web, video blog, or 3-ring binders), with regular annual updates and revisions that include the following: (1) description of all EI programs and providers, (2) identified Web sites related to deafness and hearing loss, (3) national organizations/resources for families, (4) terms and definitions related to deafness/hearing loss, (5) infrastructure of state resources for families, (6) services available through part C, and (7) communication choices, definitions, and factors to consider.
   - 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 (eg, parent organization, professional committee). Implement an ongoing quality assurance mechanism (including evaluation) related to the family resource manual.
   - Implement a mechanism of dissemination that ensures that all families with newly identified children who are D/HH receive the family resource manual and that the information is reviewed with the family and explained by the service coordinator or EI provider in a timely manner. Family-to-family support (discussed below in goal 9) is an effective mechanism for dissemination of information.[21] Ask families of newly identified infants/children who are D/HH annually whether they received the family resource manual and if a service coordinator or EI provider reviewed the information with them.

Goal 2: All Children Who Are D/HH and Their Families Experience Timely Access to Service Coordinators Who Have Specialized Knowledge and Skills Related to Working With Individuals Who Are D/HH

Rationale

The service coordinator is the person responsible for overseeing the implementation of the IFSP and coordinating with agencies and service providers. This person is generally the first point of contact for families. The service coordinator assists families in gaining access to services; facilitates the child and family in receiving information about their rights, procedural safeguards, and services available within their state; coordinates assessments; facilitates and participates in the development of the IFSP; and coordinates and monitors the delivery of services.

Optimally, the first contact with the family should occur within days of the audiologic confirmation, and the goal should be no later than a week after confirmatory testing. The individual with first contact needs specialized knowledge and experience that include infancy/early childhood, educational strategies for infants/toddlers who are D/HH and their families, parent counseling (especially adjustment counseling specific to families with children who are D/HH), development of signed and spoken language, and auditory, speech, cognitive, and social-emotional development.

Individuals who make first contact must be able to answer parents' questions about deafness and hearing loss and provide support in understanding technical concepts including the following: screening technologies; audiologic diagnostic evaluations; amplification choices; communication choices; communication development from infancy through early childhood, including language, auditory, speech, signing, and social-emotional domains; resources relevant to working with infants/toddlers who are D/HH; medical details such as likelihood of progression of or improvement in hearing levels; and auditory/visual technology (eg, frequency modulation systems or "FM" systems, light systems, doorbells, or captions).

When parents/caregivers/families receive support from professionals who are knowledgeable about infants/children who are D/HH and their families, emotional bonding between parents and infants may be facilitated. Parental stress similar to that in hearing parents is possible and parental acceptance is more likely (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2001).[22–26] Service coordinators in the Colorado EI program were specialists in EI services for families who have children who are D/HH. Studies examining outcomes of the Colorado EI program were descriptive studies and could not examine whether a causal relationship exists between provider expertise and these social-emotional characteristics. However, the studies did reveal that a program with specialized service coordinators and EI service providers is related to positive family and child social-emotional outcomes. In addition, there is evidence in the literature that some parents experience negative emotions when service coordination is provided by individuals without the core knowledge and skills for working with children who are D/HH.[27]

Recommendations

1. Develop or adapt qualifications for service coordinators who contact families after confirmation that their child is D/HH. Collaborate with part C in a manner that includes the expertise of the state EHDI team or an EHDI task force and EI specialists with expertise in supporting children who are D/HH. These state/territory guidelines should identify the professional qualifications (educational and experiential background) of service coordinators for children who are D/HH and their families.
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. Implement strategies to identify current skills of service coordinators and gaps in their knowledge and skills related to serving families with children who are D/HH. Establish and implement professional development programs that include training in dissemination of information without bias. Provide resources and other supports to assist service coordinators in the acquisition of core knowledge and skills needed to promote successful outcomes for the children and their families.
3. Identify the number and percentage of families who had timely access to a service coordinator with skills and expertise related to children who are D/HH and their families.

Goal 3: All Children Who Are D/HH From Birth to 3 Years of Age and Their Families Have EI Providers Who Have the Professional Qualifications and Core Knowledge and Skills to Optimize the Child's Development and Child/Family Well-being

Rationale

States/territories need to ensure that EI providers meet at least minimum criteria for experience and skills necessary to serve infants who are D/HH and their families. Because of the shortage of qualified professionals, it is important that a system for building capacity exists at the preservice, in-service, and mentoring levels. A primary goal of the EI program is to promote children's development of strong language skills, regardless of the route or routes taken by the family (eg, spoken language, American Sign Language [ASL], visually supported spoken language). This goal is critical because it is widely recognized that well-developed language skills serve as a foundation for communication and literacy attainment.[28] Goal 3 (and Appendix 1) promotes reliance on qualified providers, and recommends processes for ensuring that families access them. Goals 3a and 3b are not intended to be mutually exclusive; rather, they describe key quality elements when providers are using spoken or visual languages. Systems that manually code or cue spoken language are not included in goals 3a or 3b because they are not distinct languages. However, when these approaches are implemented by families, the same competencies described below apply. The purpose of goal 3 is to ensure that families and children have qualified providers, regardless of the approach taken to develop communication.

The purpose of these recommendations is to assist states and territories in the provision of high-quality EI through

- identification of the core knowledge and skills for direct EI services providers (eg, those who provide developmental, educational, and communication/language [including spoken and/or sign language] services; see Appendix 1);
- development of guidelines for the delivery and evaluation of a system of ongoing professional development for direct EI service providers.

Recent research suggests that outcomes for young children and their families are better when providers have specialized training specific to working with infants and toddlers who are D/HH and their families, although more evidence is needed.[8,9,19,29–31] Professional consensus statements acknowledge the need for service providers with specific training in serving children who are D/HH.[32,33] A survey of specialists from 17 organizations with interests in the area of EI for children strongly supported the need to identify a set of core competencies for EI specialists working with children who are D/HH (M. Sass-Lehrer, A. Stredler-Brown, M.P.M., unpublished data, 2008).

EI providers have a wide range of disciplinary backgrounds[34] and may not have sufficient preservice course work and/or practicum experiences that address the needs of children who are D/HH from birth to age 3 years and their families. As a result, they may lack core knowledge and skills to work with this population effectively (M.V. Compton, J.A. Niemeyer, E. Shroyer, unpublished data, 2001; M. Sass-Lehrer, A. Stredler-Brown, N. Hutchinson, K. Tarasenko, M.P.M., K. Clark, unpublished data, 2010).[35–38]

Approximately one-third of all states in the United States have a professional certification or credential that includes children who are D/HH from birth to age 3 (M. Sass-Lehrer, A. Stredler-Brown, N. Hutchinson, K. Tarasenko, M.P.M., K. Clark, unpublished data, 2010). However, the standards vary widely and may not specifically include course work and field experiences that address the needs of infants and toddlers who are D/HH and their families.

At most institutions specific to children who are D/HH, the wide range of disciplinary backgrounds and limited preservice training opportunities create a need for systematic capacity building. For the various disciplines working with children who are D/HH, appropriate professional development guidelines that support theory and evidence-based practice must be established. Evaluation of training and training outcomes is essential, because the quality of the professional training is ultimately reflected in the impact on child and family outcomes. Wide variations in the skills of the providers and the developmental outcomes of children who are D/HH exist throughout the United States and its territories.

Personnel development guidelines need to be in accordance with the existing legal requirements of part C of the IDEA[4] and with the requirements in each state or territory (eg, credentials or qualifications for EI specialists).

Recommendations

1. Adopt and implement guidelines that address the professional qualifications required for providing family-centered EI to families and children who are D/HH from birth to age 3. These guidelines will address educational background and core knowledge and skills for providers of EI services in areas, including developmental, educational, and communication/language.
2. Ensure that stakeholders participate in the adoption and implementation of these guidelines. Stakeholder categories will include, at minimum, the state EHDI and part C programs, EI direct service providers with core knowledge and skills serving children who are D/HH from birth to age 3, parents/caregivers with children who are D/HH, and adults who are D/HH with a background in a related area.
3. Provide the resources needed for professionals to obtain the core knowledge and skills to serve children who are D/HH from birth to age 3 and their families.
4. Following the approved guidelines, identify the number and percentage of EI providers who have the appropriate core knowledge and skills and who are currently providing services to families with infants/children who are D/HH. Consider recruiting experienced professionals to mentor others (eg, via distance technology or onsite visits).
5. Identify the number and percentage of EI providers who do not meet the qualifications required but participate in professional development activities specific to EI services and children who are D/HH each year.
6. Regularly monitor progress toward this goal by annually identifying the number of families who are receiving EI services from professionals with core knowledge and skills as determined by the state-developed qualification system.

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

Rationale

A system of highly qualified EI service providers must be available for all families across the spectrum of communication choices. An area that has been particularly deficient for families who choose ASL is access to an EI provider who is a fluent/native ASL signer*.[39,40]

Families with children who are D/HH in the process of learning ASL require access to competent and fluent language models. In EI systems,

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*Similarly, for families who choose cued speech or a manual code of English, professionals should be fluent models of those systems and skilled in enhancing both auditory and visual communication.

competency and fluency are not ensured among EI providers. To establish the basic grammatical foundations of visual language learning for a newborn infant who is D/HH, access to competent and fluent language models is vital.[41,42] However, although fluency of the language model is necessary, it is not sufficient to make a professional qualified to provide EI services. Families with children who are newly identified also need information and resources from EI professionals on how to provide an enriched language environment that supports their child's early language learning. As an example, the SKI-HI Institute Deaf Mentor program is a model that can provide resources and training for people who are D/HH to support a family's learning of ASL. The families can be given resources and support in acquiring ASL through collaboration with professionals who are D/HH and who communicate in ASL. In SKI-HI's Deaf Mentor program, adults who are D/HH are role models for the young child and family members. The child and the family learn ASL and are introduced to various deaf culture events. The SKI-HI Institute conducted a 3-year study entitled "The Deaf Mentor Experimental Project for Young Children Who Are Deaf and Their Families," and found that children of hearing parents who are exposed to a bilingual and culturally competent environment through Deaf Mentor services have positive outcomes. Not only did the children have a beginning knowledge and use of ASL but they were also developing English skills at a faster rate than children who did not receive Deaf Mentor services and received services solely from a SKI-HI parent advisor.[40]

Recommendations

1. Ensure that families have complete and accurate information about ASL.
2. Identify collaborative partners who can assist in the development of statewide systems capable of providing competent sign language instruction to families and their infants/children. Partners may include EHDI systems, EI professionals with skills in teaching families with infants/toddlers who are D/HH, and individuals who are D/HH with fluent/native ASL skills and experience in teaching families/parents of infants. Agencies that can support development of a statewide system may include schools for the deaf, local education agencies, state coordinators of services for students who are D/HH, the Registry of Interpreters for the Deaf, the ASL Teachers Association, the American Society for Deaf Children, the State Association of the Deaf, the National Association of the Deaf, and the Diagnostic Center at Boys Town National Research Hospital for use and implementation of the Educational Interpreter Performance Assessment.[43]
3. Establish a representative committee that develops guidelines related to the qualifications of sign language instructors. Committees should include specialists in EI strategies for parent/family education and individuals who are D/HH with fluent/native skills and experience in teaching families/parents of infants.
4. Conduct a needs assessment to determine (1) the number of available sign language instructors with the qualifications in sign language and family/infant education and (2) available funding sources.
5. Develop systems that ensure that neither geographic location nor socioeconomic status limits access to competent and skilled sign language instructors. State systems should consider utilization of all technology, including computer and videophones, to support teaching families.
6. Establish and conduct training for ASL instructors that includes strategies and techniques for teaching sign language to families of infants and toddlers.
7. Establish a quality assurance program for ASL instructors of parents/families. The program should (1) assess their fluency in and knowledge of ASL (existing models for such assessment include the ASL Teachers Association, the Registry of Interpreters for the Deaf, and the ASL Proficiency Interview) and (2) determine their ability to tailor the instruction so that families are prepared to communicate with infants and very young children.
8. Conduct a needs assessment to determine the number of professionals (compensated or volunteer) with the qualifications and skills required to serve as an ASL instructor for families/parents of infants.
9. Ensure that ASL instructors can accept, without judgment, a family's use of their sign language skills with or without spoken language.

Goal 3b: Intervention Services to Develop Listening and Spoken Language Will Be Provided by Professionals Who Have Specialized Skills and Knowledge

Rationale

The development of listening and spoken language skills is now attainable for the vast majority of infants/children who are D/HH (without severe additional disabilities) when they are identified early and are provided with early and appropriate EI services beginning with fitting of amplification that ensures audibility across the speech spectrum of the native spoken language.[44] The consensus of professionals who specialize in intervention for listening and spoken language for children who are D/HH is that these skills are frequently not mastered in typical preservice training programs of educators of the deaf, speech- language pathologists, or audiologists.[32]

Competent service delivery systems have a series of checks and balances, as well as cross-check processes, to ensure fidelity of intervention. For example, an EI provider should be able to share information regarding the child's behavior and response to sound across the speech frequencies with the child's audiologist. This information can assist the audiologist in fitting, optimizing, and verifying the child's hearing aids. This system should ensure that maximal audibility has been provided to the child, thus offering the child optimal access to spoken language. In addition, the EI provider should be alert for changes in the infant/child's hearing capabilities, which can occur due to permanent or medically treatable causes. These changes are most likely to be a progression of the hearing loss, although improvement and fluctuation in hearing sensitivity can also occur. EI specialists need to be able to individualize services to the child's current auditory capabilities with their technology. In addition, the EI provider needs expertise regarding listening and spoken language developmental hierarchies and the ability to use diagnostic teaching to ensure that the auditory linguistic strategies being used are the most effective.

Research indicates that there are sensitive periods for the development of auditory skills and spoken language; specifically, the first 5 years of a child's life are critical for development in these areas,[10,45,46] To optimize this short time period in a child's life, families and infants/children who are D/HH require the highest level of provider skills at the very beginning of the child's life.

Unfortunately, most EI systems currently provide limited access to professionals with expertise in listening and spoken language and do not collect system-wide outcome data on children's development of listening and spoken language skills.[47] Such data are essential to ensure that families and children have received high-quality intervention with targeted outcomes. Many EI systems do not offer professional development opportunities to ensure continuous improvement for the EI providers, nor do they offer consultation/mentorship and/or direct observation to guarantee fidelity of the intervention implementation. These are critical areas of need if best practices in listening and spoken language are to be established.

Recommendations

1. Ensure that families have complete and accurate information about listening and spoken language development.
2. Identify collaborative partners who can assist in the development of statewide systems capable of providing competent listening and spoken language instruction to families and their infants/children.
3. Establish qualifications of EI service providers with the core knowledge and skills to develop listening and spoken language (Appendix 2).[48]
4. Conduct a needs assessment to determine the number of available EI providers with the qualifications and skills required for developing listening and spoken language with infants who are D/HH.
5. Develop systems and ensure that neither geographic location nor socioeconomic status limits access to competent EI providers with knowledge and skills in developing listening and spoken language. State systems should consider utilization of all technology, including computer and videophones, to support teaching families.
6. Establish and conduct training for EI providers to increase their skills in providing listening and spoken language development.
7. Establish an evaluation of the skills and knowledge of EI providers in their delivery services for listening and spoken language.
8. Ensure that the EI providers have been observed sufficiently, have been provided with feedback, and have demonstrated skills in the provision of listening and spoken language interventions for families with infants/children who are D/HH.
9. Ensure that EI providers can accept, without judgment, the family's use of the listening and spoken language skills they have learned with or without the use of sign language or any other visual communication system.

Goal 4: All Children Who Are D/HH With Additional Disabilities and Their Families Have Access to Specialists Who Have the Professional Qualifications and Specialized Knowledge and Skills to Support and Promote Optimal Developmental Outcomes

Rationale

It is estimated from previous studies that 35% to 40% of all children who are D/HH have disabilities in addition to deafness.[10,49] These additional disabilities often affect the child's ability to access and use language. Very little empirical information is available about development in the first 6 years of life for children who are D/HH with additional disabilities. However, appropriate EI services should result in similar advantages for children who are D/HH with additional disabilities as for children who are D/HH only.[10,13,50] Children who are D/HH, were identified before 6 months of age, and had cognitive skills ranging from quotients of 20 to 80, demonstrated significantly better language scores than did later-identified children with multiple disabilities in the first 3 to 5 years of life when they were early-identified and received timely EI services.[10,50]

For some children who are D/HH and have additional disabilities, it may be determined that hearing loss is not the primary disability. Regardless of the primary disability, however, it is critical to recognize the primacy of communication for learning and the impact of communicative delays on other developmental domains. Therefore, the team of professionals serving the child must include specialized expertise in meeting the communication access needs of the child.

EI specialists serving children who are D/HH with additional disabilities should be able to

- monitor developmental needs and outcomes across domains with appropriate assessments;
- recognize developmental concerns and involve a team of evaluators before attempting to design an intervention program;
- work as an effective and integrated member of a transdisciplinary team, in a manner that optimizes child and family learning;
- modify developmental strategies to accommodate the child's special needs;
- advocate for and facilitate the parent/family understanding of medical, developmental, pediatric, and other specialty reports and their implications for the child's learning;
- collaborate with the managing audiologist to adapt assessment and amplification approaches to accommodate the child's special needs;
- recognize the child's needs and make referrals for specialty evaluations (eg, feeding and swallowing, oral motor, etc);
- assist families in prioritizing needs to optimize the level of service delivery at various ages;
- adapt EI strategies to appropriately accommodate disabilities in other developmental domains and to reinforce goals of other specialty providers on the team;
- use augmentative communication devices and strategies, including individualized evaluation and implementation;
- manage mobilization devices and other supportive equipment needed by the child.

Recommendations

1. Develop and implement a data management system capable of reporting the number and percentage of children who are D/HH with additional diagnosed disabilities, including the following: visual, intellectual, or emotional/behavioral disability; fine and gross motor delays with or without cerebral palsy; autism spectrum disorder; sensory processing disorder; and craniofacial or neurodegenerative disorders or brain malformations.
2. Develop a system with the ability to track children who are D/HH with additional disabilities regardless of the primary disability of the child, identifying the individual or agency that can and will assume responsibility for tracking these children (eg, EHDI or part C, public school programs, or schools for the deaf).
3. Ensure that the developmental monitoring protocol is adaptive and sensitive to any restrictions in performance that are due to the additional disability and that would significantly underestimate the abilities and skills of the child.
4. Implement models of transdisciplinary services, making certain that families who have children with multiple disabilities have access to EI services that meet the needs of the child and family in all developmental domains.

Goal 5: All Children Who Are D/HH and Their Families From Culturally Diverse Backgrounds and/or From Non–English-Speaking Homes Have Access to Culturally Competent Services With Provision of the Same Quality and Quantity of Information Given to Families From the Majority Culture

Rationale

The number of culturally and linguistically diverse children who are D/HH in the United States and its territories is continually rising. In some major urban areas, and in some states, the number of culturally diverse occupants is now the majority. There is a rapid and growing population of children who are D/HH living in homes in which the primary language is not English. Families who use ASL as the language of communication within the home are also a culturally and linguistically diverse population. An additional aspect of diversity is the significant portion of families who have limited levels of literacy, parental education, and/or family income. These families are at high risk of failure to access and benefit from traditional educational services. However, research within the United States has revealed that it is possible to deliver EI services that result in appropriate development of children of families from culturally diverse backgrounds.[10,17,50]

It is important that the information provided to families is of the same quality and quantity provided to native English speakers and that it is delivered in a manner that is accessible to the families. Even when culturally diverse families are able to communicate successfully in spoken English or ASL, they may have values and beliefs that affect their understanding and acceptance of information conveyed in EI. These values and beliefs may also affect their ability or willingness to follow through on recommendations. Therefore, it is essential that the manner in which information is delivered is respectful of the beliefs and values of the families and their countries of origin.[51,52]

Spoken languages throughout the world have differences in phonology, semantics, syntax/grammar, and pragmatics. For a child to successfully develop spoken language skills in any language, he or she must have access to high-quality instruction in that language.[53–55] Thus, EI providers need to learn to adapt auditory skill development strategies for the teaching of spoken English, to the acoustic characteristics of the family's native language if the family chooses a spoken language approach.

Like spoken languages, visual language systems are unique and differ around the world. However, unlike spoken language, many families are not knowledgeable about their native signed languages, and therefore introduction of ASL or other visual systems used in the United States is often appropriate when chosen by the family.

Recommendations

1. Identify the number of families who speak or sign a language other than English in the home and the percentage of families using non-English languages by native language.
2. Identify the number of families who speak English and are culturally diverse, including the areas of cultural diversity (African American, Hispanic/Latino, Asian American or South Pacific Islander, or American Indian/Native American).
3. Develop a plan for ensuring access to information for families whose native language is not English that is comparable to information provided to native English-speaking families by providing resources in the family's home language or languages. Steps should include the following:
   - Identify the number of EI providers capable of providing EI services directly in a language other than English.
   - Identify the number of families receiving services that include regular and trained interpreters (knowledgeable about the parent-infant curriculum).
   - Develop materials that are available in the home language or languages of the child or that can be adapted (not just translated from one language to another) to the particular culture and language of the family.
4. Ensure that families from diverse cultures participate in and feel comfortable giving feedback about services received, by providing diverse communication mechanisms including face-to-face feedback or surveys in the home language or languages), "buddy systems" and peer mentors from culturally diverse groups, community leaders who can serve as cultural brokers and advisers, and consistent interpreters who are trained in the EI curricula specific to families with children who are D/HH.
5. Develop professional in-service training that includes information about providing services to families who do not speak English. This training should include such topics as cultural differences in attitudes and beliefs about disability, behaviors that may be considered offensive by other cultures, avoidance of cultural stereotypes, and different cultural expectations of medical, allied health, and educational professionals. Training should also include beliefs about being D/HH not as a disability but as a cultural and linguistic difference.
6. Monitor the developmental progress of children who are acquiring languages other than spoken English. For some of the more common languages, such as Spanish, there are a few developmental instruments that can be used. As developmental assessments become available in other languages, they should be incorporated into EI programs to assist families in monitoring their child's progress and determining whether the choices made are facilitating success in communication for their child who is D/HH (see www.sci.sdsu.edu/cdi/adaptations_ol.htm for the MacArthur-Bates Communicative Development Inventories in other languages).

Goal 6: All Children Who Are D/HH Should Have Their Progress Monitored Every 6 Months From Birth to 36 Months of Age, Through a Protocol That Includes the Use of Standardized, Norm-Referenced Developmental Evaluations, for Language (Spoken and/or Signed), the Modality of Communication (Auditory, Visual, and/or Augmentative), Social-Emotional, Cognitive, and Fine and Gross Motor Skills

Rationale

The current IDEA part C developmental assessment of children with disabilities is designed to demonstrate that EI services remediate developmental delay for infants/toddlers and children with disabilities. In contrast, EHDI systems have been established for the prevention or amelioration of the developmental delays often associated with children who are D/HH. Thus, developmental assessment for this population is designed to ensure that the children are mastering the developmental skills appropriate for their age and cognitive functioning. Earlier identification of children who are D/HH has been established with the goal of prevention of delay, not remediation of delay.

The urgency of providing appropriate EI services is supported by evidence of reduced and limited success of EI strategies that are initiated after the sensitive period for language and auditory development.[8,10] The goal of EI services for infants/children who are D/HH is to provide sufficient support to ensure that the child makes appropriate progress toward expected developmental objectives. The best opportunity to accomplish this goal is the prevention of developmental disability. Therefore, progress monitoring should be done with instruments that are norm-referenced. Assessment tools should be appropriate for the language and communication system used by the child.

Monitoring of developmental progress provides parents/families and EI providers objective data about the individual rate of their child's development and can guide their decision making. In addition, systematic monitoring of developmental progress has the potential to provide states/territories, local educational agencies, and individual early childhood programs with information that can guide system change and continuous improvement by identifying strengths and weaknesses within their system.

Recommendations

1. Monitor the developmental progress of all infants identified through universal newborn hearing screening (UNHS) on a consistent schedule, every 6 months through 36 months and annually thereafter, to ensure that children are making appropriate progress in the following areas:
   - language and social-emotional development commensurate with or within 1 SD of their chronological age or cognitive development;
   - auditory, listening, vocal, and speech development leading to intelligible and age-appropriate spoken language, if chosen by the family;
   - signing, both expressivity and receptivity, leading to appropriate language development, if chosen by the family;
   - fine and gross motor development, visual and auditory perception, and measures of adaptive behavior;
   - analysis of developmental growth over time: (1) development over time can only be analyzed if the child is assessed with at least some instruments that can be repeated throughout the target age range; (2) if the child's progress in the above domains does not meet expectations, or if critical variables have changed over the course of the time of monitoring, appropriate adaptations to EI services should be made;
   - analysis of the quality of the system using progress monitoring: (1) progress monitoring should also be used to assess the quality of the system; (2) states and territories should develop guidelines for determining whether the quality, frequency, and intensity of service is sufficient for adequate progress for an individual child on the basis of his or her progress monitoring.
2. Develop a statewide standard assessment protocol used with all children who are D/HH to provide the state/territory with an opportunity to do quality assurance of components of their EI system. States could develop a standard assessment battery in collaboration with experts in their state and either directly implement the battery or ensure that it is implemented (eg, in collaboration with a university, research entity, or other program capable of collecting and analyzing statewide assessment data for children who are D/HH). This information can then be used to improve the skills of the providers and the characteristics of intervention.
3. Develop a collaborative sharing network capable of collecting developmental data for progress monitoring at regular intervals including data reporting to the EHDI database.

Goal 7: All Children Who Are Identified With Hearing Loss of Any Degree, Including Those With Unilateral or Slight Hearing Loss, Those With Auditory Neural Hearing Loss (Auditory Neuropathy), and Those With Progressive or Fluctuating Hearing Loss, Receive Appropriate Monitoring and Immediate Follow-up Intervention Services Where Appropriate

Rationale

Children with hearing loss are at risk of academic failure (math and reading), delayed language development, progression (worsening) of hearing loss, and/or psychosocial delays. This finding has been revealed in a number of studies over the past 35 years, in populations having all types and degrees of hearing loss.[56–65] Children who are diagnosed as having unilateral hearing loss may experience onset and progression of hearing loss in the formerly normal hearing ear.[62,66]

Children with relatively lesser degrees of hearing loss may experience fluctuation/progression into the more severe ranges (Yoshinaga-Itano C, unpublished data, 2011). Children with auditory neural hearing loss (auditory neuropathy spectrum disorder) have been found to have significant delays in communication, speech, spoken and visual language, psychosocial skills, and literacy development. In general, their developmental profiles are similar to children with sensory deafness.[67–69]

Very little is known about the developmental outcomes of children with permanent sensorineural hearing loss who experience fluctuation due to conductive hearing losses. Children with hearing loss are at an increased risk of increased hearing loss in the presence of otitis media as compared with children with normal hearing because of the number of children with hearing loss and craniofacial anomalies or syndromes such as Down syndrome. Appropriate amplification fitting and audiologic monitoring are required for these children to maintain optimal developmental progress.

Consistent and frequent audiologic monitoring is important for all children who are D/HH, with any type of hearing loss. However, the audiologic and medical follow-up of the children in the audiologic categories covered in goal 7 are frequently initiated by the EI service provider who, in conjunction with the parent or parents/family, notices changes in the child‘s auditory behavior and speech/spoken language development. It is hoped that more frequent audiologic monitoring of these children will result in an earlier identification of issues such as progression, improvement, or fluctuation. EI providers need to establish close collaboration with audiologists to effectively manage these children. This need for collaboration is especially the case when the EI providers do not have specialized knowledge about the auditory skills and spoken language development of children with all types and degrees of hearing loss.

Recommendations for Monitoring

1. Refer all children with unilateral or bilateral hearing loss to EI for evaluation and consideration of enrollment. If the child does not qualify for state EI services, ensure that families are provided with access to information and counseling regarding their child’s hearing loss and the potential impact of hearing loss on the child’s daily life and communication development.
2. Develop follow-up mechanisms for ongoing monitoring of hearing, speech/language, and communication for all children with hearing levels that fall outside the range of normal in one or both ears, regardless of the etiology of the hearing loss. This monitoring should include follow-up mechanisms for children with chronic, nonpermanent conductive hearing losses.
3. Monitor communication development (receptive and expressive language, speech, and auditory skills) through appropriate developmental screening protocols every 6 months in the infant/toddler period and every 12 months thereafter.
4. Identify the agency or professional responsible for surveillance and make sure that surveillance occurs (eg, either through the medical home or managing physician, the audiologist, part C, or a referral back to the EHDI system).
5. Determine and designate a provider or system (eg, part C, EHDI, primary care physician, parent/family) that ensures that developmental screening of communication, audiologic monitoring, tracking, and surveillance occurs, especially if the child has been deemed ineligible for EI services through the state part C system.
6. Develop and disseminate information about the use of amplification for children with hearing loss prepared by consulting audiologists with expertise with infants/children.
7. Provide families with an opportunity for access to visual communication, which may include sign language systems, in addition to listening and spoken language, particularly in light of the possibility/probability of progressive hearing loss.
8. Ensure that a child with a conductive hearing loss that has persisted in the first few months of life and remains for 6 months will be referred to EI services and otologic specialty care to make sure that adequate auditory access is available to the child.
9. Consider amplification, if the hearing loss has remained for 6 months even if it is temporary, to accomplish this auditory access. This group also includes children with cleft palate or Down syndrome, who are at very high risk for chronic fluctuating middle ear effusion.[70–72]
10. Surveillance should include parent/family counseling and evaluation by a speech-language pathologist to monitor progress in speech and language acquisition.
11. Limited research suggests that children with minimal/mild bilateral hearing loss may not wear hearing aids either because (1) the children reject the amplification, (2) the parents/family are

unable to promote consistent amplification usage, or (3) the parents/family are themselves not convinced of the benefit of amplification.[63]

12. Provide educational information to parents/family covering the following topics:
    - impact of hearing loss on the daily life of the child including communication challenges in noisy environments, the difficulty of incidental learning, and the possibility of language/communication delays;
    - importance of hearing protection;
    - impact of chronic otitis media on residual hearing, and the importance of audiologic and otologic monitoring of hearing status every 3 to 6 months;
    - importance of monitoring the communication and social-emotional development of the child;
    - availability of EI services (to prevent delay instead of habilitation after delay is identified);
    - pros and cons of all amplification options including cochlear implants;
    - language options including visual and spoken languages, benefits of multisensory input of language, and the need for ongoing comprehensive evaluation of communication;
    - possibility of progression or fluctuation of hearing loss and importance of surveillance by audiology and the medical home;
    - importance of medical, genetic, ophthalmologic, and cardiac (EKG) evaluations on children with any type and degree of hearing loss;
    - importance of reassessment of treatment/intervention plans regularly to consider progress in language and communication acquisition, changes in hearing status, changes in amplification choices, and/or changes in communication modes/methods.
13. Encourage primary care physicians to recognize the need for ongoing audiologic surveillance in all children, particularly those with risk factors for delayed-onset/progressive hearing loss, or those children whose hearing loss is already being treated with hearing aid amplification. This surveillance should include developmental checks consistent with the American Academy of Pediatrics Periodicity Schedule, or more frequently if concerns are raised regarding hearing or development.

Goal 8: Families Will Be Active Participants in the Development and Implementation of EHDI Systems at the State/Territory and Local Levels

Rationale

Equitable partnerships between families and EI programs and systems are critical to the success of EHDI programs and the achievement of optimal outcomes for children. Family leadership and involvement are critical when developing policies and programs to ensure that the systems of care support a genuine reflection of the day-to-day challenges and opportunities facing families.[1]

- Qualified parent/family leaders are appropriately trained on such topics as advocacy, systems building, parent/family/professional partnerships, theories of adult learning styles, and family-to-family support.
- Parent/family leaders contribute to the EHDI system by exhibiting the elements of collaboration, that is, mutual respect for skills and knowledge, honest and clear communication, understanding and empathy, mutually agreed-upon goals, shared planning and decision making, open sharing of information, accessibility and responsiveness, negotiation and conflict resolution skills, and joint evaluation of progress.
- Parent/family leaders have the capacity to look beyond their own personal experiences/beliefs to represent and support a broad community of families.

Recommendations

1. Develop or revise policies and legislation related to EHDI programs that require the meaningful inclusion of qualified families as active participants in the development and implementation of EHDI systems.
2. Report the number of professional family positions (ie, compensated rather than volunteer) and demonstrate how parents and families are involved in recruitment processes.
3. Provide resources (professional development training and mentorship) for families to obtain the necessary knowledge and skills to participate in systems and policy development and demonstrate that training is provided.

Goal 9: All Families Will Have Access to Other Families Who Have Children Who Are D/HH and Who Are Appropriately Trained to Provide Culturally and Linguistically Sensitive Support, Mentorship, and Guidance

Rationale

Given the low incidence of children who are D/HH, families often feel isolated and do not typically have support opportunities in their established communities. Being deaf or hard of hearing impacts the child as well as the parents, siblings, extended family, and community. No one understands this as well as other families with children who are D/HH. Families report that there is something unique and important in receiving support from other parents and families who have children who are D/HH and who have "been there." There is a sense of an equitable relationship between the experienced parent and the referred parent that cannot be duplicated through other dynamics.[73]

Opportunities for families to communicate with one another, chat online, and attend support groups or other activities designed for communicating with other parents and families are a valuable component of the circle of support. National organizations such as the Alexander Graham Bell Association for the Deaf and Hard of Hearing, the American Society for Deaf Children, Family Voices, and Hands & Voices (and the Hands & Voices "Guide by Your Side" program) have models for providing family-to-family support. Support models range from formalized programs in which trained parents/families provide systematic, knowledgeable support to the informal matching of families in a given community by professionals who know other families with a similar story.

Families rank family-to-family support as one of the most helpful forms of support for the family.[27,74] Parents/families reporting participation in social networks with other parents/families of D/HH children had less isolation, greater acceptance of their child, and improved interactional responsivity.[75]

Recommendations

1. Develop and implement guidelines that address family-to-family support. These guidelines should outline the background and training necessary for family support providers to interact with families of infants/children newly identified as D/HH, including the importance of objective, unbiased information.
2. Provide the necessary training for families/parents who participate in family-to-family support sessions and activities.
3. Identify collaborative channels to create sustainable and compensated family-to-family support services.
4. Report the number and percentage of families who have had access to appropriate family-to-family supports.

Goal 10: Individuals Who Are D/HH 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 of the EHDI Systems

Rationale

Adults who are D/HH comprise a heterogeneous group of individuals with a wide range of communication experiences, careers, life perspectives, and educational backgrounds. Barriers to their inclusion in EHDI systems can be overcome when professionals acknowledge, understand, and value the importance of providing children who are D/HH and their families the opportunity to meet with adults who can share their experiences being D/HH.

The goal is to have individuals who are D/HH woven into the fabric of EHDI systems at every level. Individuals who are D/HH know what works to meet their language and communication needs in a way that people who are hearing cannot. Because the support of language and communication of infants is intended to be the heart of EHDI systems, it is critical to include D/HH adults in these systems.

Currently, few EHDI systems include D/HH adults in a meaningful way. The system should have diverse representation at many levels. D/HH persons with appropriate qualifications should be included, for example, as EHDI directors, EHDI advisory panel chairs and members, administrators, part C service coordinators, audiologists, speech-language pathologists, pediatricians, counselors, mentors, ASL teachers, EI service providers, and educators of the deaf and in other roles. To achieve these goals, EHDI systems should partner with national, state, and local organizations that support D/HH persons.

Recommendations

1. Develop or revise policies and legislation related to EHDI programs to require inclusion of individuals who are D/HH and who represent a diverse range of communication, educational, amplification technology, and life experiences as active participants in the development and implementation of EHDI systems (eg, involvement of such individuals in systems will be evident in recruitment processes and in the number of compensated, rather than volunteer, positions filled by individuals who are D/HH).
2. Implement professional development training and mentoring systems and provide the resources needed for individuals who are D/HH to obtain the necessary knowledge and skills to participate in systems and policy development.
3. Report the number of professional positions (eg, compensated and volunteer) filled by individuals who are D/HH at all levels of the EHDI system.

Goal 11: All Children Who Are D/HH and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D/HH

Rationale

Research has revealed the benefits of providing children who are D/HH and their families connections to members of the D/HH community. Families who have many contacts with adults who are D/HH exhibit a strong sense of competence with regard to raising their child who is D/HH.[75] When there are no other D/HH members in the family, parents identify deaf individuals as one of the most important sources of support in addition to teachers, therapists, other parents, and spouses.[76] Community members who are deaf are able to provide children who are D/HH with unique perspectives that parents who are hearing cannot.[77]

The more interactions that families have with adults who are D/HH, the better they may envision their own child's future, including developing goals and dreams that are not limited by misunderstandings about the lives of people who are D/HH. The goal of the system is to value infants/children who are D/HH for who they are.

Starting at the time the language and communication decision-making process begins, programs such as D/HH Connections in Colorado[†] involve deaf individuals in guiding, supporting, serving as role models, and interacting with the child who is D/HH and his or her family. These individuals may share personal experiences or information about being D/HH, educational and communication opportunities, using hearing technology, or about the deaf community and deaf culture. They are available to go into the home, ideally working in close coordination with other EI service providers. They may assist families in meeting IFSP goals. Providing families who are hearing with opportunities to learn more about being D/HH reduces family stress and promotes family support of the child.[78,79]

Recommendations

1. Establish an advisory group composed of a critical mass of members who are D/HH, especially those with experience with EI services and programs, along with representatives from the state EHDI system and EI providers with expertise and skill in providing services to families of infants and toddlers who are D/HH who will
    - collaboratively identify potential funding mechanisms for sustainable support services to families from individuals who are D/HH;
    - develop and implement guidelines that address providing families with access to D/HH individuals who can provide family support (these guidelines should outline the background and training necessary for support personnel/role models who are themselves D/HH to interact with families of infants/children newly identified as D/HH; these systems should guarantee that families have access to the services regardless of audiologic status (hearing levels or type) and the geographic location of the family);
    - develop a leadership training protocol/curriculum for role models and provide leadership training for identified role models;
    - develop and implement a mentoring and monitoring system for role models.
2. Make sure that the individuals who are D/HH represent the diversity of the EHDI population (eg, deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral hearing loss, auditory neural hearing loss, cultural diversity).

Goal 12: As Best Practices Are Increasingly Identified and Implemented, All Children Who Are D/HH and Their Families Will Be Ensured of Fidelity in the Implementation of the Intervention They Receive

Rationale

Fidelity of intervention refers to assurance that the intervention provided to the family and child is sufficient to (1) promote a good quality of life for the family and the child; (2) provide strategies for the development of spoken, signed/visual, or multimodal language that are appropriate to the family's choices and the cognitive ability and age of the child; and (3) provide strategies that optimize auditory skill development with the family's chosen technology.

High fidelity of the implementation of intervention requires (1) knowledge of intervention theory and methods, (2) well-defined interventions based on theory and methods, (3) demonstration of intervention procedures, (4) supervised practice, (5) feedback on performance, and (6) data to demonstrate that the intervention strategies result in the desired goals.

Ensuring fidelity of implementation includes the following characteristics: (1) linking interventions to improved outcomes (credibility); (2) definitively describing operations, techniques, and components; (3) clearly defining responsibilities of specific persons; (4) creating a data system for measuring operations, techniques, and components; (5) creating a system for feedback and

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[†] Although the writers are aware of other states involving deaf community members in similar ways, it is not clear if they are integrated in a formal way in EI and EHDI systems. For this reason, the Colorado program is described.

decision making (formative); and (6) creating accountability measures for noncompliance.[80]

Historically, EI providers have not developed systems and programs that document the fidelity of the intervention provided to families and children. A quality EI program should have a process for continuous improvement. Therefore, it is important to establish a means of assessing and monitoring the fidelity of intervention services. This information is key to establishing an empirical evidence base for EI. Without documentation of fidelity, it is difficult to link effective interventions with successful outcomes.

EI for families and infants/children who are D/HH involves a complex interaction of many child, family, background, and intervention factors. This complexity presents formidable challenges for developing well-defined interventions, training professionals in the intervention techniques, and measuring the fidelity of these interventions. In essence, little progress has been made. Clear delineation of successful interventions is necessary to ensure replicability. However, acknowledging that we are in the infant stages of defining and measuring fidelity of intervention, it is critical that the first steps be taken.

No literature currently exists that links the fidelity of the implementation of intervention for children who are D/HH with successful outcomes. However, the extant literature reveals that assurance of the fidelity of the implementation of interventions is the key to successful outcomes for children in special education and for medical interventions for both children and adults.[80–85] In these studies, positive student outcomes were attributed to 3 related factors: fidelity of implementation of the process, degree to which the selected interventions were empirically supported, and the fidelity of intervention implementation (at the teacher level).

Recommendations

1. Develop and advance mechanisms and systems to assess and monitor the fidelity of the EI services received by families who have infants/children who are D/HH. Having developed, approved, and implemented standards for the knowledge and skills needed by providers of EI services to families and children who are D/HH (see Appendix 1) is necessary. Similarly, mechanisms to measure the application of these skills in intervention are required. The most effective means of monitoring the fidelity of intervention is through direct observation and ongoing mentorship.
2. Identify a critical core group of experts. Trainer-of-trainer and peer mentoring models can provide a system for EI providers to receive support from professionals with the greatest experience, knowledge, and skills.
3. Monitor the fidelity of intervention through direct observation by a highly qualified, experienced EI provider/supervisor. A program of mentorship should be developed with an expert through consultation with individual EI providers. Tele-education/health technology can be used for this purpose. Laptop computers with voice and video communication technology (eg, distance technology) can also provide expert observation and real-time mentoring.
4. Provide mentorship through input on lesson goals and planning.
5. Encourage and support professional development of EI providers.
6. Conduct self-assessments of EI providers to identify their perceptions of strengths and weaknesses related to the guidelines established in goal 3 (see Appendixes 2 and 3). The goal of these self-evaluation instruments of EI providers is to identify perceived programmatic strengths and weaknesses and provide professional development in the areas of perceived weakness.
7. Measure the progress of EI providers on their knowledge and skills at regular intervals.[86] Refer to Gresham et al[80] for information about how to monitor the quality of interventions.
8. Obtain families' input about the skills that they have learned through EI services and their perceptions about the effectiveness of these skills in promoting successful outcomes for their children. Questions should not be about families' satisfaction but about information they have learned through EI services.[87]

GUIDELINES AND BENCHMARKS

We recommend collecting data on each of the following recommended guidelines. Our benchmark for all of these is $\geq$90% of the children/families in each state/territory.

1. All state/territories will have a coordinated system of access to EI services. The system provides timely access to EI professionals who have the knowledge and skills necessary for promoting successful developmental outcomes for children who are D/HH and the capability of tracking individual children from confirmation to developmental outcomes in EI services.
    - Children/families are referred to EI services within 48 hours of confirmation that a child is D/HH.
    - IFSPs are completed within 45 days of referral from confirmation that the child is D/HH.

- All states/territories indicate that they have an annually updated resource manual that is made available and disseminated to all families with newly identified infants/children who are D/HH. States/territories regularly evaluate the comprehensiveness and quality of the information provided in the resource manual.

2. Children/families have timely access to service coordinators who have the core knowledge and skills to fulfill the legal requirements of part C (helping families obtain services, coordinating services, facilitating the timely delivery of services, and continuously seeking appropriate services) and the requisite knowledge and skills unique to working with children, from birth to 3 years of age, who are D/HH and their families.
3. All children who are D/HH from birth to 3 years of age and their families have EI providers who have the professional qualifications and core knowledge and skills to optimize their development and well-being.
    - Each state and territory has a statement of professional qualifications for providers within 2 years of the publication of this document.
    - All providers meet the stated professional qualifications.
    - States and territories have a statement of the systematic professional development program for EI professionals working with families who have infants/children who are D/HH within 5 years of the publication of this document.
4. Three areas have been identified as needing specialized skills in addition to the general knowledge and skills required by providers.
    - *Listening and spoken language.* States and territories will adopt a mechanism for ensuring that the professionals providing listening and spoken language services have the knowledge and skills that will facilitate the development of these skills for families who choose these objectives.
    - *Sign language instructors.* States and territories will report the percentage of families and children who are able to access ASL learning opportunities from a skilled, fluent ASL user. All families who chose ASL will have access to trained and skilled ASL instructors who use effective ASL learning programs for families with young children who are D/HH. Families who elect to use sign systems or cued speech also have access to users with fluency.
    - *Other specialized methods.* States and territories will develop a mechanism that ensures intervention providers have the knowledge and skills to teach integrated systems of visual communication and listening/spoken language.
5. States report that they have developed a system ensuring family participation in the development and implementation of EHDI policies and procedures.
    - All families report that they have access to ongoing family-to-family support.
6. States report that they have developed and implemented a system ensuring participation of individuals who are D/HH with relevant skills and knowledge in the development and implementation of EHDI policies and procedures.
    - All families report that they have access to professionals/individuals in a variety of different roles who are themselves D/HH.
7. States/territories develop fidelity monitoring systems and set the goal to begin implementation within 5 years from the publication of this document.
    - Intervention services for families and children who are D/HH are monitored for fidelity of implementation.
8. Children who are D/HH have their development monitored annually, allowing the state to determine progress toward meeting the developmental outcome goals of EHDI.
9. States/territories have a system for determining whether EI professionals working with children who are D/HH with additional disabilities have the skills and knowledge necessary to promote successful or optimal/appropriate developmental outcomes for these children and their families. Professionals will receive ongoing in-service education on developmental disabilities (eg, motor, vision, autism, and cognition) and have access to specialists/team members who are qualified to address the specialty areas needed by the child. IFSPs and individualized education programs include the interdisciplinary services necessary to address the broad spectrum of needs presented by children who are D/HH and have additional disabilities.
10. States/territories will be able to report the number and percentage of families who have children who are D/HH in nonnative English-speaking

homes and identify the home language or languages.

11. States and territories have developed protocols of care for families who do not speak English and/or are culturally diverse, as well as a data management system for monitoring, with a goal of implementation within 5 years of the publication of this document.

CONCLUDING REMARKS

In conclusion, this best practice statement has advocated for the implementation of coordinated statewide systems with the expertise to provide individualized, high-fidelity EI programs for children who are D/HH and their families. Consistent monitoring of child and family outcomes is an essential step toward ensuring optimal outcomes for the majority of children. There is a great need to strengthen the evidence base supporting specific EI approaches. The establishment of practice standards, implementation of developmentally appropriate protocols for monitoring of outcomes, and commitment to research collaborations are critical steps toward this goal.

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APPENDIX 1: KNOWLEDGE AND SKILLS OF EI PROVIDERS FOR CHILDREN WHO ARE D/HH AND THEIR FAMILIES

This appendix includes a listing of broad competencies (knowledge and skills) related to the provision of early development services for children who are D/HH and their families. These competencies, compiled from 8 different best practice and position statement documents,[1,32,88–93] are the core competencies recommended for early development providers. The compilation of these core competencies recognizes that early development providers come from diverse professions (eg, audiology, early childhood special education, educators of the D/HH, and speech-language pathology). Although organized into sections by content area, the competencies are intended to be considered as an entire set of practices needed to work with this group of children and families. For example, specific knowledge and skills having to do with cultural competency are incorporated throughout various sections in the document. Note: The Appendix 1A–I tables were developed/compiled by A. Stredler-Brown, M. Sass-Lehrer, K. Clark, and M.P. Moeller.

APPENDIX 2: EXAMPLE OF FIDELITY OF INTERVENTION MONITORING

Listening and Language Self-Checklist for Colorado Home Intervention Program (CHIP) Facilitators (Developed By Nanette Thompson) Auditory Skill Development

✓Did I do a version of the Ling 6+ Sound Test? Did I reemphasize the importance of consistency of use of hearing aids/implants throughout all waking hours? Did I do a listening check of amplification?

Appendix 1A Family-Centered Practice: Family-Professional Partnerships, Decision Making, and Family Support

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize the expertise and major impact of families on children's growth and development	1, 32, 88, 90, 93
2. Understand family systems and family dynamics	32, 88, 90, 93
3. Establish respectful reciprocal relationships with families	32, 88, 90, 93
4. Demonstrate appropriate and effective listening strategies with families and others	32, 88, 90, 93
5. Facilitate families' identification of concerns, priorities, and resources	32, 88, 90, 93
6. Implement strategies to promote infant-caregiver relationships and interactions	32, 88, 89, 90, 93
7. Promote and enlist help from family-to-family support networks	1, 32, 88–93
8. Support family health and emotional well-being	32, 88, 90, 93
9. Identify risks for abuse/neglect situations	32, 88, 90, 93
10. Provide support and recognize signs indicating the need to refer for counseling/therapy or other emotional support from specialists	32, 88, 90, 93
11. Encourage family skills for collaboration with the EI team	1, 32, 88, 89, 91, 93
12. Promote family involvement in all aspects of intervention	1, 32, 88, 89, 91, 93
13. Promote informed decision making through provision of accurate and comprehensible information, resources, and support	1, 32, 93
14. Implement strategies for guiding and supporting families' decisions regarding communication approaches/opportunities	1, 32, 88–93
15. Encourage family advocacy skills	1, 32, 88, 89, 91, 93
16. Monitor family satisfaction with intervention services	1, 32

Appendix 1B Socially, Culturally, and Linguistically Responsive Practices Including D/HH Cultures and Communities: Sensitivity to and Respect for an Individual Family's Characteristics

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand the diversity of families, languages, cultures, communities	1, 32, 88–93
2. Understand the influence of family, culture, and environment on infant development	1, 32, 88, 90–93
3. Understand the implications of socioeconomic and cultural differences in child rearing	1, 32, 88, 90–93
4. Demonstrate sensitivity to cultural, religious, ethnic, disability, gender, socioeconomic, linguistic, and geographic influences on children and families	32, 88, 93
5. Demonstrate understanding of and respect for deaf culture and D/HH communities	32, 91–93
6. Understand the role and resources of the deaf community, sign language interpreters, and cultural brokers	1, 32, 89, 92, 93
7. Appreciate the roles and access the resources of interpreters and cultural brokers when working with non–English-speaking families	32, 90, 91
8. Promote family's understanding and appreciation of "being deaf or hard of hearing"	None
9. Understand the role and include resources of D/HH adults to promote language and social development and use of technologies (auditory and visual)	1, 32, 89, 91, 92
10. Appreciate and respect cultural perspectives on selection and use of technology	32
11. Implement culturally sensitive approaches	1, 32, 88–93

Appendix 1C Language Acquisition and Communication Development: Typical Development, Communication Approaches Available to Children With Hearing Loss, and Impact of Hearing Loss on Access to Communication

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand developmental sequences across developmental domains and their complex interactions with communication	1, 32, 88, 90, 93
2. Understand the influence of variables such as age of identification/intervention on language (English and other spoken languages, ASL) and speech acquisition	32, 88, 93
3. Understand the effects of multiple language exposure on children's development (ie, bilingualism in spoken languages and in ASL), drawing upon current theories of bilingualism	32, 88, 90, 93
4. Understand the impact of hearing loss on communication, language, and speech	1, 32, 88
5. Promote the important role of caregivers in development of communication skills through caregiver-child interaction	1, 32, 88–93
6. Understand typical development sequences in auditory and visual perception	1, 32, 88–90, 93
7. Understand the array of communication approaches (eg, ASL, bilingual-bicultural, auditory/oral, auditory/verbal, cued speech, and simultaneous communication) and resources for observing and demonstrating them	1, 32, 88–90, 93
8. Understand augmentative communication approaches and circumstances in which they should be considered	90, 93
9. Understand the importance of involving D/HH adults in the promotion of children's language and social development	1, 32, 89, 91, 92

Appendix 1C Continued

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
10. Provide families and children with access to skilled and experienced professionals to facilitate language development using language and communication modalities selected by family and appropriate for the child	1, 32, 90
11. Coach families in the use of strategies that promote a language-rich learning environment to facilitate language, thought, and early literacy	1, 32, 88–93
12. Prepare families to be able to explain (or understand) the relationships among communication, language, and speech	1, 88, 93
13. Assess prelinguistic and early linguistic communication stages	1, 32, 88, 93
14. Understand communication and language assessment outcomes with reference to typical developmental sequences and stages of spoken language development	1, 32, 88–92
15. Interpret outcomes with reference to typical developmental sequences and stages of ASL for families using this approach	1, 32, 89, 91, 92
16. Promote development of phonology, morphology, syntax, semantics, and pragmatics of spoken language and/or ASL	88
17. Implement strategies to promote auditory learning in children who are D/HH	1, 32, 88–90, 93
18. Implement strategies to promote visual language learning in children who are D/HH	
19. Embed goals within daily routines and integrate communication in a variety of social, linguistic, and cognitive/academic contexts	1, 32, 88–90, 93
20. Implement strategies that promote access to language using combined or multiple modalities	32, 88, 89, 91, 92
21. Implement current practices for promoting auditory development for children with cochlear implants	1, 88
22. Implement evidence-based communication practices with young children to facilitate child learning within developmentally appropriate daily activities	88, 90, 93
23. Monitor language development outcomes to guide intervention and promote age-appropriate abilities to the degree possible	32, 88–91

Appendix 1D Factors Influencing Infant and Toddler Development

Providers have the knowledge and skills to	Best Practice Documents (Ref No.)
1. Differentiate the characteristics and stages of typical/atypical development	1, 32, 88–91
2. Appreciate the range of individual differences in development and factors that influence them	1, 32, 88–93
3. Recognize the effects of prenatal care, prematurity, health, and other biological conditions on development	90, 93
4. Be aware of the health needs of young children and collaborate with the medical community to address them	93
5. Understand contemporary infant development theories including research on brain development	32, 88, 89, 93
6. Demonstrate sensitivity to infant states/cues and understand how responses contribute to infant development in child rearing	32, 93
7. Understand bonding/attachment theories and implications for development	93
8. Monitor stages of cognitive development and recognize the impact of cognitive delays on learning	32, 88, 89
9. Recognize the impact of multiple disabilities on development and understand the interdependence of developmental domains	88–90, 93
10. Understand auditory, visual, and cross-modal perception and processing in relation to development	32, 88, 91–93
11. Recognize the role of play and daily routines in development	32, 88, 90, 93
12. Locate current evidence and resources related to contemporary studies of infant development	32, 88, 89, 93
13. Facilitate infant/toddler engagement	88, 90
14. Develop and implement age-appropriate interventions supportive of development in all domains and reflective of individuals' interests	32, 88–90, 93

Appendix 1E Screening, Evaluation, and Assessment: Interpretation of Hearing Screening and Audiologic Diagnostic Information, Ongoing Developmental Assessment, and Use of Developmental Assessment Tools to Monitor Progress

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Distinguish between screening, observation, evaluation, and assessment	90, 93
2. Understand and facilitate referral processes (from screening, evaluation, and referral for services)	32, 93
3. Understand implications of universal newborn hearing screening for families and early intervention services	1, 90, 93
4. Understand newborn hearing screening protocols, including instrumentation; appropriately interpret screening results	1, 88
5. Understand pediatric audiologic procedures, including screening, evaluation, and interventions and accurately interpret audiologic results	1, 88, 90, 93
6. Promote and provide input to appropriate audiologic and developmental evaluation procedures	32, 88, 93
7. Understand atypical development etiologies and diagnoses and refer for medical-genetic evaluation	1, 32, 88, 90, 93

Appendix 1E Continued

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
8. Know how to gather information from families that identifies their priorities, concerns, and resources related to their child's development	32, 88, 90
9. Know current cochlear implant candidacy criteria	1, 88
10. Recognize strengths and limitations of standardized instruments and adaptations for a child who is D/HH	90, 93
11. Use assessment tools and strategies that are culturally, linguistically, and developmentally appropriate	32, 90, 93
12. Understand and participate in interdisciplinary, transdisciplinary, and multidisciplinary assessment procedures and processes	90, 93
13. Implement assessment strategies and support family participation and involvement	32, 88, 93
14. Implement principles/processes to appropriately assess the child in natural environments	88, 90, 93
15. Monitor child progress by using appropriate tools and procedures	1, 32, 88–90, 93
16. Convey assessment and evaluation results and recommendations in a manner that is understandable, accessible, culturally sensitive, and confidential	1, 32, 90, 92, 93

Appendix 1F Technology: Supporting Development by Using Technology to Access Auditory, Visual, and/or Tactile Information

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize the importance of the use of technology to access auditory, visual, and/or tactile information	1, 88–93
2. Recognize benefits and challenges of technology use with infants across multiple settings and activities	32, 88, 90, 93
3. Be knowledgeable about current augmentative communication technologies and their application with infants with multiple special needs	88
4. Identify sources for obtaining assistive technology, information, funding, and support	1, 32, 93
5. Implement strategies to support families' abilities to use and monitor effectiveness of technology	1, 32, 88, 90, 91, 93
6. Promote family skills in monitoring amplification and ensuring device retention and safety	1, 32, 88–90
7. Promote family learning and involvement using household, office, and community technology	32, 88, 93

Appendix 1G Planning and Implementation of Services: Creating a Lesson Plan, Conducting a Home Visit, Developing the IFSP, and Using Appropriate Curriculums, Methods, and Resources

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Implement best practices related to the process of developing IFSPs and Individual Education Plans	1, 32, 88–90, 93
2. Collaborate with families to develop and implement the IFSPs as working documents	1, 32, 89, 90, 93
3. Plan and implement assessment-based instruction	88, 90
4. Select and systematically implement intervention strategies appropriate to the communication, hearing, speech, language, and emerging literacy needs of the child	88, 90
5. Revise intervention approaches as needed in response to the child and the family	1, 32, 88–90, 93
6. Plan and implement effective parent-child sessions in natural environments	32, 88, 90
7. Plan and implement center-based session (eg, play groups and peer groups) including developing effective lesson plans	32, 88
8. Participate in the planning and implementation of workshops/meetings for families	None

Appendix 1H Collaboration and Interdisciplinary Models and Practices

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Recognize roles and responsibilities of families and other individuals with expertise in deafness	1, 32, 89, 90, 93
2. Support consultation across disciplines and collaborate with families	1, 32, 88–90, 93
3. Recognize the roles and the importance of service coordination and medical homes	1, 32, 90, 93
4. Promote collaboration with community programs and resources to support families and children	1, 32, 90
5. Recognize intra/interpersonal variables that influence the development of collaborative relationships with parents and professionals	1, 32, 88–90, 93
6. Apply principles and strategies to support family members and professionals	1, 32, 88–90, 93
7. Implement collaborative strategies for communicating, decision making, and resolving conflict	32, 90, 93
8. Provide for a continuum of service delivery models to meet the needs of the individual child and family (eg, direct service, collaborative consultation, playgroup based)	90
9. Assume a leadership roles affecting collaboration, including self-evaluating, mentoring, networking, and advocating for families and organizations	32, 88, 90, 93

Appendix 1I Professional and Ethical Behavior: Foundations of EI Practice, Legislation, Policies, and Research

Providers Have the Knowledge and Skills to	Best Practice Documents (Ref. No.)
1. Understand history of deaf education, philosophy of early intervention, and child/family advocacy	88, 91, 92, 93
2. Understand EHDI programs and processes	32, 89, 90
3. Understand IDEA, federal legislation, and federal regulations related to infants/toddlers and their families	1, 32, 89, 90, 93
4. Recognize IDEA's support for program evaluation and system change and the limitations of the law	32, 93
5. Support the rights, responsibilities, and confidentiality of children and their families	1, 32, 89, 91
6. Understand the role of Services Coordination and assist families in linking with this service	32, 90
7. Plan and implement seamless transitions to ensure continuity of services across educational and community placements	1, 32, 88–90, 93
8. Apply principles of evidenced-based practice and be conversant about current research evidence related to early intervention	32, 88–90
9. Adhere to professional ethical standards in working with young children and families	32, 88, 89, 93
10. Take personal responsibility to demonstrate a positive attitude toward infants, toddlers, and families	93
11. Think critically and pursue life-long learning through ongoing professional development	1, 32, 88, 89, 93

✓Did I incorporate music, nursery rhymes, or singing into the session?

✓Did I demonstrate high expectations for auditory skill development in daily routines and natural environments? Did I encourage a variety of listening activities including recorded music or books on tape?

✓Did I provide opportunities to listen in a variety of environments including with varying distances and in quiet and noisy environments?

✓Did I encourage the family to organize the environment to maximize the auditory potential of the child? (Decrease background noise, turn off the TV, close the doors to the laundry room, etc.)

Language Development

✓Did I use literature in the session or reference activities that encourage early literacy skill development?

✓Did I model expanding the child's spontaneous language and discuss the importance of this strategy with the parent? Did I use the Plus 1 rule of expanding the child's utterance by 1 additional word?

✓Did I reward all attempts at communication?

✓Did I focus on the development of language through listening? Did I remind the parent to talk to the child throughout daily activities?

Speech Sound Production

✓Did I expect, encourage, and elicit verbal responses within all activities?

✓Did I use acoustic highlighting to facilitate speech sound production?

✓Did I note any speech errors and understand them to be developmental, phonological, motor- related, or hearing-related in nature?

Techniques, Strategies, and Communication

✓Did I provide commentary for parents of my session objectives and my observations?

✓Did I demonstrate scaffolding a skill up and down to ensure the child's success and discuss that important process with the parent?

✓Did I provide enough pause time and encourage the parents to do so as well?

✓Did I brainstorm with the parents ways to incorporate these strategies and objectives into their daily routines?

✓Did I follow up with other professionals working with the child?

✓Did I leave the parent feeling empowered and motivated for the upcoming week?

APPENDIX 3: EXAMPLE OF FIDELITY OF INTERVENTION MONITORING FOR ASL FOR USE BY PARENTS AND PROVIDERS/FACILITATORS WITH CHILDREN AGES BIRTH TO ≥4 YEARS (DEVELOPED BY BETH S. BENEDICT, PHD, JODEE S. CRACE, MA, AND PETRA HORN-MARSH, PHD)[94,95]

Visual Skill Development

- Did I monitor the child's progression through developmental stages of ASL? Do I know what behaviors are typically observed at the preverbal stage, single-word stage, 2-word stage, and short-phrase stage in young ASL users? Do I emphasize the importance of consistency of use of ASL by the family throughout the child's waking hours? Do I do a visual‡ check of natural and

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‡Visual checks include picking the child up so he/she has a better view of what's "up there" (ie, counter at McDonald's to order food from a cashier), carrying the infant facing forward so that the infant can see what the caregiver is doing and talking about, making sure that the child is positioned so he/she has "the best eye view of the world," and ensuring that the caregiver has a large rearview mirror in the car so that the parent and child can see each other better and thus the caregiver can "communicate" with the infant or child.

structured development opportunities and interactions that foster skill growth?

- Did I model infant-directed sign ("motherese"), utilizing my facial expressions and hand touches on the baby?
- Did I model the use of and support the family in ways to incorporate finger play, nursery rhymes, gestures, body language, or facial expressions into daily routines (active and passive activities)?
- Did I demonstrate high expectations for visual skill development in daily routines and natural environments? Do I encourage a variety of visual activities including DVDs, print books, and storytelling that are interactive?
- Did I provide opportunities for joint engagement, incorporating eye contact, eye gaze, and eye shifting in a variety of environments, at varying distances, and in nondistracting visual environments? Do I know that the child is able to pay attention and is aware of the words being exchanged? Do I support the family in providing ample opportunity for turn-taking to foster skill development?
- Did I encourage the family and other people to organize the environment to maximize visual potential of the child (eg, the room is well-lit, the background is not too graphic, the seating is in appropriate proximity, and there are plenty of meaningful conversational exchanges, appropriate to the child's developmental level)?
- Did I respond appropriately to the child's attempts to initiate and express self (eg, do I show that I understand through my ASL and then build on to the child's communicative attempt)? Do I model these skills for families and promote their use?

Language Development

- Did I use children's literature and other strategies to encourage early literacy skill development?
- Did I model expanding the child's spontaneous language and discuss the importance of this strategy with others involved? Do I use a language development checklist or scale to ensure that the child is making language gains within age-appropriate intervals? Do I expose the child to other language models (adults and peers) so that the child can acquire a variety of developmental styles?
- Did I motivate, encourage, and reinforce all attempts at communication, supporting semantic, grammatical, social-pragmatic, and verbal reasoning skills?
- Did I recognize the effects of the child's learning style and temperament on language development so that individual needs are consistently nurtured and supported?
- Did I expect ASL acquisition to follow the developmental milestones similar to those of spoken language?
- Did I focus on monitoring the child's development of language through watching/observing/attending and measuring outcomes? Do I recognize that the child has initiated, maintained, and responded to conversation, including appropriately answering basic questions?
- Did I coach the other parents/providers to communicate with the child in ASL throughout daily activities and routines, including incidental conversation, side conversations, and background noises?

ASL Production

- Did I expect, encourage, and elicit signed responses from the child within all activities?
- Did I support the family in developing similar expectations for the child's ASL production?
- Did I incorporate hand-shape, location, movement, palm orientation, facial expression (non manual markers on eyes, face, and head), and body posture to facilitate ASL production?
- Did I note any ASL grammatical errors made by the child and consider whether they are developmental, cognitive, motor, or visual in nature?

Techniques, Strategies, and Communication

- Did I suggest and encourage the family to use Videophone, Skype, iChat, ooVoo, or other visual technology for ongoing communication in ASL?
- Did I provide commentary for parents and/or providers/facilitators on the language goals and observations of the child's emerging skills and ongoing needs?
- Did I demonstrate ways to scaffold[§] a child's emerging skills to ensure the child's success? Do I support the family in developing methods for scaffolding the child's development (eg, assisting the child in making the appropriate hand-shape, beginning with the 6 basic hand-shapes [B, A, C, 0, 5, 1], then increasing to more complex hand-shapes [claw-5, claw-3]; supporting the caregiver in knowing that the child learning ASL typically has

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[§] Did I foster skill growth to the next level using visual aids, manipulative, concrete examples, and situations? For example, asking a child "which" question occurs before the next questioning level, such as who, what, or where?

a vocabulary of *x* number of signs by age 2, etc)?

- Did I provide enough pause time and encourage the parents and/or providers/facilitators to do so as well? Do I coach them on "give and take" strategies so that the child can develop independent critical thinking skills?
- Did I brainstorm with the parents and/or providers/facilitators on ways to incorporate these strategies and objectives into their daily routines?
- Did I collaborate with other providers/facilitators (eg, occupational therapist, physical therapist, speech language pathologist) serving the child and family members, sharing input, and providing ongoing development as well as opportunities to increase their ASL skills?
- Did I leave the parent and/or providers/facilitators feeling empowered and motivated to support the child's ongoing ASL development?

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Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing

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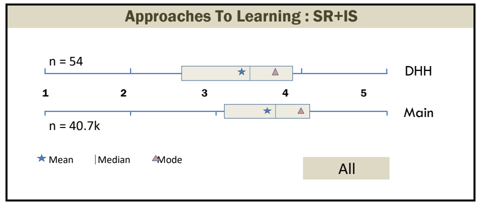
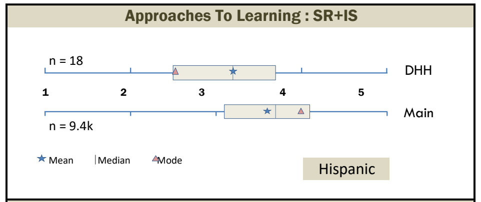
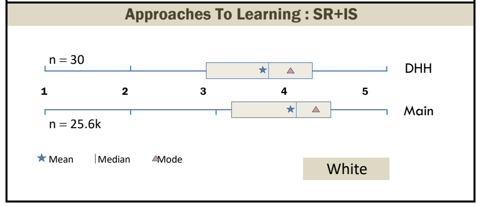
Kindergarten Readiness Assessment

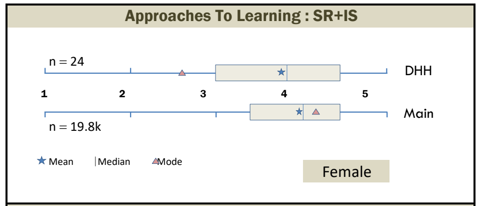
Fall 2016

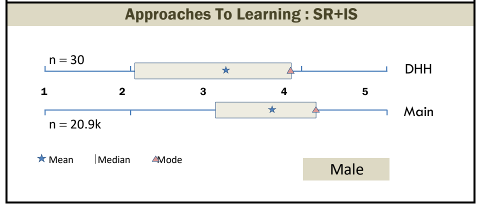
Approaches To Learning : SR+IS



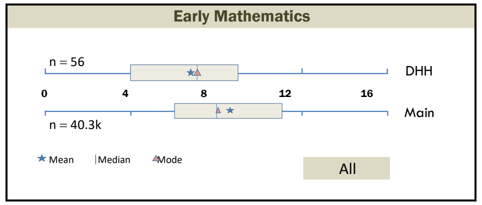


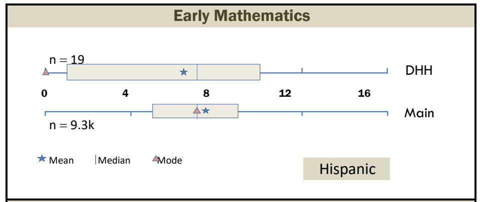


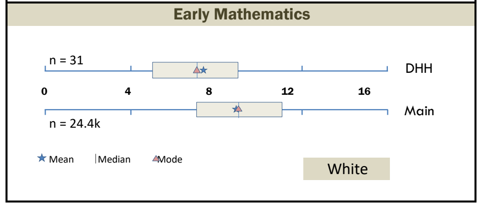


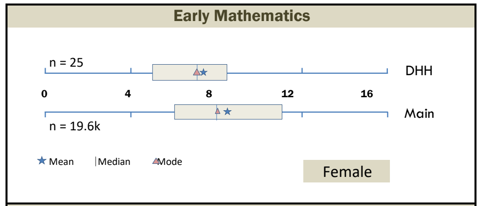


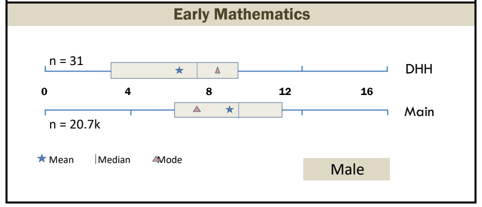
Early Mathematics



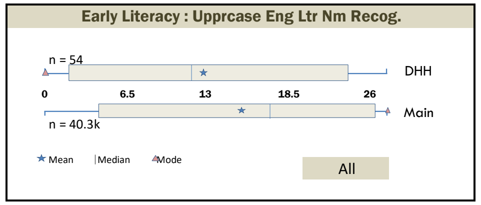


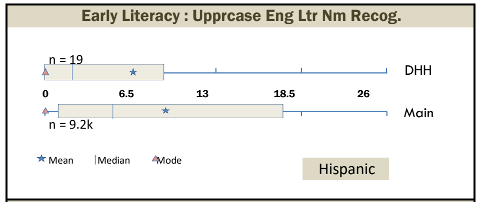


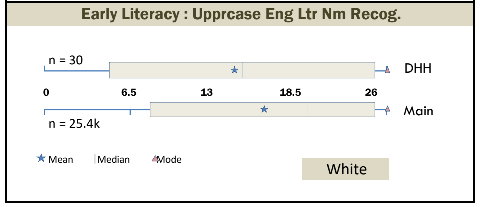


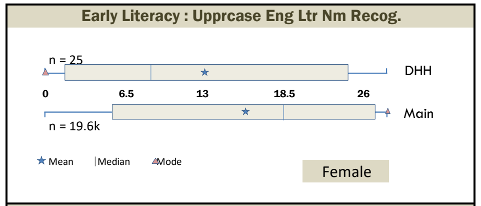


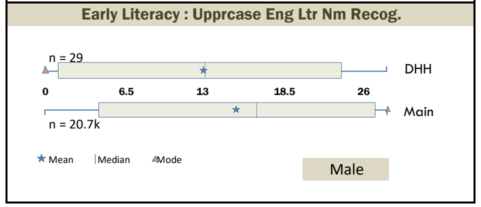
Early Literacy : Upprcase Eng Ltr Nm Recog.











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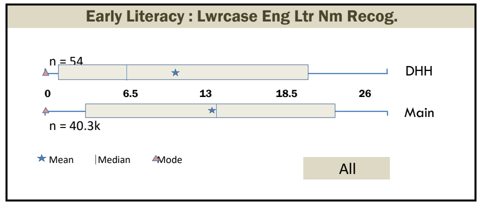

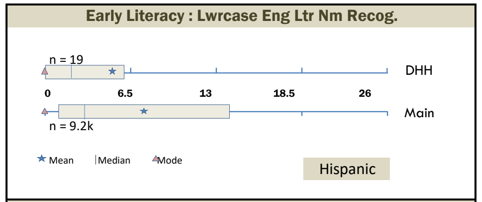

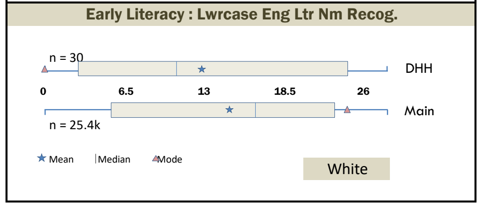

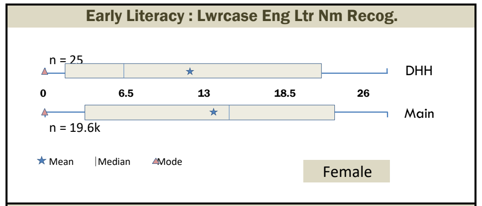

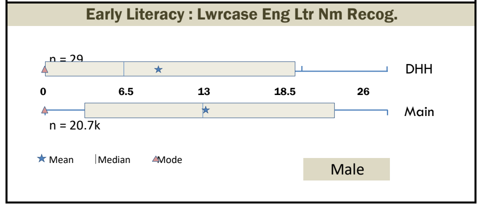

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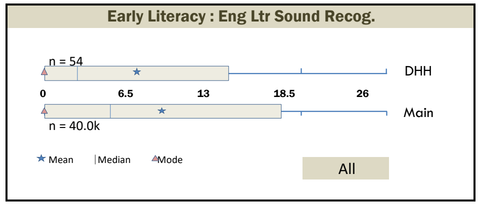

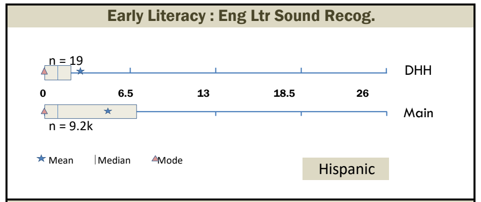

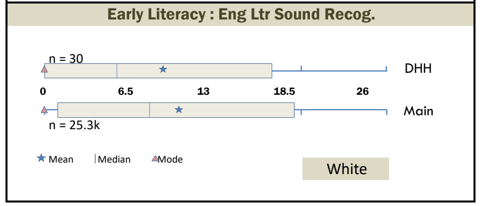

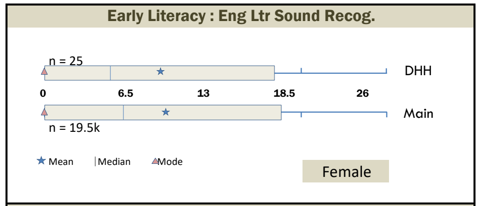

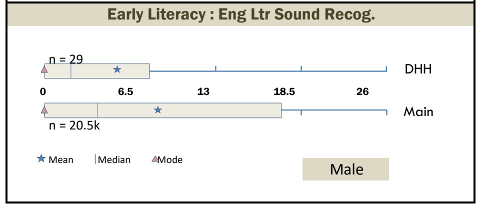

LEAD-K:

LANGUAGE EQUALITY & ACQUISITION FOR DEAF KIDS

Mythbusters

The purpose of the Mythbusters is to address misinformation about the LEAD-K bill. The goal of LEAD-K is to ensure a foundation for English literacy among deaf and hard of hearing children whether they use one or both languages, American Sign Language and English for K-readiness.

MYTH	FACT
The LEAD-K bill is a mandate for American Sign Language	**The LEAD-K bill does *not* require American Sign Language.** **The bill provides for language milestone information & assessments for kids who use *one or both* of the languages of American Sign Language (ASL) and English. For purposes of the bill, "English" includes spoken English, written English, or English with the use of visual supplements**
MYTH	**FACT**
This bill does not support parents' choice to have their deaf child learn to listen and speak and to "assimilate" into hearing society, without using sign language	**The LEAD-K bill does not and will not interfere with a family's decision to have their deaf child learn to listen and speak. Again, the assessments are conducted in *one or both* languages, American Sign Language and English. How to communicate with your child is the family's decision.**
MYTH	**FACT**
The advisory board takes away the autonomy of the IFSP and IEP teams that are charged with providing individualized plans for each child	**The advisory board is a short term adhoc made up of volunteers whose role is to identify existing resources already developed to be made available for use by families, local education agencies, and the IFSP team or IEP team. Once that task is done, the advisory board is done. The advisory board will not and cannot replace the critical function the IFSP or IEP team.**

MYTH	FACT
The advisory board does not include the parents/caregivers as essential members of this process.	The bill’s advisory board includes parents/caregivers as essential members of the process.
MYTH	**FACT**
A family who has a deaf or hard of hearing child is forced to participate in the assessment.	*Any* assessment must be conducted in compliance with federal law which requires both parental notification and consent, so it is a family choice to participate or not. 34 CFR §303.321; 34 CFR §303.405.
MYTH	**FACT**
LEAD-K places additional responsibilities on educators	Educators doing assessments *is not a new or additional responsibility* for them. They are already required to do assessments. The LEAD-K bill simply requires utilizing one with language milestones. Note: Federal law defines an assessment as the ongoing procedures used by qualified personnel (educators) to *determine the individual child's present level of performance and early intervention or educational needs.* 34 CFR §303.321(a)(2).
MYTH	**FACT**
The data collection does not protect the privacy and confidentiality of the children and the families involved	Privacy and confidentiality will be protected & preserved. Any data collection and any implementation of this bill must be consistent with federal law regarding the privacy of pupil information and be consistent with federal law regarding the education of children with disabilities.

MYTH	FACT
The assessment must be appropriate for an individual child, not selected from a list created by a workgroup.	**Existing assessment materials, as required by federal law, *must be appropriate to assess the specific areas of developmental need* and are used for the specific purposes for which they were designed. 34 CFR §303.322 The bill requires language development inclusion but will not prevent the IFSP team or the IEP team from utilizing any assessments the team sees fit to best serve the individual child.**
MYTH	**FACT**
The proposed law does not address the rights of non-English speaking children, children who are not eligible for special education, or children with unique needs.	**Any assessment is administered in compliance with federal law requiring the assessment to be conducted in a nondiscriminatory manner, in the native language of the child or family, and by qualified personnel. 34 CFR §303.322.**
MYTH	**FACT**
Requiring assessments of children with disabilities and not requiring them of other children is discriminatory and a civil rights violation.	**Any assessment provided must comply with federal law that such assessments are *selected to accurately reflect the child's developmental level.* 34 CFR §303.322 Again, with respect to the above, any assessment must be administered in compliance with federal law requiring the assessment to be conducted in a nondiscriminatory manner, in the native language of the child or family, and by qualified personnel. 34 CFR §303.322. The LEAD-K bill simply requires a language assessment to be included as part of IFSP and IEP assessments.**

MYTH	FACT
Some children who are deaf or hard of hearing are not in the special education system, but yet this law would require them to be assessed.	**Any assessment must be conducted in compliance with federal law which requires both parental notification and consent, so a family as they see fit, can either chose to or *not to* participate. 34 CFR §303.321**
MYTH	FACT
Federal law already requires an assessment. State law can't "require" an assessment.	**State law cannot require less than federal law requirements, but state law can provide *more protection* than what federal law provides.** **IDEA leaves room for the state to interpret the federal rules and pass their own laws. Thus, a state law providing for language inclusion is not in conflict with federal law in any manner.**
MYTH	FACT
An assessment must be deemed to be appropriate for that individual child, and not be restricted to just language.	**While LEAD-K requires *inclusion* of a language development assessment, it does not restrict other assessment domains.** **As required by federal law, assessment materials must be appropriate *to assess the specific areas of developmental need* and used for the specific purposes for which they were designed. 34 CFR §303.322**

For more information please contact: info@lead-k.org

ASL Stages of Development (American Society for Deaf Children, 2012)

2– 6 Months

- Pays attention to faces
- Follows things with eyes
- Is fascinated by his or her own hands
- Copies movements and facial expressions
- Babbles with his or her hands

6 – 12 Months

- First hand shapes emerge; ”5” and “S”
- First signs may emerge – “Mommy,” “Daddy,” “More,” “Milk,” “Bath,” “Bed.”
- Mimics signs and facial expressions
- Points to people, objects and places not at self

12 – 18 Months

- Uses at least 10 signs
- Begins to use points as pronouns
- Acquires new signs but does not mark with inflections
- Responds to signed requests

18 – 24 Months

- Points to things or pictures when named
- Knows names of familiar people
- Follows simple instructions
- Repeats signs seen in conversation
- Understands and carries out complex commands and requests
- Shows interest in “how” and “why”

2 – 3 Years

- Uses directional verbs – “Give Me”
- Expresses possessives – “My Shoe”
- Uses action and object forms –

Signs to self

- Signs throughout the day
- Sign order used to show semantic relations
- Begins to use classifiers to represent objects
- Demonstrates negation with headshake or sign “No”
- Begins to use possessive (your, mine) and plural (“Us-Two,” “You-Three”) pronouns
- Refers to things around them during conversations and storytelling; may copy the actions and facial expressions of others in a story

LEAD-K™

LANGUAGE EQUALITY & ACQUISITION DEAF KIDS

LEAD-K's GOAL: Kindergarten-Readiness = Lifetime Success!
All children are born ready to learn, however far too many deaf children are deprived of early language development and are not kindergarten ready. Research has shown that language deprivation or delays between ages 0-5 is the main cause of many deaf children's eventual reading, academic, and social struggles. The type of language-rich environment and the quality of interaction to which children are exposed in the first five years of life greatly influence the outcomes of their adult lives.

The Problem

Research has shown that the first 3 years of life are crucial for language development and the basis for kindergarten-readiness. Early intervention programs for deaf children continue to be based on auditory language, spoken English, which, according to the growing research does not ensure a deaf child's full access to a language-rich environment. Deaf children's success in acquiring language at age appropriate levels when exposed to sign language is well documented; however the majority of deaf children continue to be denied exposure to a visual language. It is a denial of their human right to language and the ineffective educational system policies that perpetuate this injustice. This failure by the educational system to acknowledge a deaf child's visual experience of the world does not reflect the deaf child's full potential.

The Solution

Research has shown that when deaf children are exposed to a rich visual language environment (American Sign Language) they are provided the foundation for a first language and school readiness. The focus of LEAD-K is to promote language equality, a basic human right for all deaf babies by advocating for deaf children to have access to both American Sign Language and English.

The Strategy

LEAD-K's strategies are twofold: 1) raise the awareness and understanding of the general public, parents, and the education system of the Deaf child's experience in language learning, the role of visual learning for a Deaf child and how that impacts their educational success; and 2) to work with other partners to change public policy related to the education of Deaf children who use ASL and English, both or one of the languages toward Kindergarten-readiness.

Key Facts

- By age 5, a child's brain is already 90% developed, yet most deaf children enter kindergarten without language.
- The results of Deaf children not provided access to early language development:
  - Average reading level by 18 years of age has remained at 3rd or 4th grade level for more than a half a century.[1]
  - Only 6% of deaf students scored proficient in English[2]
  - 51% of deaf students scored at the "far below basic" level which is the lowest level of performance[3]
- The lack of early and full accessible visual language exposure may be a contributing factor to the low levels of reading achievement in the deaf population[4].
- Children are born ready to learn, but for a quarter of a million U.S. children who are deaf, they enter school not prepared to succeed.

For more info contact: info@lead-k.org

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[1] Visual Language & Visual Learning Research Brief: Reading Research & Deaf children; Donna A. Morere, PH.D., June 2011

[2] 2008 California Special Education Management Information system (CASEMIS) Report, California State Department of Special Education

[3] Ibid.

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FOR IMMEDIATE RELEASE

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Clerc Center Announces Contract Award for Development of American Sign Language Content Standards for Grades K-12

WASHINGTON, DC — February 7, 2011 — The Laurent Clerc National Deaf Education Center at Gallaudet University (Clerc Center) today announced it has awarded a contract for the development of American Sign Language (ASL) content standards for students in grades K-12. These content standards will outline the ASL skills that students should have at each grade level and allow teachers to plan instruction by comparing student skills against the standards. The recipient of the contract is an innovative team composed of university-based researchers renowned for their expertise in deaf education, language and literacy development, and ASL assessment; as well as administrators, teachers, and specialists at three elementary and secondary schools for the deaf.

Individual members of the unique coalition that is receiving the contract are from Boston University; University of Manitoba; University of California, San Diego; University of Illinois at Urbana-Champaign; California School for the Deaf-Riverside; Indiana School for the Deaf in Indianapolis, Indiana; and The Learning Center for the Deaf in Framingham, Massachusetts.

“The development of ASL content standards is a key component in our ongoing efforts to facilitate linguistic competence for deaf and hard of hearing students in both ASL and English,” said Clerc Center vice president Ed Bosso. “The importance of this work cannot be overstated and is vital to the academic and linguistic development of deaf and hard of hearing students. The Clerc Center is privileged and honored to be able to provide the necessary support for this work.”

The Clerc Center will provide periodic updates regarding the progress of the development of ASL content standards. The target date for nationwide dissemination of the final ASL content standards is early 2013. For more information about this contract, the award recipients, and a video of this announcement in ASL, visit http://clerccenter.gallaudet.edu/asl_standards.xml.

The Clerc Center provides information, training, and technical assistance for parents and professionals to meet the needs of children who are deaf or hard of hearing. Our mission is to improve the quality of education afforded to deaf and hard of hearing students from birth to age 21 throughout the United States.

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