



The Case for Deaf Self-Advocacy Training

The Need for a National Curriculum
on Communication Access

**Deaf Advocacy Training Work Team
of the National Consortium of Interpreter Education Centers (NCIEC)
January 2009**

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NCIEC Mission

NCIEC builds and promotes effective practices in interpreting education. NCIEC draws upon the wisdom and energy of expertise, consumers and other stakeholders to advance the field. The National Consortium is dedicated to challenging the status quo by promoting innovation, strong partner networks and multiculturalism throughout its programming. As responsible stewards of public funding, the Consortium is committed to products, programs and services that maximize resources and are replicable, measurable, sustainable and non-proprietary

Deaf Advocacy Training (DAT) Work Team Purpose

The Deaf Advocacy Training work team was created for the purpose of increasing the Deaf Community's ability to self-advocate for effective communication by developing educational training opportunities which are culturally relevant and linguistically appropriate.

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Introduction

The National Consortium of Interpreter Education Centers (NCIEC) is pleased to present “The Case for Deaf Self-Advocacy Training: The Need for a National Curriculum on Communication Access.” This report is part of a larger effort by the NCIEC to improve the American Deaf Community’s utilization of interpreting services through the development and implementation of a self-advocacy training.

“The Case for Deaf Self-Advocacy Training: The Need for a National Curriculum on Communication Access” shares the outcomes of the work conducted by the DAT work team between 2006 and 2008 to determine the need for deaf self advocacy training, as well as identify the current and best practices around this topic to ensure the development of an effective curriculum. More specifically, this document reports the findings of three major undertakings by the DAT work team towards this determination and identification over the two year period.

Section 1 reflects the work of CSD (formerly Communication Service for the Deaf) of South Dakota to identify current and promising practices related to self-advocacy and obtain direct feedback from the deaf consumers regarding self-advocacy. Through a contract with the work team, CSD collected data through a nationwide survey of Deaf individuals, as well as targeted focus groups and deaf leader interviews. Over 2,000 deaf, deaf-blind and hard of hearing adults who use interpreting services participated in the survey. Responses were received from every state in the nation, at all levels and across all demographics, and as far away as the territories of Puerto Rico and the Virgin Islands. The purpose of the survey and the focus groups was identifying the Deaf Community’s needs in relation to self-advocacy education, and the best means of delivering such information.

Section 2 provides an annotated bibliography on Deaf Advocacy. This resource, completed by T.S. Writing Services, supported the findings of CSD, further validating both the need for a training and the tools to ensure an effective training product.

Section 3 shares the findings of a survey of state vocational rehabilitation counselors. In 2008 the Deaf Advocacy Training work team, seeking to build even further upon the findings of CSD and the annotated bibliography, partnered with state vocational rehabilitation (VR) to conduct a survey of VR counselors and rehabilitation counselors for the deaf. The survey’s purpose was two-fold. First and foremost, the survey sought to glean vital information from counselors regarding their perspective on potential difficulties VR consumers with hearing loss may have when self-advocating for interpreting services. Secondly, the survey sought counselor input regarding the self-advocacy training formats that would be of most benefit to VR consumers. Survey design and distribution was done with support from one state VR agency’s DHH services state coordinator; further, external vetting support was enlisted from the research chair of the Council of State Administrators of Vocational Rehabilitation (CSAVR), and survey distribution was via CSAVR’s Rehabnetwork; DAT team members contributed to the final report.

We hope you find the information in “The Case for Deaf Self-Advocacy Training: The Need for a National Curriculum on Communication Access” beneficial, and look forward to receiving your feedback on it.

Section I

Deaf Advocacy Training

CSD's Findings

Larry Puthoff, CSD
July 2007

Executive Summary

Introduction

CSD (also known as Communication Service for the Deaf, Inc.) conducted a data collection project, made possible through a grant awarded by the National Consortium of Interpreter Education, to identify and validate effective practices or methods needed to educate the Deaf Community regarding its rights to communication access as it pertains to interpreting. This project enabled CSD to seek a broad consensus of not only research-based opinion on best practices for teaching the deaf community members what they are advocating for and how to advocate for themselves effectively, but from experienced stakeholders and the signing deaf community itself.

CSD was established in 1975, primarily to provide sign language interpreting services to deaf and hard of hearing adults in South Dakota. Today, CSD employs over 2,000 individuals in offices across the nation, providing a broad continuum of social and human services programs, as well as telecommunications relay services. CSD is a private nonprofit agency dedicated to providing quality services; ensuring public accessibility; and increasing awareness of issues affecting the deaf, hard of hearing and individuals with speech disabilities.

The National Consortium is a collaborative network comprised of a National Interpreter Education Center and five Regional Interpreter Education Centers. All six centers are supported through grant funds from the U.S. Department of Education, Rehabilitation Services Administration. The goal of the National Consortium is to significantly increase the number of qualified and credentialed interpreters in the field by forging collaborative links and facilitating practice and product sharing among interpreter education service providers, practitioners, educators, and consumers nationwide.

It is estimated that some 30 million Americans (approximately 10% of the population or one out of every 10 people) have some degree of hearing loss. Approximately 4.8 million of these individuals cannot hear or understand speech (Adams, Hendershot and Marano 1999). Like their hearing counterparts, deaf people build successful careers, have families, watch television, go to the movies, talk on the telephone, participate in sports and watch sporting events and travel throughout the world. Most deaf people don't view their deafness as a disability or as a problem that needs to be fixed. For many of them, it's a natural part of a cultural experience that they share with friends, both deaf and hearing. Deaf culture can be defined as a sense of community among deaf people. Cultural activities can include communicating in American Sign Language (ASL), sharing information about resources that can enhance deaf people's lives, performing and attending theatrical events with no spoken language, joking about the experience of being deaf, and reflecting on role models and events important to deaf people.

Many deaf, deafblind and hard of hearing consumers or individuals who use sign language and interpreting service lack adequate skills and access to information relating to self-advocacy. Additionally, the surveys conducted suggest that there is a negative stigma attached to self-advocacy and its efficacy.

Project Goals and Objectives

The primary purpose of the Deaf Advocacy Training (DAT) project was to identify and validate effective practices or methods needed to provide communication advocacy education to the deaf community in order to enhance individual's ability to self-advocate his/her rights to communication access as it pertains to interpreting. The goals of conducting a national survey were twofold: 1) to determine the type of advocacy information that the deaf community should know to self-advocate for their communication rights as it pertains to interpreting and, 2) to determine the most effective methods for delivering (teaching) this information to the deaf community.

Overview of Project Activities

The data was collected by means of a nationwide survey, focus groups, and expert interviews. The first component of the project was the survey designed in English text with an ASL video format. The survey was posted on CSD's website, using "Survey Monkey" software, a tool that easily summarizes data. The survey was designed with the intent to be attractive and brief and as easy for responders to use as possible. The survey began with a letter of introduction explaining the purpose the survey.

The second component of the project was the focus groups, conducted in the states of Ohio, Maryland, South Dakota, and Oklahoma. The directors of the CSD branch offices in the above four states coordinated the focus group component of this project. The purpose of the focus groups was to learn of participants' opinions and thoughts regarding to the deaf community's ability to self-advocate for interpreting services. The project director explained, step-by-step, the instructions, guidelines, and directions to the CSD branch office directors. This was accomplished through a videophone conference call, followed up via e-mail messages.

The third component of the project was the expert interviews conducted with leaders in the deaf community to learn their experiences and opinions in the following areas: 1) what they believe deaf community members need to know in order to advocate for their communication rights; 2) what best practices or effective methods they (deaf community leaders) known or have experienced where deaf persons successfully advocate for themselves; 3) what kind of training the experts recommend for the deaf community to embrace self-advocacy; and, 4) to find out if the experts think self-advocacy training for deaf community members would change behaviors, and why or why not?

Outcomes and Findings

The findings of this project strongly suggest there is a need and desire for deaf, deafblind and hard of hearing sign language users who use interpreting service to learn self-advocacy skills. Self-advocacy training needs to be offered in a mode that best fits the learning styles of sign language users who need access to interpreting services. Many responders that use ASL prefer a group where ASL is the medium of instruction.

In addition, the survey, focus group and expert interview data suggest, it is recommended that self-advocacy training be provided for the deaf community throughout the country, and that it

will be effective in changing behaviors. More than 50% of the respondents say they will take self-advocacy training if it is offered. More than 32.4% of the respondents said “maybe” and 11.1% said that they didn’t know. Only 5.4% of the respondents said they would not take self-advocacy training if it is offered. It is likely that many of the “maybe” and “don’t know” respondents will attend self-advocacy training if a well-developed curriculum is in place.

Recommendations

It is the responsibility of deaf, deafblind and hard of hearing individuals who need interpreting services to make the request for the services they need. Making a simple request for interpreting services, more often than not, requires self-advocacy skills.

It is recommended that self-advocacy training be provided to deaf community members who use interpreting services with consideration of offering it to adults who eventually will need sign language interpreting services. Such training needs be offered and available throughout the country.

A self-advocacy curriculum needs to be developed and used to ensure training consistency. Input, feedback, and suggestions for a curriculum should come from deaf community leaders, national and state organizations serving the deaf, state vocational rehabilitation offices, interpreting agencies, interpreter training programs, deaf community leaders, etc.

Summary

A peer education or “train-the-trainer” model is recommended in developing the self-advocacy training whereby all the trainers will receive consistent information related to federal and state laws and the RID Code of Professional Conduct for Interpreters, along with skill building activities in learning about advocacy and role play activities on how to advocate.

According to the responders, self-advocacy training needs to be offered in face-to-face type settings by deaf presenters, leaders, or instructors who have had training in the area of advocacy.

As advocates, the role of deaf, deafblind, and hard of hearing individuals is to provide information to businesses and service providers and to know they are in a position to help them understand the laws and their responsibilities under the laws.

Setting up these specific kinds of workshops and peer-to-peer self-advocacy models is the most effective path to creating a higher percentage of deaf and hard of hearing communication rights’ self-advocates.

Project Description

Project Purpose

The primary purpose of the Deaf Advocacy Training (DAT) research project conducted by CSD is to identify and validate effective practices or methods needed to provide communication

advocacy education to the deaf community in order to enhance individual's ability to self-advocate his/her rights to communication access as it pertains to interpreting. The goals of conducting a national survey were twofold: 1) to determine the type of advocacy information that the deaf community should know to self-advocate for their communication rights as it pertains to interpreting and, 2) to determine the most effective methods for delivering (teaching) this information to the deaf community.

The survey was intended for dissemination to deaf, deafblind, and hard of hearing users of sign language interpreting services at all levels, including a key segment of the American deaf adult population served by educational and rehabilitation programs where professional literature has historically used terminology such as "minimal language skills," "at-risk," "traditionally underserved," "underachieving," "low-functioning," "multi-disabled," etc. The data does not indicate how many individuals responded under the above categories. Names were not used and surveys were completed in a confidential manner.

Literature Review

Many interpreters and interpreting agencies have expressed that many deaf, deafblind, and hard of hearing people who use their services lack advocacy skills for themselves. Often this is because they (members of the deaf community) do not know how to advocate for themselves, or do not have the training or are afraid to advocate for themselves. Advocating for members of the deaf community who use sign language interpreting services is not the role of interpreters, therefore, it is imperative that deaf, deafblind, and hard of hearing consumers be provided with training in the area of self-advocacy.

It is essential that deaf, deafblind, and hard of hearing consumers thoroughly understand the services that are provided to them to achieve desirable interpreting-consumer working relationships. (Source: Articles found on the following web sites: www.nad.org, www.wrightslaw.com/info/advo.index.htm, www.thechp@syr.edu/saspeak.htm)

An extensive literature review for information on best practices and self-advocacy was conducted. Search topics included: effective advocacy approaches, advocacy and the disability community, best practices in deaf education, employment and vocational rehabilitation, working with low functioning deaf, outreach and people with disabilities, effective practices for teaching ESL (English as a Second Language), interpreting best practices, developing cultural competence, and community based participatory research. However, a search for best practice in educating and training adults that are deaf, deafblind and hard of hearing yielded absolutely no results.

A finding in the literature is that one of the major criticisms of inclusive programs in public schools is the lack of appropriate role models. Integration should not imply or require deaf and hard of hearing individuals to reject their peers or community. Rather, the goal should be that they feel comfortable in a variety of educational and social environments, have friendships with both deaf and hard of hearing and hearing peers, and pursue educational opportunities based on their interests rather than their hearing loss (Shirin & Stinson, 1999). These principles can be applied to deaf adults when it comes to their educational and social environments. Role models

will always play a major role within the deaf community whenever workshops, classes, training, etc. are provided to them.

Best practice for non-college bound students who are deaf is to determine if they can independently perform competencies (knowledge of resources, possess interpersonal skills, comprehend and process information, understand social, organizational and technological skills systems, know how to use technical equipment) and possess basic and thinking skills and personal qualities (Muth, 1999). In some parts of the country “transitional skills” are provided to non-college bound students to help them build skills needed to find and keep a job and to live independently. It is daunting and overwhelming if a student does not have a connection to a supportive services and a network of friends and family.

In her research related to *Health Care Delivery and Deaf People* (Harmer, 2000), referring to patients’ understanding of health care relationship, Harmer points out, “Effective health care consumers in the United States today have mastered at least three skills. These individuals have gathered information about available health care services and their alternatives, have an understanding of which services they need at a given point, and possess the skills to obtain those services through self-advocacy and persistence. Deaf individuals are at distinct disadvantage in all of the areas.” This finding directly relates to the reasons deaf community members find themselves reluctant to advocate for interpreting services. As a result of limited knowledge and/or understanding of the laws applied to people with disabilities and limited access to information, many deaf, deafblind, hard of hearing adults may be poorly prepared to advocate for themselves. Many may even be unaccustomed to sharing responsibility for advocating for interpreting services whenever appropriate, have little or no experience with self-advocacy in the area of requesting for interpreting services, or have difficulty selecting the proper venue for their interpreting needs.

Research shows that the complex communication issues faced by a majority of members of the deaf community pose staggering challenges. This includes the obstacles posed in self-advocating for ones rights to communication access.

According to the National Council on Disability (NCD) (www.ncd.org), the promise of the community integration and self-determination policies outlined in President Bush’s New Freedom Initiative have not been realized by people with disabilities from underserved populations. Likewise, the common notion that federal disability laws and policies amended and passed during the last twenty-five years, i.e., the Individuals with Disabilities Education Act and Vocational Rehabilitation Act of 1973 have eliminated barriers is largely untrue. Research indicates that barriers include lack of culturally appropriate outreach, language and communication barriers, and attitudinal barriers. NCD research describes advocacy in terms of being the distinguishing factor between benign community help and outreach. The difference is to provide advocacy messages that result in transformation of lives that can somehow be evaluated and monitored for success. A wide range of outreach programs, models, and strategies were cited for their successful implementation. Those include a range of model programs from the American Indian Elders working with youth to the Buddy System for homeless citizens, from Train-the-Trainer projects to Peer Educator projects, and from the deaf teaching the deaf and the

blind teaching the blind models to African American, Hispanic/Latino and Asian American outreach programs.

Self-advocacy training needs to be offered in an environment where there is trust and mutual respect – in an environment where deaf culture is understood and accepted. In their research related to *End of Life Care for Elderly Deaf* (Allen, Meyers, et al, 2004), reveal significant findings related to “best practices” that inform this project’s goal. The basis for adding “participation” to Community-Based Participation Research (CBPR) acknowledges the importance of building trust and mutual respect among entities, i.e., community members, researchers and healthcare professionals. The process supports cultural competence by first taking into account community members’ knowledge, attitudes, beliefs, behaviors (KABB) or “culture” then building partnerships, relationships and social structures that are empowering and allow full participation for deaf in learning and training. Allen describes the deaf community in terms of being a “languaculture” because understanding the world depends on precise cultural and language differences. The study also concludes that “information gathered from a self-administered questionnaire will be less effective in collecting reliable data than interviews conducted by deaf interviewers in ASL. Translations of English language questionnaires by non-native ASL users are likely to be ineffective in capturing the subtleties of cultural difference between members of the deaf community and hearing ASL interpreters.”

Perhaps the best examples of “best practices” are not necessarily found in the literature, but rather in practice today throughout the country. There are many pockets of *successful model* deaf advocacy projects and practices across the country. Each shares a core value and basic philosophy of deaf culture and the underpinnings of cultural competency practices, i.e., language barriers eliminate, direct communication in ASL by knowledgeable professionals. To name a few:

- CEPIN Emergency Preparedness Training sponsored by TDI
- ADWAS – Abused Deaf Women’s Advocacy Services
- Deaf ABE – Minnesota Adult Basic Education Program
- Deaf HIV Peer Education Program – GLAD
- Deaf Hospice Volunteer Program
- Deaf Consumer Mental Health Services/Advocates

CEPIN (Community Emergency Training Information Network) – This was a two year project that began in 2005 and funded by a grant from the U.S. Department of Homeland Security to TDI (Telecommunications for the Deaf and Hard of Hearing, Inc.) The project’s goal was to empower individuals nationwide, who are deaf or hard of hearing, to work alongside their neighbors before, during and after a crisis in order to prevent and minimize damages and promote faster recovery in disaster situations. Training for the deaf and hard of hearing community was developed after one year of intensive effort with deaf, deafblind and hard of hearing individuals and with a team of first responders, local fire and law enforcement, service and health agencies, local government staff and academic personnel. The product is one that takes into account deaf culture, the tenets of adult learning, and an interactive learning methodology. Workshops were given across the country to mixed audiences. The purpose of the mixed “hearing and deaf audiences” was to encourage discussion and relationship building in case of future disasters. www.cepintdi.org

ADWAS (Abused Deaf Women Advocacy Services) – This program was established in 1986 to provide services to deaf and deafblind victims of sexual assault and/or domestic violence. The mission of ADWAS is a belief that violence is a learned behavior and it should not be tolerated. ADWAS established a model that has been replicated in 14 other cities across the United States. Its methodology is based upon peer education theories – deaf advocates assist deaf victims seeking the services they need to attain safety. www.adwas.org

Deaf ABE (Minnesota Adult Basic Education) – This program was established in 1979 by a group of teachers and administrators seeking a solution to the provision of effective educational services for deaf adults. Deaf adults enrolling in regular adult education classes relied upon classroom interpreters instead of direct interaction with a deaf teacher. Attendance dropped off after the first two weeks of each semester. The solution was to offer bilingual classes – taught in ASL and written English – by qualified and licensed deaf teachers or hearing teachers fluent in ASL. Curriculum follows the school district and is the same for hearing and deaf learners; teachers adapt some materials that rely on audio educational tools and replace them with highly visual materials. Deaf ABE continues to be offered to citizens of Minnesota and is recognized as a national model.
www.c-s-d.org

Deaf HIV Peer Education Outreach Program – The Greater Los Angeles Agency on Deafness, Inc. (GLAD) offers a number of programs and services to ensure equal access of the deaf and hard of hearing community to the same opportunities afforded their hearing counterparts. The organization's general purposes and powers are directed around the promotion of the social, recreational, cultural, educational, and vocational welfare of its deaf and hard of hearing constituents. Specifically, the GLAD Health Program provides an array of services to deaf and hard of hearing women and men throughout Los Angeles. Group sessions and private sessions provided in ASL include: risk reduction counseling, negotiation skills, referrals & resources, relationship issues, and new information on HIV/AIDS & Sexually Transmitted diseases. www.gladinc.org

Deaf Hospice Program – The Deaf Hospice Volunteer Training Program, spearheaded by efforts of the College of St. Catherine, St. Paul, MN, had as its goal the establishment of a culturally and linguistically appropriate hospice volunteer training program, that would effectively train deaf individuals as hospice volunteers. The training that was developed used Brenda Dervin's actor-centered, Sense-Making methodology and associated interview technique in the interviewing of deaf and hard of hearing users of hospice care, both as hospice patients and relatives receiving hospice care. A group of interested partners met in 1998 to formally devise a plan; the Deaf Hospice Education Project (DHEP) received funding from the Sisters of St. Joseph's Social Justice Fund to discuss, plan and implement a program specifically to improve end-of-life care. What evolved after four years was a 20-hour hospice volunteer orientation program through Allina Hospice and Palliative Care. It is important to understand that DHEP does *not* provide hospice services, but serves as a resource for hospice information. DHEP helps volunteers connect with hospice services so that services are provided quicker. DHEP also works to connect the Deaf community with hospices for better access to information.
<http://minndeaf.org/aboutdeafHospice.htm>

Deaf Consumer Mental Health Services/Advocates – Culturally appropriate mental health services are finally becoming the norm. Often parents would have to search for programs across the United States to find a specialist to assist their child. Or adults would have to fly across the country to enter a treatment program. One example is at Gallaudet University in Washington, DC where a mental health center serves both the Gallaudet community and deaf and hard of hearing individuals from outside the Gallaudet community. In addition, the Gallaudet Research Institute publishes a mental health directory, "Mental Health Services for Deaf People: A Resource Directory." Mental health services for deaf people are becoming more accessible through the internet; the Alternative Solutions Center, a deaf-owned practice, provides psychotherapy and consulting through video and e-mail as well as in-person consultations.

<http://infotogo.gallaudet.edu/mentalhealth.html>

In addition, efforts have been made by deaf consumers to collaborate and team-up with consumer driven national organizations like NAMI (National Alliance for Mental Illness) to voice their concerns regarding the existing gaps in services and the specific communication needs of deaf and hard of hearing mental health consumers. The Ohio Mental Health and Deafness Resource Center, operated by CSD, has worked for the past five years with state entities to train deaf and hard of hearing consumers to become advocates. This train-the-trainer series is expected to be released in 2008. www.c-s-d.org

Language and cultural differences need to be taken into consideration when it comes to adopting “best practices” for providing self-advocacy training to ensure that trust and mutual respect among community members prevail.

The literature supports the concept that effective advocacy approaches include, but are not limited to: 1) knowing what an advocate is, 2) knowing how to advocate, understanding the law(s), 3) engaging in the interactive process with people in authority, 4) be a partner in the solution, 4) recognizing the power of word choice and the timing in the interactive process 5) emphasizing the mutual benefits to both sides, and 6) avoiding conflicts. (Articles found on the following web sites: www.nad.org, www.wrightslaw.com/info/advo.index.htm, www.thechp@syr.edu/saspeak.htm).

Research for this project began by seeking a broad census of research-based opinion on best practices for teaching deaf community members what they are advocating and how to advocate for themselves effectively. Collecting such information from experienced stake holders and from the deaf community itself also was explored. Gathering critical sources to inform this project was a challenge.

The literature showed a scarcity of practical studies for KABB (Knowledge – Attitude – Belief – Behavior), Community Based Participatory Research (CBPR) and Deaf Advocacy models. The review yielded plenty on general community based participatory research but no specific references for deaf. However, research in educational settings was plentiful. The majority of studies related to deaf education focusing on the academic, linguistic, and social development of deaf and hard of children from kindergarten to age eighteen. There was limited research on deaf

advocacy per se, while there is plentiful research on the subject of self-advocacy in the general disability community.

Data Collection Survey

Process of Conducting

The first component of the DAT research project was conducting a nationwide survey. A multi-use survey was designed in English text with an ASL video format. The survey was posted on CSD's website, using "Survey Monkey" software, a tool that easily summarizes data. This software was selected because it had the capability of embedding video that other software packages did not. The survey was designed with the intent to be attractive and brief and as easy to respond to as possible. The survey began with a letter of introduction explaining the purpose of the survey.

Evaluation specialist Howard Johnson, from Michigan State University's Department of Counseling, Educational Psychology, and Special Education, provided expertise in developing the survey and the questions for each assessment tool. Various individuals and organizations were included to help us gather information and solicit constructive criticism and input as well as suggestions in regard to the content of the survey itself. Once the survey was developed it was field tested in the CSD Headquarters, CSD Branch Offices and a limited number of consumers and leaders within the deaf community. This survey consisted of twenty questions, including a question on feedback, comments or suggestions.

The survey was intended for widely dissemination to deaf, deafblind, and hard of hearing users of sign language interpreting services at all levels, including a key segment of the American deaf adult population served by educational and rehabilitation programs. The survey was widely distributed through its project partners and other sources. Through CSD's national networking ability and resources, e-mail messages, direct contacts, press releases, word of mouth, publications, announcements, and faxes were sent out to individuals, organizations, agencies, associations, state vocational offices serving deaf, deafblind and hard of hearing clients, etc. throughout the country, explaining the purpose of the survey along with an attachment of the survey and directions to access the survey online. These entities were also asked to post the information on their web sites and set up a link to the survey. E-mail messages and faxes were also sent to the Virgin Islands Department of Human Services, the Guam Ministry with Persons with Disabilities and the Puerto Rico Administrative Services Administration encouraging them to contact deaf, deafblind and hard of hearing adults, eighteen years and older to participate in the survey.

CSD's six branch offices also played a large role in assisting with the dissemination of the survey in their respective regions of the country. Additionally, CSD had the opportunity to set up booths and send representatives to various conferences throughout the country during the project period. The DAT survey was distributed to individuals who voluntarily responded to the survey at the conferences.

Approximately 2,047 deaf, deafblind and hard of hearing adults, 18 years and older, who use sign language and interpreting services participated in the surveys. Responses were received from every state in the nation, at all levels and across all demographics, and the territories of Puerto Rico and the Virgin Islands.

Data Obtained

A high degree of consistency was found in comments and perspectives across all individuals who participated in the survey, focus groups and interviews. Overwhelmingly, individuals were very pleased to be asked information in the survey; they were pleased the survey was offered in English and ASL; they were interested in knowing the results of the study; and, they wanted to learn how to better advocate for themselves and their families.

A total of 2047 survey responses were tabulated. Out of the 2047 responses, 163 responders did not answer every question. Responses came from all 50 states, the Virgin Islands and Puerto Rico. Additionally, the survey responses implied there was a good balance of grassroots deaf and deaf professionals. After approximately 750 responses it was noted that the findings/results of the remaining responses were fairly consistent with the first 750 responses. The complete summary of responses can be found in the attachment section.

The survey responses provided information that have implications for training design:

- Female 65% Male 35%
- Most over the age of 35
- 84.1% White, 5.9% Black, 4% Hispanic/Latino, 2.1% Asian, 1.1% Native American, 1.4% Mixed Race, 0.2% Native Hawaiian/Pacific Islander
- 43.3% live in suburban area, 31.7% in urban areas, 17.7% in small towns or rural areas
- 31% high school or below, 27% some college, 40.9% college background
- 30.2% use interpreters everyday, 33.6% more than once a week, 36.2% once a month
- 72% ASL users, 13.7% Manually Coded English, 4% Cued Speech, 3.5% Tactile Sign
- 49.8% said sign alone was best mode of communication, 45.6% said speech and sign
- 94.8% indicated they had a computer at home
- 92.6% said they use email everyday, 86.4% use Internet, 86.7% use cable or DSL service, 63.3% use a videophone, and 60.3% use instant messaging
- 32.4% prefer face-to-face training and 27.8% prefer to receive information from other deaf people, friends or deaf leaders
- 51.2% said they would attend advocacy training, 32.4% maybe, 11.1% don't know and 5.4% said no
- A high percentage (75-96%) understand interpreters must be provided for medical, legal, law enforcement and employment situations
- 36.7% believe hearing people responsible for scheduling interpreter compared to 32.95% for self and 21% for agency being responsible
- If not satisfied with interpreter, 79.1% said they would let interpreting agency know, 75.7% would request another interpreter, 42.3% said they ask to speak to interpreter and provide information on how to improve

- If an interpreter does not show up, 49.2% said they would go ahead with meeting, 72.4% said they would reschedule, 56.8% said they use paper and pencil, 28% said they would file a complaint
- When asked reasons for not advocating for themselves, 30.4% said it wouldn't make a difference, 27.8% felt they didn't have the background; 27.4% said it takes too much time, 19.3% said it was a waste of time, 14.5% were afraid to say anything, 10.4% said advocacy was not their responsibility, and 24.1% gave other reasons, most often saying they do advocate for themselves

Summary Findings

A total of 1,306 (67.9%) of the survey participants responded they use sign language interpreters somewhere between once a week and every day. (33.3% use interpreters everyday and 33.6% use interpreters more than once a week.

Results of survey questions # 3, 4, and 6 indicated more education, training, information sharing, etc. is needed in the following areas:

- Who is responsible for scheduling interpreters
- The role of interpreters
- Understanding my rights to an interpreter

Responses to some of the survey questions were more thought provoking. If a sign language interpreter is not provided, 49.2% responded they would go ahead with the appointment/meeting and 56.8% said they would use paper and pen to write back and forth at the meeting.

Responses to question # 8 – What are your reasons for not advocating for yourself – indicated there is a high need for self-advocacy training. Only 24.1% of the survey participants advocated one way or another for themselves. Results from 726 survey participants indicate advocating for themselves is either a waste of their time or it takes too much of their time. More than 30% or 474 participants responded that it won't make a difference if they advocate for themselves. "I'm afraid to say anything" is another reason given why they (226 participants) do not advocate for themselves and 162 participants indicate it's not their responsibility. This suggests that there is a negative stigma attached to self-advocacy and its efficacy.

Taking the survey data from these respondents outlines the methodology needed in order to effectuate appropriate self-advocacy training for the deaf and hard of hearing community, taking into account that 32.4% prefer face-to-face training and 27.8.% prefer to receive information from other deaf people, friends or deaf leaders.

The consensus was that self-advocacy training needs to be offered in face-to-face type settings by deaf presenters, leaders, or instructors who have had training in the area of advocacy. Teaming with a hearing person is an option.

Focus Groups

Process of Conducting

The second component of the DAT research project was conducting focus groups. Focus groups were conducted in the states of Ohio, Maryland, South Dakota, and Oklahoma. The directors of the CSD branch offices in the above four states coordinated the focus group component of this project. The project director went, step-by-step, through the instruction, guidelines, and directions to the CSD branch office directors. This was accomplished through a videophone conference call, followed up via e-mail message.

The focus groups opened with an explanation of the purpose of the DAT project and the purpose of the focus group(s) and their role as participants. Each and every participant was informed that participating in the focus group was completely voluntarily. Prior to the focus group sessions the directors obtained each participant's signature on consent form to assure him/her of anonymity and confidentiality. The thirty-nine participants were asked to sign the forms before the beginning of the focus group meeting, followed with the directors signing their names as a witness on the same forms. All questions were provided in ASL for the focus group discussions. A note taker or recorder was assigned to record all the comments and information expressed by the participants.

Focus group discussions opened up with the participants addressing three separate scenarios – typical situations that may happen every day. The three scenarios are listed below. After each scenario was role-played, three questions were asked of the participants: How do you feel? What do you do? What should you do? After discussing the three scenarios five other questions, not pertaining to the scenarios, were asked and discussed among the participants. The five questions had to do with self-advocacy and the understanding of one's legal rights as it relates to communication access.

Scenario I:

You make an appointment to meet with someone at the Social Services Office and request interpreting services for the appointment. You show up on the date and time of your appointment. However, no interpreter shows up.

Scenario II:

You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. There's a communication break-down because the interpreter has a difficult time following and understanding you. You must stop, start, stop, and start over and over.

Scenario III

You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. The interpreter does a very good job and communication is easy, comfortable and fluent (accessible) throughout the appointment.

The five other questions asked of the focus groups, following the three scenarios are listed below.

1. What skills will help the deaf, deafblind, and hard of hearing consumer resolve the situation in Scenarios I and II?
2. Do you feel deaf, deafblind or hard of hearing consumers need to learn self-advocacy? Explain why or why not.
3. From your experience, what barriers prevent deaf, deafblind, or hard of hearing consumers from self-advocating effectively for quality interpreting services?
4. What is your understanding of your legal rights to an interpreter?
5. Education on how to self-advocate will be developed. What is the best way for you to learn how to self-advocate for yourself? If training was offered in the community would you attend?

Data Obtained

Some of the synonymous and/or common responses to the three scenarios, expressed by the focus groups participants in their own language, are listed below.

Scenario I

- Very frustrating
- Feels like a punch in the face
- I hate the idea of writing
- Waste my time
- Reschedule the appointment
- Let the interpreter agency know

Scenario II

- Give lousy interpreter dirty look
- Interpreter should know better to accept job or not
- Stop meeting to explain lag in conversation
- Inform SS office/terp agency about the situation
- Reschedule – ask for a different interpreter
- I would change interpreters

Scenario III

- Very satisfied – no stress or pressure
- Compliment interpreter
- Don't take interpreter for granted
- Tell SS to use interpreter again
- Give recognition in front of case worker

The overall responses to the first question, pertaining to what skills will help resolve the situation in Scenarios I and II and if consumers need to learn self-advocacy were overlapping.

Assertiveness skills, reading skills, skills on how to use referrals and how to find resources were the skills that the participants believe would help resolve the situations mentioned in Scenarios I and II.

Most of the focus group participants feel that deaf, deafblind and hard of hearing consumers need to learn self-advocacy for a number of reasons. Not being aware of their rights; most materials are hard to understand and read; learning from role models; the importance of understanding laws (ADA, etc.); the interpreter Code of Professional Conduct; understanding the role of interpreters and interpreter agencies; and, the need for learning to speak for themselves were major reasons why most of the focus group participants believe consumers need to learn self-advocacy skills. The complete summary of responses can be found in the attachment section.

The following barriers that prevent deaf, deafblind, or hard of hearing consumers from self-advocating effectively for quality interpreting services most frequently mentioned by the focus group participants are:

- Fear
- Habits (relying on family members and hearing people)
- Negative attitude of hearing people
- Hard to educate hearing people on deaf culture
- Costs money
- Feeling of failure and oppression
- Lack of resources and information
- Lack of leader in deaf organizations and clubs
- Mainstreamed programs tend to “take care” of deaf students by providing interpreters without teaching them how to use interpreters
- Deaf clubs are dying – losing networking through clubs
- Lack of consumer education
- Schools for the deaf not teaching students about their rights
- Interpreting agencies have too much power and control deaf people
- Lack of qualified interpreters
- Confidentiality

Summary Findings

In summary, focus groups responses reinforce the survey data by suggesting that self-advocacy training for deaf and hard of hearing people would be most effective if they attend “ASL-type” workshops, emphasizing the need to keep the group small enough to encourage group interaction and discussion. The consideration of involving deaf role models or ASL master signers to provide self-advocacy training is also recommended. There is an emphasis on including information on ADA laws, rights to an interpreter, understanding the interpreter’s role and the Interpreter Code of Professional Conduct in the self-advocacy training.

Expert Interviews

Process of Conducting

The third component of the DAT research project involved gathering information from the expert interviews, which took approximately between thirty to forty-five minutes per interview. Individuals with expertise in the fields of deafness, cultural competency, vocational rehabilitation, education, consumer advocacy, and interpreting were identified and interviewed to

discuss and observe practices. These experts provided important validation of the information gathered from consumers in the survey and focus groups. Twelve expert interviews were conducted. This group of participants consisted of seven males and five females. The expert interviews were mostly conducted by videophone, e-mail, or face-to-face. Each interviewee was asked the same five questions. Videophone interviews were conducted using the communication mode the interviewees felt most comfortable using. The interviews lasted from thirty to forty-five minutes each.

The project director contacted each individual via videophone or e-mail, explaining the goal of the DAT project and the expert interviews portion of the project. The individuals contacted were given the opportunity to participate in the interview with the consent that his/her participation would be completely voluntarily. After the individuals agreed to be interviewed, a date and time was set up for each to be interviewed by the project director. A copy of the interview questions were sent to the individuals approximately one week prior to the time the interview took place.

Each interviewee was asked to give information on his/her background and experience working with the deaf community. The other four questions were based on knowledge needed, best practices or effective method of training, and type of training needed for the deaf community members to result in behavior changes. The interviews were transcribed by the project director and analyzed for their content.

Data Obtained

The primary data collection technique employed with the experts was the semi-structured thematic interviews. The interviews were informal and structured conversations rather than formal, closed-ended ones. The data obtained from the experts include information on: 1) what they believe deaf community members need to know in order to advocate for their communication rights as it pertains to interpreting, 2) any best practices or effective methods they know about where deaf persons successfully advocate for themselves, and 3) the kind of training they believe would be necessary for the deaf community to embrace self-advocacy. The complete summary of responses can be found in the attachment section.

Summary Findings

Consistency was found in the responses to expert interview questions. Again, the information gathered validates the findings in the surveys and focus groups. Nearly all of the expert interviewees strongly felt the deaf community members need to know and have a better understanding of 1) laws, such as the American with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973, 2) the role of the interpreters, 3) basic knowledge of how to use an interpreter, 4) how to make better use of their state associations when it comes to advocacy, 5) Code of Professional Conduct for interpreters, and 6) the basic teachings that are taught in Interpreter Training Programs.

Based on the experts' knowledge, education or experience in the deaf community, workshops, activities sponsored by organizations, training sessions where role play is included and facts are shared were most mentioned as best practices or effective methods where deaf persons

successfully learn to advocate for themselves. Workshops, classes, etc., using deaf role models, local experts, Certified Deaf Interpreters (CDI) were highly recommended by the interviewees.

Ten interviewees firmly believe advocacy training for deaf community members would change behaviors. Another interviewee agreed that advocacy training would change behaviors as long as the training is provided on a one-to-one basis and not as a group. And one did not give a yes or no answer, stating that some individuals are receptive to change and some or not. This interviewee added, “It takes a positive, strong and supportive community to facilitate change in attitude toward self-advocacy. If started early, good habits regarding personal advocacy could be developed successfully.”

The interviews emphasized self-advocacy training would empower deaf, deafblind and hard of hearing people and they need to be given the tools to be self-advocates. When deaf people understand why and how some things are done, they are more accepting of change. Another important comment made was, “If training is done correctly – in ASL by deaf presenters with concrete examples and role plays to integrate application and practice – it must be a hands-on experience to learn and apply the skills.” Such training will enhance confidence and knowledge.” Another interviewee stressed the importance of the leaders being diplomatic and not militant in providing self- advocacy training.

Another interviewee commented, “Every year deaf and hard of hearing individuals leave high school/college and begin lives on their own with having no training in self-advocacy.”

Conclusion

Participation in self-advocacy training can be a vital part of life-long learning for deaf, deafblind and hard of hearing individuals who use sign language and interpreting services.

Based upon the data gathered in the survey, focus groups and expert interviews, it is recommended self-advocacy training be provided to the deaf community throughout the country, and that it will be effective in changing behaviors. More than 50% of the respondents say they will take self-advocacy training if it is offered. More than 32.4% of the respondents said “maybe” and 11.1% said that they didn’t know. Only 5.4% of the respondents said they would not take self-advocacy training if it is offered. Chances are that many of the “maybe” and “don’t know” respondents will attend self-advocacy training if a well-developed curriculum is in place.

Small communities and rural areas need to be considered as well as the urban and suburban areas of the country.

A peer education or “train-the-trainer” model is recommended in developing the self-advocacy training whereby all the trainers will receive consistent information related to federal and state laws and the RID Code of Professional Conduct for Interpreters, along with skill building activities in learning about advocacy and role play activities on how to advocate.

Self-advocacy for deaf, deafblind, and hard of hearing individuals who use sign language and interpreting services are tomorrow's self-advocates, they must be encouraged and allowed to develop self-advocacy skills. This project implies that self-advocacy is needed and will play an important role in the lives of deaf, deafblind, hard of hearing individuals as they go about self-advocating for themselves.

The data indicates only 82 (5.4%) participants would not attend if self-advocacy training is offered. On the flip-side of the coin, 782 (51.2%) said they would attend and 496 (32.4%) responded they may attend. An 11.2% (170 participants) do not know if they would attend. Keep in mind the participants responded maybe or don't know more likely will consider yes if the training and training materials are attractive enough in order to meet their self-advocacy needs.

According to the DAT survey, the consensus felt self-advocacy training needs to be offered in face-to-face type settings by deaf presenters, leaders, or instructors who have had training in the area of advocacy.

Setting up these specific kinds of workshops and peer-to-peer self-advocacy training models is the most effective path to creating a higher percentage of deaf and hard of hearing communication rights' self-advocates.

Recommendations for Curriculum Development and Implementation

A self-advocacy training curriculum designed with the deaf community rather than for the deaf community is strongly recommended. The curriculum must be designed to meet the various needs of participants who are high functioning, low functioning, with vision problems or with learning disabilities. A curriculum designed to provide participant skill development training appropriate and inappropriate to the deaf community needs to become better self-advocates, ranging from self-esteem, to knowledge of communication rights, to being assertive.

The summary findings of the focus groups reinforces that self-advocacy training for deaf and hard of hearing people would be most effective if they attend "ASL-type" workshops, emphasizing the need to keep the group small enough to encourage group interaction and discussion.

The self-advocacy training curriculum content needs to be relevant and provide meaningful examples for their lives along with visual materials and/or videos showing examples of ways and to advocate for one's communication rights pertaining to interpreting services. Interactive role play activities also provide an excellent avenue for teaching self-advocacy to deaf community members.

Hearing people need to be included in the training to portray how advocacy is critical and that communication barriers can be a factor. It is believed that individuals in need of advocacy skill training need to hear from the dominant culture that advocacy is widespread and necessary. Deaf, deafblind and hard of hearing individuals need to know that there is plenty of room for improvement in societal attitudes and how those advocacy skills contribute to universal benefits,

not only for sign language interpreter services but for everyone. Self-advocacy training will help remedy the gaps created by the loss of incidental learning opportunities for deaf individuals. By becoming more comfortable with self-advocacy, deaf, deafblind and hard of hearing individuals realize it is an appropriate and entitled skill.

Information on how to request an interpreter with emphasis on the concept of what I “need” and not I “want” when requesting for interpreting services needs to be part of the curriculum.

The self-advocacy training curriculum needs to include the following (but not limited to) information on:

1. Understanding the elements or steps needed to prepare participants to become positive and successful self-advocates.
2. Skill building activities related to self-esteem and self confidence needed for advocacy.
3. Role-play activities on how to advocate; practice exercises.
4. Federal laws, such as Section 504 of the Rehabilitation Act of 1973 and the ADA.
5. State interpreting laws as it pertains to each state where training will be conducted.
6. Understanding the RID/NAD Code of Professional Conduct.
7. Basic knowledge of how to use an interpreter, the role of an interpreter, the different types of interpreters and how they are compensated, not all interpreting service is free.
8. Basic information about Interpreter Training Programs, i.e., the curriculum, difference between a certified interpreter and qualified interpreter, length of time it takes for interpreters to develop interpreting skills, etc.
9. Local flavor – discuss resources available and the ways in which state agencies, deaf service agencies, office of state commissioners of the deaf, national organizations, state associations, independent centers can help when it comes to advocacy.

It is suggested to first set up at least eight locations throughout the country where Peer Education or Train-the-Trainer workshops will take place. It is recommended that selected trainers must then work with national and state organizations in coordinating the self-advocacy training workshops. National conferences such as the National Association of the Deaf, National Black Deaf Advocates, Deaf Seniors of America, National Asian Deaf Council, National Council of Hispano Deaf and Hard of Hearing, Hearing Loss Association of America, American Association of the Deafblind, would be feasible places to start. The workshops should then be offered at state association conferences and at workshops and meetings at the local level to assure self-advocacy training is offered to those who live in small towns and in the rural areas. Consider offering the training at all the Expos, the National Deaf Bowling Tournament, and Deaf Campvention,

It is strongly recommended that an instructor’s manual and a participant manual be developed before self-advocacy training is offered to the members of the deaf community. A section in the instructor’s manual must be made available for instructors to add and include self-advocacy teachings/information as it pertains to their local areas.

An evaluation tool must be developed and used to measure the outcomes of the self-advocacy training workshops. This can be done with a pre-test and a post-test approach or a pass/fail

approach to receive a “certificate of completion.” Consideration, planning and funding for a long term evaluation project will provide information related to the degree to which behavioral change is achieved.

Deaf community members who have vision problems, learning disabilities or have other special needs may require more time for self-advocacy training.

Appendix A. Survey Assessment Tool

Deaf Advocacy Training Project Survey

**1. How often do you use sign language interpreters?
(Please select one)**

- ☐ Everyday
- ☐ More than once in a week
- ☐ Once in a month

2. How often do you personally request interpreters for any of the following means of communication?

	Mostly	Often	Sometimes	Never
American Sign Language (ASL)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Manually Coded English (e.g.: Signed English, PSE)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fingerspelling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cued Speech	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tactile Sign	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. Who is responsible for scheduling interpreter requests for your appointments?
(Please select one)**

- ☐ Self
- ☐ Interpreter
- ☐ Interpreting service agency
- ☐ Hearing person (e.g.: doctor's office, employer, business, lawyer, school)
- ☐ Family member

**4. I understand the interpreter role is to:
(Check all that apply)**

- ☐ Keep information private
- ☐ Interpret information/questions and allow me to respond
- ☐ Know how to match my signing style with English
- ☐ Talk privately with others during session
- ☐ Not be a family member
- ☐ Be neutral

- ☐ Explain to me after meeting/appointment if I don't understand
- ☐ Tell hearing people to look at me when they talk

5. I understand my rights to an interpreter. (Please select all that apply)

- ☐ When I go to the hospital, they must provide an interpreter
- ☐ When I go a restaurant, they must provide an interpreter
- ☐ When I go to church, they must provide an interpreter
- ☐ When I go to the police station, they must provide an interpreter
- ☐ When I go a job interview, they must provide an interpreter
- ☐ When I go an amusement park, they must provide an interpreter
- ☐ When I go to a football game in a stadium, they must provide an interpreter
- ☐ When I go to court, they must provide an interpreter
- ☐ When I go to see a lawyer, they must provide an interpreter

**6. If I am not satisfied with the interpreter, I _____.
(Check all that apply)**

- ☐ can ask for another interpreter
- ☐ can let the interpreting agency or office know
- ☐ can contact lawyer and sue
- ☐ have no choice and accept that interpreter
- ☐ ask interpreter if hearing person did not understand how to use an interpreter and made it hard to do a good job of interpreting
- ☐ can ask to speak to interpreter to give information about how to improve
- ☐ will not do anything

**7. If a sign language interpreter is not provided, I would most often:
(Please check three)**

- ☐ go ahead with the appointment/meeting
- ☐ reschedule the appointment/meeting
- ☐ ask referral agency what to do
- ☐ complain to my family
- ☐ call a friend and talk about what to do
- ☐ use paper and pen to write back and forth
- ☐ protest or file a complaint
- ☐ not do anything about it

**8. What are your reasons for not advocating for yourself?
(Check all that apply)**

- ☐ I am afraid to say anything
- ☐ It won't make a difference if I advocate for myself
- ☐ It's a waste of my time
- ☐ It takes too much time to advocate for myself

- ☐ I don't have the background or training to advocate for myself
- ☐ Advocacy is not my responsibility

9. Self-advocacy training will be developed. What ways do you prefer to learn new information? (Please select one)

- ☐ Face-to-face
- ☐ Read information (on paper or computer)
- ☐ Watch video
- ☐ From other deaf people, friends, deaf leaders
- ☐ From my school or college
- ☐ Other _____

10. If self-advocacy training is offered, will you attend? (Pick one)

- ☐ Yes
- ☐ No
- ☐ Maybe
- ☐ Don't know

11. Do you have a computer at home?

- ☐ Yes
- ☐ No

12. Check all that apply

	Everyday	Once a week	Once a month	Never
<input type="checkbox"/> I use instant message	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I use the Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I use email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I use a videophone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I use cable service or DSL service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. Which of the following is the best mode of communication for you? (Please select one)

- ☐ Sign alone
- ☐ Speech and sign
- ☐ Speech alone
- ☐ Cued speech
- ☐ Tactile sign
- ☐ Other _____

14. What is your highest level of education?

(Please select one)

- ☐ Attended grades 1-8
- ☐ Attended high school 9-12
- ☐ Achieved GED/high school diploma
- ☐ Some college
- ☐ Achieved Bachelor's degree
- ☐ Achieved Master's degree
- ☐ Achieved Master's degree plus

15. Your age is:

(Please select one)

- ☐ 18-25
- ☐ 26-35
- ☐ 36-45
- ☐ 46-55
- ☐ Over 56

16. Your gender is:

(Please select one)

- ☐ Female
- ☐ Male

17. Your Ethnic background is:

(Please select one)

- ☐ Black/African-American
- ☐ Asian
- ☐ White (non Hispanic origin)
- ☐ American Indian or Alaskan Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Hispanic or Latino/Latina
- ☐ Mixed Race
- ☐ Other

18. I live in:

☐ State/Territory _____

19. I live in:

- ☐ an urban area (large city)
- ☐ a suburban area (near a large city)
- ☐ a small town or village

☐ a rural area (country, farm prairie, etc)

Please add feedback, comments or suggestions below:

Thank you for taking the time to answer this survey.

Your participation is greatly appreciated. Your participation will help us recommend ways to educate and help deaf, deafblind and hard of hearing individuals become better self-advocates.

Appendix B. Survey Results

Deaf Advocacy Training Project

Date: 7/12/07

Total Started Survey: 2047
Total Completed Survey: 1884 (92.2%)

Page: Question 1 of 20

How often do you use sign language interpreters? (Please select one)

		Response Percent	Response Count
Everyday		30.3%	619
More than once in a week		33.6%	687
Once in a month		36.1%	738
answered question			2036
skipped question			3






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How often do you personally request interpreters for any of the following means of communication?

	Mostly	Often	Sometimes	Never	Rating Average	Response Count
American Sign Language (ASL)	72.0% (1293)	13.3% (238)	9.9% (178)	4.8% (87)	1.48	1801
Manually Coded English (e.g.: Signed English, PSE)	13.7% (243)	14.6% (260)	25.4% (452)	46.3% (825)	3.04	1783
Fingerspelling	10.5% (188)	14.3% (254)	24.6% (439)	50.6% (903)	3.15	1787
Cued Speech	4.0% (72)	3.3% (58)	7.5% (133)	85.2% (1520)	3.74	1784
Tactile Sign	3.5% (63)	2.6% (46)	7.9% (140)	86.0% (1536)	3.76	1786
answered question						1802
skipped question						245




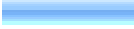




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Who is responsible for scheduling interpreter requests for your appointments? (Please select one)

		Response Percent	Response Count
Self		32.9%	563
Interpreter		5.4%	93
Interpreting service agency		21.0%	359
Hearing person (e.g.: doctor's office, employer, business, lawyer, school)		36.9%	633
Family member		3.8%	64
answered question			1712
skipped question			335










Page: Question 4 of 20

I understand the interpreter role is to: (Check all that apply)

		Response Percent	Response Count
Keep information private		87.0%	1445
Interpret information/questions and allow me to respond		77.5%	1287
Know how to match my signing style with English		57.7%	958
Talk privately with others during session		20.3%	336
Not be a family member		41.2%	682
Be neutral		66.0%	1096
Explain to me after meeting/appointment if I don't understand		28.7%	477
Tell hearing people to look at me when they talk		41.9%	697
answered question			1661
skipped question			386

Page: Question 5 of 20

I understand my rights to an interpreter. (Please select all that apply)

		Response Percent	Response Count
When I go to the hospital, they must provide an interpreter		96.2%	1567
When I go a restaurant, they must provide an interpreter		5.5%	89
When I go to church, they must provide an interpreter		36.2%	590
When I go to the police station, they must provide an interpreter		88.7%	1445
When I go a job interview, they must provide an interpreter		75.8%	1234
When I go an amusement park, they must provide an interpreter		12.8%	208
When I go to a football game in a stadium, they must provide an interpreter		6.8%	110
When I go to court, they must provide an interpreter		93.9%	1530
When I go to see a lawyer, they must provide an interpreter		84.2%	1372
answered question			1629
skipped question			418

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If I am not satisfied with the interpreter, I _____. (Check all that apply)

		Response Percent	Response Count
can ask for another interpreter		75.7%	1219
can let the interpreting agency or office know		79.1%	1273
can contact lawyer and sue		7.3%	117
have no choice and accept that interpreter		17.6%	283
ask interpreter if hearing person did not understand how to use an interpreter and made it hard to do a good job of interpreting		26.2%	421
can ask to speak to interpreter to		42.4%	683

give information about how to
improve

will not do anything



8.0%

128

answered question

1610

skipped question

429

Page: Question 7 of 20

If a sign language interpreter is not provided, I would most often: (Please check three)

		Response Percent	Response Count
go ahead with the appointment/meeting		49.2%	778
reschedule the appointment/meeting		72.4%	1145
ask referral agency what to do		27.2%	431
complain to my family		5.9%	93
call a friend and talk about what to do		7.0%	111
use paper and pen to write back and forth		56.8%	899
protest or file a complaint		28.5%	451
not do anything about it		8.1%	128
answered question			1582
skipped question			457

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What are your reasons for not advocating for yourself? (Check all that apply)

		Response Percent	Response Count
I am afraid to say anything		14.5%	226
It won't make a difference if I advocate for myself		30.4%	474
It's a waste of my time		19.3%	300
It takes too much time to advocate for myself		27.4%	426
I don't have the background or training to advocate for myself		27.8%	433

Advocacy is not my responsibility		10.4%	162
Other (please specify)		24.1%	375

answered question 1557

skipped question 482

Other (please specify)
I advocate for my clients so much that I wear out that I could not advocate for myself.
I always do
I can advocate for myself just fine
n/a
i do advocate for myself
I do advocate myself!
I was raised in hearing world for too long to even remember that I should care to advocate.
noneof above - I do advocate for myself
Where did it say that I don't advocate for myself. I always do....
NA
knowing state odhh wont do anything as he just a pencil pusher nothing more--plain lazy in erie pa area odhh
I do not have time to do so because I am taking college classes.
I do advocate for myself...big time!
I m advocating for myself
some hearing people are ignorant and snobby
igronance in WVA
N/A
I advocate for myself.
agency still stubborn
other do not listen or do nothing about it
n/a
i always advocate for myself
I advocated myself
lack of knowledge
I do Advocate for myself
I DO advocate for myself
I do advocate for myself. I am a disability service provider at a community college
no reason
I do advocate
None of above! I advocate - and depends on how Fed & State Statutes applies to each setting to use it effectively
spanish

they will be mad and hold it against me (terps, referral svcs, job opportunities, etc.) And I *am* a professional advocate, but still face that oppression possibility
always advocating myself plus others also.
I have no problem advocating myself
n/a I am a good advocate for myself!
na
I know how to advocate for myself
Im hard of hearing and use voice
Who say I dont advocate for myself?
don't know
don't use interpreter often, maybe once every two months as needed
need know / teach more about advocate
I DO Advocate - don't trust my local center to do this
i do advocate for myself..
sometime limited support to do it alone
I do advocate for myself
I would say something if i'm not satisfied with the interpreter. or notify the agency.
I have the ability to advocate for myself and other individuals
na
none!
I advocate for myself as much as possible.
if time does not permit but I will continue to advocate for my rights
i cant ignore by not advocating
I had done what I can do is report to interpreter agency
only not advocate for myself when situation not good for it
we all h ave to advocate for ourselves no matter what
hearing people usually don't care
I do
I speak up for myself
I do advocate
always ask/fix situation myself in varies ways
high frustration level sometimes
I advocate all the time.
Not applicable. I advocate for myself.
I become too upset; flustered and not use the proper words
depends on situation and need
no comment
appointment reschedule takes months
I do advocate myself regardless.
I ask for an interpreter and if one cannot be found ask them to try again until one is found. This is very important in an E. R. setting.

I never NOT advocate for myself
I do advocate for myself.
no reason listed above
not sure about this
I am legal studies and psychogy student and specialize on ADA issues and advocate other deaf clients.
I am used to not having interpreters most of my life that I am able to go on by myself, It is nice have interpreters available when I need them altho very rarely.
I will continue advocating for myself until I am heard and someone will listen to me.
I would pursue any issue.
dont want to Hurt any one feelings
People wont listen
I am able to talk and write if needed
depend advocating
wish to learn about advocacy and take a class.
speak on my own
they didnt announced for training to advocate
Deaf people are big-mouthed!
to support the Interpreter for ASL
well self advocate
nned to explain what you mean about advocoting
NO PROBLEMS!
I always advocate for myself, period!
none
Im always advocating for myself.
I would rather work with someone who wants to work with me rathe rthan fight someone to provide me with services
I do advocate for myself
need communcation
Inability to make sure everything is understood on both sides all the time.
none of the above
lack of training information about advocacy
agency revenge
I get tired of people not understanding!
I do advocate... best I can...
speak up with nice talking
I'm deaf
NOT CLEAR
Depends on my mood sometimes.
I advocate for myself when necessary
Sometimes i prefer writing back and forth
None

I always do advocate myself
Often times I do advocate for myself but because I have good speech skills the hearing individual will assume I do not need to advocate since I already "TALK."
none, I am always advocating for myself
I speak so I speak up. I was asked to be a deaf/blind advocate.
I do advocate for my self
Have done some advocacy when warranted
I do advocate for myself
I do advocate and have nat'l reputation of this
Childhood training to be a "nice girl" and never say anything negative. I'm overcoming it, but slowly.
Question does not apply to me.
I do not afraid to ask for adovcate
In most situations, I advocate for myself.
Never give up!!!!
I always advocate for myself
Sometimes I do not know who is the right person (directly) to speak about
Usually do advocate for self and others
No Time , I always busy my life
no reason, I would advocate for myself as well as help other deaf people if asked. Cuz there are so many things I see most certified interpreters are taking "advantages" of deaf consumers dialy.
indenpent
It depends on the importance of the job or task and the existing relationship with other party involved.
I do advocate for myself
I ALWAYS advocate for myself!
this is non applicable since I always advocate for myself
Due to work shift scheduling
Does not apply to me
ignorance of policies
Not afraid to advocate
live in a small communtiy, people dont listen here to deaf needs
I would advoate for myself.
I advocate for myself, it is my right.
If last minute, interpreter wasn't provide, I'd have to go ahead advocating for myself if urgent, but at court, still no excuse for them. I'd reschedule or complain against court.
I always advocate for myself.
Does not apply to me.
I do advocate for myself so can't check any of these
discuss after the meeting to advocate for myself
Some Deaf consumers are afraid it will cause animosity with the service providers, ei: doctors offices.
Usually advocate for myself
I do advocate for myself

sometimes no choice / cant win everything
Question not understandable.
Education is necessary, they will do nothing if it is just my complaint.
As a Deaf Interpreter, none of these apply to me. I always advocate for myself and others.
Sometimes, it's a waste of time
not worth the bother
I am strong Advocate for self
frustrating sometimes
question doesn't apply to my situation
My hearing loss is not that severe. I have a moderate loss in one ear and a profound loss in the other ear. With the use of hearing aid, I get most of the information. If I don'
when I am too ill or focal person of the situation. Too complicated dealing with issues thus hard to advocate for self.
I advocate for myself
it gets old after a while! (same old thing)
I would advocate if necessary
I have advocated for myself to no avail!! It seems like we cannot make anyone understand. So sad!
I do advocate for myself!
the ADA law has no teeth, hard to file complaint, complicated to follow up with non-compliance
not applicable
I do advocate for myself.
I understand most things without an interpreter and don't want to waste my time when I've already got an appointment or an important meeting. However, I have never experienced not receiving an interpr
with interpreter? No problem; Important topic?? If no, waste of time. If yes, does the terp know what he/she is doing so require patience on my part???
I already do
never think
Time management- sometimes the frustration takes up too much energy which results in my lacking in following up.
sorry, dont know what this means.
not involved in deaf advocacy
I'd explain and work out a solution
I do advocate for myself or other deaf people
I always advocate for myself
I can advocate for myself!
I advocate for myself
i advocate for myself
Advocate myself
Advocate for myself
I advocate for myself
most hearing people don't care, they think if your deaf you can read lips.
Limited Time -- I spread myself too thin by being involved in many things that I couldnt do one extra step
i do advocate for myself and for the future of others

I can advocating myself
nothing
I advocate for myself.
Too focused on advocacy for consumers
Know how to advocate
Know how
Satisfy most of the times!
Not afraid to advocate
none of the above
I do speak up
Depends on situation and feeling... hard to advocate when hurt or in pain or need the situation taken care of immediately
It depends on what I need to advocate for - some things I can and will, some things I might not.
No knowledge in whose responsibilities it is
Afraid I d look stupid
I am not afraid to take an action.
I don't have time to do that. I'm very busy man wearing many hats.
have other priorities
It's a waste of company time
I do...
Able to write or protest for myself.
We need more community interpreters and sometimes it would be nice if the interpreting agencies work harder to locate interpreters
I am a competent advocate.
nothing here apply
Find Other Way For Advocate For Me.
potenital for misunderstanding
i advocate for myself
no reasons
I do advocate for myself
I do advocate for self
I do advocate for CART first.....
I am not sure what do you mean...
have no problem advocating
I don't have the documents or the proper procedures beforehand that's needed to make a case.
involve with organization in advocate
I do advocate for myself
NA
Hearing people don't take me seriously
Advocacy is important to do
I always advocate for myself!

I do advocate for myself.
can do without interpreter as best i can
takes so much energy - don't always have it
Society is impatient and it may take to long to get things set up again
I know how to speak up
I do advocate for myself!
I consider myself as a self-advocate
n/a
none
I would do this myself
I simply call the interpreting agency to tell them to never schedule this particular interpreter forme again.
depending on what kind of advocate
I do advocate!
Not given the opportunity to advocate for myself
I speak well and able to understand hearing people if they talk slow.
particular laws and legal information pertaining to communication rights, I do not have on hand or knowledge of so I can't "repeat" that information when advocating for myself.
I don't want to cause trouble.
i will advocate for myself
HUH? I do speak out!
I am a mother of three. It is not easy just to reschedule because there is not one available when you schedule a last-minute doctor appointment for your kid.
I do advocate
none
too time consuming
want to get it over with
I don't know
I advocate myself!!!!
i am not sure what it is meaning ?
I advocate for my son
i do speak for myself!
i do advocate for all of us, depending on the situations
Will they listen my advocate?
I do advocate for myself.
sometimes doing self-advocacy everyday causes burnout and negative thinking that nothing changes
I ALWAYS advocate for myself
I do speak for myself :)
because I am hard of hearing and can speak
i am advocate for deaf people in anne arundel county.....it is tough task sometimes i lost or won
search for right resource to advocate for myself
I am not afraid to say anything.

communication difficulties
not understanding
always advocate for myself
n/a
cant say to them
I do advocate for myself
I'm a pro advocatoring others and myself
I do advocate for myself
i am an advocate myself..
I always advocate for myself.
sometimes requires the use of a lawyer - expensive - even for mailings, Long distance calls etc
I'm not completely deaf so I could get by without one if needed to.
sometimes time-consuming
I would be avocating the uses of Interpreters.
Conflict of interest. When I advocate for myself, it leads doctor offices more confusion and resistance from me as a patient.
have been advocating myself most of the time.
need more advocacy training for community
I am hearing
bad reputation
None of the above
Often my concerns or complaints are not heard or ingnored
I always advocate for myself
I DO advocate for myself and others!
I am able to advocate myself
I Do advocate for myself
Community not do anything
Afraid of getting fired.
I do my best, choose my battles.
did apply one but long procrodure through dept of justice
being threatening
I do advocate myself.
I don't have enough knowledge of the laws, my rights, what is expected, what are my responsibilities and what are theirs, etc
advocate for myself makes me happy
I advocate for myself
I do advocate
I am a self-advocated person.
I always advocate for myself.
because of the rural area i live in services are very limited and i almost have to 'take' what i can get
NEED MORE ADVOCACY TRAINIGN IN THE AREA FOR SYRACUSE, NY

i do advocate for myself but depending on the situation ie job interview i can usually make do with out an interpreter, but if it is at the hospital, where ive had most of my problems i'm afraid to sue because of future neccesities.
I advocate for myself
low self esteem and no confident myself
no comments
n/a
i will speak out for myself by voice or pen and paper
none
Catch 22 position
it didnt show the word to support or speak in favor
my job is advocate,,,
I don't know my rights.
I do advocate for myself
I do not have problems advocating for myself
I want to advocating for myself to fights for our rights
Hearing persons tend to listen to hearing person rather than deaf person
i do advocate all the times for myself since i am a community advocate :-)
I do advocate for myself
I'm not afraid to self-advocate
I do advocate for myself, thus none of the above apply to me.
neither/nor
I have no one supports me
hard to talk
I "choose my battles." I choose the times when I must have an interpreter.
I advocate
i do advocate for myself
I would said something to reason to you.
i do
I do advocate myself.
I'm never shy about expressing myself regarding terp services. I know my rights within limits.
NA
in past doctor's office canceled my appointment and would not accept additioanl appointments. They said they refused to hire an interpreter. I do not want to be embarrassed in front of people about it.
I usually do.
I DO advocate for myself
I advocate myself often depending on the situation
not always understand
Limited support system
I attempt to advocate for deaf (I am deaf too) "customers" so I have no reason not to advocate for deafs
I speak up when it warrants it. I disagree that I do not advocate for myself.
I do advocate for myself everyday as every person should rather than relying on others

Rural areas make it extra difficult to obtain interpreting services
Advocacy doesn't guarantee immediate results.
I advocate every chance I can
I do advocate
i do advocate
I DEAF SPANGH..
it hard of wait longer
I do advocate for us
I would advocate for myself. period
no comments for this question
I always advocate for myself
I always advocate for myself
I advocated myself well
I don't know enough about laws.
I am multiply handicapped and unable to advocate for myself.
none
It's difficult to advocating for myself while I'm the person who need the immediate service. I have no time to play 2 roles being an advocate and a person who need the service.
Often the situation becomes worse
im always advocating for myself
I do advocate for myself
I may not have had the time at the moment
I advocate all the time
I advocate depending on topic
I advocate for myself
I advocate
I advocate for myself
None of the above
I do advocate
I advocate
I advocate for myself
I advocate depending on topic
I advocate depending on topic
I do advocate
I advocate

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Self-advocacy training will be developed. What ways do you prefer to learn new information? (Please select one)

Response Percent	Response Count
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Face-to-face		32.4%	499
Read information (on paper or computer)		13.6%	209
Watch video		19.9%	306
From other deaf people, friends, deaf leaders		27.8%	428
From my school or college		2.1%	33
Other (please specify)		4.2%	65
answered question			1540
skipped question			499

Other (please specify)
not sure
csd
leadership traning
Agencies
workshops
workshop
Role playing scenarios through video - read is easy to do, but "HOW" to do it with the right attitude, approach, etc. is what many of us do not excel well at
internet
providing advocacy support group with deaf to discuss issues and how to address it
Deaf Community need the workshop to develop their comprehensive about how to use the interpreter, make report, etc
Self
Self-empowerment
Deaf Service Center
From work
I am not self advocacy. I am Deaf and Use ASL
all above
at a workshop
workshop
all of above
seminar or conference
Deaf Agency
Vlog
I would love to participate in this kind of committee and present myself first to the deaf people and then the interpreters and eventually to both of them at the same time.
I don't feel I personally need further training.

few workshops to development understanding and easily ask and answer and be with others who go thru this to build self-Confidence to be self advocacy
advocacy workshop (comprehensive training)
workshops
Presentation
Depends on the kind of information
question doesn't apply to my responses
workshop/training programs
workshop or presentation
see previous question
workshop
Workshop
Group meeting
depend on what!
ALL THE ABOVE
my choice is ALL of above
Watch Video, Information and Events
Video in ASL
from HoH, CART, VCO via VRS,etc
Independent Living programs
Workshop by Dead Person
my video is not play proper i am not sure what is it
must new with vp
any of these
workshop
It's always good to learn -even new things frequently, i'd select all.
Workshops
group face to face training (for more feedbacks from this way)
Prefer a mixture of print and face to face.
depending
all of above
training/workshop at conf
Training
Training
Workshop or one day outing
Advocacy Workshop
All of the above!
NEED I DEAF OTHER
from any sources

workshop
workshop
Workshops

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If self-advocacy training is offered, will you attend? (Pick one)

		Response Percent	Response Count
Yes		51.2%	784
No		5.4%	82
Maybe		32.4%	496
Don't know		11.1%	170
answered question			1532
skipped question			507

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Do you have a computer at home?

		Response Percent	Response Count
Yes		94.8%	1449
No		5.2%	79
answered question			1528
skipped question			511

Check all that apply

	Everyday	Once a week	Once a month	Never	Rating Average	Response Count
I use instant message	60.3% (869)	15.3% (221)	8.1% (117)	16.2% (233)	1.80	1440
I use the Internet	86.5% (1286)	7.5% (112)	1.5% (22)	4.5% (67)	1.24	1487
I use email	92.6% (1391)	4.4% (66)	0.3% (4)	2.7% (41)	1.13	1502
I use a videophone	63.3% (928)	18.7% (274)	5.3% (78)	12.7% (187)	1.68	1467

I use cable service or DSL service	86.7% (1273)	2.9% (43)	1.2% (17)	9.2% (135)	1.33	1468
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answered question 1518

skipped question 521

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Which of the following is the best mode of communication for you? (Please select one)

	Response Percent	Response Count
Sign alone 	49.8%	758
Speech and sign 	45.6%	695
Speech alone 	1.2%	18
Cued speech 	0.2%	3
Tactile sign 	0.4%	6
Other (please specify) 	2.8%	43

answered question 1523


skipped question 516


Other (please specify)
speech alone but sign to deaf friends
Sign and lipreading
Speech (mouth moving) and sign in English grammar with important words or names spelled out.
ASI and proper mouth movements
Sign alone most of time. Except - Victim of hearing families - gotta use voice sometimes
moving lips and sign without sound
can read lips
ASL
combination
Am legally blind. My needs vary with the situation. from speak and sign to tactile sings.
total communication
Sign with everybody
Sign with everybody

speaking and signing/I am hard of hearing
speech and sign to hearing people only.
ASL
depends on situation: with hearing people, I speak. With deaf people, I sign.
ASL alone
sign alone mostly, speech and sign sometime if asked.
Total Communication
Again, it depends on the situation
sign and mouth movement
commuicate and sign
ASL it is! No other forms of sign languages even if not done with speech.
Speech with no voice and Sign
Sign and e-mails.
VRS/VCO speech/speechreading/signs
sign and mouth words
sign and mouthing
sign and lipread
Sign and Lip Movement
asl
speech, signed, cued
i sign only with deaf and speech with hearing people unless they are signers.
depending on who I am talking with... if I am not familiar with people, I would prefer to sign alone... if I am familiar with people, I would use sign and speech together...
sign and lipreading
lipreading
ASL
ASL
Sign with mouth movements
asl
whichever fits the situation and i don't mind speech and sign at the same time either, I use speech the most
NOT KNOW I DEAF

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What is your highest level of education? (Please select one)

		Response Percent	Response Count
Attended grades 1-8		3.1%	47
Attended high school 9-12		16.7%	254

Achieved GED/high school diploma		11.1%	169
Some college		27.9%	424
Achieved Bachelor's degree		20.7%	315
Achieved Master's degree		11.4%	173
Achieved Master's degree plus		9.0%	137
<i>answered question</i>			1519
<i>skipped question</i>			520



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Your age is: (Please select one)

		Response Percent	Response Count
18-25		5.2%	79
26-35		12.3%	187
36-45		22.9%	347
46-55		28.3%	429
Over 56		31.2%	473
<i>answered question</i>			1515
<i>skipped question</i>			524









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Your gender is: (Please select one)

		Response Percent	Response Count
Female		65.6%	993
Male		34.4%	521
<i>answered question</i>			1514
<i>skipped question</i>			525





























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Your Ethnic background is: (Please select one)

		Response Percent	Response Count
Black/African-American		5.9%	89
Asian		2.1%	32
White (non Hispanic origin)		84.1%	1269
American Indian or Alaskan Native		1.1%	16
Native Hawaiian or Pacific Islander		0.2%	3
Hispanic or Latino/Latina		4.0%	60
Mixed Race		1.4%	21
Other (please specify)		1.3%	19
answered question			1509
skipped question			530

Other (please specify)
Jewish
FULL MEXICAN
prefer not to answer
white
NO RESPONSE
mix
human
causaion white
Amercan Black Person
private
CAUCASIAN
mix
HUMAN BEING
american citizen hispanic
Indian/Irish
Prefer not to Say
Prefer not to say
American Indian/White
First Nation from Canada

I live in

		Response Percent	Response Count
Alabama		0.3%	5
Alaska		0.1%	2
Arizona		0.7%	11
Arkansas		0.3%	4
California		9.1%	137
Colorado		1.0%	15
Connecticut		0.7%	11
Delaware		0.9%	14
Florida		5.1%	77
Georgia		1.5%	22
Hawaii		0.1%	1
Idaho		0.3%	4
Illinois		3.5%	53
Indiana		1.3%	19
Iowa		0.9%	13
Kansas		0.3%	5
Kentucky		1.5%	23
Louisiana		0.6%	9
Maine		0.5%	7
Maryland		10.5%	159
Massachusetts		2.7%	40
Michigan		2.3%	34
Minnesota		3.9%	59
Mississippi		0.3%	5
Missouri		1.2%	18
Montana		0.3%	5
Nebraska		0.6%	9
Nevada		0.3%	4

New Hampshire		0.7%	10
New Jersey		1.1%	17
New Mexico		0.4%	6
New York		4.4%	66
North Carolina		1.3%	20
North Dakota		0.7%	10
Ohio		8.1%	122
Oklahoma		2.9%	44
Oregon		2.5%	38
Pennsylvania		2.3%	35
Rhode Island		0.2%	3
South Carolina		0.3%	5
South Dakota		5.9%	89
Tennessee		0.4%	6
Texas		10.0%	151
Utah		0.3%	5
Vermont		0.9%	13
Virginia		2.4%	36
Washington		1.3%	19
West Virginia		0.3%	4
Wisconsin		1.4%	21
Wyoming		0.1%	1
Other (please specify)		1.5%	22

answered question 1509

skipped question 538

Other (please specify)
District of Columbia
Washington, DC
Washington, DC
Washington, DC
Washington, DC
Washington, DC

Eritrea (Africa)
uk
Newfoundland and Labrador, Canada
Washington, DC
puerto rico
London, England
Germany
Nova Scotia but am American
D.C.
dc
Washington, DC
Currently in Netherlands
Washington, DC
Washington, DC
Virgin Islands
Washington, DC

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I live in: (Please select one)

		Response Percent	Response Count
an urban area (large city)		31.3%	469
a suburban area (near a large city)		43.3%	650
a small town or village		17.7%	265
a rural area (country, farm prairie, etc)		7.7%	116
<i>answered question</i>			1500
<i>skipped question</i>			539

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	Response Count
	315
<i>answered question</i>	315

Please add feedback, comments or suggestions below

Respondents	
1	My clients needs to understand more about their rights esp. ADA Law, same with many deaf
2	I think community advocates will always be needed to assist some members of the deaf community advocate for services - similar to vulnerable groups in the hearing community; I like the concept of broadly offering self-advocacy training, especially in rural and ethnic communities.
3	The survey is super! Easy to follow! Hope others will do the same!
4	i wish that people to listen careful and not misunderstand common or whatever and that how one of person got fired for that due misunderstand and manything and they should ask someone to make sure not misunderstand what they talk abt it same with me i can read pretty good and i catch one person misunderstand what i say and i told one person be careful or i will find another person so thank u
5	I like to see more ASL survey with vary of subject near in the future. Thank you!
6	This is cool! Friendly user! Thanks for video provided.
7	Training would be especially beneficial if deaf people and interpreters were in the same room, feeding off each other's knowledge and perspectives.
8	Hopefully the results of this survey will be shared.
9	The Video did not work for me. I got the picture of the interpreter but it on jerked from one position to another and semed to skip. I have the saame trouble with video messages from VRS services. It is the MS Videoplayer. Maybe just my machine is too old.
10	Seems to me that some of these questions asked are directed to as if we do not have any advocacy skills, where are the questions asking for those who do possess the skills of self-advocacy?
11	Would be nice to mention that there are 19 questions in this survey. Thank you.
12	I am an interpreter as well.
13	let be noted that not all asl is used in all cities especially there is no school such as wspd in erie area, more likely psee is used due the fact lack mingling with wspd students and main streamed people who have no idea what is out there for deaf!!!!
14	Wow !! That was neat and easy.. i look forward to seeing more done for the Deaf and Hard of Hearing.. Thanks Again,
15	i am deaf and not know any interperter in Ga since wehn i was move from texas to Ga.. i know i used to call interpreter in texas when i was lived in tx. most i depend my sister sign lang abc. iread that and lip very clear. or write paper most.
16	Thanks for letting me take this survey! :=)
17	My clients needs to understand more about their rights esp. ADA Law, same with many deaf.
18	I am an interpreter, for about a year now, so some of the questions didn't really apply
19	Self advocacy workshops would be a big boost to the deaf community. It will help us develop self-confidence, understanding of rights among other things.
20	I would like to see more Deaf services to be provided for all communication needs where there is not here in Florida. Thank you.
21	nothing to said so Keeps Up I put mark on Sign VRS videophone are not In because Still waiting for VRS thank you
22	No comments at this time. Thank you
23	I am want more education and i hope get Deaf Advocacy Training project B/c in my country they are more deaf with problem no sign language. I hope fund support from all organization.

24	Good Questions!!!
25	Would ne nice to have a brochure or paper of some sorts...to be able to give to those who need to request an interpreter for me. Something with information on how to get an interpreter...on how to use an interpreter...And basic information about deaf people, such as looking at the deaf peorson when they are talking. Maybe this could be a laminated index card, with information on front and back. There could be a blank area where the deaf person can write a phone number for their preferred interpreting agency.
26	i wonder if i can get vp for free or pay it?? thanks
27	OK!
28	Very nice idea. I am quite sure that this survey will benefit the Deaf Community to understand better. That is cool. Thank you!
29	This sounds like a wonderful idea to teach us about our rights and/or how to solve problems the proper ways. Thank you so much. Looking forward to it.
30	I am employed at a community college as the disability service provider.
31	need interpreter spanish , not use team interpreter and need improve to spanish interpeter and need full time 24 hours
32	Please post the survey when completed! I'm interest in the overall result! Fantastic survey!
33	I wouldn't attend a training because I have given these trainings, to HH, deaf, and deaf-blind.
34	If need to contact me, I had been advocating for 9 years in NYC and Boston, now just start my ownin Florida and not easy in Florida, because many Deaf and Hard of Hearing people does not talk about it. :-) have a good day.
35	I am VR counselor and have done lots to advocacy for deaf/HH and D/B individuals in rural area. Also depending on individuals, I empower them to do themselves. However, I think it would be a good idea to have some kind of self advocacy support group once a month to discuss our issues and how to address this problem solving.
36	I like to have newsletter about this company thanks
37	Thank you. have great week. smile
38	I have a lot of experiences that most of the doctors, lawyers, government offices and some hospitals won't want to provide the interpreters because of very expensive fee. I believe the expensive interpreter fee drives them away from hiring them for us the deaf people! Find a solution to make the fee less expensive.
39	I suggest there need have Advocacy (mispell) workshop So We can learn more about that... Thank you
40	Really like having the Video in case I didn't understand the questions - but all of the questions were clear. Thanks for asking !!!
41	n/a
42	n/a
43	Great survey!
44	FARF !!!!
45	I have told my doctors that they should request for interpreter each time for my appt and my kids' appt when I am there. Every time, they would say they would do that but when I arrive into a little waiting room for dr.- there is no interpreter. What's up with that???
46	Hope you gather whole data and able to share the result and improve better way for deaf to advocate their right for getting an interpreter. Thank you!
47	none
48	Sign sign speech was confusion!!! Meaninig speaking and signing at the same time??
49	Superb! The lady who signs is very clear and readable especially with fingerspelling.
50	it seems everything fine. it never bother me at all.
51	Swell!!!
52	D/deaf, DeafBlind, and hard of hearing need to attend the workshop about the interpreter topic. They can understand better of how to use the interpreter, their right and preference in usage of the language mode as well self-advocates. Thanks for bringing up this issue.
53	how you respond me?

54	this community very hard deep other peoples hearing some of part hard system deaf try write paper or face lip mouth word spell.comments want know clear about this!
55	<p>Hello to Deaf Advocacy Training Project,</p> <p>I would like to know what are you asking those question ? can you explain what is Advocacy ? I can explain to deaf friends.</p> <p>Thank you.</p> <p>Have a great Day!</p>
56	<p>Terp alays 2-face & cause troubles</p> <p>Terp refuse to work with me want me in mental hospital</p> <p>still rumor 32 years</p>
57	<p>I like to get my own preferred terps; gender too</p> <p>Avoid workshops</p>
58	No skilled terps in my area.
59	Very Good survey Thank you
60	There is a shortage of interpreters in all situations
61	Love to have interpreters. We need them!
62	I would like to see the results of this survey and how we really can help others with this.
63	This survey was easy to take and did not require alot of time. Good luck wiht your proposals and recommendations for self-advocacy!
64	I appreciate the attempt at adding the questions in ASL, however the interpreter used a lot of fingerspelling and English order and words. This made it difficult to understand.
65	I like how you had a signing avatar in the survey. Wish more people would do it that way! I have been HOH since birth and can't believe I wasn't sure of a couple of the correct ansers, such as "Am I entitled to an Interpreter for a football game?" Good questions!
66	Some questions were too narrow on the response. For example, I don't use the videophone everyday, but I use it more than once per week. There was no in between choice.
67	<p>good questions, also possible to attend workshops.</p> <p>I have had one very very upsetting experience with a doctor who decided he would not accept to treat me; I did not know what to say or how to plead my case. This was for my first pregnancy.</p> <p>The doctor might have known that I would be having a miscarriage or problem fetus. He would not state the truth why he would not accept me;he had his worker tell me he would be on vacation when I was due. PLEASE, I am not stupid.</p> <p>My husband was there and he saw how poorly they treated me (he is hearing), yet both of us did not say the correct things. The interpreter did try. I cried all the way home. Later went to doctor with UT Medical Branch in Galveston. Some dr. don't want to pay interpreter fees so they do not accept the deaf patient. Interpreter fees need to be acceptable and reasonable for all.</p>
68	this is great and empowering. i love it when i see a video of asl go longside with the english text. and the idea of self advocacy material is to come.
69	SOME BUSINESS AND OTHER OFFICES AVOID FROM INTERPRETERS. INTERPRETERS CHANGE TOO MUCH LIKE #120.00. THANKS
70	I enjoy that help me lot and encourage.
71	Please let me know when give training
72	I'm glad take the survey. I learned alot!
73	<p>It does not make any difference whether we lived in a high demanding society for many deaf communities we will always be having an interpreters for years to come. I do.</p> <p>Thanks !!</p>
74	Need more interpreters trained to interpret for a deafblind person. This is some what different from a deaf person. One must be care to stand where the light hits the interpreter so the db person can see them well.

	Never with a light to one side or in back of them. That puts the person in silhouette.
	They may need to slow down, it depends on the eye problem that person has. Like being 20/200 or 20/300 which means you can only see for a few inches. NOT feet.
	Thanks
75	I prefer to ask for an interpreter from different agencies and video phones
76	I have not had to use an interpreter yet but know how to get hold of one if necessary
77	Thank you for let me know about it..
78	SOUND GOOD IDEA THIS SHOW ON THE VIDEO SIGN LAUNGE MAKE MANY DEAF OR INTERPETER SHOULD TO BE UNDERSTAND ABOUT THIS SYSTEM THANK
79	some deaf give up their deaf advocacy because on one teach them their palnning goal
80	hi i did my best for ur answers !!!!!
81	It would be neat to provide advocacy training to the deaf community and they could have good opporunity to approach others appropriately especially with good self-esteem/self-confidence. Thank you for doing this survey. :-)
82	Not enough interpreters when needed
83	IT IS IMPORTANT FOR DEAF & HARD OF HEARING TO NEED ANY INTERPRETERS ON VIDEO REPLAY SERVICE TO TALK ANYTHING WITH A LAWYER , ETC.... I USE ALOT ON VIDEO INSTEAD OF TDD BUT SOMETIMES IF VIDEO IS NOT WORKING SO I HAVE TO USE TDD WHAT I KEEP IT IN CASE... IT IS WONDERFUL TO HAVE VIDEO AS SO AMAZING TO USE ANY INTERPRETERS... THANKS !!
84	We need to get provider for lawyer, courts, dental, doctor , surgery center, job interviews and profess. business and more ... on time and dont make delay time longer or resheadules ... be ready to serve same day or next day instead of 5 days or one weeks or later.....
85	I TOOK TO ANSWER THIS SURVEY. THANKS AGAIN
86	hope that everything will be smooth.. thanks
87	I think if there are large crowd, there should be at least one interpreter to help us and if it is the hospital, they should provide interpreters as some don't. Thank you
88	a woman is very good job to explain me or anyone when i do understand very clearly to click this survey question better than read on this survey
89	Survey is great.
90	I HOPE TO IMPROVE IT IN THE FUTURE. HAVE A NICE DAY AND GOODBYE
91	What about hard of hearing person....I myself am one and I often do interpreting for my friends but I would not be qualified to be a certified interpreter due to my hearing loss. I do interpreting on a one to one basis and have enjoyed it. What can be done for the hard of hearing???
92	I am interesting to attend a deaf traning advocate internship.
93	Develop a guideline brochure or business card for self-advocates to carry
94	thank you
95	thank for survey and updates in future to improve ASL and my Communication Rights Thanks
96	I use interpreters mostly for non-personal reasons. I don't feel comfortable using them in medical situations. I consider them as third persons. Altho, I know they have to comply with the code of ethics, I still hesitate to use or ask for the service. I have been able to get along in many situations without using the interpreters for a long time that I don't think of getting interpreting services. I appreciate having them for any stage presentations. Anyway, the advocacy training is a good idea especially for those who are not self sufficient.
97	Keep up with your fine projects for the deaf communities, and try to bring in more awareness to the hearing people who reside in Florida who are not familiar with the deaf cultures, etc. End! With pleasure!
98	:o)

99	No comment
100	I wonder why Debbie's name was not listed as the person on the video. Some might think she is Larry P. :) She signed very clear and the survey was simple to follow. I enjoyed doing it.
101	Hello Debbie! You did a good job! Good luck!
102	to educate all gov officer, federal, state,city,police,etc of deaf rights and to understand deaf ways
103	I am complaining about VP. I email to VP technical service but no replay or not coming to fix at VP-100. I am disabled. Im hard to walk with crutch for a long time because of my hip and knee. I need to swap from vp-100 to vp-200 with flash light. I will be happy to get VT-200 instead 100. I will be happy get VP-200. I am sure to use VP often. I am frustrated to struggle with VP-100 because Im hard to walk with crutch to fix adjustment on VP_100. Pain in the neck for me. I hope to hear from you. Thanks.
104	Thank you for asking me questions and I appreciated your asking me. I hope you have a good day.
105	I do not want videophone or VRS in hospitals. I prefer a live interpreter. Why? I had been there and was not happy with VRS. I ended up using paper and pen. In short, I prefer a live interpreter or paper & pen, period.
106	this is very interesting about Self-advocacy with Deaf Advocacy training project. Good luck with this new Deaf advocacy training Project.
107	some questions are uncomfortable because I have few options but it limited me to pick one...very back and white questions...wished some questions has a "comment section" so can add myself.. good luck
108	very peaceful
109	Keep with feedback
110	PLEASE KEEP AN INTERPRETER FOR THE DEAF PEOPLE VERY IMPORTANT TO HAVE COMMUNIONS. I HATE TO WRITE THE NOTE TO HEARING PEOPLE.
111	IT IS VERY INTERESTING!
112	HELLO THERE!! I WOULD LIKE TO LET YOU KNOW THST DRS WON'T PROVIDE ME AN INTERPRETER DUE THE VERY COSTING PRICE. SO I HAVE TO USE MY DAUGHTER. I FRUSTRATE ABOUT DRS' UNPROVIDING AND THEY SIMLY INGROE ADA. I WISH THE HOSPITAL FOR EM ONLY HAVE VRI AS SOON AS POSSIBLE. I WISH THE NURSES SHOULD LEARN HOW TO SIGN. BUT FOR ME, TO WRITE TO COMMUNICATE TO MY OWN DR
113	I am currently in the process of filing a suit with the DOJ via NAD against a group of doctors in the Delaware area for failing to provide interpreter services. Advocacy is greatly needed in this area!!!!!!
114	Thankyou for survey I look forward to learn more about self advocacy for deaf. :)
115	i really like to be interested to learn how with communicate video on my computer for my new training survey. and it make me feel better to understand you clearly with communicate ASL video on my computer, wow, so I like to do it again for my new survey on my computer with video to the future. Thank you very much.
116	Need training to advocate for myself as at times when requesting for a sign language interpreter the business wont allow us to have one and then filing a complaint works.. Need not have to go thru this ...
117	n/c
118	some questions, especially #4 were worded vaguely and watching interpreter sign did not help ie: interpreter must match with english (I assume you mean my ASL register must be accurately trasnlated into spoken English..) Not to pick on Deb but I felt that the ASL Version of what she signed was exactly what I saw on paper... Sort of defeats the purpose of the ASL version..
119	nice being able to do questionairre with questions done in ASL!
120	need Communcation and use sign langague , need to help for understand , my deaf brother cannt write down

	and read because not understand. then use sign language better for him and he happy to use on video phone than tty . also I am deaf too thank you for help .
121	need college refreshing courses to help my mental abilities and to improve my communication method through the videophone from anywhere - college like RIT or Gallaudet. do not need credit courses but need refresh courses. Thank you.
122	WHAT, I KNOW OF IS WHEN I GO ANYWHERE SUCH LIKE LAWYER DR OFFICE, ETC IT CAN HURT THEIR MONEY TO PAY INTERPRETER VERY HIGH COST, HOWEVER MANY LAWYER OR DR AVOID TO DEAF TO MAKE AN APPT. AND DROP MY APPT OR DROP MY CASE. I HAD A PROBLEM WITH LAWYER MANY TIME AND I GET NOTHING FROM LAWSUIT. BECAUSE OF INTERPRETER.
123	We love vrs so much cuz of it is more easy than tty it is clear talk face to face
124	Would be better to tell us if they have a kit for self-advocacy program?
125	I think some Deaf people will have difficulty understanding the written questions because of not being proficient with English skills. Also, the video is very, very slow and requires patience to wait on the signed questions. This may cause frustration for some Deaf people and they may not want to continue with the survey. I think some who really need DATP might give up and miss this opportunity, which would be a shame.
126	Again, my biggest issue with self advocacy is that I have been doing it for SO very long, I'm tired! I wonder why people still do not "get it" after so many years now. It's a frustration.
127	Video Phone is great for all the deaf people & even hard of hearing too. It is very easy to call for an appointment or any business rather than tty.
128	Would like to know what comes of the results and follow up. Thanks
129	This is very good idea the survey. The interpreter is very clear signs. Smiling.
130	I'm curious and see if how will u help me about the self-advocates? Let me know if I pass the tests????
131	No comment.
132	I appreciate your efforts to make the survey for the improvement. Mostly, I have had no major problems. We are able to have medical appointments always with interpreting at U. of M. hospitals. That is best thing in our lives.
133	Need better service to get interpreters and fast way to get them when it is need.
134	Need better service to get interpreters and fast way to get them when it is need.
135	Thank you for asking for questioning me
136	I really enjoyed the video. Although I would usually read before I would use an interpreter, I found myself mostly watching the interpreter. There were a few questions that said to select only one, but I had a hard time picking cause for me the correct answer were 2.
137	THERE NEED MORE INTERPRETER AND GOOD PLACE COMMUNICATE
138	Your survey does not ask hearing loss of the person filing your survey which I believe would make a difference in responses to your survey. For example, I am a fluent ASL signer, 2nd generation deaf family and I am also hard of hearing. Because of my hearing ability, I do not always require an interpreter because I can hear and speak quite well and use the telephone to make calls to hearing people.
139	This was an interesting survey and one sorely needed in order to access the various kinds of communication modes for deaf/blind, deaf and hoh individuals.
140	I'm more than happy to help you out with survey.. thank you
141	I was asked two weeks ago at AIDB Alabama Institute for the Deaf/Blind to teach Advocacy. This shocked me and took me by surprise. I am the only Deaf/vision impaired person who speaks up for myself most of the time. Here in Alabama we have such a hard time getting the help we need and we are ran over by so many people. No one will hire us plus 'Terps will not show when needed. Terps come when they want to be there. If a 'Terp says they do not want to go to a meeting or be there at a certain time then we have to reschedule to a date they say they can make it. I honestly believe it is not fair since they get paid by our families tax dollars. Even though it is the law that we must have a 'Terp I have asked for one many times when I was going to

	my doctor appointment. The doctors always tell me they can not set the appointment for on that it is my responsibility. My husband ends up Terping for me, and he is still trying to learn sign. I appreciate all he does but he is not as good as a 'Terp. How do we get doctors and all to abide getting a terp?
142	I am a priest of a church for the deaf and lost my hearing as a child after I developed English skills. Normally I am the person who arranges an interpreter for such things as diocesan meetings and workshops. This may be several times a month, but not every week. We do not use an interpreter for church services as I am deaf myself and both sign and speak at our services. My husband was deafened as a teenager and all our children (grown up now) are hearing and all are bilingual...speech and ASL. I prefer to use English for myself but use ASL with my congregation. I worked in the medical field for many years before becoming a priest and so rarely bother to use an interpreter for medical appointments; most interpreters do not understand medical terminology as well as I do, and I like to have written notes from the physician to refer to later if needed. I am a so-so lipreader; I prefer to speak for myself and use the interpreter primarily for meetings, workshops and for interpreting when a hearing person speaks, but I answer them in my own voice. I do use an interpreter when I speak to large groups of hearing people, since I do not hear well enough to adjust my voice's pitch and loudness for various size rooms and groups. As to advocacy, I TEACH advocacy for individuals and groups, so it is rather in the air if I would attend such workshop when I am already involved in teaching it.
143	We need a flyer to distribute on need and value of interpreters and their performance competencies. Flyers may be given to deaf consumers who may give a copy to their service providers. A reference to advocacy laws may be helpful. Include names and addresses of State Commission for guidance should be helpful.
144	look great show cool neat !
145	Appreciate and hope things will be getting better . have a pleasant day
146	no comment that i think of.
147	no comments
148	I am actually 12, but I didn't see until the middle of the survey that I wasn't old enough to fill this out. The rest of my information is accurate.
149	First Time I see that and That was good sound... smile Well, Sometime Interpreter still dont understand Deaf Customer sign Language full of ASL... so that Interpreter was wrong sign Language cuz of it use full of English language not ASL so We are nt use English language so We tried figure out it.. so Suggest IMPORTANT It is coming first of ASL than English Language Thanks Have a nice day to u
150	Well, I'm glad you asked this and thank you, Larry for putting my name on the list. Larry, you have been my old friend for years. Anyway, I think this survey is wonderful but it could be in vain and waste of time if we do this alone. We need to do something first such as setting up a priority of all surveys in order? Thus, this survey could be on the top or second to others? For a couple of reasons through my years of experience and observations as a deaf person, teacher, professor, and as "advocate/consultative" person for deaf individuals if asked, the issues over those situations are hot and are still existing. I am afraid that most interpreters do not deserve the level of certificate they possess, yet, they still earn high and decent pay for their service? Most of them are incompetent and their "hidden" attitudes are terrible (90% of them). And for this reason, I am afraid that we should include it as the top on the priority. I have plenty of incidents and remarks I could share them with you. Again thank you and since you said it is confidential, I trust you to put my name on this message. good luck with your survey and I hope it will be effective. Take care.
151	it would be interesting to know that you will have a new training for us
152	I appreciated the visual video instructions. It is a great tool for individuals who need ASL assistance when reading the questions.
153	i would like to interpreter only women while in hospital another subject dont mind any men or women smile (female respondent)
154	I always ready letter from deaf advocacy training programs have a nice day smile take care of us ok
155	provides a region training.
156	Get an interpreter or need help work a job which I am unhappy with a few workers then I'll ask
157	No questions
158	No comments
159	lol all your question is Cute !
160	add on the survey "non-applicable" option in case some do not apply.
161	Please consider a presentation for Imperial Valley. We have approx 150 individuals that are deaf and

	historically do not use or aware of thier rights.
162	Community Based Interpreters are difficult to find because most of them are working for VRS. We need CBIs.
163	In reference to Question no. 1 (I think), it asks if you request an interpreter using a specific mode of communication.. you should include one more question...I never ask for any specific interpreter.
164	I am one of 7 deaf family. My deaf parents (they're in 80's) often misunderstand the conversation between hearing people, mostly doctors because they didn't request for interpreters. They often get in office and start to complain "no interpreter show up". I have to keep track with their appointments to get interpreter, but while on my vacation, no interpreter. I feel that the elders need to be educated how to "request for interpreter". They need to learn "STOP" not go ahead without interpreter and make too many misunderstand and frustration. They need to learn to make appointment in advance of time.
165	Good survey with video! Just that sine questions need additional answer for individual with Usher's Syndrome. Prefer mode of communication it all depend on the settings, lighting, etc. Thanks
166	I would love to be a part of this training as a possible trainer? If you allow non csd employees to do that! SMILE
167	with spouse and friends, i use ASL and at work, i use both ASL and tactile signs due to my nature of work.
168	I am an interpreter. (hearing) I have endeavored to answer the survey questions in a way that best represents the Deaf consumers I have come into contact with in my area. I strongly believe self-advocacy education and support is needed. I have seen unnecessary suffering due to a lack of effective advocacy (self, or otherwise)in this area. Thank you.
169	Nice.... Simple it is. Hope to have a workshop somewhere. If not, try to have more videos on the computer for us to learn more info from this project or from the CSDVRS like this. It is neat.
170	Some questions that I want to make the selection more than one so need to change on "check in apply" because some questions fit more than one selection.
171	Cool concept of video questionnaire for deaf readers.
172	The survey is wonderful and some of the questions are kind of too general. Some do not apply for Deaf Interpreters for DeafBlind people, Deaf Individual or team interpreting.
173	Many of the questions in this survey provided such a limited subset of possible answers that that I am not certain of how useful you will find the results. Nonetheless, I wish you well, and hope that this project will lead to more opportunities for development of self-advocacy skills in your target populations.
174	Thought it is great idea to check with Deaf community members regarding needing to learn about Advocacy or not. Thanks! Good luck with the project. It would be great if can give me final report/results from this survey
175	I would love to take the deaf advocacy training. I notice that is a big gap for people with hearing loss.
176	I think this is a very good survey and I hope the results will help you gain more experience on helping the deaf.... thank you!!!!
177	No Comments
178	Questions asked of me weren't matching my responses, especially about no self-advocacy? Well, I'm well versed in self-advocacy and have no problem doing so for myself. :-) Maybe there's a bug in the survey? Thanks..
179	Nice job with interpreter showing and explaining the questions...was a huge help!!! Thanks and I look forward to attending some advocacy training if have any soon in the area I reside. Thanks again!
180	My hearing loss is moderate in one ear and profound in the other ear. I use interpreters in my school system at meetings when needed. I usually just use ALD FM system to help.
181	GIVE ANY OPPORTUNITY INTERPRETER TO ACCEPT TO DRIVE LONG TRIP. I KNOW THAT INTERPRETER DON'T LIKE TO DRIVE DURING TRAFFIC. NO CHOICE BECAUSE OF INTERPRETER'S JOB TO DO AND CAN'T IGNORE ANYONE HAS THEIR APPT.
182	I strongly recommend that a self-advocacy training workshop be offered at NCOD on the CSUN campus. CSD could do a workshop as part of the students' orientation before the beginning of every academic year.
183	If I have two interpreters for my class, both of them needs to be a team player and help each other improve

	their duties.
184	This survey should be avail at all IL centers in USA.. Not all have Deaf direct services, but at least they could forward the survey around.
185	A variety of trainings would be good - via video link (let people know of the availability of various trainings on a website via various list-servs and get word out through human service agencies) AND in-person training led by deaf people in different parts of the country.
186	pleased to have your informations so i answerwd it all but some questions are rough decision on my experinced it smile thanks again
187	enjoy!
188	I'm interested in materials developed for teaching self-advocacy to my students. I'm an itinerant teacher of the deaf.
189	Important for consumers to be flexible to give terps a chance but not too much that consumer gets lost in the communications. Rigidity on the part of consumer or terp is not the solution. Important for both to know the other's background and/or limitations to create an effective team. Balance may be difficult at times. Main deciding factor is the situation... Medical, legal or educational setting is critical... social setting might be more liberal. Family settings like weddings, funerals, graduations or once in a lifetime situations can create emotional factors that need to be acknowledged or respected.
190	Video tape show to help sign for follow each question which someone make understandable to match for read only english or different language with foriegn.
191	A wonderful survey that needs to be filled.
192	im look for free voucher
193	Thank you for this survey and I think its an important one to check on how deaf people think about interpreters and then offer training or advice about this extremely valuable service. Im deeply appreciative of this vital service. Hope you can share the results with us.
194	Hi I am deaf.
195	[I'm hearing] and filled out this questionnaire regarding our clients. Many need to be taught how to advocate for themselves. I work at EDD in San Diego and assist clients with job services to look for employment. THis is a much needed training in our area.
196	Need to reach
197	Need to reach out for more Black/African American people
198	I work part time three days a week and meeting takes only 15 minutes each day without interpreter.. I dont understand them at all but when the meeting is done, my leader explained to me by lip reading and he uses fingerspell and somtimes I dont understand , then he is willing to write down for me .. When the two new deafies were hired and the human resorce lady asked me to interpret to them for her ,, I told her Im sorry , cant to that cuz Im not expert lipreading and better off to call and ask for interpreter.. The leader said okay and she did ... I dont like to be asked to interpret for human resorce and I believe she wanted to save money.. thats all ,,
199	Look forward to seeing the results of the survey! Great questions. Keep it up!
200	Great survey - Good job
201	Just try your best. It worked for me when i work hard for myself
202	I myself "GLUE" to VRS! Most Interpreters are doing their job greatly! Smile!
203	Interesting. Curious to see the results of the survey.
204	I enjoyed the survey and would like to take more surveys of this nature.
205	Might be better to provide examples of situations, such as when you would not advocate for yourself -- different situations might warrant different responses. You might get better data for the survey from seeing how people might respond depending on the situation
206	Great survey. Please have the signer in your video use a more authentic ASL structure. She signs very closely with English's structure and mouths English words all the way. I need to see adjectives and adverbs on the mouth, ASL mouth morphemes, which are the authentic ASL. Thank you.
207	Self-advocacy's imperative! But some needs to be educated about advovacy!
208	N/A. // Thank for answers this survery for you.
209	Provide for our deaf communication access now and the future with FCC.
210	I don't know , give us try...It's really new to me for this....thanks you !

211	I like that method for survey. Thank you. :-)
212	NOT EVERY BODY HAS THE VRS PLUS I USE MOST A TTY .
213	I want to say that your survey with your video is excellent and clear for many Deaf people with limit education who would answer your survey. Thank you for developing your project.
214	I am a leader of small group in very small town and it's hard to find certified interpreter to serve us legally but we have a really good friend who can sign fluently and she did wonderful job for us in almost every meeting with law and hospital. We mostly use computer and VP for our communication with both hearies and deafies...
215	IT IS NICE TO HAVE VIDEO WITH SURVEY. GOOD JOB.
216	Hope help others !
217	Thanks You For Your Information Survey-CSD or Other New Things. I really learning about that.
218	please develop a self advocacy program for Deaf teenagers as well as better to train them when younger.
219	Hard of Hearing advocacy needs are different from ASL cultural needs.. VRS with VCO, speech, speechreading needs to market BETTER to HoH community... Are you planning to make a tape of how HoH can advocate via VRS VCO, etc.... HELP team at each VRS should have at least one person who is familiar with VCO and can talk freely with HoH. (Having all deaf member HELP team is limiting the market to HoH quite a bit....)
220	I would like to watch your video about advocating information again. It has been a long time. I need some new update from you... Thanks
221	Sometimes it's too much effort, time, energy to advocate for myself because in my job I do a lot of advocating -- I just would like to be taken care of once in a while. And it takes a lot of gumption to stand up and say, "You need to stop this.....I don't have equal access".
222	Self advocating is no good without strict enforcings on ADA Laws and ADA Laws Awareness throughout enforcement agencies, all lawyers, all judges and all legal systems per chamber of commerce. Deaf people are outnumbered and easily shoved aside and forced to endure endless delaying tactics. What works for Hearing People within the Legal System does not work for Deaf People is a state of totalitarianism reinforced by white collar terrorism.
223	I noticed that there was a question on your survey about "why don't you like to advocate for yourself?" Well, you should have two questions. One question for people who don't like to advocate for themselves and question for people like me that like to advocate for themselves.
224	I am very happily for truly your supportives of the Deaf/hard of hearing Advocacy. I need be requesting for an interpreter services for a job interviews, go to courts or in hospitals or different things. I am truly understand do private informations for ur supportive an interpreters with a hearing people also I really accept them make clearly do understanding with each others. I really happily and u need some helping me to do best way for explaining about things. Please be happily and always very respective and very deeply with our customers or employements too. Have a wonderful day. Let me know about u but if can please send me by Email. Thank you for everything else then I will see u forwarding by yourself soon. Smile. I'm deaf adult person and I use my ASL and in second English language. Take care of it.
225	This was a great tool to use as often people just send words with not signing! Thank you!
226	We need more Surveys like this one but for every categories.
227	I work for an Independent Living Program, we provide services to deaf, hard of hearing, late deafened consumers. Just wished it would have better pay so that the consumer will get the best services available.
228	Very much good message...hope I could participate in workshop....Thanks
229	Thank you for asking me this survey.
230	I need to know that about information and what? and I'm not sure because you tell me that explain to what? you mean job or not? Let me know it and question it. Thank you
231	This survey is interested; one thing I like about interpreters is that they give me advices when I have problems about my friends, family, and other stuff. Cool survey ^ _ ^
232	nice asl survey

233	police dept. need an interpter when any problem arise in deaf community.
234	Sometimes when you are faced with an emergency, or something pertinent in your life, it is often difficult to take the energy to advocate yourself. The availability of interpreters, the quality of interpreters, or even the professionalism of interpreters are also the barriers of why I don't often ask for interpreters at times of need.
235	No comments. Thank you for the survey
236	No Comment
237	thank you for this survey!
238	We need to understand the hearing perspective as the majority of hearing have never met a deaf person, let alone know how to serve them correctly. Perhaps have a hearing myth busters as part of self-advocacy. I look forward to seeing this advocacy project come out as it is much needed!
239	great bi-lingual survey
240	none
241	Hi Larry from a former class of 1971er
242	Very Cool! I like it very much!
243	no comment
244	thank u help me video give to me easy for video understand i have vp give to u my vp is xxx xxx xxxx for situation question everything ok let know thank u help me ok
245	Thank you for sharing your survey with me!! Am a student at san antonio college taking sign language 2.On my Final xam I got a B..I really enjoyed!! Will return again the fall.What class? Visual Gester Communication.. P.S.Wish could have more C D;S,D V D,VSH,ect,to practices signing.At public library its hard to find it.Do u know any website?? Thank you!! Bye!!
246	Good luck with your survey :)
247	Interpreters should be required in most cases to avoid being involved in court. Improvement in recruiting ASL interpreters is needed.
248	i dont know what i say ! But I hope so interpter need more improve and also dont need tell everybody about who someone !! likely stable back who name that why better shut up mouth and dont need tell everybody what the problems !!
249	whom may it concern, Must interpreter, I have right for VRS for deaf and hard of hearing. we need communication each other on VP for important doctor, meeting, emergency, police and etc. FCC can't cutour VRS. FCC dont dare to ignore deaf people like in 1950 anymore. Everything new tech for us, deaf and hard of hearing that who excite on VP and VRS. It's really very important to us present and future for VP. It is worth better than tty We need to understand very clear thru VRS what is going on with my doctor, meeting, job, emergency etc. Please dont ignore deaf community in the world. Thank you
250	I hate that when (CSD) interpreter called and said they can not make it two hours before my doctor appt. the clerk asked if i want to make another appt.. I can't do that because it will be another two weeks to a month before I can get in.
251	I would like to see Deaf Advocacy Training spread and come to Allentown, PA because Allentown really need Deaf Advocacy so bad. It's really great to see this plan and hopefully it will come true someday. Thank you for working so hard to research! Wish you succeeded!
252	Had fun answering the survey questionnaires.
253	I'm very much looking forward to participating in this project. I am Deaf and I am the president of a local Deaf organization geared towards self-advocacy and the rights of individuals in the local Deaf community. If you would like to contact me directly as to how I can help your project in this area, please contact me at xxxxxxxx. Also, if it is okay, I would like to post your link to our website. Please check it out if you have the chance. Thanks you
254	Please tell all Deafies to please make good use of interpreters... Writing on pen and paper is cheap and not

	equivalent to using interpreters which will provide much more information. Also Deafies need to know that it is not usual or normal for hearing people to use pen and paper. It will reduce tolimited communication and info.
	Thanks!
255	So great to have this kind of the survey.
256	That's All I say
257	Deaf community in the south, eastern and western is really far behind with just about every needs compared to central and northern KY. Because of the larger cities and the Capital is up north. I would very much like to work in any service-in anyway to serve most of the Deaf/Hard of Hearing of South, Eastern and Western KY. I live right at the South Eastern KY. We have an organization for our area - meet about 8 times a year - money is tough for rental and other assistance needs. Thank you.
258	need send to dr to interputer that we need with us so send dr to videphone for deaf need talk dr.
259	i am doing training in emergency prepardenss in the community in case of terriost bombs,floods fire earth quakes educate public and deaf and hard of hearing and deaf blind people where to go in case of crisis happens
260	generally, people look down on us when we advocate like we are nobody. It makes it harder for people to listen to us, thus the reason a lawyer is more effective. However, most of us are poor and cannot afford a lawyer.
261	I am born to became a deafness. I was one years old
262	Hello, We live in the West Texas Of Midland, Tx and the we need to find more deaf and Hard of Hearing some of them hiding and not familiar to be moving from the state and some stay at home and not to attend the church or association for the social time that we will love to survey more of them in our deaf community to service for the better social and church in West Texas in Midland/Odessa, Big Spring, etc. Sometime we went to Lubbock for social once a month in one year....Thanks
263	Need in Eastern Shore and Western MD (ie, Washington, Allegany, Garret counties) more trained job coaches, DAWN centers and we need to collaborate more with other disability(challenged) groups. The 3rd grade/4th grade reading level is a national disgrace. We need more Deaf/HH socialization -- especially in areas not Baltimore or DC or Frederick.
264	What a GREAT survey with the use of Interpreter in the screen with questions to click on. I am impressed! I look forward to further information to learn how I can participate to get the word out on Deaf Advocacy uses of Interpreters.
265	I completed this on behalf of my brother who is deaf. He sent it to me and I felt I should respond. Unfortunately, I have seen first hand, this group of people get treated very poorly from more agencies than can be mentioned here. Families try to help, but with privacy act and medical privacy, it becomes a nightmare and they get taken advantage of.
266	This is a great idea. I look forward to seeing this soon.
267	It is awesome to see an interpreter along with the questions to help others who cannot understand English well.
268	The deaf community in rural area really needs self-advocacy trainings. I am VR counselor and I have empowered them to do their part (depending on individuals). I have worked closely with Hospitals here in our area and they have improved the services for the deaf and hard of hearing. This deaf community needs to learn to do self advocacy to get interpreter service for DR's office and other setting.
269	I appreciate this survey. This is definitely needed! I hope this would be helpful for Deaf people who have to work with the interpreters.
270	I am hard-of-hearing but I also communicate in sign language. Often when I am training with other deaf colleagues I utilize the interpreter for clarity becuae my hearing aids along with the acoustics of certain environments prevents me from being able to understand what is being said. I have just come into the knowledge that I can request a ASL interpreter for my communication needs.
271	please provide and promote information on upcoming self-advocacy workshop in Arizona or wherever one is provided. I am interested. Thank you.
272	A definition of "self-advocacy" at the outset of this survey would have been helpful. If you intend that "advocacy" focus solely on my ability to demand an interpreter (as a previous question on the

	survey suggests), this would limit my involvement (and interest) in your training quite significantly.
273	DO YOU HAVE INTERPRETERS INFORMATION. I WOULD LIKE TO CONTACT INTERPRETER WHO SUPPORT MY WORK AND CHURCH THANK YOU
274	yes we need for Interpreting like go to Dr. make health my goal. and other police need sign language we need the .
275	I am not a deaf or HOH person, I am an IL worker who assists pwd's and thought it would be helpful to send this survey.
276	Thank you.
277	I feel the need to take ADA and Adocate workkshop to gain the knowledge of ADA and how to become better adocate. Besides, I just approved to add new duties to become the Adocate to assist deaf and hard of hearing people. I work for deaf living skills agency. I need the education to gain the knowledge. I hope you can help me to provide that information. Thanks.
278	It's best service CSD than sorensonvrs relay service because very good quickly interpreting CSD relay service vp that cool..
279	Thanks for doing this survey!
280	I enjoy this survey;I will start the ITP in the spring of 2008
281	In Delaware is the first state and they are still lack with Deaf and hard of hearing people needs....can someone educate those people how to provide interpreters for the deaf and willing to hire them a job without being discrimination?
282	I would love to participate more than just 20 questions. Hope you can contact me thru xxxxxxxxx@xxxxx.com and upgrade information
283	I believe many in the deaf community need this kind of training. I know I would appreciate learning how to self advocate. I have done some, but there are times when I feel I'm stuff between two 'guns'; the catch 22 .
284	beautiful sign video. Great job!
285	I said I wouldn't attend an advocacy training because I know how to advocate for myself.
286	I would like to thank you for this survey.
287	Very well done; needs to be dispersed to minorities
288	I wish ALL the interpreter would use their lip/speech while they sign. I depend mostly on lip reading and most interpreter forget to move their mouth and I miss alot what was saying. I think this should be required to learn to do both lip reading and signing at the same time. thank you.
289	no comment
290	You might want to consider asking for more demographic info i.e. income, employment, employment in or out of field of training/expertise/degree, whether or not respondent's community has a deaf or deaf-friendly service agency I also think it would be helpful to ask if respondent's employer(s) provides communication accommodations
291	I represent the National Council of Hispanic Deaf
292	easy to use this survey. best wishes
293	Thank you for the opportunity for me to take the survey. I hope this will be of help to you.
294	Create a Training for Educators to learn how to teach/support students to be self advocate
295	Very good questionnaire!
296	I am using mac that not able to see your video here. Make sure you use other program that both pc and mac can see video. Maybe mac can see your video but I may not have this kind of program. Not sure what program. Better have videotape at the library so everyone who have or not have computer can see tape. Make sure to have tty and vp number included in case we need to call for any questions. Thanks
297	I would like to have the same two or three interpreters for my agency so they and I know my routing work style instead of having different interpreter number of times. Interpreter and I are fitted in signing like that.
298	it two thing important in emergency room and Eduaction for deaf children that an interpreter will always be there for in case.. Also, deaf children need an asl interpreter for eduaction..Also need asl interperter in court @ Ohio.. It very poor heARIN G PEOPLE DOES NOT KNOW IR NOT RESPEONSIBLE TO GET ASL INTERPRETER IN JUDGE OR COURT EVERYWHERE IN OHIO.....PLS HELP DEAF PPL, UJ KNOW THAT HEARING PPL

	IGNORING DEAF PPL WHO NEED AN INTERPRETER THAT IS BIG PROBLEMS!!!!!!!!!!
299	I don't use computer, my wife does She not deaf
300	June 14, 2007 This is an excellent survey for all Deaf Americans. This should be obtained and used by the Community Centers in many states. We have 10 in Ohio. A new advisory committee comprised of community center leaders and representatives from CSD would be helpful to get feedback and to give input on the proposed projects in the future. Sincerely, xxxxx from Ohio
301	Good to have this Deaf Advocacy Training survey
302	Give an option for individuals to say that they actually do advocate for themselves. I do so for myself everyday and that is what all people should do as it is one's responsibility to their self. The video didn't work for me which was ok. Maybe ask on a sliding scale or something what people use for communication. I use English 98% of the time but I am also comfortable with sign, and speech and sign. I like interpreters when I am in large groups such as graduations.
303	Video Interpreting Service's availability should be publicized to hospitals, clinics, lawyers, and employers in the areas where there is very scarce human interpreting service available. This way, it would open more venues for the Deaf and HOH citizens to take advantage of the new service thanks to new technology now available to everyone. High speed connection is getting widespread than before, therefore, we should grab this opportunity to spread this information.
304	There is a deaf inmate who is illiterate (can't read, talk, type, write, and sign ASL) who was arrested without an interpreter.
305	Wonderful!
306	I suggest that deaf people who can make a new friend w/ hearing people because they can use their sign language and need to communicate/learn together each other in the success future
307	I suggest you that all interpreter have workshop 10 credit per year improved sign
308	to access (everywhere) the TDD and need to hang on picture of ASL interpreters on the wall in business building so that a deaf person's act of pointing with a finger for requesting in providing ASL interpreter If the business office won't hang on pictures of ASL interpreters in DR's office, how can a deaf person to request for? They could or can't ask for providing interpreters if no pictures on the wall
309	Hello interpreter r good job and hard work pls keep still and don't give up.. Becuz deaf pplez need interpreter for vrs... thank u smile
310	very good survey but you should use "lipread and sign" instead of "speech and sign".
311	Thank you
312	I feel not enough people and businesses understand my need for an interpreter especially in this area of Carroll county where there are few deaf people and no one advocates for themselves so the business will think if it good enough for other deaf not have interpreter then it good for me too but it not!
313	Please consider the special communication needs of multiply handicapped deaf people. I have unique communication needs and not all certified interpreters are capable of doing a good job for me. (This survey was transliterated by a certified interpreter.)
314	I WAS HAPPY TO MEET YOU .. GLAD TO BE OF HELP AND LOOK FORWARD TO GOING TO COLLEGE TO GET MY DEGREE AND WORK WITH MY FELLOW PEOPLE IN THE DEAF COMMUNITY!!
315	Very informational survey I enjoyed it and learned somethings about myself!

Appendix C. Focus Group Assessment Tool

The goal of this project is to identify and validate effective practices or methods needed to educate the Deaf Community regarding its rights to communication access as it pertains to interpreting. On a national level, CSD will conduct a comprehensive needs assessment to: 1) determine the type of advocacy information that the Deaf Community should know to self-advocate for their communication rights as it pertains to interpreting and 2) determine the most effective methods for delivering (teaching) this information to the Deaf Community.

Activities will be national in scope and reflect the geographic areas served by the National Consortium of Interpreter Education Centers. This geographic area includes all 50 states and the territories of Puerto Rico, Virgin Islands, Guam, and the Marshall Islands.

All questions will be provided in ASL for focus group discussion.

We will now provide three typical situations that may happen every day. Your comments and feedback will be requested.

Scenario I:

You make an appointment to meet with someone at the Social Services Office and request interpreting services for the appointment. You show up on the date and time of your appointment. However, no interpreter shows up.

How do you feel?

What do you do?

What should you do?

Scenario II:

You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. There's communication break-down because interpreter has a difficult time following and understanding you. You must stop, start, stop, and start over and over.

How do you feel?

What do you do?

What should you do?

Scenario III

You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. The interpreter does a very good job and communication is easy, comfortable and fluent (accessible) throughout the assignment.

How do you feel?

What do you do?

What should you do?

1. What skills will help the deaf, deafblind and hard of hearing consumer resolve the situation in Scenarios I and II?
2. Do you feel deaf, deafblind or hard of hearing consumers need to learn self-advocacy skills? Explain why or why not.
3. From your experience, what barriers prevent deaf, deafblind, or hard of hearing consumers from self-advocating effectively for quality interpreting services?
4. What is your understanding of your legal rights to an interpreter? (printed on a hand-out card for quick knowledge check)

Yes	No	When I go for doctor and or medical appointment
Yes	No	When I go for a job interview
Yes	No	When I go to a Tupperware party
Yes	No	When I take a class at a college, universities, or technical institution
Yes	No	When I go to a football game in a stadium
Yes	No	When I go to my child's parent/teacher conference
Yes	No	When I go to a poker game at a casino.
Yes	No	When I go to a city hall meeting
Yes	No	When I go to a state legislature committee hearing
Yes	No	When I attend a Mary Kay cosmetic party
Yes	No	When I go to court
Yes	No	When I go to church
Yes	No	When I go to see a lawyer
Yes	No	When I go to the police station
Yes	No	When I go to a restaurant

5. Education on how to self-advocate will be developed.
 - a. What is the best way for you to learn how to advocate for yourself?
 - b. If training was offered in the community would you attend?
 - c. If training was offered online would you take it?

Appendix D. Focus Group Results - Transcripts

Columbus, Ohio; June 12, 2007

Scenario I: You make an appointment to meet with someone at the Social Services Office and request interpreting services for the appointment. You show up on the date and time of your appointment. However, no interpreter shows up. How do you feel? What do you do? What should you do?

“I would reschedule or postpone the appointment.”

“At a Doctors appointment... they asked if I mind that they call for an interpreter and I wait for 30 minutes for the interpreter to come---I have to wait for 30 minutes.”

“It depends....for doctor appointment... I write notes. But with SSN office I will request to postpone the appointment.”

“Writing is too hard for me to understand.”

Deaf-Blind: “I hate the idea of writing.... I object. I will reschedule again for another appointment.”

“I have experienced staff telling me (pressure me) to go ahead with the appointment. Too important... so I have to communicate thru lipreading and/or writing.”

When interpreter doesn't show up... I can use the video interpreter. But if no video interpreter...I ask for a new appointment.”

“For example, at work... I don't understand the writing and reading. I am willing to do a little bit of writing but most of the time; I have no idea what they are talking about... I like interpreters—it helps me to understand better. If I have to, I will use my voice for short talks.”

“My opinion, writing is a battle... Doctors and SSN appointments can be very technical and sometimes the words they use I don't understand. I don't always understand. The language is too hard for me to understand. I don't want that experience so I will reschedule.”

“I make an appointment with the Doctor and if the interpreter doesn't show up, I may have no choice but to write.”

“One SNN office has a staff member who is losing her hearing. She is learning sign language and takes all of the Deaf people who come to their office. It would be easier and helpful if someone can really sign.”

“When the police approached me, there's no interpreter. No time to get one--what do I do? I had to write. That is a problem. I had to be patient and suffer. They said they tried to get an interpreter but the office is closed. I thought interpreters were available 24/7!”

“Where I work... I need to ask questions to the boss... I have to write...it is too frustrating! When we have meetings, I asked to schedule an interpreter. The hearing boss would ask why...I said I don’t understand and communications is not clear. Hearing people think I can lip read...it is so aggravating! I become so disgusted and my patience runs out!!”

“When there is an accident and the police was involved, some [hearing] witnesses will explain what happened but since I don’t know what they are saying, I can’t trust their statements.”

“Police often refuse and ignore my rights! They were very rude. Police say no time to get one. I need an interpreter to understand. Many of my friends feel the same.”

“At my doctor appt, they use Ohio Health interpreters—the doctors’ office will call for an interpreter. But one interpreter is not professional. I don’t want to tell her and hurt her feelings. I call Deaf Services Center but they don’t know about Ohio Health. I don’t have their phone number so it is frustrating!”

“What about cab drivers.... I don’t know how to communicate with cab driver.”

“For me, I play games with hearing person... If I can’t understand them and I have to write, I get the dictionary. I tell them I am looking for the appropriate word. The Hearing person gets frustrated with me—English is not my language!”

“Some of us get angry, emotional and lose control when there aren’t interpreters! I feel like I am helpless and have been defeated!” Then I end up not caring what happens!”

“Chiropractor won’t provide interpreters... we should have a right to an interpreter with all Doctors...but they won’t pay for it!”

Scenario II: You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. There’s communication break-down because interpreter has a difficult time following and understanding you. You must stop, start, stop, and start over and over. How do you feel? What do you do? What should you do?

“I like most interpreters but there is one who talks like she’s smart and thinks she knows everything! I am smart in health-related things but she had an attitude like she’s smarter than me—I was turned off by that! I want an interpreter who is neutral. I am interested in neutral and kind person with good interactive communications.”

“I feel like stopping the appt and requesting another interpreter but sometimes I am stuck with that interpreter. I get mad and disgusted. I, myself have anger problems. I have to ignore those feelings and learn to complain to Deaf Service Center or where the interpreters are from. It took me fifteen years in prison to deal with anger.”

“At one of my doctor appointments, there was an interpreter who had a silly attitude. She sat with her feet up on the desk with her legs crossed at the ankles—that behavior was not polite!

The interpreters used to have name badges but I don't see those anymore. It's hard to find out their names to inform the managers."

"I notice that I understand interpreters who grew up with deaf parents. They understand Deaf Culture and are more expressive. I don't have to explain what certain signs mean—they understand me. Those who did not grow up in the deaf community, they really don't have the full skills to be an interpreter."

"I don't like it when I have to watch an interpreter who uses English. I like CODA interpreters because they know ASL. The meaning gets lost... and it's a waste of time and I become disgusted with interpreters."

"How can I find out which agency those interpreters are from? I am afraid to hurt their feelings. We really need more professional interpreters."

"It's hard for me to communicate with my family...I feel bored and isolated because I can't understand their communications. They make me go to church and they don't have an interpreter. Why can't they get an interpreter? I get so frustrated!"

"For me, if I really like the interpreter I will ask them for their business card so I can remember their names and the name of their agency. Later if I need one, I can call and request for a specific interpreter. If I don't like the interpreter, I can protest and complain about them. I remember a situation when I was at Deaf Services Center for an appointment for tax services. They told me I was not blind and know that I can see them. I made an appt with the CEO of DSC to complain about the services. I wanted them to document in their records that I use tactile interpreters. I depend on them for interpreters and want them to screen their interpreters for my tactile interpreter needs. I don't want to be questioned if I am really blind or not."

"There was a new interpreter who interpreted my meeting at Target. She was a nice person but when I went to ask a question about a situation, the boss blamed her for the miscommunication. He did not understand Deaf Culture!"

"I will just reschedule and I say I didn't like the interpreter... it is not working out & need to get a different interpreter."

"I would say go find another interpreter."

"In a group situation where we meet weekly, I become frustrated when I get a different interpreter each time. The Sex Offender group complained about the changing of interpreters every week. The interpreters do not know the topic and I have to repeat & explain over and over every week!"

"I bring a friend or family member to come with me. If the interpreter is lousy then I have them interpret for me."

“I’ve attended many Funerals... a large percent of the Funeral Homes will not pay for interpreters.”

“Some of the interpreters I have had, I have to repeat myself ask again and again. I can’t believe that interpreter is being paid a lot of money! I don’t understand why they are being paid!”

“During group meetings, I don’t know what he is talking about—I don’t understand. My parole officer gets all confused with the information and they put handcuffs on me. So I have to watch the interpreters’ lips to make sure he is voicing me right. I have hard time reading the interpreters’ lips to make sure what they say are right.”

“CDI allowed? I learned what that is just this recently...it would be nice to have a CDI but would that mean they have to pay double??”

“I like to attend church with my family but there is no interpreter. They said they can’t help with interpreter. I sit there but I don’t understand the church services. I told the church I wanted an interpreter but they won’t do anything so there are no interpreters at the church.”

“I had a friend in the hospital. When the Dr. came in to see him, there was not an interpreter. What the doctor was explaining to him was a very important—it was about his breathing treatment. It was very frustrating and I had to calm down my friend. The Dr. wanted me to interpret for my friend. I was so scared—I am not a professional, I felt stressed and I don’t know where to go to get help!”

Scenario III: You show up at the Social Services Office for your appointment. The interpreter shows up for the assignment. The interpreter does a very good job and communication is easy, comfortable and fluent (accessible) throughout the assignment. How do you feel? What do you do? What should you do?

“I feel wonderful!!

“I feel good!”

“When I understand clearly, I feel good!”

“I am pretty independent when communications are clear & we understand each other!

“There’s no stress or pressure!”

“Relieved!”

“In court, I must have an interpreter... I like the CDI!”

“In court when there’s a trial with jury, there are two interpreters. They have a camera on the interpreters to make sure they aren’t off the point. There are different styles of interpreters that

caused a lot of confusion. When the interpreters switch, it takes time for me to get used to their style—sometimes frustrating!”

“When I go to the SSN office, and if my interpreter is good, I will compliment them. I will let the interpreter know that she or he was good. I will want to ask for that interpreter again. But the problem with SSN office, it is hard to let them know that I would like to use that interpreter again.

Other Questions

6. What skills will help the deaf, deafblind and hard of hearing consumer resolve the situation in Scenarios I and II?

“We should know what to do. The responsibility should be 50/50. I need to know what agency the interpreters are from, which interpreting agency they have a contract with. They are all different and I am confused. I thought Deaf Services Center was the only interpreting agency—but it is not true.”

“I prefer to see a name tag on the interpreter so I know who to complain about—that would be easier.”

“We need to learn about the law related to interpreting services and the interpreting code of ethics. Also I need to know what my rights are and the policies about this.”

“I remember when I called to get an interpreter for one of my appointments. They asked me if I wanted English, ASL, Tactile or Oral...I didn’t know they were all different.”

7. Do you feel deaf, deafblind or hard of hearing consumers need to learn self-advocacy skills? Explain why or why not.

Yes... I do.

Yes

I need learn to speak up for myself

I don’t know.

8. From your experience, what barriers prevent deaf, deafblind, or hard of hearing consumers from self-advocating effectively for quality interpreting services?

“Fight for your rights until you succeed! I finally got an interpreter in prison!”

“Fear”

“Habits—we’re used to relying on parents or other hearing people.”

“I tried to cooperate and work hard. I want other deaf to come to Target but hearing people feel very negative towards deaf and I feel discouraged.”

“How to combat the hearing resistance?”

“We need to teach hearing people that the Deaf really need interpreters, TTY or VP without having to fight so hard and becoming frustrated. How do we teach them?”

“It costs money.”

“I wonder why hearing people are so afraid of deaf and deaf-blind people? Why can’t they learn our language and make the world more equal?”

“I have experienced seeing many hearing people show their fear of deaf people ... we don’t bite them!”

“Experience of failure and oppression. There aren’t any resources and there’s a lack of information

9. What is your understanding of your legal rights to an interpreter? (printed on a hand-out card for quick knowledge check)

12 - Yes	0 - No	When I go for doctor and or medical appointment
12 - Yes	0 - No	When I go for a job interview
9 - Yes	3 - No	When I go to a Tupperware party
11 - Yes	1 - No	When I take a class at a college or technical school
3 - Yes	9 - No	When I go to a football game in a stadium
12 - Yes	0 - No	When I go to my child’s parent/teacher conference
12 - Yes	0 - No	When I go to a poker game at a casino.
11 - Yes	1 - No	When I go to a city hall meeting
12 - Yes	0 - No	When I go to a state legislature committee hearing
1 - Yes	11 - No	When I attend a Mary Kay cosmetic party
12 - Yes	0 - No	When I go to court
9 - Yes	3 - No	When I go to church
12 - Yes	0 - No	When I go to see a lawyer
12 - Yes	0 - No	When I go to the police station
1 - Yes	11 - No	When I go to a restaurant

10. Education on how to self-advocate will be developed.

a. What is the best way for you to learn how to advocate for yourself?

“ASL workshops.... That would be good. Deaf don’t understand big words or sometimes the computer crashed, just like mine just did! It also depends on what kind of workshops.”

“I am flexible--you can teach me one on one or in group but in sign language.”

“I like computers!”

“I think if I attend a workshop, I can learn from others—that would be good.”

b. If training was offered in the community would you attend?

“Of course!!”

“Yes, “

“Yes, Yes, Yes!!”

“This is an easy place to find so I can come and learn.”

“Yes, I am willing to come if I can have the same interpreters (Tactile interpreters for Deaf-Blind participant).

c. If training was offered online would you take it?

Most Deaf people don’t want online... but I like it because I am a book worm! It’s easy for me to learn from reading. I like written information because I can keep it and keep reading it over and over.

“I don’t like computers—I prefer people.”

“I want to learn with some papers with pictures--I like that. I want to learn more. I need bear down and learn!

Prince George County, Maryland; May 23, 2007

Scenario I

How do you feel and what would you do?

Walk out

Reschedule appt

Pissed off, waste of time, mad, upset

There is a difference if SSA vs. hospital – different reaction. Hospital more urgent.

What should we do?

Hire a deaf rep- most preferred choice or ASL signer (more empathetic)
SSA needs to hire full time interpreters
Train deaf consumers to keep up with laws, rules, and interpretations

Scenario 2

How do you feel and what would you do?

Feel small
Walk out
Reschedule

What should we do?

Interpreter should talk with SSA examiner. Talk to each other with client's involvement.
Less manipulative of the situation.
Client to explain why interpreter is not qualified to interpret.

Scenario 3

How do you feel and what would you do?

If the interpreter is good, go ahead.
The interpreter must be certified regardless
SSA to provide a list of interpreters for deaf clients to choose from even if it means
a delay in getting an appointment. A good interpreter is more important.

What skills will help the deaf, deafblind, and hard of hearing consumers solve the scenarios?

Underprivileged deaf consumers will not know any difference. They will accept the way it is.

If deaf leader and empowered, they will do differently. They may walk out or reschedule.

Need to educate low functioning deaf consumers not to bring a relative or family member to use them as an interpreter.

Deaf with low verbal skills should see qualified examiner who can sign or interpret to prevent being exploited.

Do you feel deaf, deafblind need to learn self-advocating skills? Explain why or why not?

Deaf need skills to learn how to use referrals. Learn to empower themselves. Be assertive. Learn to find resources.

Mentoring needed. Modeling from deaf adults.

Revise ADA resource book (pocket brochure) for deaf to carry.

Need more reading skills. Incorporate materials in Adult Education classes.

What barriers prevent deaf, deafblind, and hard of hearing from self-advocating for quality interpreting services?

Schools for the deaf do not teach students to be educated about their own rights.

Organizations, clubs and adults need to learn leadership skills

Mainstreamed programs tend to “take care” of deaf students by providing interpreters without really teaching them how to use interpreters. Students do not know the proper way to use interpreters. They are also their friends.

Deaf clubs are dying. We lose network through clubs and usually there is a great deal of information exchange that deaf people learn through them. They are being empowered through each other. Where can new young deaf adults learn from?

Providing freebies reduce the ability to know their rights. A distraction from standing up for their rights. Companies competing for services and deaf become passive.

What is your understanding of your legal rights to an interpreter?

Medical – most clients do not know their rights. Most doctors do not want to provide interpreters. Deaf patients need to know the options.

Job Interview- yes they know to ask for an interpreter depending on which company. Most government jobs should provide interpreters. Legislative Branch agencies are under ADA and many people do not know. Judicial, and Executive branches are under Rehab Act 504.

Tupperware- many do not know that they can request for one if this is for distributors.

Colleges and Universities- yes many would know that they must provide interpreters. Some private colleges are not required to provide interpreters. How can we educate deaf students they have the same right?

Football stadium- under Title III. They need to learn they have the right to captioning. They cannot hear announcements. What will patrons do? Need training for professionals to educate deaf community.

Parent conferences- yes, they are required to provide one. Most deaf parents know that.

Casino/Poker – some do not know they can ask for one. Need to focus on reading skills

City Hall – yes, they need to know procedures. Government needs training how to serve deaf consumers and they need to understand bidding process for interpreting services. A 2-week request for accommodations can be unrealistic.

State Legislature –yes, but more places will use computers which mean more deaf people with low verbal skills will not be able to follow. They need reading and writing development skills. More training is needed.

Mary Kay Cosmetic party- same as Tupperware. Still need to get more info whether or not deaf can request accommodations.

Court – yes, however more training is needed for deaf consumers on procedures, certification levels, etc.

Church- no not required, but do deaf people need training.

Lawyers- deaf people need education. Lawyers need to be educated. Consumers need to be empowered. Learn to negotiate.

Police- training is needed for deaf consumers. Know their Miranda Rights and use interpreter is necessary. Provide interpreters at police station. Police need training as well.

Restaurants- no they are not required to provide interpreters except when they have public functions. Need training.

What is the best way to learn how to advocate yourself?

Home experience from parents

School

Adults share stories with children about life

Camp experiences

World/travel experiences

Reading

School share stories/history/culture

If training was provided, would you attend?

Change wording from an option to mandatory for ALL. Need ASL master signer if offered online for deaf to follow new information. Depends on deaf person's English skills.

Frederick, Maryland; May 31, 2007

Scenario I

How do you feel and what would you do?

Pissed off, fuming

Waste of time, took off time from work

Nothing new

Sign to receptionist – “you get the point” (receptionist do not know signs).

Mad, upset, disappointed

Reschedule and ask receptionist to confirm my appt for my next appt. (I showed up the office for nothing)

Wait for 15 minutes and if no show then leave. Make another appt.

Please reschedule the appt to tomorrow (demand that the receptionist get an appt fast); wait until new appt has been confirmed before leaving SS office

Give SS the interpreting agency their phone number to call (more guaranteed)

If receptionist does not have the interpreting agency’s phone number, have them call 411.

What should we do?

What are federal mandates? ADA mandates? Find out.

Scenario 2

How do you feel and what would you do?

Change interpreters

Reschedule

Depending on the appt if interpreter is acceptable or not

Ask interpreter if s/he is certified; find out who the interpreting agency is and complain to agency not to send non-certified interpreters.

Tell the interpreter you need more training

Clients need to tell interpreters not to assume responsibility and role as a deaf client

What should we do?

Include form for agency and SS office to identify and screen interpreters in order to match clients’ needs.

SS office should ask clients if they want an interpreter for their meeting. Some deaf clients get upset if an interpreter was arranged.

Deaf clients need training on accountability.

Scenario 3

How do you feel and what would you do?

Feel good

Thank the interpreter

If good interpreter, but client failed to get SSDI, they should not put blame on the interpreter.

Tell SS examiner that the interpreter is excellent. Tell them to use the interpreter again.

Interpreter should receive compliments.

What should we do?

Educate the examiner that there are good and bad interpreters. Inform them of RID certification requirements, etc.

Deaf people need training. Some deaf feel obligated to bribe or give something back to the interpreter.

What skills will help the deaf, deafblind, and hard of hearing consumers solve the scenarios?

Yes, most deaf people need training.

More training is needed for deafblind.

Need role clarification for SSP/Deafblind interpreter

SSP training is needed. “Feed and Care Interpreters” workshop

Skills training needed: assertiveness, positive approach, role of interpreting, ability to

Understand people (sensitivity training), be more informed, and learn to respect interpreters,

Need training how to work with interpreters, teamwork skills with interpreter and deaf person

Do you feel deaf, deafblind need to learn self-advocating skills? Explain why or why not.

Deaf people tell other deaf people to accept the way things are – “settle for less”

Many are not aware of their rights (teach them)

Not enough use of interpreters

Hearing parents need more training –advocate their deaf children the right way

What barriers prevent deaf, deafblind, and hard of hearing from self-advocating for quality interpreting services?

Interpreter’s role takes over and set precedent for meeting. Not good. Need to work with deaf people. Educate them about empowerment

Oppression – lack of knowledge from deaf consumers’ part

Deaf consumers hold your feelings- not good – so used not to speak out.

Consumer education is needed mostly for those who are deprived from good education at home and in school.

What is your understanding of your legal rights to an interpreter?

Medical- yes doctors need to provide interpreters but most doctors ignore or do not practice ADA. Why should doctors pay for interpreters? Interpreters are needed depending on the type of appointment.

Job interviews- if interpreter will not be provided, consumers assume they will have to pay for interpreter. Yes deaf people need to ask for interpreter. It depends who will pay for interpreter. Ask Human Resources department if they are required to pay for interpreter if supervisor says no. Need training.

Tupperware- no, the company is not required to pay for interpreters. If high level meetings for distributors, then the company is entitled to pay for interpreters. If it is a demo party at home, the company is not entitled to pay for interpreter.

Colleges and Universities- yes, it is a must. If private college, then there are some sticky questions. Other say it is mandatory that all educational institutions must provide interpreters.

Football Stadium- not required to abide ADA. Yes, public entities should follow ADA. All public entities can make accommodations.

Parent conferences- yes the school is required to provide interpreters

Casino- no, they are not required to provide interpreters. Yes in Las Vegas. They have performances and they are required to provide interpreters.

City Hall- yes they are required to provide interpreters. Government system.

State legislature – yes, some deaf people do not want interpreters so they can get waived (i.e. traffic court). Yes and no. Need more info.

Lawyer- yes, lawyers should provide interpreters. Abide ADA regulations. Similar to medical settings. A must. If interpreter is denied, file complaint with DOJ. Most deaf people complain to each other. They need to take action.

Police stations- yes they are required. The bad part is they call their family members to interpret. Or they call another police who can sign to interpret. Very bad practice. Also deaf people need to know their Miranda Warning Rights

Restaurants- no they are not required. If restaurant has a theatre, they are entitled to get one. If it was a fundraiser activity the restaurant will need to cover it. Public accommodation.

What is the best way to learn how to advocate yourself?

- A. Training for community members
 - Role-play activities, use situations to incorporate info
 - Avoid using PP
 - Provide workshops

Website, brochure

Video in ASL

Online not for deaf people with low verbal skills. VLog may work. Host VLog party for those who do not have computers

B. If training was provided, would you attend?

Yes, also training for middle and high school deaf students is needed.

Deaf adults need training as well.

Tulsa, Oklahoma; May 18, 2007

SCENARIO 1:

How do you feel?

Pissed because no support, they don't understand

Not surprised.

Waste of time

Frustrated,

Feel like punched in face

What do you do?

Complain

Why didn't you provide?

Feel like others do for us

Make repeating appointments

Make prostrations

Scheduling

What should we do?

SUE them

Complain

File complaints

Contact TSHA to give an explanation why interpreter did not show up or to response to the complaints

SCENARIO 2:

How do you feel?

Frustrated

Miscommunication

Pissed off

No patience for BS

What do you do?

File complaint

Give the lousy interpreter a dirty look

Do not want to go into it again with lousy interpreter

Ask to reschedule with different interpreter

What should you do?

Interpreter should know better to accept job or not if can interpret or not

Make sure get right level of interpreter certification for that situation

Explain why interpreter not qualified for this situation

SCENARIO 3:

How do you feel?

Happy

Feel good

Very satisfied

Satisfied service

What do you do?

Praise let them know you appreciate it (everyone nods after this person made this comment)

What should you do?

Nothing

Show praise to interpreter

Don't take for granted

Kiss interpreter (joking)

What skills will help deaf, deafblind or hard of hearing consumers to resolve the scenarios?

Need to educate the consumers on civil rights

Become more informed

Need more advertising

Need more materials

Distribute because there is nothing out there for us to use and learn

Too much legal information is confusing

Don't feel like fix the problem - too many headaches to fight

Don't have time to fight for our right

Don't know how

Do you feel deaf /deafblind need learn self-advocating explain why or why not?

Yes

Some don't know how stand up for themselves

Need to teach them

Need role model

Need proper outlet for situations

Materials hard to understand and read – need simple ASL video or easy read materials

From your experience what are the barriers preventing deaf, deafblind, hard of hearing from self-advocating for quality interpreting services?

- Money
- Interpreters always think for themselves and forget the deaf people – feel oppression from the interpreter community
- Not enough information where to complain – no materials tell us where complain DOJ is too hard understand
- Interpreting service has too much power and control deaf people
- Agency does not care about us if complaining about lousy interpreters. They care about interpreters more than consumers because they make money from interpreters' work
- Interpreters control clients in appointments
- CONFIDENTIALITY – BIG PROBLEM
- Won't ask for interpreter because of breach of confidentiality
- Need stronger grievance process who to file, who to go to
- Make sure code of ethics are complied
- Afraid if file complaint, it won't be confidential and cause problems
- Wants stronger sanctions against those who breaks the code of ethics
- Fear of possible revenge from interpreter is a problem (retaliation)
- Attacks culture – put interpreters needs over consumers
- Interpreter not taking interpreting seriously
- Attitude should reflect action – support consumers
- Interpreting agency always listens to interpreters' complaints and ignores consumers' complaints because they depend on interpreters to fill in all assignments to make money
- Consumers are not making money for them
- Deaf should have code of ethics same as interpreters so deaf feel more power over interpreters

What is your understanding of your legal right to an interpreter?

- Lot of clients don't know they have rights to ANY interpreters
- You can say you don't want that interpreter (strongly agreed by several)
- Have right to get transliterate instead of ASL
- Need explain legal terms more of our rights – not understand it and not clear
- CODE of Ethics I feel interpreters have power because they have code of ethics while deaf don't have anything like code of ethics - means should make one for deaf showing we have rights to which interpreters and which agencies to use

What is best way for u to learn how to advocate yourself?

Education workshops

Use small group – not big audience

Do not like large group with big audience

Food provided – people will show up
Help pay mileages for those who live far
Small groups is better than large group
Small groups easier to listen and focus better
Large group hard to follow and too many people discussion
Better group discussion in afternoon or early evening - not morning
Prefer interactive group discussion - not lecture coz too boring
Prefer discussion and activities – role play and open discuss ideas

If training was provided in community will you come?

See above – answers apply

If training was offered online would you take it?

NO.

Lack of human contact
Don't have time to sit and don't like stare at computer all day to look at video online
Too boring
What if have question and can't ask anyone
Maybe live chat good for discussion and share
Lack of resource – high speed internet not available in my home (live in rural area)
Time consuming to try fix video clip if computer is old and slow
Not accessible for those without computer

Sioux Falls, South Dakota; July 6, 2007

For Scenario I, the participants all responded with feeling upset, irritated, or disappointment. As for what to do, most responded with leave, reschedule the appointment, approach the receptionist to inform her that I've been waiting, or contact the interpreting department and asked if they were contacted for an interpreter. Participants felt that they should contact the interpreting department, ask questions of the SS office and the interpreting department, and file a complaint.

For Scenario II, the participants all responded with feeling embarrassed, disgusted, angry, and frustration. As for what to do, participants responded with reschedule the appointment in order to get a different interpreter, ask for a different interpreter, explain to the caseworker that the misunderstandings and time lag is because of the interpreter, and demand to have an interpreter of my preference. Participants felt that they should inform the interpreting department of preferences for interpreters and inform the director not to use that interpreter again.

For Scenario III, the participants all felt appreciation, great, pleased, and satisfied. As for what to do the participants responded with giving compliments to the interpreter, ask to have that interpreter from here on out, and give thanks. Participants felt that they should give compliments,

ask to have the same interpreter for next time, and give recognition with the caseworker's knowledge.

Question 1: The participants felt that one may feel helpless in these situations so the best thing to do is to get involved. Getting involved gets results.

Question 2: The participants feel that each and every one should know how to self advocate in order to be able to speak up.

Question 3: Barriers such as not receiving necessary information, lack of quality interpreters, not following the consumer's preference, and the variety of interpreting services here in Sioux Falls.

Question 4:

Doctor and/or medical appointment: YES: 9 NO: 0

Job interview: YES: 6 NO: 3

Tupperware party: YES: 2 NO: 7

Class at a college, universities, or technical institution: YES: 7 NO: 2

Football game in a stadium: YES: 0 NO: 9

Child's parent/teacher conference: YES: 9 NO: 0

Poker game at a casino: YES: 0 NO: 9

City hall meeting: YES: 8 NO: 1

State legislature committee hearing: YES: 8 NO: 1

Mary Kay cosmetic party: YES: 1 NO: 8

Court: YES: 9 NO: 0

Appendix E. Interview Assessment Tool

The goal of this project is to identify and validate effective practices or methods need to educate ways to the Deaf Community regarding its rights to communication access as it pertains to interpreting. On a national level, CSD will a comprehensive needs assessment to: 1) determine the type of advocacy information that the Deaf Community should know to self-advocate for their communication rights as it pertains to interpreting and 2) determine the most effective methods for delivering (teaching) this information to the Deaf Community.

Activities will be national in scope and reflect the geographic areas served by the National Consortium of Interpreter Education Centers. This geographic area includes all 50 states and the territories of Puerto Rico, Virgin Islands, Guam, and the Marshall Islands.

1. Explain your background and experience working with the deaf community.
2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.
3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?
4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?
5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Appendix F. Expert Interviews - Transcripts

Expert Interview #1

1. What do you believe Deaf community members need to know in order to advocate for their communication rights as it pertains to interpreting?

Hearing people are accustomed to using the phone as a normal part of their lives. They use it regularly and without thought. I was talking with my friends... and interestingly, we shared that many Deaf people will say to the VRS Interpreter, “do you mind if I made one more call or a couple more calls?” Why do we do this? We pay them for their services. We should be able to feel that we use the service at any time we desire even if its all day. It is our right. But we (Deaf) are not aware like the hearing people are in relations to our phone use.

My opinion really depends on where the Deaf individual is from... My frame of reference is from Little Rock, Arkansas – which is a small rural town. The resources are limited. In larger cities if one has a complaint, they can call the interpreting agency for assistance in advocacy. In Little Rock, you don’t have that option. We have a referral agency but no physical office where a Deaf person can go to. People will need training to fit the type of “options” they have where they live. When an advocacy situation comes up, they need viable and clear options to experience successful advocacy.

2. From your experience in the Deaf community, describe best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why is it successful?

The key to successful integration of advocacy is teaching the information in American Sign Language. I am not talking about college level information but to design the delivery of information to work with grass roots Deaf folks Be aware of the demographics of the individuals. Again, I am referring to the small rural grass root deaf individuals that I know in Little Rock. These individuals need to obtain information that matches their experience and knowledge. A personal experience illustrates this example.

I serve on the Arkansas Association of the Deaf board. The members wanted a workshop on ADA and Advocacy. We brought in a person from an interpreting agency that was knowledgeable in this area. This person was Hearing but signed well enough. We noticed that the information conveyed to the Deaf participants did not truly make a connection or encourage integration of the new knowledge. The information was lost and the participants felt uncomfortable. We scheduled another workshop but this time with a Deaf presenter. The Deaf audience was able to connect with the presenter readily. The information was shared in their language and in their culture. The content was delivered in simplistic concepts and incorporated concrete, real life examples. The workshop included role plays. Role play is an important effective method. Another consideration is being very aware of the existing resources and options for the individuals residing in their area of residence. For examples, in Little Rock, many hospitals will refuse to provide interpreters. What are the options for Little Rock Deaf residents? Often, they are left to advocate on their own. This does not always happen regularly.

3. What kind of training would be necessary for deaf community to embrace self advocacy? What are your recommendations for effective training?

I want to mention certification issues. In interpreting training programs, pursuing and preparing for certification has always been a priority. Deaf people are not “trained” about certification. We don’t think about it. Deaf people need training about this issue. Not only in this issue, but understand what is a certified interpreter?

Many video relay services are underused by Deaf people. For a number of reasons, there is a lack of confidence, understanding of how to use interpreters, fear of not being understood, language issues, and being judged how well they sign in the eyes of the interpreter. They feel self conscious about signing to an interpreter. This is more prevalent in the Black Deaf community. NBDA is our Black NAD. So who you see here are those who have jobs, education and money. Most likely, they use VP and interpreters. Those who are not here, do not. Granted, there are grass roots Black Deaf leaders here but they do have money, jobs and education. The gaps are wide for the Black Deaf community. The black deaf individuals will hesitate to use interpreters. There is a lack of attention to the black deaf community in terms of education and advocacy.

An important issue to keep in mind is that there are very few black interpreters. This results many Black deaf not using interpreters to facilitate communication. The issue of trust and empowerment is challenged.

4. Do you think advocacy training for deaf community members would change behaviors? Why or why not?

Yes. If the training is done correctly – in American Sign Language, by Deaf presenters with concrete examples and role plays to integrate application and practice. You cannot just do a “lecture.” It must be a hands-on learning experience to “learn and apply the skills.” This type of training will enhance the confidence and knowledge. You have to realize this may be the “first time” they have received or learned this information.

Recommendations:

- Check general literature in relations to: Social Skills Training and Problem Solving Training. Refer to University of Arkansas’ website. Steve Boone has authored a number of articles. It may not be “downloadable”.
- Check with National Council on Disability. The website is www.NCD.gov. There are excellent articles in relations to “advocacy.” Check under publications and newsroom. The articles are downloadable. This expert feels the disability and advocacy articles can be very applicable to Deaf individuals.

Expert Interview #2

1. Explain your background and experience working with the deaf community.

This Deaf expert has a background as director of a non-profit advocacy agency addressing communications access, and experience overseeing state services for the Deaf and Hard of Hearing.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

The Deaf Community members need to know how to make better use of their state organizations, such as state associations of the deaf, when it comes to advocacy. Deaf Community members need to know and understand there is a great need for more Interpreter Training programs in each state. There's a need for more ASL classes. They need to understand just because a hearing person is a good signer doesn't make him/her a good interpreter; just like a deaf person being a great signer doesn't make him/her a good ASL teacher.

Deaf Community needs to understand that not all interpreting services is free. If they want an interpreter at a family function, the deaf person or the family is responsible to pay for interpreting services.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

Interpreting Training Programs need to offer training or classes Deaf Community members. Deaf clubs throughout America are not what they used to be. Deaf, deafblind, and Hard of hearing individuals need to get information via ASL Classes, Interpreter Training Programs rather than at the local deaf clubs.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

Workshops on the difference between a certified interpreter and a qualified interpreter; Panels of interpreters to provide feedback to deaf community members and vice versa; and, Deaf Community members need to understand there is a length of time for interpreters to develop good skills.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes, as long as the training is done in groups (face-to-face). On-line training is good as you will hit more people in remote areas. However on-line training will not be as effective because there would be very little or no interaction.

Expert Interview #3

1. Explain your background and experience working with the deaf community.

This Deaf expert's background includes director of the Kentucky Commission for Deaf and Hard of Hearing, extensive involvement in the National Association of the Deaf, as well as additional experience in organizations related to interpreting and teaching ASL.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

Basic knowledge on how to use an interpreter

Knowledge of what is acceptable and what is not; should know and understand the ADA, Section 504 of the Rehab Act, and have an understanding of the RID Code of Conduct.

ITPs need to solicit input from the Deaf Community as to what the deaf community would like to see in interpreters. The Deaf Community and Interpreter agencies need to have better interaction among each other.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

In my opinion individuals rather than groups or the government have proven to be more successful as advocates. I am talking about individuals who have self confidence, knowledge of ADA, and other laws. My opinion is based on what I have what I have witnessed at workshops at various conferences. In other words, the best practice is to provide advocate tools to a few individuals at a time in workshop settings

Groups (State Associations, etc); Policy (Government); Individuals

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

Training on self-esteem and self confidence; Tools on how to become more self-confidence; Role-play – training ; Training on ADA and on other laws and how to apply them

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Not as a group; as individuals, yes; Look at all the Volgs and Blogs going on today. Many deaf and hard of hearing people take these Vlogs and Blogs as if they were the Gospel; ITP – needs to take measures in empowering deaf people.

Expert Interview #4

1. Explain your background and experience working with the deaf community.

This Deaf expert has been involved in the New Mexico School for the Deaf, National Association of the Deaf, and has also worked with other Deaf organizations including CSD, GLAD and the National Council of Hispano Deaf and Hard of Hearing.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

Deaf Community members need to know and understand the role of interpreters; understand the “dos and don’ts”; when they can and can’t use interpreters.

They need to understand the basic rulings of the ADA, Section 504 of the Rehabilitation Act (1973)

Need to be more diplomatic whenever they advocate for their rights to an interpreter

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

Learn from the experts; role playing; let the experts become their mentors. This type of practice is successful because it involves hands on experiences.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

There is a great need for more advocacy leader’s workshops. Agencies/organizations such as CSD, GLAD, ADARA, State Associations of the Deaf should provide self-advocacy training workshops. Train the trainer workshops will be a good start

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes, if the leaders are diplomatic and not militant in providing training. Hearing people want and need to see deaf professionals who act in professional manners with requesting interpreters or advocating for their communication rights

Expert Interview #5

1. Explain your background and experience working with the deaf community.

This Deaf expert has a background of working with Intertribal Deaf Council. IDC is a national organization focused its mission to serve Deaf, Deaf-blind, hard of hearing American Indians, Alaska Native First Nations of Canada individuals in advocacy, education, information and referrals. Family members, tribal councils, and other groups may comprehend the needs of this population in improvement in social, vocational, education, health and spiritual individuals.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

Most tribal councils are not aware of our rights with ADA. It may be difficult to have services provided on the tribal lands. They need to know their rights and be assertive to get the necessary communication barriers across by. I think it is easier in big cities compared to tribal lands within the deaf community. We could provide trainings to IDC members on communication rights.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

Based on my experience, they strive best from leaders and individuals within the IDC community to know what the scope is and we encouraged them to be part of the IDC community as individuals when we have IDC events

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

We need to provide face to face training or group trainings during the IDC events on communication rights. IDC members can obtain information on self-advocacy.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes they can change behaviors and become a better member to know their rights.

Expert Interview #6

1. Explain your background and experience working with the deaf community.

This Deaf expert has 20 years of experience working with the deaf community in various capacities, including work as a tribal government employee. He also has been a speaker and presenter to parent groups, tribal councils, deaf communities in North Dakota and Minnesota.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

Understanding of the laws (ADA, Section 504 of the Rehab Act)

Interpreter's role

Communication access rights for all deaf people

Interpreter's rights

History of interpreting in Deaf America and the history of the RID

Need to better understand their culture and the culture of hearing people

How/Ways to handle sticky interpreting situations

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

Local workshops on getting the right facts

One-on-one approach to training

Role play

Involving and using deaf leaders and role models

By giving examples of good ways to advocate for your rights

By giving facts

Successful because of peer training and peer pressure; learning from the mistakes of others (trial and error situations); deaf adults teaching younger deaf individuals (teens)

Develop simple "road maps" on how to use interpreters, how to request for interpreting services, including examples.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

Local workshops with "house rules" where no one would be offended (such as cochlear implant users, oral persons who are beginning use sign language and interpreting services, senior citizens and deaf youth)

Use both deaf and hearing people in these workshops, but let the deaf person(s) take the lead

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes. Many Deaf Community members are always looking for new ideas, ways to improve their lives and ways to have better self-esteem and feel good about themselves.

Expert Interview #7

1. Explain your background and experience working with the deaf community.

I have Usher Syndrome Type II, I feel very fortunate to have the skills to communicate with both the hard of hearing and the deaf. I have been involved in the Sea-King Club for Deaf (President and Treasurer) and Usher Syndrome Support Group in Seattle as a consumer during my college years in Seattle, Washington. I am now on the board with DBSC of Austin as a Treasurer, as well as the consumer and planning committee member with the Usher Syndrome Support Group in Austin, Texas. I am currently a Senior Occupational Therapist at Brackenridge Hospital, a regional trauma hospital.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

A deaf community members need to know that they have their rights to know the information that being told and shared in any situations, not case by case, or limited to certain situation.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

In a college. A great place to be in a situation that required them to advocate for themselves. They may not have a person to rely on to help advocate. They are on their own, away from a comfort zone environment.

5. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

Active participation and hands on experience with a mentor to guide them along.

Expert Interview #8

1. Explain your background and experience working with the deaf community.

I have a Bachelor of Communication degree from the University of Texas at Austin, where I majored in Deaf Education, I did not actually become involved with the deaf community until 12 years ago during the early development of our regional Usher Syndrome Support group. Over the past 10 years, my interaction with the deaf community (as more and more Usher Type I folks joined our group) has increased, although my involvement in the deaf community itself has been limited, mainly because of my signing skills, and of course, being an Usher Type II person.

I had the opportunity to attend a weeklong training seminar for leaders in the deafblind community sponsored by the Seattle Lighthouse for the blind. I was the only hearing person in my class and was during this time that I discovered those absolutely wonderful persons called “Support Service Providers.” They made it possible for me to communicate at every level with my fellow deaf classmates as well as with all the deaf instructors and presenters at the training.

Upon my return to Austin, I began setting up a Deafblind Service Center, modeled after the one in Seattle. Ever since my interaction with the deaf community here in Austin has increased yearly. Our Usher Syndrome Support Group has had an annual statewide conference at the end of National Deafblind Awareness Week every June and the Deafblind Service Center of Austin is now incorporated by the State of Texas.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

I believe it is imperative that an advocate know his/her rights as they pertain to the ADA laws. If a person is not adequately knowledgeable about his/her rights under the ADA laws, they cannot be expected to gain the respect of the person or persons they are advocating to. The Division of Deaf and Hard of Hearing Services here in Texas has provided excellent ADA training throughout our community for interested deaf and hard of hearing persons. I also think it is necessary for deaf persons to know all there is to know about what they are advocating for – the history, the problems with, life experiences, possible solutions to the problem, what works and what doesn’t and why, etc. You have to know and love what you want to advocate for inside and out! And lastly and probably most important (at least it has been my experience), a deaf person should know exactly how to advocate for him/herself. In November 2004, Mr. McNulty, Director of Helen Keller National Center in New York, provided training to the AADB board and committee members of the National SSP Pilot Project regarding how to advocate for our cause with state representatives in Congress. It was extensive training which included role playing and lots of question and answer time.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

I'm not sure I can answer this question only because of simple ignorance. I can tell you that fundraising efforts here in Austin sponsored by organizations such as Sprint relay, CSD, NAD/TAD have been successful. My guess is because they have well planned events. Letter-writing campaigns to congressmen are successful too (i.e., regarding closed-captioning issues presently)

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

I am a firm believer that one cannot ever have enough training!!! Knowledge is power! I believe a successful advocate needs to avail themselves to every single opportunity available regarding training on how to advocate, training on learning the ADA laws, how to communicate well and effectively, training on empowerment of self, leadership training and list goes on and on. I myself have gone to many of these trainings over the past 5 years and I can tell you it has helped increase my self-esteem. Self-esteem is essential to being the best advocate you can be. I also believe it is important to look at and find out how other cultures (i.e., blind, deafblind, etc) have successfully advocated and what works. Everyone knows that the blind community has done wonderful advocating for themselves and thus have gained some really excellent benefits – I should know, I am the recipient of such. Deaf persons should be comfortable with and able to call upon the leadership of their support groups, organizations and state agencies for whatever appropriate training they might need to learn the ropes of advocating. Also, just as important is to have task forces or timely meetings/town hall meetings amongst the community members to foster camaraderie, support and encouragement to maintain a certain level of humbleness. This will serve to gain the public's respect and admiration and to educate the general public that we (deaf, deafblind, blind community) are not different than normal members, but rather unique and can be valuable and contributing members of a society. A 'soapbox' comment here: it is the "fear of the unknown" that keeps the general public from being acceptable of a different culture from their own. The guard will come down when we (the deaf, blind, deafblind) make the time and effort to educate them about our culture so that they will become more comfortable with us. The right training can teach a unique person how to do this!

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Most definitely! Give them the tools they need to educate and advocate – it has worked for me!!

Expert Interview #9

1. Explain your background and experience working with the deaf community.

Born deaf, I grew up oral within a hearing family and began signing at the age of 15 after a profound experience of competing at the 1981 World Games for the Deaf. I earned my bachelor's degree in communication from the University of California, San Diego and a master's degree in rehabilitation counseling for the deaf from San Diego State University. In addition, I graduated with honors and an award for "Highest Grade In legal Research" from the University of San Diego's Parlegal Training program.

I am also a paralegal, specializing in criminal law, family law, immigration law, disability law and legal research. I serve as a consultant with a private law firm that specializes in disability law and am involved with a local mental health service community group that collaborates to improve the quality of existing services and creates innovative services for the deaf community and deaf families involved with Child Protective Services. I am a volunteer mediator with the Legal Aid Society of San Diego. For this volunteer work, I received the Wiley M. Manuel award in 2003 from the California State Bar.

Past leadership stints include board of directors with Deaf Community Services of San Diego from 1994-2000; elected Chair of the Board in 2000; Co-founder and president of the San Diego chapter of Deaf Women United from 1994-2000. My tenure with the National Asian Congress, a nonprofit organization dedicated to the growth and well-being of the Asian Deaf Community in the USA, began as board member from 1997-2000; vice president/acting treasurer from 2000-2004; and currently serving as president. I also serve as a member of the National Advisory Council for Media Captioning Services, Inc. a small business that provides real-time captioning for national cable news.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

- 1) Their right to accessible communication under the ADA.
- 2) Their right to accessible accommodations under Section 504 of the Rehab. Act of 1973.
- 3) Their right to equal opportunity and information during employment related in-service training, meetings with their boss, employees, and clients; and workshops.
- 4) Their right to submit/request an interpreter according to their preferences regarding gender, language, communication mode; and whether for a specific interpreter or anyone the agency provides.
- 5) Their right to request an interpreter who is certified, trained and/or educated.
- 6) To be informed of the reasonable timeframe an interpreter can be provided by the office, agency, institution, hospital, or law enforcement.
- 7) Their right to accept or deny written communication in lieu of an interpreter.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

- 1) The individual provides the contact information for the local agency serving deaf or hard of hearing or a free-lance interpreter and educates the potential provider on the steps for securing an interpreter;
- 2) Offers to make the interpreter arrangements for the vendor;
- 3) When making an appointment, immediately requests an interpreter, rather than wait for the provider to initiate the process;
- 4) When the vendor asks why an interpreter is needed, the client explains why/how having an interpreter will benefit the deaf person (it touches the provider's sense of compassion for the deaf person) (even if the client is a deaf parent of a hearing child being seen by a doctor);
- 5) Follows up quickly on an upcoming appointment, court hearing, meeting by submitting a request for an interpreter (rather than wait until 3 days before appointment);
- 6) For recurring appointments, directs the vendor to contact the agency or free-lance interpreter and set up a schedule for consistent accommodations;
- 7) Politely declining staff whose basic "signing" does not adequately help the client understand the teacher, doctor, lawyer, etc.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

- 1) A series of trainings to cover all the basics of self-advocacy radically speaking, I suggest beginning with middle school students up to adults.
- 2) The training would include opportunities for the clients to practice role-play of common situations of requesting an interpreter from various vendors (i.e., doctor's office, hospital, attorney, school, conference, employment).
- 3) Train the trainer; recruit 2 or 3 leaders (local community members) to facilitate the training/
- 4) Work together with local interpreting agency and/or organizations, to promote teamwork and community cohesiveness.
- 5) Suggested specific training that focuses on the following scenarios:
 - a) When a request is denied over the phone, develop a script of what to say;
 - b) When a request is denied at the doctor's office, request the manager and explain the need for an interpreter; Be aware of the chain of command regarding submitting requests and/or filing a complaint;
 - c) When making an appointment and the request for an interpreter is denied on the basis of the vendor not knowing how to find an interpreter, model the appropriate attitude while educating the vendor on finding an interpreter.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Some individuals are receptive to change and some are not. It takes positive, strong and supportive community to facilitate change in attitude toward self-advocacy. If started early, good habits regarding personal advocacy could be developed successfully. If started late in life, old

habits are hard to break. Thus old habits regarding interpreters and how to retain their services through a third party are difficult, but not impossible, to change.

Facilitating a change of attitude of professionalism instead of anger would bring about positive results as a self-advocate. The consequences of professionalism and maturity would be an improved working relationship between the deaf person and the vendor. Furthermore, an appreciation of interpreting profession would be greatly enhanced.

Culturally speaking, it helps to be aware of cross-cultural aspects of the deaf community and that each person of color has different ways of being assertive (or learning how to be assertive). For instance, we people of color still struggle with asking for what we need; when our request is denied (on the basis of funding or apathy), we tend to give up easily. We may be intelligent people but it is difficult to break the stereotype of our shyness or low self-esteem and fight for our rights, politely and professionally.

It helps to know that it is important we maintain a positive attitude on how we want to accomplish specific changes in our community such as self-advocacy. If during this process, we practice mutual respect and share “success stories,” then in the long run, advocacy training would be something people feel is effective for changing their lives for the better.

Expert Interview #10

1. Explain your background and experience working with the deaf community.

I have worked for a Deaf Service agency for 15 yrs. I have been involved in all areas of services we provide, case management, interpreting, scheduling interpreters etc. I am also a deaf person.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

I strongly feel that deaf needs more training in advocating in a tactful and “hearing” culture way. I think we sometimes forget that we are dealing with a group of people who are uneducated about deafness and think all deaf are the same and that we can all lip read and writing is good enough etc. and when deaf are told no we become angry and start threats etc.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for them. Why was it successful?

I think it is doing a comparison.... For example, in trying to convince an apartment complex to provide flashing smoking alarms for deaf people in apts, we say that hearing folks can hear the alarm and rescue themselves but deaf can't without the flashing smoke alarms. We are pointing out that the apt complex is making the home safe for hearing but not for the deaf and the message from this is that deaf lives are not worth saving.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

Understanding exactly what the ADA says. There's a difference between certificate and qualify interpreters. There are other options, options to compromise, like ok I don't need an interpreter to come in and have lab work done (blood drawn) but an interpreter to discuss the results of the lab etc.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes. The ADA language is hard to understand just by reading it. Often times we need someone to interpret it and give examples and explain what it mean. We can also learn tricks (for lack of better word) such as, I have noticed when I go to doctor office and there is no interpreter and we communicate by writing, the doctor will keep our conversation in my file. I was very upset about this because that is a conversation and asked the doctor if he keeps tapes of his conversations with his hearing patients. He said no but our communication became his notes. I still felt this wrong and so the next time I visited him without an interpreter, I brought my own paper. My paper, he can't keep it. So I end up walking out with our conversations.

Also every year new deaf/hard of hearing individuals leave high school/college and begin their own lives and have had no training in advocacy. Also every day a hearing person loses their hearing and then have to start advocating for their needs.

Expert Interview #11

1. Explain your background and experience working with the deaf community.

I was exposed at an early age to learning sign language and being surrounded by deaf individuals. My sister attended a few different residential schools for the Deaf and because I was the little sis, I followed closely behind to various events and functions. After I graduated from college and moved on to my career, I found myself going back to working with the deaf community. I have been privileged enough to have worked for CSD for the last 14 years. I started as a Branch Office Manager/ Interpreter in Pierre, South Dakota and eventually moved to Sioux Falls where I am now working as the Director of Interpreting Operations for CSD's Community and Video Interpreting Operations. I have been very fortunate to work with some outstanding deaf people and have learned a great deal about deaf culture and community.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

I sincerely feel that the Deaf community has an opportunity to work more closely with Interpreters to ensure they are asserting equal access to every communication encountered. I

believe this is an exciting time in the history of the Interpreting profession where there has been a shift from the “Helper Model” to “Machine Model” to “Communication Facilitation” and now to the “Bilingual-Bicultural” approach. The latter obviously empowers Deaf people to advocate for themselves more than ever before. By cultural mediating, Interpreters are ensuring sensitivity to all people involved in the process. This levels the playing field and allows equal power and communication between Deaf and people who can hear. Advocacy skills need to be taught (ADA rights; What can I do if an interpreter is requested and the business refuses? What can I do if an interpreter is not qualified or certified for an assignment? How do I provide constructive feedback to an interpreter and work with them to help enhance their skills? Why does an interpreter need to understand what things mean before they can interpret accurately? What are the new Code of Professional Conduct tenants that Interpreters must follow? How are they different than previous Code of Ethics tenets?). These are all topics that will enable an Interpreter, person who can hear and a Deaf individual to succeed in communication and walk away knowing that communication access was accomplished!

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

I believe that the Deaf community feels the most empowered and attempts to advocate for themselves when provided facts and visual examples of how to advocate. Interpreters and Deaf community members can be a powerful educational tool for each other if we approached new experiences as a TEAM and worked together. The Deaf community is such a “collective” community that they can really learn a great deal from each other’s positive and not so positive experiences as well.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

I believe there is a need for Deaf people to understand various resources within their own communities. As hearing people we have to access information based on superficial information we may hear in passing (IE: Did you know you had to cover with a tarp things in the back of a pickup before going to a landfill or you will be fined?). I believe if there were a Deaf clearing house website or “yellow pages for Deaf people” it would be a tremendous asset for the Deaf community. The traditional yellow pages are not always the best resource because of the differences in communities (IE: linguistic, vocabulary, organizational, etc). This could consist of non-emergency phone numbers, Social Security office, Poison Control, Landfill, and various resources within their local communities. I believe this type of advocacy would be a tremendous benefit. Advocacy is all about gaining enough facts and information to know how to move forward.

In my opinion, more workshops within the Deaf community should happen. Incorporate people from the hearing communities in these workshops to give them a glimpse of Deaf culture and the community.

I also believe that in order to preserve the heritage and deaf culture of one's community it is imperative to get Senior Citizens and youth working together. There is a tremendous amount that can be shared and learned from each other. It saddened me when I recently attended a portion of the State Association of the Deaf conference and there were minimal number of youth to middle age present. It is my belief both groups need to be working together to preserve the heritage and culture so many have come to love.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not?

Yes, I believe advocacy training would certainly be a great start in changing behaviors. I believe when people understand why and how something are done, they are more accepting of change. Deaf community leaders need to talk the talk and walk the walk....model behaviors and share success stories.

Expert Interview #12

1. Explain your background and experience working with the deaf community.

I have worked with the Deaf community for 17 years. In that time I have been an outreach specialist for NTID providing workshops and performances for thousands of people on the topic of ASL/Communication and Deaf culture. I began interpreting in 1991 and was certified in 1996 NAD level IV. In 1997 I was awarded a deaf/blind certification fellowship to attend an intensive training designed to enhance services to the deaf/blind communities throughout the nation. In 2000 I was selected as a Bush Foundation Leadership Fellow and obtained my Masters degree from Gallaudet University in American Sign Language Interpretation. For the past 5 years I have worked for Communication Services for the Deaf as an interpreter mentor/trainer. I assisted the local interpreter training program in transferring their two-year degree program to a four-year. I also assisted in curriculum development and will begin teaching as an adjunct professor in the fall of 2007. Last but certainly not least, I am married to a member of the deaf community.

2. Please explain what you believe Deaf Community members need to know in order to advocate for their communication rights as it pertains to interpreting.

I cannot speak for the Deaf community but what I would like for Deaf people to have access to is a DVD or VHS tape that provides them with basic information about the interpreting profession, code of professional conduct, and the ADA as it pertains to interpreting. This DVD would need to be set up in a format that provides many examples or scenarios that are acted out and expanded upon not just English text that is translated. A guide to troubleshooting such as:

1. You are seeking financial advice and you are denied an interpreter because the counselor works on commission. What do you do?
2. The interpreter you prefer is very clear but always late for assignments. What do you do?
3. You believe an interpreter has broken the code of professional conduct. What do you do?

Again these scenarios should be acted or expanded upon in ASL instead of presented in a power point as text.

3. From your knowledge, education or experience in the Deaf Community, describe any best practices or effective methods you know about where deaf persons successfully advocate for themselves. Why was it successful?

The deaf individuals who most effectively advocated for themselves were either CDI's (Certified Deaf Interpreters) or were trained very young on how to use an interpreter effectively. The best practices that I recommend are written about monthly in the RID Views. I would like to see more deaf people attending interpreting conferences and more interpreters attending deaf conferences.

4. What kind of training would be necessary for Deaf Community to embrace self-advocacy? What are your recommendations for effective training methods?

I believe the above DVD/VHS idea would be a great supplement to a workshop held by a CDI and a certified interpreter trainer. This workshop and DVD needs to be fun, informative, and highly visual. The more creative the more people will remember the information.

5. Do you think advocacy training for Deaf Community members would change behaviors? Why or why not

Absolutely but I believe it needs to be presented to them by a member of their community and a member of the interpreting community. I think that people are people and that some will learn and apply the information and others will not be interested in doing so. I think it is important to at least give those individuals that want to learn the opportunity to learn.

Appendix G. Informed Consent Form



800-642-6410 (Toll Free Voice)
866-273-3323 (Toll Free TTY)
605-367-5958 (Fax)
www.c-s-d.org

CSD Headquarters • 102 N. Krohn Place, Sioux Falls, SD 57103

Informed Consent Form Needs Assessment for Deaf Advocacy Training Project Focus Group

The National Consortium of Interpreter Education Centers has awarded CSD a grant to conduct a research project. Larry Puthoff is the project coordinator. The goal of this project is to identify and validate effective practices or methods needed to educate the Deaf Community regarding its rights to communication access as it pertains to interpreting. On a national level, CSD will conduct a comprehensive needs assessment to: 1) determine the type of advocacy information that the Deaf Community should know to self-advocate for their communication rights as it pertains to interpreting and 2) determine the most effective methods for delivering (teaching) this information to the Deaf Community.

Your participation in the focus group is voluntary. You are free not to answer any questions. You are free to withdraw from the focus group at any time without penalty.

Information collected from individuals participating in the focus groups will remain anonymous.

Your participation should not pose any potential risks (e.g. mental, social, financial, dignity or physical) to you. If you have any questions about this project, you may contact Larry Puthoff at LPuthoff@c-s-d.org

By your signature below, you voluntarily agree to participate in the focus group. You will be given a copy of this form.

Participant's Signature

Date

Witness

Appendix H. Recruitment Letter

Date

Name

Address

Dear

I would like to invite you to participate in a Focus Group on _____ from _____ to _____ am/pm at the CSD offices.

CSD is conducting a nationwide Needs Assessment for the Deaf Advocacy Training Project funded by the National Consortium of Interpreter Education Centers (NCIEC). Your participation is confidential and your feedback will be anonymous.

The purpose of the Needs Assessment and the Focus Group is to learn your opinion and thoughts regarding the Deaf Community's ability to self advocate for interpreting services.

Based on the information gathered from you and others in Focus Groups, NCIEC and its partners will develop training for Deaf persons interested in advocacy for interpreting services.

Please let me know if you are available to join the Focus Group by _____ (date). Light refreshments will be served.

Thank you in advance for helping us with this important Deaf Community project.

Sincerely,

Name

CSD Director

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Section 2

Deaf Self-Advocacy

An Annotated Bibliography

T.S. Writing Services
November 2008

Self-Determination

Abery, B. (1998). Research-to-practice: Facilitating the self-determination of youth and young adults with deaf-blindness. *Deaf-Blind Perspectives*, 6(2). Retrieved August 30, 2008, from <http://www.nationaldb.org/ISSelectTopics.php?topicID=18&topicCatID=12>

A Winter 1998-1999 *Deaf-Blind Perspectives* article written by Abery views self-determination as the power to make choices that reflect the individual's personal preferences and interests, and offers the freedom to develop a vision for a personal future that is respected by others. A sense of self-determination is important for the development of identity, since it paves the way for independence and autonomy, and vastly improves the quality of life. Being self-determined can consist of realizing what personal preferences are, setting goals, using skills to achieve said goals, and having the ability to evaluate progress and learn from experiences.

Individual self-determination is imperative in order to avoid living, working, and socializing in environments that, rather than having been chosen, are thrust upon individuals and do not meet their preferences or needs. The specific advantages of self-determination, according to Abery, include: improved learning, enhanced community participation, increased personal responsibility and higher self-awareness and self-esteem. Self-determination can be promoted through the use of augmentative communication technology, mobility training, interveners and supporting American Sign Language (ASL) instruction for parents and family members. Abery's article is ideal for a quick overview of the needs of individuals who are Deaf-Blind.

Deci, E., & Ryan, R. (Eds.) (2002). *The handbook of self-determination research*. Rochester, NY: University of Rochester.

Over the past twenty years, researchers from several universities have investigated issues related to motivation and the self-regulation of behavior. Using either the self-determination theory or closely related theoretical perspectives, laboratory experiments have been conducted as well as field studies in a variety of real-world settings, including education, work, parenting, health care, sport, and protection of the environment. In April 1999, researchers met at the University of Rochester to present their findings, share their thoughts, and discuss future research directions. *The Handbook of Self-Determination Research* is the outcome of that meeting, and summarizes the research programs of these social, personality, clinical, developmental, and applied psychologists who have a shared belief in the importance of self-determination and for understanding basic motivational processes, among other areas of interest.

DO-IT at University of Washington. (2006). *Self-determination*. Retrieved August 30, 2008, from <http://www.washington.edu/doit/MathSci/self.html>

The DO-IT Scholars Program at The University of Washington in Seattle supports the idea that when one works with an individual with a disability, such as hearing loss, that person should talk with the individual about how the disability affects the learning and

performance process, if at all. Certainly, there is no one who knows more about specific needs than the individual with the disability. Having the individual involved in the accommodation process for support services helps in developing the necessary skills to lead a self-determined life. Suggestions for interacting with people who have a hearing loss include facing them so that they can see the speaker's lips, speaking clearly at a normal volume instead of yelling or exaggerating lip movements, using paper and pencil as a means of communication if reading lips is not successful or upon request, and speakers raising their hands in a large group situation so that deaf individuals can see who is speaking at that moment. This article is an ideal summary for individuals wanting to gain a quick understanding of what self-determination entails, and how to accommodate specific needs.

Field, S., Martin, J. E., Miller, R. J., Ward, M. J., & Wehmeyer, M. L. (1998). *A practical guide for teaching self-determination*. Reston, VA: The Council for Exceptional Children.

The authors of this book view self-determination as a combination of skills, beliefs and knowledge enabling one to participate in goal-oriented, independent, controlled-from-within behavior. An awareness of one's strengths and limitations together with a belief in one as capable are important to self-determination. When acting on the basis of such skills and attitudes, individuals have greater ability to take command of their lives and assume the role of successful, independent adults in society. Although this practitioner's guide focuses on the individualized education plan and on students with disabilities in general, it offers valuable definitions, insight and ideas for how to incorporate self-determination lessons into the classroom.

Wehmeyer, M., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities: Basic skills for successful transition*. Baltimore, MD: Paul H. Brookes Publishing Co.

Providing instructional methods for teaching basic self-determination skills to students with disabilities, this book explores self-determination from an educational approach. Discussed are risk-taking, safety and independence skills, in addition to social problem-solving and decision-making skills. This book is targeted at teachers, and although it approaches self-determination training from a developmental disability perspective, it provides excellent information about the teaching and development of self-advocacy skills.

Self-Advocacy

The Georgia Tech Research Corporation (2004). *Speak out! About inaccessible information and telecommunications technology*. Retrieved August 30, 2008, from <http://www.ittatc.org/technical/speakout>

Although many of the specifics discussed within this Web site are indeed about technology, the actual premise is that consumers must be in control of the services they need, and that they should speak up when services do not meet their needs. As written on the Web site, “How do you tell people you’ve never met that you don’t think they are doing their job as well as they could?” This is the dilemma of many deaf consumers who are dissatisfied with the services they receive. Listed suggestions for expressing concerns and addressing them are understanding the problem, considering solutions, gathering documentation, identifying who the recipient of the complaint should be, understanding legal rights, being persistent, recognizing the positive features of the situation, and determining when legal remedies are best.

Access as a right under the Americans with Disabilities Act (ADA) is discussed, as well as ADA-related complaint procedures and forms. This Web site is an excellent resource for any advocate, deaf or hearing. Even if the specific technologies are not of interest, the procedures related to articulating a problem and seeking out solutions are beneficial. The tips and information provided could be incorporated into a self-advocacy curriculum for individuals who are deaf, deaf-blind or hard of hearing.

Hands and Voices. (n.d.) *Self-advocacy for deaf and hard of hearing students*. Retrieved August 30, 2008, from <http://handsandvoices.org/needs/advocacy.htm>

Self-Advocacy for Deaf and Hard of Hearing, an informative article posted at the Hands and Voices Web site, defines self-advocacy as “having a clear understanding of your needs and rights and knowing how to access services to meet those needs.” Included is an outline for a lifetime course in advocacy training. While the “outline” is in actuality several general paragraphs, the concepts are valid: self-advocacy is a skill that takes a lifetime to master and must also be taught.

Lang, H. (2002). Higher education for deaf students: Research priorities in the new millennium. *Journal of Deaf Studies and Deaf Education*, 7, 267-280.

Lang presents an overview of support services that contribute to higher education for deaf students, such as interpreting, note taking, real-time captioning services, and tutoring. Although this article does not specifically address advocacy issues, Lang discusses the importance of emphasizing the proliferation of educational research findings that come together to create improved access for deaf students at the college/university level. This article serves as a handy resource examining cited reasons for students leaving college, and can be used as a tool for identifying possible solutions to strengthen self-advocacy strategies.

National Black Deaf Advocates. (2007). *The art of self-advocacy*. Retrieved August 30, 2008, from <http://www.nbda.org/Advocacy/whatisadvocacy.html>

The Art of Self-Advocacy, a short article found at the National Black Deaf Advocates’ Web site, differentiates self-advocacy from system advocacy and legal advocacy – useful distinctions to note. The article also suggests a four-step process to follow if needs are not

met: define the problem, get information about how to ensure accommodations are provided, write a proposal addressing this, and contact the appropriate individuals for a discussion. The article, which refers to the National Association of the Deaf Web site, would be practical for inclusion in a self-advocacy curriculum.

Psychiatric Patient Advocate Office. (2006). *Four steps to successful self-advocacy*. Retrieved August 30, 2008, from <http://www.ppao.gov.on.ca/pdfs/inf-slf4.pdf>

The Psychiatric Patient Advocate Office article refers to self-advocacy as something performed in order to achieve a specific goal or outcome for oneself. The unnamed author writes that self-advocacy is about knowing what one wants, knowing what one needs, and following through to achieve that. Additionally, successful self-advocacy involves planning, preparing, researching and knowing when to reach out for support; it also requires knowing legal rights and entitlements. Four steps considered necessary for successful self-advocacy listed in this article are defining the problem, developing an action plan, carrying out the action plan and evaluating the results. This easy-to-read document is similar to other resources, although it specifies four steps. It could be easily adapted to individuals who are deaf, deaf-blind or hard of hearing, with customized situations focusing specifically on self-advocating for communication access.

Self-advocacy. (2001). *NADmag*, 1(3), 22. Retrieved August 30, 2008, from <http://www.nad.org/selfadvocacy>

In 2001, *Self-Advocacy* was published in *NADmag*. The article offered seven suggestions for deaf self-advocates: requesting specific accommodations, knowing your rights, educating others, understanding who you are dealing with, following procedures, being tactful, and compromising. The information provided in this article is simple, meaningful, and practical. Although it provides only general information rather than specific communication/self-advocacy incidents, the steps contained in the article easily adapted to different groups.

Smithdas, M. J. (1994, Spring). Self-advocacy: Attaining personal stature. *The Helen Keller Technical Assistance Center Newsletter*, 7(1), 1-2.

Smithdas, in her 1994 article, discusses self-advocacy, advocating for our needs, the making of a self-advocate, strategies for advocacy among youth who are deaf-blind, and resources for self-advocacy. This article is a good source of functional information, and while it is not classified as formal "literature" and focuses on people who are deaf-blind, the content is solid and should be required reading in any self-advocacy curriculum for deaf consumers.

Valenti, R. A. (2005). *Developing self-advocacy: A practical guide and workbook for preparing the high school learning disabled student for post-secondary success*. Available from <http://www.amazon.com>.

Valenti stresses the importance of a constant support system for high school students who have disabilities. Addressing those specifically in high school headed to college, the

author states that studies show that those who self-advocate and have a strong support system while in high school often lose that support when leaving home. As a result, they frequently don't know where to turn. In a post-secondary education setting, many individuals drop out of school or turn to substance abuse or other criminal activities, and/or they isolate themselves from everyone else. Support services are important for continued success, and are something that must remain constant and available.

Assertiveness and Community Organizing

Des Jardins, C. (1993A). *How to get services by being assertive*. Chicago: Family Resource Center on Disabilities.

One approach to the issue of deaf advocacy in terms of interpreting services is to think of it as an assertiveness issue. A slightly outdated, but excellent, text is Des Jardins' (1993) book, *How to Get Services by Being Assertive*. While Des Jardins writes specifically for parents of children with developmental disabilities trying to get quality special education services, her instruction is every bit as valid for deaf adults struggling for quality interpreting services. Her strategies include an exploration with the reader to determine if the reader is currently assertive, an explanation of the values of assertiveness, and encouragement to not feel guilty about asking for what is needed and what the reader is entitled to. Sections include titles such as: "How to get off the guilt trip," "How to get around the runaround," and "When you know it, flaunt it."

Teaching Self-Determination and Self-Advocacy

Goode, B., & Kolkman, S. (1995). *The beliefs, values and principles of self-advocacy*. Baltimore, MD: Paul H. Brookes Publishing Co.

A committee of seven self-advocates from seven nations on three continents formulated a compelling manifesto of the disability movement, which became a booklet published by The International League of Societies for Persons with Mental Handicaps (1994), *The Beliefs, Values and Principles of Self-Advocacy*. The first part of this booklet addresses the beliefs and values of the movement, and the second part addresses the principles of their campaign. The authors stress the significance of being a person first with an identity, making your own decisions, and believing in your own value as a person. Principles the authors mention are empowerment, equal opportunities, non-labeling, closure of institutions, and support.

Van Reusen, A. K., & Bos, C. S. (1994). Facilitating student participation in the individualized education programs through motivation strategy instruction. In Test, D. W., & Melia, N. (2004). Using the self-advocacy strategy to increase middle graders' IEP participation. *Journal of Behavioral Education*, 13(2), 135-145.

Further demonstrating the importance of self-advocacy on the effects of teaching, middle-grade students with disabilities were urged to participate in their individualized education

plan (IEP) meetings using the self-advocacy strategy. This strategy is an empirically-based motivation and self-determination method designed to help students become more involved in their education and/or transition planning meetings. Four students with high-incident disabilities were taught to be active participants in their IEP meetings. Findings indicated the self-advocacy strategy was a very effective instructional tool that could be used to teach middle-grade students with disabilities to be active participants in their IEP meetings. Although this strategy was originally designed for group settings, the researchers discovered that it could also be used in one-on-one settings.

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Section 3

Survey of Vocational Rehabilitation Counselors

Seeking VR Counselors' Perspectives on Deaf Consumers'
Ability to Self-Advocate for Interpreter Services

Pauline Annarino, MS and Cheryl Davis, Ph.D

December 2008

Introduction

Brief History

In the summer of 2006, the National Consortium of Interpreter Education Centers (NCIEC) Deaf Advocacy Training (DAT) work team, made up of individuals who are Deaf¹, interpreters, and a representative from a state Vocational Rehabilitation agency, began an initiative to enhance the Deaf Community's utilization of interpreting services through the implementation of a self-advocacy training initiative. The project has been divided into three primary activities: 1) data collection; 2) development of curricula; and 3) delivery of a self-advocacy training.

As part of this initiative, Communication Service for the Deaf (CSD) was contracted in 2007 to identify those best practices or methods that would result in a successful educational approach toward enhancing Deaf people's ability to self advocate for their communication and interpreting needs. CSD sought a broad-based consensus regarding the Deaf Community's knowledge and beliefs regarding these best practices. Information was gleaned from research-based opinion as well as from experienced stakeholders and the Deaf Community itself.

To obtain its data, CSD conducted a nationwide survey of deaf consumers. A multiple-use survey was developed by CSD, with the survey tool available in English text and ASL. Over 2,000 deaf, deaf-blind and hard of hearing adults who use interpreting services participated in the survey. Responses were received from every state in the nation, at all levels and across all demographics, and as far away as the territories of Puerto Rico and the Virgin Islands. Survey findings indicated that:

- More than 50% of the respondents say they will take self-advocacy training if it is offered. 43% of the respondents were ambiguous, while 5.4% of the respondents said they would not take self-advocacy training if it is offered.
- There is a negative stigma attached to self-advocacy and its efficacy. 35% of respondents indicated they did not self advocate. Of this number (726 respondents), 30% said their efforts would not make a difference; 27.8% felt they didn't have the background to advocate; 27.4% said it is a waste of their time; 14.5% were afraid to say anything; while 10.4% of the respondents stated advocacy is not their responsibility.
- 32.4% of community members prefer face-to-face training and 27.8% prefer to receive information from other deaf people, friends or deaf leaders.

In 2008, DAT sought to build upon CSD's findings by conducting a follow-up survey of vocational rehabilitation counselors and rehabilitation counselors for the deaf. The purpose of this survey was two-fold. First, and foremost, the survey sought to glean vital information from counselors regarding any difficulties their caseload may have when self-advocating for interpreting services. Secondly, the survey sought counselor input regarding the self-advocacy training formats that would be of most benefit to VR consumers.

¹ Unless otherwise indicated, the term "deaf" refers to all members of the Deaf Community, including deaf and hard of hearing persons.

Survey Design

In the spring of 2008, a seventeen-question survey for vocational rehabilitation counselors was developed by DAT work team members and consultant Cheryl Davis, and then distributed to state VR agencies via the Council of State Administrators of Vocational Rehabilitation (CSAVR)'s electronic network, Rehabnetwork.org. The survey was designed to capture data that provided the following information:

- 1) A snapshot of deaf, hard of hearing and deaf-blind consumer caseloads of Vocational Rehabilitation Counselors (VRCs), including an overview of the cultural and linguistic characteristics of deaf consumers who make up their caseloads, including primary communication modes, and use of interpreters;
- 2) VRCs perceptions of their caseload's ability to self-advocate for interpreter services; and
- 3) Suggested self-advocacy training formats.

Survey design and distribution was conducted by the NCIEC Deaf Advocacy Training work team, with the guidance of Minnesota's VR State Coordinator for Services to Persons Who are Deaf or Hard of Hearing Rubin Latz. The survey was vetted with the Council of State Administrators of Vocational Rehabilitation (CSAVR) research committee Chair. The survey was distributed only once and generated a return of 178 responses. Thirty-one out of 50 states were represented in the combined responses. While there were respondents from all of the NCIEC regions, the response rate was not equally distributed across NCIEC regions. Since the survey was deployed only once, there was not an opportunity to solicit responses from under-represented regions.

NCIEC Regions

NCIEC is made up of five Rehabilitation Services Administration (RSA) designated regions, with Regional Centers serving as hubs for the geographic area. In some, but not all, instances, survey results were tabulated in relationship to these regions. To aid the reader, a map of the regions with their Centers is illustrated in Figure 1.

Figure 1
NCIEC Center Map

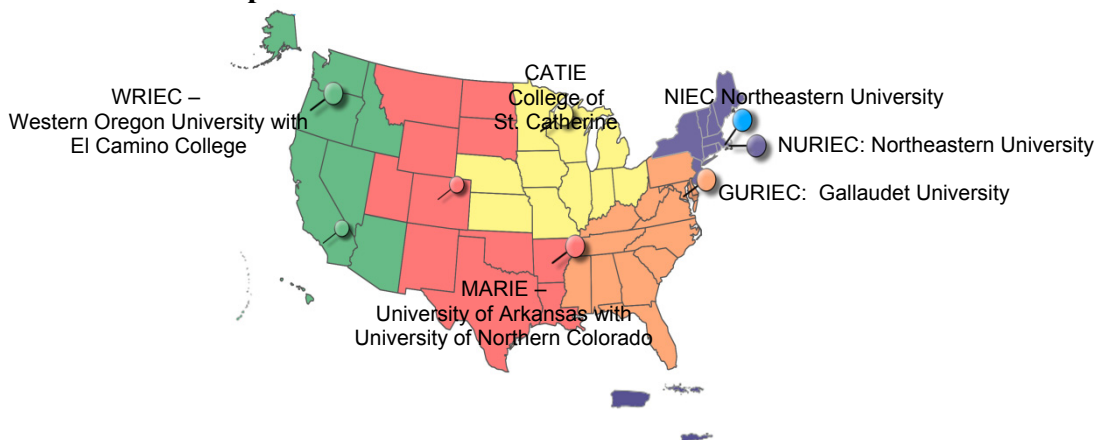


Table 1 NCIEC Regions Represented in VR survey	
NCIEC region	% of respondents
CATIE Center	19%
GURIEC at Gallaudet	33%
Mid-America at UALR	26%
Northeastern University	2%
Western and WOU	20%

Survey Findings

About the Consumers in the VR Caseload

Questions 1 through 4 of the survey sought to obtain a snapshot of the responding VR counselors' caseload makeup. Question 1 addresses the percentage of VR consumers who use sign language interpreters, while Question 2 attempts to ascertain more specifically the “type” of deafness exhibited by these consumers. Questions 3 and 4 take it one step further to determine the primary modes of communication believed to be used by those consumers and the frequency in which they utilize interpreters.

1. Approximately what percentage of consumers in your caseload utilizes sign language interpreter services?

Table 2.1 VR Consumers Who Utilize Interpreter Services		
Consumers Utilizing Interpreters	# of Respondents	% of Respondents
None	6	3%
Fewer than 20%	67	38%
21-40%	34	19%
41-60%	24	14%
61-80%	25	14%
81-100%	21	12%
Total	177	100%

Because we have been mandated to create a tool to support self-advocacy for interpreting services by deaf VR consumers, we wanted to be sure that in this survey we were reaching VR

counselors who have individuals in their caseloads who use interpreting services. Table 2.1 reveals that 97% of all respondents serve consumers who utilize interpreting services. Since this survey was not exclusively distributed to counselors for the deaf, it was expected that a large percentage of counselors (38%) would note that less than 20% of their caseload use interpreter services. This outcome is likely due to service provision models which have VR counselors providing services to individuals with a wide range of disabilities, including deafness. Nonetheless, 26% of the respondents indicated primary caseloads of deaf consumers who utilize interpreter services.

2. Of the following, which three descriptors best represent the makeup of your caseload?

Table 2.2 Three Primary Deafness Descriptors Seen in the VR Caseload Percentage of Respondents who selected one of the top three types of consumers by NCIEC Region as their top three						
	TOTAL # / % of Respondents	CATIE Region	Gallaudet Region	Mid- America Region	Northeastern Region	Western Region
Hard of hearing	121 / 30%	87%	65%	81%	50%	33%
Low functioning Deaf	99 / 24%	53%	60%	67%	75%	57%
Grassroots deaf	60 / 14%	50%	33%	33%	50%	33%

Table 2.2 tabulates the three primary deafness descriptors selected by counselors. Counselors were asked to identify the top three “descriptors” that best represented the caseload makeup from the following nine descriptors.

Youth	Low functioning deaf	Grassroots deaf
Professional deaf	Deaf-blind	Deaf foreign speaking
Late deafened	Hard of hearing	Other

Based upon a total of 416 responses, the **top three descriptors** identified by counselors included:

- 1) **30%** of counselors indicated ***hard of hearing*** as one of the top three descriptors;
- 2) **24%** of counselors indicated ***low functioning*** deaf as one of the top three descriptors;
- and
- 3) **14%** of counselors indicated ***grassroots*** as one of the top three descriptors.

As follows with population estimates, “hard of hearing” was reported the most often across all of the regions. “low functioning deaf” and “grassroots deaf” noted second and third respectively. The fourth highest category was “youth” which was selected by 26% of the counselors. The descriptors “deaf-blind” and “deaf foreign speaking” had the fewest responses with 2% each. The descriptor “other,” (6%) noted a clear split of half the counselors indicating a general

caseload outside of deafness, with the other half indicating a mixed caseload that included deaf, hard of hearing, and other disabilities.

There appear to be a number of factors affecting the data outcome, including the lack of standardized definitions for the terms “low functioning deaf” and “grassroots deaf.” Within the fields of deafness and rehabilitation, there continues to be a lack of agreement as to the definitions of both these terms, with a possible greater consensus of the definitions found among specialized Rehabilitation Counselors of the Deaf (RCD).

3. What percentage of these consumers communicate in the following modes?

Respondents were asked to estimate the percentage of consumers that utilized one of the following:

1) American Sign Language (ASL); 2) Manually Coded English (MCE); 3) Cued Speech; 4) Tactile or Low Vision Support; and 5) Other. Respondents indicated very few consumers in their caseload used either cued speech or tactile or low vision support.

Table 2.3 Communication Modes Used by Consumers in VR caseload				
Communication Mode	Consumers in Caseload Who Use:			
Count of respondents / Percent of total respondents selecting the option.	Less than 20%	40%	60%	Greater than 80%
American Sign Language (ASL)	44 / 25%	42 / 24%	43 / 25%	45 / 26%
Manually Coded English (e.g., Signed English, PSE, etc.)	92 / 67%	29 / 21%	14 / 10%	3 / 2%
Cued Speech	87 / 88%	10 / 10%	2 / 2%	0 / 0%
Tactile or Low Vision Support	93 / 93%	4 / 4%	3 / 3%	0 / 0%
Other (Please specify)	38 / 57%	13 / 19%	3 / 4%	13 / 19%

Table 2.3 reflects the primary communication modes utilized by the VR counselors’ consumers. Counselor responses fell into the following three primary categories:

- The use of ASL was evenly distributed across the percentages; however, it was the only communication mode to receive a significant response in the “greater than 80%” category.
- **67%** of respondents indicated that **less than 20%** of consumers used a Manually Coded English system; only 2% indicated that more than 80% of consumers use this communication mode.
- **88%** responded that **less than 20%** of consumers used Cued Speech, while 93% indicated that **less than 20%** of consumers in their caseload relied on tactile communication.
- Responses from the category “other” reflected oral/aural communication (e.g., speechreading, lip reading, spoken English, oral).

With ASL noted in Table 2.3 as the primary mode of communication, even with a primary caseload of hard of hearing consumers as noted in Table 2.3, it appears that that a fairly large number of deaf consumers of VR services have ties to the Deaf Community. Should this be the case, this factor may indicate that a deaf advocacy training taught by peer members of the Deaf Community would be received favorably by the target audience.

4. How frequently do you estimate these consumers access the following types of interpreters?

Respondents were also asked how frequently these consumers who use one of these communication modes access the following types of interpreting services: 1) American Sign Language (ASL) interpreters; 2) Manually Coded English (MCE) transliterators; 3) Video relay service interpreters; 4) Video remote interpreters; 5) Deaf interpreters; 6) Cued Speech transliterators; 7) Tactile/Low Vision; and 8) Other.

Table 2.4 Frequency and Type of Interpreters Utilized						
Type of Interpreter	Number and Percentage of Consumers Who Use:					
Count of respondents / Percent of total respondents selecting the option.	Less than 20%	21-40%	41-60%	Greater than 80%		
American Sign Language (ASL) Interpreters	53 31%	40 23%	43 25%	36 21%		
Manually Coded English (e.g., Signed English, PSE, etc.)	85 67%	27 21%	10 8%	4 3%		
Video Relay Service Interpreters	39 25%	34 22%	41 26%	41 26%		
Video Remote Interpreters	91 72%	18 14%	7 6%	11 9%		
Deaf Interpreters	98 79%	14 11%	1 1%	11 9%		
Cued Speech Translitterators	98 95%	3 3%	1 1%	1 1%		
Tactile or Low Vision Support Interpreters	95 85%	9 8%	7 6%	1 1%		
Other (Please specify)	21 81%	1 4%	2 8%	2 8%		

It has been noted that because percentages were grouped in increments of 20%, it is difficult to ascertain percentage extremes, in particular 0%. Nonetheless, it is easy to identify which types of interpreting services were most and least used. Not surprisingly, there was a strong parallel between the perceived consumers' preferred communication mode and the type of interpreters they preferred; with 46% of respondents indicating 40% or more of their caseloads used ASL interpreters.

Regardless of communication mode, 52% of respondents estimated that 40% or more of deaf consumers use VRS. On the other hand, VRI is not accessed as often: 86% of respondents estimated that less than 40% of consumers use video remote interpreting services. While it is not

too surprising that few respondents indicated many consumers using deaf interpreters, 9% indicated that over 80% of consumers did so. This raises the possibility that the term “deaf interpreter” may have been misunderstood by some respondents. In addition, none of the other responses provided were for interpreters. They included other communication access options.

Consumer Approaches to Self Advocating for Interpreter Access

The following questions were intended to identify the content believed to be most beneficial in a self-advocacy training module. To that end, questions 5 – 11 are devoted to identifying consumer knowledge, attitudes, behaviors and beliefs regarding self-advocacy from the perspective of the VR counselor. The surveyors were most interested in determining whether counselors perceived a need for consumers to have better or enhanced self-advocacy skills and if so, what factors were contributing to consumers’ ability or inability to self advocate.

5. Of those consumers who utilize interpreters, what percentage has difficulty self-advocating for interpreter services?

Table 2.5		
Consumers Having Difficulty Self-Advocating for Interpreting Services		
	# of Respondents	% of Respondents
Fewer than 20%	43	25%
21-40%	36	20%
41-60%	40	23%
61-80%	33	19%
81-100%	22	13%
Total	174	100%

The data in Table 2.5 can be described by three primary caseload categories: 1) those with a relatively small critical mass of consumers unable to self-advocate; 2) those with a balanced caseload of those able to self-advocate; and 3) those with a large critical mass of deaf consumers unable to self-advocate.

Category 1 represents those with a relatively small critical mass of consumers unable to self-advocate. In this category only 25% indicated that less than 20% of their caseload was unable to self-advocate.

Category 2 represents those caseloads with a near balance of deaf consumers able and non-able to advocate for themselves. In this category, 43% indicated that approximately half of consumers are not able to self-advocate.

Category 3 represents those caseloads with a large critical mass of deaf consumers unable to self-advocate. 32% of all respondents indicated that more than 60% of the caseload is made up of consumers unable to self-advocate. More significant is the 13% who indicated that more than 80% of the consumers are unable to self-advocate. Combined with Category 2, a total of 75% of

all respondents indicate a critical mass of consumers who could benefit from self-advocacy training.

6. Do you think those consumers who have difficulty self advocating understand their rights to an interpreter in the following situations?

Table 2.6 Consumer Understanding of their Rights					
Situation	Ranking	# indicating Yes	% indicating Yes	# indicating No	% indicating No
Entering a hospital or medical center	1	90	53%	81	47%
During a job interview, or job orientation	2	89	52%	82	48%
Meeting with police, corrections or for court proceedings	3	84	49%	86	51%
Meeting with a lawyer, accountant or other service professional	4	69	41%	101	59%
Meetings with employer at workplace	5	65	38%	104	62%
Attending church, temple, mosque or faith community	6	47	28%	118	72%
Other (please specify below)	7	13	43%	17	57%

The three highest ranked areas were also the highest risk situations: entering a hospital, interviewing for a job, and legal situations. In each of these areas, approximately 50% or more of VRCs expected that consumers would have the least understanding of their rights to an interpreter. The fewest believed that they would have difficulty self advocating in their church, temple, mosque or faith community.

Within the situation “other,” respondents added “college, mental health, K-12 educational meetings, social services and social security” as additional situations that may require self-advocacy skills.

7. Do you think these consumers understand the following interpreter roles/responsibilities relative to self-advocacy?

Table 2.7 Consumer Understanding of Roles/Responsibilities in Self-Advocacy					
Tenet	Ranking	# indicating Yes	% indicating Yes	# indicating No	% indicating No
An interpreter must demonstrate respect	1	135	78%	38	22%
An interpreter must keep information private	2	134	77%	40	23%
An interpreter must interpret all information/questions and allow the deaf person to respond	3	122	70%	52	30%
An interpreter must be ethical	4	105	60%	69	40%
An interpreter must be professional	5	97	56%	76	44%
An interpreter must know how to match the deaf person's signing style with the correct English register	6	65	38%	107	62%
An interpreter must tell hearing people to look at the consumer when talking to the consumer	7	59	34%	116	66%
An interpreter must be neutral and not counsel or advise	8	59	34%	114	66%
An interpreter must not be a family member	9	43	25%	132	75%

Items for this question were drawn, in part, from the interpreter's Code of Professional Conduct. It was not surprising that issues of respect, privacy and empowerment rose to the top as having concern/understanding by deaf consumers. However, it was surprising to note that 66% of VRCs do not believe consumers understand the role of the interpreter as it relates to neutrality, counsel and advisement.

8. Do you think these consumers (when not satisfied with interpreting services) know that they can or would:

Table 2.8 Consumer Understanding of Advocacy Choices					
Advocacy Choice	Ranking	# indicating Yes	% indicating Yes	# indicating No	% indicating No
Choose to do nothing	1	141	83%	29	17%
Speak directly to the interpreter and express concerns	2	66	38%	109	62%
Let the interpreting or hiring agency know	3	64	37%	111	63%
Ask to replace the interpreter	4	55	32%	119	68%
Ask to replace the interpreter	5	55	32%	119	68%
Ask to replace the interpreter	6	55	32%	119	68%
File a complaint with the RID against the interpreter	7	18	10%	156	90%
Contact the NAD for advocacy assistance	8	17	10%	155	90%
Contact a legal aid project, advocate or lawyer for help	9	16	9%	159	91%
File a complaint with the Department of Justice	10	8	5%	167	95%

This item was designed to determine whether deaf consumers are aware of their options as they pertain to mitigation, and if they would exercise their right to seek remedy. This table indicates that overall, less than 40% of the respondents believe that deaf VR consumers have an understanding of possible remedies, and of this 40%, 10% or less realize that they can seek formalized advocacy and legal remedies. Recognizing these figures, it is not surprising that 83% of respondents believe/perceive these consumers currently do or would choose to do nothing. The information gleaned from this table 1) reinforces the understanding that one cannot act if they do not have knowledge; and 2) training around this topic area is necessary.

9. If a sign language interpreter is not provided, what percentage of your consumers would respond in the following manners?

Table 2.9 Consumer Responses to Absence of Interpreter									
Consumer Choice	<20%		40%		60%			>80%	
	#	%	#	%	#	%	%	#	%
Go ahead with appointment, using paper and pen or other means to communicate and make do	31	18%	53	30%	41	24%		49	28%
Reschedule appointment/meeting	78	46%	53	31%	26	15%		14	8%
Ask interpreter service/agency for help	85	50%	47	28%	23	14%		14	8%
Call a friend to talk about what to do	59	35%	47	28%	44	26%		19	11%
Leave appointment and complain to VR counselor	49	28%	51	30%	42	24%		30	17%
Leave appointment and complain to family	42	25%	37	22%	56	34%		31	19%
Protest or file a complaint	133	81%	21	13%	8	5%		2	1%
Leave and not do anything about it	57	33%	49	29%	38	22%		27	16%

It is not unusual for an individual to make a request for an interpreter and arrive at the appointment only to find for any number of reasons that an interpreter is not available. This situation provides the deaf consumer with ultimate decision making power in the moment, and perhaps reveals their knowledge, skill and behavior regarding self-advocacy. In review of this question, it might have garnered more information had certain, specific situations been described. Obviously, some situations may not require an interpreter in order for successful communication to occur. Recognizing this caveat, a level of information may still be extrapolated. According to this table, more than 50% of VRCs believe that the majority of consumers would proceed with paper and pen, while only 23% believe that the majority of consumers would reschedule the appointment. Most agree that consumers would complain to family, friends and the VR counselor. The vast majority of VRCs (81%) agree that only a very small percentage (1%-5%) of consumers would formally protest or file a complaint.

10. Which of the following statements do you think the majority of these consumers would cite as reasons for not self-advocating? (Check all that apply)

Table 2.10.1**Consumer Reasons for Not Self-Advocating**

Consumer Reason	Ranking	# Responding	# Responding
I don't know what to do.	1	135	78%
I was afraid to say anything.	2	104	60%
It is too hard.	3	80	46%
It's a waste of my time.	4	67	39%
It is not my responsibility.	5	42	24%
Other, please specify	6	19	11%

VRCs believe that the reason why consumers choose not to advocate is that first, they don't know what to do; second, they are afraid to say anything; and third, that it is too hard. Surprisingly, almost 25% of the VRCs believe that consumers do not believe that it is their responsibility to advocate for themselves.

Table 2.10.2**Consumer Reasons for Not Self-Advocating****Comparing CSD Consumer and VR Counselor Responses**

Consumer Reason	Ranking CSD/VR	CSD Percentage	VR Counselor Percentage
I was afraid to say anything.	4 / 2	14%	60%
It's a waste of my time. It won't make a difference.	1 / 4	40%	39%
It is too hard.	NA / 3	NA	46%
I don't know what to do.	2 / 1	28%	78%
It is not my responsibility.	5 / 5	10%	24%
It takes too much time.	3 / NA	27%	NA
Other, please specify	NA / 6	NA	11%

Table 2.10.2 compares the findings of the consumer survey conducted by CSD in 2007 to the findings of this survey. It is interesting to note that approximately 40% of deaf respondents surveyed by CSD reported that the number one reason they do not advocate for themselves is that "their efforts would not make a difference...it's a waste of time." This response ranked first by consumers, while VR counselors ranked it fourth.

In terms of the consumer reason descriptor "I don't know what to do," CSD consumer respondents and VR counselor respondents were closely aligned, with VR counselors ranking it first and CSD consumers ranking it second. However in terms of the descriptor "...afraid to say anything," VR counselors ranked it second while CSD consumers rated it fourth. And as noted above, CSD consumers have a greater recognition of their responsibility to self advocate with only 10% reporting that it is "not their responsibility." Close to 25% of VR counselors believed that consumers would not see it as their responsibility.

11. What do you think are the **three primary factors that hinder their successful self-advocacy?**

Table 2.11.1 Factors Hindering Successful Self-Advocacy			
Factor	Ranking	# Responding	# Responding
Language barriers	1	122	70%
No idea of how to start	2	110	63%
Lack of knowledge of the law	3	109	63%
System barriers	4	72	41%
Believe it will make no difference	5	71	41%
Lack of self esteem	6	58	33%
Other, please specify	7	6	3%

Table 2.11.2 Factors Hindering Successful Self-Advocacy by NCIEC Region						
Factor	#/% CATIE	#/% Gallaudet	#/% Mid- America	#/% Northeastern	#/% Western	#/% Total responses
Lack of self esteem	13 / 23%	21 / 36%	8 / 14%	2 / 3%	14 / 24%	58 / 100%
Language barriers	23 / 19%	40 / 33%	31 / 25%	4 / 3%	24 / 20%	122 / 100%
System barriers	13 / 18%	25 / 35%	16 / 22%	2 / 3%	16 / 22%	72 / 100%
Lack of knowledge of law	18 / 16%	36 / 33%	30 / 28%	2 / 2%	23 / 21%	109 / 100%
No idea how to start	20 / 18%	36 / 33%	30 / 27%	2 / 2%	22 / 20%	110 / 100%
Believe it will make no difference	14 / 20%	22 / 31%	24 / 34%	0 / 0%	11 / 15%	71 / 100%

The three highest rated factors that hinder efforts at self-advocacy included language barriers, not knowing how to start, and lack of knowledge of the law. Only 10% of the responses indicated that a lack of self of esteem hindered self-advocacy efforts. The finding of this table reinforces the data noted in previous tables; that being the need for increased knowledge of the topic, skills to mitigate the language barriers, and tools to engage in the act of advocacy.

Self-Advocacy Training Formats

This section of the survey sought to determine appropriate training formats; those that would have the most appeal to the target audience, would have ease in execution and be cost efficient. This section also sought to determine whether such training would be perceived as beneficial, and attended by the deaf consumers of VR services.

12. Which of the following training formats would best meet the need of these consumers?

Table 2.12 Successful Training Formats		
Training Format	# of Respondents	% of Respondents
Interactive with other deaf people, friends, deaf leaders	148	86%
Group Activities	117	68%
One-to-one tutorial	94	54%
Instruction over video	39	23%
Computer-based instruction	28	16%
Lecture	14	8%
Other, please specify	11	6%

The top three formats included 1) interactive, 2) group activities and 3) one-to-one tutorial, which is consistent with CSD's findings. In terms of how to provide instruction, three main themes prevailed: 1) start education young; 2) keep it simple and concrete; and 3) engage in active role playing. In addition, 86% of respondents indicated the need for an interactive format with other deaf leaders and participants.

The formats least likely to achieve success were identified as lecture, computer-based instruction and instruction via video.

Lastly, while a category for "other" was reserved for respondents, and six percent checked that category, all comments reflected the categories above except for one, which was "mentoring." It is interesting to note that among these survey researchers, the CSD researchers and more than 2,000 surveys, only one individual mentioned mentoring, a viable training alternative, as a format.

13. If you were designing a self-advocacy training curriculum, what three topics do you feel must be included?

This was an open-ended question, requiring respondents to describe the three topics that must be included in an advocacy training. The fact that 80% of respondents completed this question speaks to rehabilitation counselors' belief in the need for self-advocacy. The 142 respondents generated more than 300 responses. The most frequent responses are described below.

Table 2.13
Suggested Curriculum Topics

Topic Areas	# of Respondents
Knowledge of Information	
Knowledge of the role of the interpreter, including how and when to request interpreter services	19
Knowledge of ADA, the Law and a deaf person's rights under the law	59
Knowledge of resources/systems to help in the advocacy process	23
Knowledge of what is "effective communication"	2
Knowledge/Skills of Processes	
Knowledge of where and how to file a complaint or start the formal advocacy process, file paper work, etc.	14
Knowledge of knowing when and how to ask/advocate	27
Knowledge of knowing how to educate the hearing society	3
Personality Enhancement	
Self-esteem, self-respect, empowerment, self confidence, assertiveness	54
Motivation, Persistence, Fighting Spirit	12
Patience, remove arrogance and entitlement, have proper social skills	3
Instill comfort with authority and be assured that no harm will come via advocacy	3
Instill confidence that their voice will make a difference	6
Support Systems	
Importance of family, counselors and teachers to provide support	31
Importance of working with trained advocates and deaf peer advocates	8
Importance of understanding responsibility and connection to Deaf Community	3
Have or be exposed to previous successes	7

In their commentary, several respondents welcomed the idea of providing self-advocacy training to deaf and hard of hearing consumers. When asked the three factors that contribute to successful self-advocacy, one VR counselor summed it up best with "Education, education, education." Numerous respondents suggested that workshop participants should have knowledge about the ADA law, their rights, and available resources would contribute to successful advocacy. Additionally, VR counselors mentioned self-esteem as a contributor. A respondent from Florida noted that "deaf/ hearing impaired persons need to be aware of their rights starting in high school" which speaks to the possibility of this training being provided to youth and adults. Another respondent from California suggested broadening the audience by stating, "it would be great to include the employers of deaf and hard of hearing clients in the training too!" which was echoed by another VR counselor in California.

Consistent with the findings of CSD, in almost all cases, counselor responses fell into four topic categories:

1. Topics that increased knowledge of the law
2. Topics that enhanced knowledge and skills regarding advocacy processes
3. Topics that increased self-determination
4. Topics that stress the importance of support systems

One VR counselor offered this note of caution: “I don't know that one can teach self-advocacy. It's a natural result of having general knowledge of the rules of the world, and how one fits in, and what one's rights are. Then having the language and self-esteem to feel comfortable enough to request what is lacking. Where to start? With families and educational system. It's pretty hard to start with adults who are lacking in all those areas.”

14. If self-advocacy training designed with the above topics in mind is offered, do you think it would benefit these consumers?

Table 2.14 Training of Benefit to Consumers?		
Training Format	# of Respondents	% of Respondents
Yes, significantly	121	70%
Maybe, some	46	27%
Maybe, a little	5	3%
No, not at all	0	0%
Total	172	100%

With 70% of respondents believing a training of this nature will “significantly benefit” consumers and an additional 27% believing it will “maybe benefit,” Table 2.14 clearly reflects the perceived need for a training of this nature. Furthermore, Table 2.15 below indicates that more than one third of counselors believe deaf consumers would attend such training, with an additional 55% of counselors indicating that possibility that consumers would attend. Only 1% of 172 responses reported that caseload consumers would not attend.

15. When a self-advocacy training designed with the above topics in mind is offered, would these consumers likely attend?

Table 2.15 Consumer Attendance Likely?		
Training Format	# of Respondents	% of Respondents
Yes	61	35%
No	1	1%
Maybe	95	55%
Don't know	15	9%
Total	172	100%

16. Do you think your state VR agency may be willing to host, co-host or co-sponsor a self-advocacy training when such a training is made available?

Table 2.16 VR Willingness to Hold a Training		
Training Format	# of Respondents	% of Respondents
Yes	98	55%
No	1	1%
Maybe	42	24%
Don't know	37	21%
Total	178	100%

The strong support for the need for this training was clearly illuminated by the counselors' responses.

- 55% indicated they would be willing to host a training
- 45% they might or didn't know if they would be willing to host a training, while
- 0% noted they would not be interested in hosting a training.

17. Feedback and Comments

In keeping with the survey's other open ended questions, fifty-one respondents took the time to share their thoughts and comments. A cross-section of them is listed in table 2.17.

Table 2.17 Feedback and Comments	
Comments	
Support for the Need for This Type of Training	
<ul style="list-style-type: none"> ▪ We do quarterly meetings for all our deaf and hard of hearing consumers - we'd be glad to do the advocacy training at one of those meetings. It would be good to have representatives from businesses; hospitals; doctor's offices get the training, as well. 	
<ul style="list-style-type: none"> ▪ This is a great step forward. 	
<ul style="list-style-type: none"> ▪ This is a great idea and I think our state could definitely use the training! We have a large population of low functioning/grassroots deaf people here, and a very small professional deaf community here. We have recently been using CDIs, and I think everyone could use some training on this, as there are a lot of interpreters & companies who are resistant to working with/hiring a 2nd interpreter. 	
<ul style="list-style-type: none"> ▪ There is such a great need not to only education the consumers, but the community as well. 	
<ul style="list-style-type: none"> ▪ The most important result of this is to educating consumers of their actual, legitimate rights as consumers of interpreting services and how they can properly file legitimate complaints. 	
<ul style="list-style-type: none"> ▪ Thank you for letting me participate in this. The sophistication of the questions in the survey engendered confidence in me with this movement. 	

▪ Sounds like a good idea.
▪ My deaf community is really in need to be educated about self-advocacy.
▪ In addition to hosting training opportunities, I would love to have a "tool kit" of materials that I can use on an individual basis when counseling and possibly even with prospective employers and other community resources.
▪ I think workshops for the deaf community would benefit them understanding the use of interpreters as well as self-advocacy.
▪ I think this is an excellent idea and an excellent program. The lack of provided accommodations in this area is a concern and potentially dangerous problem. There are health and mental health providers diagnosing and treating Deaf with no appropriate communication. I also appreciate that you are including hard of hearing in this as they don't generally require sign language interpreters but do often need additional communication means.
▪ I think Self-Advocacy in the appropriate way is important. I forgot to state in one of the questions, I feel Self-Advocacy should be taught in residential schools for the Deaf as well.
▪ I think it is great way to interact with someone and to increase my knowledge of how to assist consumers.
▪ I strongly believe that training clients with this information is strongly needed!
▪ I am excited about the possibility of having this training as it would greatly benefit our deaf, hard of hearing, and deafblind communities in Washington State.
▪ Excellent idea, to provide comprehensive self-advocacy training to the deaf communities.
▪ Definite need for this curriculum.
Concerns/Issues Surrounding Advocacy
▪ Unfortunately this is designed almost completely for deaf population when the hard of hearing population is having difficulties of their own.
▪ We have not had a lot of deaf clients recently. They generally are not aware of resources available to them. There are not enough qualified (certified) ASL interpreters in the Reno/Sparks area.
▪ Our biggest problem is finding qualified interpreters to supply the need for our clients for educational and medical purposes. In our area the people with hearing impairments are very isolated which really affects their self esteem and approach to advocacy.
▪ The biggest problem I have is the distance that a qualified interpreter has to travel to serve my customers. If there is a job closer, they are more likely to take that one. Thank you for the opportunity to participate.
▪ There needs to be more information available to those who need hearing aids concerning financial assistance available in the community & nationwide to help pay for all or part of the costs. Technology that can contribute to independence needs to be readily available to those who need it regardless of ability to pay.
▪ There is a need of more clubs for the deaf regarding jobs, advocacy and understanding their rights. Usually, no deaf people would show up and it is probably because they do not want to or have excuses for not going. So instead of saying job club - make the event sound more interesting so more deaf people could attend to learn more about advocacy.
▪ There are a variety of consumers who have different opinions, some demand interpreters

when not appropriate, other don't want them when the RS counselor recommends they have one. Some are afraid they will not get employment or keep employment if they ask for an interpreter. Some want family member to interpret or speak for them at doctor's appointments although this counselor's opinion is that they should have an interpreter and a family member there. Some do not know how to ask for a qualified interpreter when an employer brings in an employee of theirs to sign or interpret for a meeting who have no qualifications to interpret. It is difficult to educate employers regarding the need for interpreter (they want to write or get another employee of theirs to interpret and not go through hiring a qualified interpreter-- they lack understanding of deaf language needs and problems in comprehension of written language.

- The state of Florida does not have a program in which interpreters are provided to consumers for non-related VR needs, at no cost to the consumer. If a situation requires an interpreter, only few business, private and governmental agencies understand their role in the provision of this vital service. It is difficult for consumers to learn self-advocacy when individuals or business do not understand its role in the provision of services. In this regard, there are a great deal of system changes that need to take place so that people who are deaf and advocate for themselves.
- The incidence of deafness in the population we serve is small - we are mandated to provide services to individuals who are legally blind - so any person we deal with who is deaf is also legally blind. Of course, this presents additional challenges to the consumer's ability to self-advocate.
- Self-esteem and understanding they have rights will prevent them from self-advocating. Also apathy.
- Self-advocacy skills in order to access quality, professional, and ethical interpreting services has long been needed.
- My area mostly has deaf individuals who identify with their cultural ethnic group as their primary identity (Mexican, African American) as opposed to cultivating a deaf-based identity.
- Looking forward to seeing Self-Advocacy training in our area (soon).
- It will be GREAT to have advocate training not just for consumers but Deaf Professionals to understand some legal issues.
- In my field, many of the deaf and hard of hearing are located in rural and out of reach due to no transportation to attend this kind of workshop if offer. Thus on-one-one tutorial is feasible as back up.
- I work with individuals who are deafblind. Some of the questions asked related well to what the individuals needs appear to be in MS. However, some of the individuals that I work with do not fit into this category and would be considered low functioning. I don't really like that term but it is what is being used. I have several individuals who fall between the cracks of services and the families do not know what to ask for.
- I wish we could make attending this training as part of the consumers IPE-Individualized Plan of Employment and then we would use this as training before they pursue a job. Our state is heavily involved in HS transition and I am liaison to WSD. The school could also include this in their IEP.
- I think public education open to the Deaf community and the public as well would be the best approach to get all the necessary feedback. Encouragement to employers and educators should be included.

<ul style="list-style-type: none"> ▪ I have only had my position for three months. I have found that the younger the client/consumer is, the more aware they are of the requirements of the law.
<ul style="list-style-type: none"> ▪ I am anxious to see what comes of this survey for our D/HH consumers.
<ul style="list-style-type: none"> ▪ I am a VR counselor who is also deaf and does sign therefore many of the issues in the survey does not apply to my situation.
<ul style="list-style-type: none"> ▪ Some of the older lower functioning deaf individuals are so accustomed to being dependent on others that they do not allow themselves to learn self-advocacy. "But me deaf" is a very common excuse given whenever a problem arises. There are some that will benefit from self-advocacy training. The challenge does lie in getting them to attend the training. One tried and true method is to make sure there are plenty of good free refreshments provided. That, by itself, is a major draw. Another method that has been effective is the opportunity to win door prizes. The value of the prize isn't so important, just that they can walk away with something concrete in their hands. I've had good success with restaurants donating gift certificates, those are pretty popular.
<ul style="list-style-type: none"> ▪ As the SCD, I completed this survey based on the caseload that I am currently covering. A recent Town Hall meeting on DHH/DB/LDA issues was held in this community. 90% of the issues were related to interpreting and lack of support of rights to communication. I can see this Advocacy training as a great partnership with the VR & DHH agencies and state association of the deaf.
<ul style="list-style-type: none"> ▪ Deaf/ Hearing Impaired persons need to be aware of their rights starting in high school, so they are better prepared when entering the work world.
<ul style="list-style-type: none"> ▪ CA Dept of Rehab offers "Windmills" training to employers about disability rights and I think it would be great to include the employers of Deaf and Hard of Hearing clients in the training too!
Comments Regarding the Survey Itself
<ul style="list-style-type: none"> ▪ Very good questions to ask us about self-advocacy which would be helpful, thank you.
<ul style="list-style-type: none"> ▪ This survey would have been more accurate with a column called don't know or neutral.
<ul style="list-style-type: none"> ▪ This survey was a bit difficult to answer only "yes" or "no" to... so many variables.
<ul style="list-style-type: none"> ▪ This is a good survey.
<ul style="list-style-type: none"> ▪ This is an excellent survey, good questions which it made easier to answer.
<ul style="list-style-type: none"> ▪ Some of these questions are vague and hard to answer based on information and resources available.
<ul style="list-style-type: none"> ▪ Some of the questions were not clear. Some did not give enough specificity to allow for clear answers. Hope it helps.
<ul style="list-style-type: none"> ▪ Good survey questions.

Conclusion

The survey authors are grateful to the rehabilitation counselors who took time to complete the survey, and gratefully acknowledge support of CSAVR leadership and staff. In spite of survey design shortcomings, this instrument provided the NCIEC DAT work team with critical information supporting the need for and design of a “deaf self-advocacy” training for deaf consumers of rehabilitation services.

Among a wealth of other demographic information, the survey revealed that 97% of respondents serve deaf consumers who depend on sign language interpreters to some degree, irrespective of the fact that hard of hearing consumers make up almost a third of those VR caseloads. And of those who use sign language, the language of choice is American Sign Language. In hindsight, this survey overlooked two important demographic questions: 1) the actual percentage of the respondent’s caseload that was deaf; and 2) was the respondent deaf? This information would have been very helpful in the analysis.

The data revealed that a third of all VRC respondents serve a majority caseload in need of advocacy training, with another third with near half of their caseload in need of training. Respondents reported the belief that less than 40% of consumers have a clear understanding of the interpreter role and function; that more than 83% of consumers would most likely not take any action when faced with some form of communication discrimination, and in most cases were either unaware or uncomfortable seeking remedy through formal advocacy and legal channels.

As to why deaf consumers do not advocate, the lack of knowledge and fear lead the list of advocacy inhibitors.

Rehabilitation counselors were clear in their support for advocacy training. They were also almost unanimous in their belief that a training is necessary and must include deaf role models, be interactive, with group activities, and create opportunities for one-to-one tutorials. The three main themes emerged: 1) start self-advocacy education at a young age; 2) keep it simple and concrete; and 3) engage in active role playing. The formats least likely to achieve success were identified as lecture, computer-based instruction and instruction via video. And consistent with CSD, the vast majority of respondents noted four primary topics for inclusion in a training of this nature: 1) topics that increase knowledge of the law; 2) topics that enhance knowledge and skills regarding advocacy processes; 3) topics that increase self-determination; and 4) topics that stress the importance of support systems.

With 70% of respondents believing a training of this nature will “significantly benefit” consumers of VR services, and an additional 27% believing it will “maybe benefit,” the need for a training of this nature is clearly illuminated. In further support, the vast majority of counselors believed that consumers may, or would attend such a training. Only 1% of 172 responses noted that consumers comprising their caseload would not attend.

With 80% of respondents completing the open ended questions, this survey revealed a real interest in the topic area and the importance for self-advocacy training. Based upon the information gleaned from CSD and the responses of 172 rehabilitation counselors, the NCIEC

Deaf Advocacy Training work team believes deaf consumers and vocational rehabilitation have a belief in the merit of such a training and that the topics and teaching approaches with the greatest chance for a positive outcome that have been identified.

The next step in the development of the self-advocacy training initiative is the design and implementation of the curriculum. To this end, the DAT work team will continue to engage state vocational rehabilitation agencies, state commissions, deaf community advocacy organizations and other stakeholders to provide guidance, information and training access to their constituents.