

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

Lead Investigator: Denise Thew Hackett, Ph.D, M.S.C.I.

Co-Investigator: Cheryl D. Davis, Ph.D.

Data Analyst: Sybille Guy, Ph.D.

12/30/2016

*DHS Interagency Agreement #151333 (DHS-4131-16)
Western Oregon University
Regional Resource Center on Deafness*

Table of Contents

| | |
|---|----|
| Acknowledgements | 5 |
| Executive Summary..... | 6 |
| Background of Needs Assessment..... | 9 |
| Study Requirements | 9 |
| Methods of collecting and reviewing data..... | 9 |
| Areas of Focus..... | 11 |
| Demographics | 11 |
| Communication Access to Public Services | 11 |
| Barriers and Strategies..... | 11 |
| Communication Access | 11 |
| Methods | 11 |
| Overview..... | 11 |
| Key Data Collection/Data Checking Components | 13 |
| Results | 15 |
| Community Advisory Board..... | 15 |
| Focus Groups | 16 |
| Key Informant Interviews..... | 16 |
| On-line Survey | 16 |
| Demographics..... | 17 |
| Residency | 17 |
| Race/Ethnicity | 19 |
| Gender | 20 |
| Age..... | 20 |
| Age at Hearing Loss | 21 |
| Hearing Loss Identity..... | 21 |
| Communication Preference | 22 |
| Hearing Aid and Cochlear Implant Use..... | 23 |
| Accommodations in Public Settings..... | 27 |
| Financial Barriers Related to Hearing Aids | 28 |
| Education..... | 28 |
| Education Barriers Related to Learning Needs Accommodations | 29 |
| Barriers Related to Education Options and Information | 30 |
| Financial Barriers to Education..... | 35 |
| Postsecondary Educational Settings | 36 |
| Employment..... | 37 |
| Treatment at Work..... | 41 |
| Barriers Related to Employment | 41 |
| Socioeconomic Indicators | 42 |
| Number in Household..... | 42 |
| Household Income | 42 |
| Housing..... | 43 |

| | |
|---|----|
| Other Barriers Faced in Housing | 45 |
| Transportation | 45 |
| Transportation Barriers..... | 46 |
| Public Services | 47 |
| Vocational Rehabilitation Services..... | 51 |
| Barriers to Public Service Agencies..... | 51 |
| First Responders | 52 |
| Text to 9-1-1 | 52 |
| Fire Alarm Devices | 53 |
| Emergency Management | 53 |
| Foster System Barriers..... | 53 |
| Barriers to Housing Services for Individuals who need Additional Services | 54 |
| The Court System | 56 |
| ADA in Court System..... | 57 |
| Barriers Related to Legal System | 57 |
| Quality of Life..... | 59 |
| Overall Indicators | 59 |
| Health..... | 59 |
| Communication Barriers in Medical Settings | 64 |
| Mental Health | 66 |
| Available of Mental Health Services | 67 |
| Isolation as a Mental Health Issue | 68 |
| Mental Health System Barriers | 68 |
| Substance Use and Treatment | 69 |
| Harassment, Bullying, and Abuse..... | 69 |
| Limitations of the Study | 72 |
| Findings and Recommendations | 73 |
| Biographies | 84 |
| Appendix A: Definitions | 79 |
| Appendix B: NASADHH 2009 Survey of State Commissions, Divisions, and Councils Serving Deaf and Hard of Hearing People..... | 82 |

List of Tables

| | |
|---|----|
| Table 1: County Density and Response Rate for each County | 17 |
| Table 2: Citizenry of Parents and Children | 19 |
| Table 3: Gender | 20 |
| Table 4: Age of Respondents at the Time of the Survey | 20 |
| Table 5: Chosen Identity with Regard to Hearing Loss | 22 |
| Table 6: Communication Modes used by Respondents | 23 |
| Table 7: Assistive Technology (including Interpreters) in Any Hearing Environment | 27 |
| Table 8: Highest Level of Education | 28 |
| Table 9: Accommodations used in Postsecondary Education Settings | 37 |
| Table 10: Employment Status..... | 37 |
| Table 11: Employment Status..... | 38 |
| Table 12: Annual Household Income by Number in Household | 38 |
| Table 13: Perceived Impact of Hearing Loss on Employment..... | 39 |
| Table 14: Causes for Not Finding Job..... | 40 |
| Table 15: Difficult Communication Situations in the Workplace | 40 |
| Table 16: Number Living in Household..... | 42 |
| Table 17: Annual Household Income from All Sources | 43 |
| Table 18: Household Income by Number Living in Home | 43 |
| Table 19: Current Living Situation..... | 43 |
| Table 20: Difficulties in Obtaining Safe, Affordable Housing | 44 |
| Table 21: Transportation Most Frequently Used..... | 46 |
| Table 22: Difficulties in Accessing Public Services in the Past 12 Months | 50 |
| Table 23: Reasons Involved in Court System | 56 |
| Table 24: Accommodations used in Court Settings..... | 56 |
| Table 25: Overall Quality of Life Indicators | 59 |
| Table 26: Type of Medical Coverage | 60 |
| Table 27: Treatment in Healthcare Settings..... | 62 |
| Table 28: How Much Thought given to Hearing Loss..... | 67 |

List of Figures

| | |
|---|----|
| Figure 1: County of Residence by Population Density | 18 |
| Figure 2: Residence by Region | 19 |
| Figure 3: Age at the time of Hearing Loss..... | 21 |
| Figure 4: Identities Selected by Respondents to Describe their Hearing Loss | 21 |
| Figure 5: Communication Preference | 23 |
| Figure 6: Use of Hearing Aids and Cochlear Implants by Loss in One or Both Ears | 24 |
| Figure 7: Comparison of Satisfaction with Hearing Aids and Cochlear Implants | 25 |
| Figure 8: Hearing Aid and Cochlear Implant Users' Ratings of their Speech Perception..... | 26 |
| Figure 9: School Program Attended..... | 29 |
| Figure 10: Flow Chart of Services Involved in Child's Education Path | 33 |
| Figure 11: Use of Accommodations in Postsecondary Settings | 36 |
| Figure 12: Currently seeking work | 38 |
| Figure 13: Hours Worked per Week at all Jobs..... | 39 |
| Figure 14: Concerned about Ability to Pay Mortgage/Rent in last 12 months..... | 44 |
| Figure 15: Does Transportation Meet Needs? | 46 |
| Figure 16. Services Received..... | 47 |
| Figure 17. Number of Services Applied to and Received in the Past Year..... | 48 |
| Figure 18. Overall Agency Usage | 48 |
| Figure 19. Agency Application Status | 49 |
| Figure 20. Perceived Accessibility of Each Service..... | 50 |
| Figure 21. Difficulties Communicating with Emergency Responders | 52 |
| Figure 22: Physical or Mental Health Interference with Usual Activities | 60 |
| Figure 23. Length of time Since Routine Checkup..... | 61 |
| Figure 24. Satisfaction with Healthcare in Past 12 Months | 61 |
| Figure 25. Timeframe of Seeing Dentist | 62 |
| Figure 26. Problem Understanding Medical Situation | 63 |
| Figure 27. Confusion about Prescriptions because of Communication | 64 |
| Figure 28. Able to Receive Mental Health Services | 66 |
| Figure 29. Felt Emotionally Upset over Treatment Based on Hearing Loss/Deafness | 67 |
| Figure 30. Frequency of Substance Use (at least once a week) | 69 |
| Figure 31. Experiences of Harassment or Bullying | 70 |
| Figure 32. Where Harassment/Bullying Occurred..... | 71 |

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.

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.