Assessing Deaf Awareness:
Training and Attitudes of Recent Genetic Counseling Graduates

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The Faculty of the Graduate School of Arts and Sciences
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by
Honey Nagakura

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ABSTRACT

Assessing Deaf Awareness: Training and Attitudes of Recent Genetic Counseling Graduates

A thesis presented to the Department of Biology, Genetic Counseling Program

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Honey Nagakura

Previous research has suggested when healthcare providers lack cultural competence, minority groups, including the Deaf community, may be adversely affected. Although most genetic counseling programs incorporate cultural competency training to educate students regarding the needs, concerns, and cultural values of specific minority groups, there is limited information on the extent of Deaf Awareness training. The purpose of this study was to assess the Deaf Awareness training of recent genetic counseling graduates and the impact of such training on both knowledge of deafness and Deaf culture and attitudes toward deaf people. We recruited genetic counselors who graduated within the past five years through the NSGC listserv for participation in an anonymous, online survey. Of the 135 respondents analyzed, twenty-six percent (n=35) reported no Deaf Awareness training and 51% (n=69) reported limited training (1-2 hours) conducted primarily by a program instructor, using tools such as readings and discussions. Almost one-third (31%) of respondents felt that their Deaf Awareness training was insufficient. When assessing knowledge of deafness and Deaf culture, respondents lacked knowledge regarding the effects of cochlear implants on residual hearing, communication between deaf children and hearing parents, and working with sign language interpreters. Overall, there did not appear to be significant differences
between respondents who had Deaf Awareness training and those who did not, with respect to knowledge of deafness and Deaf culture or attitudes toward deaf people. These findings suggest that genetic counseling students may not be receiving adequate training regarding Deaf Awareness during their graduate education. Future efforts should focus on designing more effective Deaf Awareness training for genetic counseling students, and investigating whether improved Deaf Awareness results in better genetic counseling experiences for Deaf individuals.

Keywords: Deaf Awareness. Cultural competency. Genetic Counseling. Deaf. Hearing Loss. Graduate Training. Deaf cultural competency
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INTRODUCTION

The Deaf community is comprised of individuals who identify with and share a common culture and language. This distinct Deaf culture has its own language (in the United States it is American Sign Language, ASL), beliefs, and behavioral and social norms. Being Deaf can also be an attitude and be seen as a way of life. Those who identify with Deaf culture and are part of the Deaf community represent themselves with a capital “D”. In this paper, we follow the general convention of using the term Deaf as distinct from deaf (with a lower case d), which refers simply to an audiologic phenotype.

Research has shown that lacking cultural competence as healthcare providers directly affects health care provisions for various minority groups, particularly the Deaf community (Barnett, 1999). The hearing world isolates Deaf individuals by both oral language and by written language. Although this may be true of individuals from other minorities, Deaf individuals have more obstacles to overcome in terms of understanding medical information. An example of this barrier is how medical documents such as brochures are readily available to individuals of other minorities in their native language. However, Deaf patients receive documents written in English regardless of their English proficiency level. People often forget that Deaf individuals have their own language, ASL, which does not translate to written English. The average Deaf individual reads at a fourth grade level (Allen, 1986). This is just an example of the inadequate services Deaf individuals are receiving from health care providers (Meador and Zazove, 2005). Additionally, given that deaf individuals cannot overhear side conversations about health care and medicine, it limits their exposures to general health care discussions with family and providers, which can lead to poor health literacy (Barnett et al., 2011).

Health disparities experienced by the Deaf community mainly stem from health providers’ lack of understanding of Deaf culture and unfamiliarity with signed languages, thereby creating a language barrier (Ebert and Heckerling, 1995). This barrier creates an aversion for Deaf individuals to seek out
medical care, which in turn, contributes to their lower health literacy (Steinberg et al., 2002).

Furthermore, Deaf patients discouraged by health care providers’ lack of knowledge of their culture may choose to forego treatment and shun medical assistance. Studies have shown that many physicians lack knowledge of Deaf culture and deaf patients’ rights in a medical setting (Hoang et al., 2011; Meador and Zazove, 2005).

Prior research suggests that healthcare providers who have limited understanding and exposure to Deaf culture often exhibit discomfort during sessions with Deaf patients (Iezzoni et al., 2004; Enns et al., 2010) and this can result in a lack of trust between the patient and healthcare provider. Furthermore, while the Deaf community is very proud of their difference and has created a distinctive culture and language around it, it sees the medical community's view of deafness as a pathophysiological disease as a threat to their way of life. Historically the Deaf community has been wary of the intentions of genetics providers, genetics research, and genetic testing due to abuses during the eugenics period where sterilization and killings of Deaf individuals occurred (Padden and Humphries, 1988; Lane, 1999; Schuchman, 2004). In addition to discrimination from the health care community, Deaf individuals experienced intolerance from the general population by having mainstreamed education and oralism, a teaching method that banned sign language, gaining prominence in the education of Deaf individuals in order to reduce the number of marriages between deaf individuals (Bell, 1884).

Recent studies have shown an increasing interest in genetic testing for deafness within the Deaf community (Boudreault et al., 2010). However, due to a variety of historical, social, cultural, and institutional factors, many Deaf individuals do not understand how genetic factors may explain why they are deaf/hard-of-hearing (Abe et al., 2010). More importantly, many Deaf individuals are unfamiliar with the role of genetics and family history in serious medical diseases unrelated to deafness, such as inherited forms of cancer, which adds to their lack of knowledge of cancer prevention (Zazove et al., 2009). Genetic counselors are providers who can potentially reduce the barriers that have excluded the Deaf community from receiving genetic services. For this to happen, genetic counselors must be culturally competent about the Deaf community and Deaf culture.
Deaf Cultural Competency of Medical Professionals

Numerous studies have demonstrated the importance of cultural competence in the provision of health care services to deaf individuals (Hoang et al., 2011; Matthews et al., 2011; Fileccia, 2011; Barnett, 1999). In 1989, Cross et al. described cultural competence as:

“… a set of congruent behaviors, knowledge, attitudes, and policies that come together in a system, organization, or among professionals that enables effective work in cross-cultural situations. “Culture” refers to integrated patterns of human behavior that include the language, thoughts, actions, customs, beliefs, and institutions of racial, ethnic, social, or religious groups. “Competence” implies having the capacity to function effectively as an individual or an organization within the context of the cultural beliefs, practices, and needs presented by patients and their communities.”

In 1999, the University of Rochester, School of Medicine and Dentistry implemented a program called Deaf Strong Hospital (DSH) to educate future healthcare providers on Deaf cultural competency and cultural awareness (Richards et al., 1999). The project involved a role reversal where Deaf individuals play a healthcare provider and the student assumed the role of the “Deaf” patient. The exercise proved to be effective in teaching students the difficulties in obtaining proficient healthcare as a Deaf individual. The Wegmans School of Pharmacy at St. John Fisher College in Rochester, New York adopted this program as a required Introduction to Diversity course (Mathews et al., 2011).

In 2011, Hoang et al. published a study assessing the Deaf cultural competency of physicians and medical students through a fellowship program created at the University of San Diego School of Medicine. The Deaf Community Training (DCT) program involved multiple semesters of ASL classes, a summer at Gallaudet University’s residential ASL/Deaf culture immersion program, completion of research relating to the Deaf community and rotations interacting with Deaf individuals. The study compared the cultural competency of the medical students who participated in DCT and medical students
and medical school faculty who did not participate in DCT. The results showed that individuals who participated in DCT were more culturally competent and had better knowledge of Deaf culture. This suggested the need for additional training in Deaf culture and ASL for medical professionals who work with deaf and hard of hearing individuals.

*Genetic Counselors and Deaf Awareness*

Familiarity with Deaf culture and experience in working with deaf people is important for genetic counselors, given they may encounter deaf individuals in various ways in their clinical practice. Since greater than 90% of deaf babies are born to hearing parents, it is likely that genetic counselors will interact with hearing parents far more often than Deaf or hard of hearing parents when the discussion is about deaf genetic testing (Moores, 1987). Hearing parents of deaf infants may not have the experience or understanding of the challenges and joys that they and their child will experience. Genetic counselors, therefore, can play an important role in providing these parents with well-rounded information about being deaf; information that ranges from genetics of deafness to Deaf culture, as well as provide opportunities to meet deaf people, so parents can make informed decisions about the upbringing of their child. Genetic counselors may also encounter Deaf individuals in prenatal, cancer, ophthalmology, or pediatric settings for indications both related and unrelated to their deafness. It is important that genetic counselors, in any of these counseling scenarios, have the experience and knowledge of Deaf culture, allowing them to be prepared and feel comfortable conducting these sessions.

In 2010, Enns et al. published a study on genetic counselors’ attitudes toward deaf people, which showed a relationship between contact with D/deaf people and their attitudes toward deaf people. Specifically, counselors who had experience within the Deaf community held more positive views on deaf individuals than those without experiences within the Deaf community. As a whole, however, the majority of genetic counselors reported limited exposure to deaf individuals and Deaf culture. The results also showed that 70.3% of the participants reported receiving some form of training on deaf genetics and
culture through their graduate program. However, they did not collect details regarding the extent and type of training participants received.

Training students to recognize and accept diversity is an essential aspect of genetic counseling program curricula. The Accreditation Council for Genetic Counseling (ACGC) has developed standards of accreditation for genetic counseling programs. Based on the specific requirements for accreditation in genetic counseling, the curriculum must include multicultural sensitivity and competency as part of the psychosocial content of the curriculum (ACGC-Required Criteria for Graduate Programs in Genetic Counseling Seeking Accreditation by the American Board of Genetic Counseling, 2010). Genetic counselors strive to provide accurate information and options by means of non-directive counseling for all individuals and families of different backgrounds. Students' exposure to various families and individuals serves to enlighten and educate them on the fundamentals and the lived experience of having a disability or being different from the majority culture. Although it appears that genetic counseling training programs provide some training in Deaf Awareness (Enns et al., 2010), there are no studies of the nature and extent of the training and its impact on genetic counselors’ knowledge of deafness and Deaf culture and attitudes toward deaf people.

Study Aims and Significance

The aim of this project is to assess Deaf Awareness training (DAT) provided in genetic counseling graduate programs and its impact on knowledge of Deaf culture and attitudes toward deaf people of recent genetic counseling graduates. As defined in the survey, Deaf Awareness may include but is not limited to understanding the difference between upper case Deaf and lowercase deaf, the culture and language of Deaf people, how to optimize communication between deaf and hearing individuals, and the rights of the deaf individual within the healthcare setting. Results of this project will provide insight into whether there is a correlation between the training received and the impact on Deaf Awareness. By identifying the extent of Deaf Awareness genetic counselors possess, we can better understand how to modify diversity training in these programs and train future genetic counselors to be more culturally
aware of the Deaf community. Genetic counselors who become more Deaf aware may better address the needs of Deaf and hard of hearing individuals during genetic counseling sessions and potentially reduce health disparities experienced by this linguistic and cultural minority group. In hopes of building a stronger relationship with this community, we can slowly bridge the gap and improve the views of the Deaf community towards genetics healthcare professionals.
METHODS

Study Design and Measures

Using a cross-sectional study design, we surveyed genetic counselors who have graduated from a genetic counseling training program within the last five years, via an online anonymous survey instrument (Appendix B). The survey consisted of four sections: Demographics, Deaf Awareness Training, Attitudes towards Deaf people, and Knowledge of deafness and Deaf culture.

Demographics. In addition to traditional demographic questions (age, gender, year graduated, training program, etc.), we inquired about participants’ interactions with deaf individuals and the Deaf community both in and outside of work, as well as ASL interest and proficiency.

Deaf Awareness Training. Questions relating to graduate education included whether the participant received any Deaf Awareness training, the duration, who provided the training, topics covered, and tools used. We developed these items specifically for this study, and designed them to obtain essential information on Deaf Awareness training.

Attitudes towards Deaf people. We used a survey developed by Cooper et al. (2004) containing 8 positive attitude towards deafness statements and 14 negative attitude towards deafness statements (Figure 1). Participants rated the extent of agreement with each statement on a 5 point Likert scale (1= “Strongly disagree”, 2= “Disagree”, 3= “Neither Agree nor Disagree”, 4= “Agree”, 5= “Strongly agree”). Negative attitude statements were reverse coded and we computed an attitude score for each respondent. Total scores could range from 22 to 110, with higher scores indicating attitudes that are more positive. This scale, previously used in several studies of healthcare providers, including a sample of genetic counselors (Enns et al., 2010), has been shown to have high internal reliability with Cronbach’s alpha of 0.61-0.71.
Knowledge of deaf cultural competency. We used knowledge items from the study by Hoang et al. (2012), which includes 6 multiple-choice questions and 28 true or false questions. We recorded responses to the 34 knowledge questions using a binary coding system where 0 = incorrect and 1 = correct. We computed a total knowledge score for each participant, where higher scores indicate greater knowledge. The highest total knowledge score attainable on the knowledge questions was 39: 11 points on the 6 multiple-choice questions (some questions had more than one correct answer, thus participants received one point for each correct answer), and 28 points on the true and false questions.

We included open-ended questions in the survey to allow participants to elaborate on their responses to certain questions. Participants had the option to skip questions and exit the survey at any time.
Sample and Recruitment

The Brandeis University Institutional Review Board (IRB Protocol # 13092) approved this study. We recruited participants through the National Society of Genetic Counselors, using an E-blast containing the recruitment notice (Appendix A) and a link to the online survey (Appendix B). Individuals were eligible to participate in the study if they were older than 18 years-old, an NSGC member, and had graduated within the last five years from a genetic counseling training program. There was no restriction based on number of interactions with Deaf individuals, and all recent graduates were encouraged to participate. The survey was open for four weeks between February 2013 and March 2013.

Data Collection and Analysis

We collected data through the online survey program, Qualtrics and analyzed it using SPSS 19. We produced and assessed descriptive statistics, using Microsoft excel in the analysis of data and data organization. We classified participants into two groups: having DAT and not having DAT. We assessed the primary research questions, i.e., do genetic counselors who received DAT training and those who did not differ in terms of their attitudes toward deaf people and knowledge of Deaf culture, using independent t-tests for quantitative outcome variables and Chi-square tests for categorical outcome variables. An alpha score of 0.05 determined statistical significance. We did not make any corrections for multiple testing.
RESULTS

Sample Demographics

There were 181 total survey responses, of which 46 were not completed and therefore discarded, leaving 135 surveys for analysis. Table 1 provides a summary of the sample demographics. The majority of participants were female (96.3%) and Caucasian (86.7%). Nearly every accredited genetic counseling training program was represented (29/34), with 8% of participants as the maximum representation of a single program. Just over half of the participants graduated from a genetic counseling program within the last two years (53.3%) and 60% of the participants have been a practicing genetic counselor for 2 years or less. The two primary clinical settings most respondents reported working in were prenatal (33.3%) and pediatrics (26.7%), although 25.9% of respondents reported working in more than one clinical setting. Of the 128 respondents who reported their hearing status, 99.2% were hearing individuals. Two individuals (1.5%) reported that they consider themselves part of the Deaf community. A few individuals (2.2%) reported having family members who were born deaf and a small percentage reported having culturally Deaf friends (11.1%) and non-culturally deaf friends (3.7%). Fewer than half of the participants (44.4%) reported interacting with deaf or hard of hearing individuals outside of the clinical settings, mostly in their circle of friends and in their communities.

According to the professional status survey from 2012, 512 individuals (44%) have been working for 1-4 years and 363 (31%) individuals have been working for 5-9 years. If we assume individuals working for 5, 6, 7, 8, and 9 years are divided equally, we can assume approximately 6% have been working for 5 years. Therefore, approximately 584 individuals (50%) have been working for 1-5 years. This study represents 135 recent genetic counseling graduates. Based on the data provided by the professional status survey, we estimate that 23.1% of genetic counselors who have graduated within the last 5 years participated in this survey. The demographic characteristics of this sample such as age and gender were consistent with those of the genetic counseling population reported in NSGC’s Professional
Status Survey (NSGC PSS, 2012). However, it is not possible to compare all demographic characteristics of this sample to the population of genetic counselors who graduated within the last 5 years due to limitations of the PSS dataset.

*Interactions with Deaf Individuals in the Clinical Setting*

The majority of participants reported they do not have deaf or hard of hearing colleagues at their workplace (74.8%). Less than half of the participants (47.4%) reported they had never counseled a deaf patient. Approximately 41% of the participants reported counseling a deaf patient at their current job. The number of deaf patients respondents reported counseling in the last year were none (57.0%), 1-10 patients (37.0%), 11-20 patients (3.7%), 21-48 patients (1.5%) and more than 48 patients (0.7%). According to the 80 individuals who have encountered deaf patients, the specialty in which most participants encountered deaf patients, specifically counseling parents of a deaf child, was in pediatrics (48.7%).

Of the 70 participants who had counseled deaf patients, the majority (74.3%) reported inquiring about the patients’ preferred mode of communication ahead of the appointment, 18.6% inquired at the beginning or during the appointment, and 5.7% indicated that they did not ask about the patient’s preferred mode of communication. Although participants with deaf clients identified a variety of modes of communication (n=70), results show that ASL was commonly used, either indirectly via certified ASL interpreter (75.7%) or directly through the participant’s own knowledge of ASL (5.7%). Participants also identified relying on a family member or a friend as an interpreter (42.9%), relying on a patient’s ability to lip read (28.6%), writing back and forth (18.6%), and hand gestures (10.0%). Those who selected “other” (11.4%) indicated additional modes such as the use of hearing aids and tele-typewriters (TTY). Additionally, some participants indicated that their patients were deaf children or infants with hearing parents and therefore utilization of other modes of communication was unnecessary.

*Interactions with Deaf Individuals Outside the Clinical Setting*
The majority of participants (55.6%) stated they have not interacted with deaf or hard of hearing individuals outside of the workplace (n=60). Approximately a third (30.4%) of individuals reported interacting with deaf or hard of hearing individuals outside of the workplace less than once a month, and the remaining 14% reported more frequent interactions with deaf or hard of hearing individuals. While some indicated that their interactions occurred through their circle of friends (31.7%) or at home (20.0%), 23.3% of participants also stated that their interactions with the Deaf community occurred in their communities. Specifically indicated locations included the church and the grocery store. This study did not investigate the details and duration of these interactions.

*American Sign Language*

Among those who indicated they counseled deaf patients, 47.8% reported they always use a certified ASL interpreter and 23.2% of participants stated they never use a certified ASL interpreter. The majority of participants (65.2%) reported knowing how to secure the services of a certified ASL interpreter. Most participants (85.9%) indicated they have not taken ASL classes, and only 3.7% of participants stated they could communicate moderately well in ASL. When asked about interest in learning ASL, 17% had no interest in learning ASL, 34% were somewhat interested in learning ASL, 24.4% were interested, 21.5% were very interested, and 2.2% already know ASL, or are currently taking ASL classes. Among respondents who provided comments, the most common motivation for learning ASL was being able to communicate with Deaf and hard of hearing patients: "I would like to know a few simple child friendly signs. In my current position, I counsel hearing parents of young deaf/hearing impaired children. Often interpreters are not scheduled for the child and the parent does not translate to the child. For adult or older children I have had an interpreter". Others were motivated to communicate in ASL to help build rapport with Deaf patients: "It might help build rapport with deaf patients. Knowing even a bit of ASL might show the deaf patients that I am not uncomfortable interacting with the deaf community."
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Table 1: Summary of Sample Demographics</strong></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>135</td>
</tr>
<tr>
<td>Females</td>
<td>96.3%</td>
</tr>
<tr>
<td>Average Age, years (SD)</td>
<td>28 (4.5)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>86.7%</td>
</tr>
<tr>
<td><strong>Primary Work Setting</strong></td>
<td></td>
</tr>
<tr>
<td>Prenatal</td>
<td>33.3%</td>
</tr>
<tr>
<td>Cancer</td>
<td>29.6%</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>26.7%</td>
</tr>
<tr>
<td>Adult</td>
<td>15.6%</td>
</tr>
<tr>
<td>Other</td>
<td>13.3%</td>
</tr>
<tr>
<td>Laboratory</td>
<td>12.6%</td>
</tr>
<tr>
<td>General Genetics</td>
<td>7.4%</td>
</tr>
<tr>
<td>Number of Training Programs Represented</td>
<td>29</td>
</tr>
<tr>
<td>Average years worked as a genetic counselor</td>
<td>2.4 (1.3)</td>
</tr>
<tr>
<td><strong>Total deaf patients seen</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>57.0%</td>
</tr>
<tr>
<td>1-10 deaf patients/year</td>
<td>37.0%</td>
</tr>
<tr>
<td>ASL fluency</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>71.9%</td>
</tr>
<tr>
<td>Poor</td>
<td>24.40%</td>
</tr>
<tr>
<td>Moderate</td>
<td>3.70%</td>
</tr>
<tr>
<td>Fluent</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Personal interactions with the Deaf community</strong></td>
<td></td>
</tr>
<tr>
<td>No interaction</td>
<td>55.6%</td>
</tr>
<tr>
<td>Friends (Deaf)</td>
<td>11.1%</td>
</tr>
<tr>
<td>Friends (deaf)</td>
<td>3.8%</td>
</tr>
<tr>
<td>Colleagues</td>
<td>8.9%</td>
</tr>
<tr>
<td>Community</td>
<td>23.3%</td>
</tr>
<tr>
<td>Volunteering</td>
<td>4.4%</td>
</tr>
<tr>
<td>Family Member</td>
<td>2.2%</td>
</tr>
</tbody>
</table>

**Respondent had the option of selecting more than one response.**
Deaf Awareness Training

One hundred individuals (74%) indicated they received Deaf Awareness training. For the 29 graduate programs represented by respondents, at least one participating graduate for 26 (89.7%) of them reported receiving DAT. However, individuals from 16 (55%) programs indicated that they did not receive DAT. In five cases, individuals who were from the same program and graduating year had opposing answers on whether they received or did not receive DAT. Of those who had received Deaf Awareness training, the majority (69%) reported having a 1 to 2 hour class on this topic (Figure 2). Participants indicated that the individuals who conducted Deaf Awareness training were predominantly genetic counseling program instructors (n=79), followed by a member of the Deaf community (n=13) and members of a deaf advocacy group (n=12) (Figure 3). Participants could choose more than one type of individual if it applied to their DAT. The two topics that participants most often reported their Deaf Awareness training covered were the genetics of deafness and Deaf community and culture (Figure 4). Tools most commonly used during DAT were readings and discussions followed less frequently by movies and documentaries, hearing and deaf guest lecturers, and fieldtrips (Figure 5).

Among participants who provided written comments, the most commonly noted helpful tool was the movie, Sound and Fury, a documentary of a Deaf family battling the idea of having their daughter undergo a cochlear implant. Although their story does not represent the experiences of all Deaf families, it gives some valuable insight into issues and concerns that resonate strongly in the Deaf community. Additional helpful tools noted include guest lecturers who work with the Deaf community, readings such as “articles written from the perspective of those who are culturally Deaf”, discussions involving documentaries and readings, interpreters and group projects and presentations of Deaf culture and the “cultural awareness toolkit for GC website”. A couple of participants commented on how their field trips to Deaf schools were most helpful: "I think our field trip was the most informative. In order to navigate the campus to our lecture each of us had to check in at the front gate and communicate with deaf and hard
of hearing students. We also got to have lunch in the eating hall and walk around the campus to get a sense of what the university was like/how it was the same or different from other universities”.

Figure 2: Duration of Deaf Awareness training

Deaf Awareness Training Duration (n=100)

- 1-2 hour class: 69%
- Half a day of training: 10%
- 1 day of training: 7%
- > 2 days of training: 9%
- In-class student presentations: 5%

**Respondent had the option of selecting more than one response.**
Respondent had the option of selecting more than one response.

Figure 3: Individuals who conducted Deaf Awareness training

<table>
<thead>
<tr>
<th>Who Conducted Training? (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Counseling program instructor</td>
</tr>
<tr>
<td>Member of the Deaf community</td>
</tr>
<tr>
<td>Member of a deaf advocacy group</td>
</tr>
<tr>
<td>Certified American Sign Language interpreter</td>
</tr>
<tr>
<td>Classmates/Class Projects</td>
</tr>
<tr>
<td>Other (Professor of Psychology, Professors at Galludet, Special...)</td>
</tr>
<tr>
<td>Physicians</td>
</tr>
<tr>
<td>Genetic Counselors</td>
</tr>
<tr>
<td>Audiologist</td>
</tr>
<tr>
<td>Parent of a deaf child</td>
</tr>
</tbody>
</table>

Figure 4: Topics covered during Deaf Awareness training

<table>
<thead>
<tr>
<th>Topics Covered (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetics of deafness</td>
</tr>
<tr>
<td>Deaf community and culture</td>
</tr>
<tr>
<td>Cochlear implants</td>
</tr>
<tr>
<td>Terminology and types of deafness</td>
</tr>
<tr>
<td>Communicating with a Deaf individual</td>
</tr>
<tr>
<td>American Sign Language interpreters</td>
</tr>
<tr>
<td>Relationship between culture and language</td>
</tr>
<tr>
<td>Introduction to American Sign Language</td>
</tr>
<tr>
<td>Other (Psychosocial issues related to having a deaf...)</td>
</tr>
</tbody>
</table>

Respondent had the option of selecting more than one response.
Respondent had the option of selecting more than one response.

Opinions on Deaf Awareness training

We asked all participants several general questions about Deaf Awareness training regardless of whether or not they reported having DAT in their training program. Approximately half of the participants (49%) strongly agreed or agreed that their Deaf Awareness training was sufficient, 31% disagreed or strongly disagreed, and 20% neither agreed nor disagreed that their Deaf Awareness training was adequate. The bulk of participants (82.7%) were in agreement that having Deaf Awareness training would make one a better counselor for deaf clients. However, only 48 participants (35.8%) agreed or strongly agreed that there should be more emphasis on Deaf Awareness during graduate training while most participants (51%) neither agreed nor disagreed. Of the 48 participants who agreed that there should be more emphasis on Deaf Awareness during graduate training, 20 individuals were representative of those who did not receive any DAT.

Attitudes towards Deaf People
In addition to the total scores for the attitude questions, we also calculated the cronbach alpha to determine the reliability of the scale used to analyze the attitude scores. Cronbach’s alpha was computed from the sample scores and found to be consistent with previous studies (alpha = 0.75). The total score obtainable for the questions regarding attitudes towards Deaf people are as follows. Questions consistently answered with a negative attitude would result in a total score between 22 and 44. Questions consistently answered with a neutral attitude would produce a total score around 66. Finally, questions answered consistently with a positive attitude would result in a total score between 88 and 110. The average score for the whole sample was 79.07 (SD=6.93) (Table 2). The mean score of those who had Deaf Awareness training was 79.2 (SD=7.01, n=99), while the mean score of those who did not have Deaf Awareness training was 78.7 (SD=6.81, n=35). The difference between those with Deaf Awareness training and those without training was not statistically different (t=0.36; p=0.72). The mean scores in both groups are suggestive of neutral-positive attitude towards Deaf people. Figure 6 is a graph of the raw data of the strength of agreement with the attitude statements. In this sample, the average strength of agreement for positive statements was higher than for negative statements.

<table>
<thead>
<tr>
<th>Attitudes Score of Sample Population</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
<td>64.00</td>
</tr>
<tr>
<td>Maximum</td>
<td>98.00</td>
</tr>
<tr>
<td>Mean</td>
<td>79.07</td>
</tr>
<tr>
<td>S.D</td>
<td>6.93</td>
</tr>
<tr>
<td>Cronbach’s Alpha</td>
<td>0.752</td>
</tr>
<tr>
<td>Total Score</td>
<td></td>
</tr>
<tr>
<td>DAT</td>
<td>79.2</td>
</tr>
<tr>
<td>No DAT</td>
<td>78.7</td>
</tr>
</tbody>
</table>

**Table 2: Statistics of Attitude scores**

Positive Attitude Statements

Overall, the majority of participants did not strongly disagree or disagree with any of the positive statements. Most participants agreed or strongly agreed with the following statements: Interpreters should
be available for deaf people at work (att13) and Deaf people have their own culture (att22). Most participants neither agreed nor disagreed with the following statements: I would like to have more deaf friends (att3); I would like to have more deaf colleagues (att11) and Deaf people are safe drivers (att10).

**Negative Attitude Statements**

Overall, the participants did not strongly agree or agree with any of the negative statements. The majority of participants were in disagreement with the following negative attitude statements: having deaf colleagues would cause problems in the workplace (att17); Deaf couples should receive genetic counseling to avoid having deaf children (att1); training more professionals to work with deaf clients would be a waste of time (att16) and Deaf people should learn speech rather than sign language (att5). Participants neither agreed nor disagreed with the following statements: more research should be done to find cures for deafness (att7); all deaf people should be offered corrective surgery (att15) and Deaf people should learn to lip-read (att12).
We compared the results from this study to the Enns study (2010), with the main difference being the Enns study was open to all genetic counselors and 56.1% of those who participated were individuals who has been working for five years or less. Despite the slight difference in years of experience of the two study groups, there were no differences in attitudes towards Deaf people. Table 4 shows the comparison of the two studies.

**Table 3: Comparison of Attitude scores**

<table>
<thead>
<tr>
<th>If questions answered with:</th>
<th>Nagakura Total Score</th>
<th>Enns Total Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative attitude</td>
<td>22-44</td>
<td>22-66</td>
</tr>
<tr>
<td>Neutral Attitude</td>
<td>&lt;66</td>
<td>N/A</td>
</tr>
<tr>
<td>Positive attitude</td>
<td>88-110</td>
<td>88-132</td>
</tr>
<tr>
<td>Minimum</td>
<td>64.00</td>
<td>61.00</td>
</tr>
<tr>
<td>Maximum</td>
<td>98.00 (110)</td>
<td>127.00 (132)</td>
</tr>
<tr>
<td><strong>Average</strong></td>
<td><strong>79.07 (less positive, more neutral)</strong></td>
<td><strong>98.30 (more positive)</strong></td>
</tr>
</tbody>
</table>

**Knowledge of Deafness and Deaf Culture**

Out of a possible total knowledge score of 39, in this study, those who had any type of Deaf Awareness training achieved a mean score of 26.8 (SD 4.1, n=100) and those who did not have Deaf Awareness training achieved a mean score of 26.8 (SD 3.9, n=35). There was no statistical difference between the scores of these two groups (t=0.14; p=0.91).

The participants, regardless of whether they had Deaf Awareness training, had an average of 69% of the questions correct. We analyzed each item separately, and there were no significant differences between the two groups in percent correct responses on any item. However, there were a few questions that study participants, as a whole, answered poorly (Table 4, Table 5). As examples, the majority (61%) of participants did not know that cochlear implants destroy any residual hearing in the ear that the patient may have had. When asked about what you should do when you have a deaf couple who declines to have
their newborn baby's hearing tested, the majority of participants (69.7%) failed to answer the question correctly. The majority of participants (82.7%) also did not know the minimum time per session for hiring a certified ASL interpreter is 2 hours.

Table 4: Poorly Answered Multiple Choice Knowledge questions—with the correct answers.

<table>
<thead>
<tr>
<th></th>
<th>Had Deaf Awareness Training (100)</th>
<th>No Deaf Awareness Training (35)</th>
<th>Total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent Correct % (n)</td>
<td>N</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. A cochlear implant:
   
   B. Destroys any residual hearing in the ear that the patient may have had
      
      41.7%  40  31.4%  11  131

2. *The hospital has arranged for you to give a presentation on an important health topic with the assistance of an ASL interpreter. The audience, which consists mainly of deaf patients, are all socializing prior to the presentation. You are ready to begin your presentation. You should:
   
   A. Stand on stage and wait patiently for the audience to settle down
      
      25.0%  25  17.1%  6  135
   
   B. Flick the light on and off several times in order to get the audience's attention
      
      40.0%  40  42.9%  15  135

   *This question had two correct answers

3. You have a deaf couple who declines to have their newborn baby's hearing tested. You should:

   C. Accept their decision
      
      29.9%  29  31.4%  11  132

4. *You go to get your patient from the waiting room. You call for your patient several times. Others in the room point to a person reading a magazine and say "She's deaf". You should:
   
   A. Approach the patient and gently tap her on the shoulder
      
      50.0%  50  62.9%  22  135
   
   C. Approach the patient making small gestures in her field of vision to try to get her attention
      
      45.0%  45  45.7%  16  135
Table 5: Poorly Answered True and False Knowledge questions

<table>
<thead>
<tr>
<th>TRUE AND FALSE QUESTIONS</th>
<th>Had Deaf Awareness Training (100)</th>
<th>No Deaf Awareness Training (35)</th>
<th>Total respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. The majority of hearing parents with deaf children never learn to sign (T)</td>
<td>29.9% 29</td>
<td>31.4% 11</td>
<td>132</td>
</tr>
<tr>
<td>14. When hiring an interpreter, the minimum time per session is two hours. (T)</td>
<td>15.3% 15</td>
<td>22.9% 8</td>
<td>133</td>
</tr>
<tr>
<td>17. Deaf patients generally do not participate in support groups such as those that help patients cope with disease or death. The main reason for this is due to the language barrier. (T)</td>
<td>29.5% 28</td>
<td>40.0% 14</td>
<td>130</td>
</tr>
<tr>
<td>.27. If you suspect hearing loss in an infant, you should make a note to recheck the infant’s hearing on the next visit. (F)</td>
<td>22.9% 22</td>
<td>11.4% 4</td>
<td>131</td>
</tr>
</tbody>
</table>

We next investigated whether having certain topics covered during Deaf Awareness training was correlated with participants’ knowledge of that topic. For these analyses, we focused on the 100 participants who reported having DAT. Among the 68 individuals who reported having exposure to the topic of cochlear implants as part of their DAT, 37 out of 68 (54%) answered this question incorrectly and did not know that cochlear implants destroy residual hearing. Among the 28 individuals who did not report exposure to the topic of cochlear implants as part of their DAT, 19 (68%) answered this question incorrectly. There was no statistically significant difference between these two groups in the responses to this item (p=0.225). Fifty individuals reported they learned about the relationship between culture and language during their DAT, however, 66% of those individuals did not know that most parents with deaf children do not know how to sign. Of 47 individuals who did not learn about the relationship between culture and language in their DAT, 35 individuals (74%) did not know that most parents with deaf children do not know how to sign. This was not found to be statistically significant (p=0.363). Finally, 77% of those who reported that ASL interpreters as part of their Deaf Awareness training answered the question regarding certified ASL interpreters incorrectly. Of those who had DAT but did not learn about
ASL interpreters, 43 (93%) individuals answered the question regarding certified ASL interpreters incorrectly. There was no statistically significant difference between these two groups in the responses to this item (p=0.023).

The following table compares the knowledge scores from genetic counselors surveyed in this study to those of medical students surveyed by Hoang et al. (2010) (Table 7).

<table>
<thead>
<tr>
<th>Total Summary Score (True and False + Multiple choice questions)</th>
<th>With Deaf Awareness training Mean score (SD)</th>
<th>Without Deaf Awareness training Mean score (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recent Genetic Counseling Graduates (Nagakura et al.)</td>
<td>26.8 (4.1)</td>
<td>26.8 (3.9)</td>
</tr>
<tr>
<td>Medical Students (Hoang et al.)</td>
<td>26.90 (5.34)</td>
<td>13.79 (6.39)</td>
</tr>
</tbody>
</table>

While both genetic counselors with DAT and without DAT scored similarly to the medical students who received Deaf Community training in the Hoang study, medical students who did not receive Deaf Community training performed half as well as genetic counselors who have not had Deaf Awareness training.

**Attitude towards Deaf people and Knowledge of Deafness and Deaf Culture: Increased interactions with Deaf people**

Given the lack of correlation between Deaf Awareness training and both attitudes towards deaf people and knowledge of deafness and Deaf culture, we looked to see if amount of interaction with Deaf people was a significant factor in participants’ knowledge and attitudes. For this analysis, we classified participants into one of two groups: individuals with little to no interactions with Deaf people, and individuals with interactions with Deaf people. We classified individuals as interacting with Deaf people if they reported at least one of the following: deaf family members or friends, deaf colleagues, interactions with deaf individuals in their community, currently seeing deaf patients, and those who have had more than 1-2 hours of Deaf Awareness training. We pooled these participants together (n=87) and
compared their results to those who did not report any of these forms of interaction with Deaf people (n=48). These two groups did not have statistically significant differences in knowledge scores or attitude scores (p’s>0.05).
DISCUSSION

This study provides empirical data on recent graduates’ exposure to Deaf Awareness in genetic counseling training programs, and their knowledge of deafness and Deaf culture and attitudes towards Deaf people. The majority of recent genetic counselors in this study reported receiving some form of Deaf Awareness training during their graduate program. However, we found no evidence that Deaf Awareness training improved participants’ knowledge of deafness and Deaf culture or attitudes toward Deaf people. Overall, this sample of recent genetic counselors has neutral-positive attitudes towards Deaf people and adequate knowledge of deafness and Deaf culture, with deficits in certain relevant topics. Our respondents represented most genetic counseling programs; therefore, our results give insight into how recently graduated genetic counselors had Deaf Awareness Training. As reported by participants, program instructors most commonly conducted the Deaf Awareness Training, using similar tools (readings, discussions), and covering similar topics (genetics of deafness, Deaf community and culture). The duration of Deaf Awareness Training was typically 1-2 hours.

To assess the effectiveness of DAT, participants completed the attitudes toward Deaf people questionnaire developed by Cooper et.al (2004) and the knowledge of deafness and Deaf culture items developed by Hoang et al. (2011). The average attitude scores for the groups were 79.2 for those with DAT and 78.7 for those without DAT, indicative of neutral-positive attitudes toward Deaf people and consistent with findings of an earlier study of genetic counselors’ attitudes toward Deaf people (Enns et al. 2010). The average knowledge scores for both those with DAT and for those without DAT was 26.8 out of 39, indicative of an average of 69% items answered correctly.

We can interpret the lack of differences between the two groups as evidence that either DAT is not a necessary component of genetic counseling graduate training, or DAT may not be comprehensive enough in graduate programs. However, this conclusion is not consistent with our results demonstrating
better knowledge on selected items among participants who indicated certain topics covered in their DAT compared to those who did not have those topics covered during DAT. Nor is such a conclusion consistent with a recent study of the effectiveness of Deaf Awareness Training for medical students (Hoang et al. 2011). In that study, which used the same knowledge items used in the current study, the average knowledge score for medical students with Deaf Awareness Training was 26.9 (69% correct) and medical students without Deaf Awareness Training was 13.79 (35% correct). This result clearly demonstrates the value of Deaf Awareness Training in enhancing knowledge of deafness and Deaf culture in that sample. However, it is interesting to note that recent genetic counseling graduates with and without Deaf Awareness Training performed just as well as medical students who had DAT on the knowledge items. This comparison raises the question of whether the field of genetic counseling draws individuals with interest in topics relevant to deaf cultural competency, and whether these individuals were more likely to participate in this study.

We must also consider the possibility that Deaf Awareness training as currently structured is not effective enough to improve Deaf Awareness of genetic counselors given their potentially good baseline knowledge of deafness and Deaf culture. Areas of education to evaluate critically are duration, materials and tools, and topics. The most frequently reported training duration of 1 to 2 hours may be insufficient to yield a meaningful increase in Deaf Awareness. Correspondingly, nearly a third of respondents indicated that DAT was not sufficient during their training. In terms of materials and tools, engagement with Deaf individuals may be a critical missing element from Deaf Awareness training in many programs. This is important to consider because previous research has demonstrated that contact between Deaf and hearing individuals is a key factor in hearing individuals’ attitudes toward deaf people (Enns et al. 2010; Hoang et al. 2011). It is interesting to note that respondents mentioned tools that engaged students with Deaf people either directly or indirectly most frequently in the comments, but actually used the tools least frequently as part of Deaf Awareness Training.

Regarding topics included in DAT, those presented to students may have been inadequate to yield a meaningful increase in Deaf Awareness. Although our results demonstrated that the genetics of deafness
and Deaf community and culture were the most commonly addressed topics in Deaf Awareness Training, we identified a number of instances in which participants incorrectly answered knowledge items on topics that they reported as part of their DAT. Areas of weak knowledge include the effects of cochlear implant on residual hearing, communication between a deaf child and hearing parents, and working with sign language interpreters.

One important area is ensuring clear and appropriate communication between genetic counselors (who typically lack fluency in ASL) and Deaf patients. Although approximately 75% of respondents who have seen Deaf patients indicated using a certified American Sign Language interpreter during clinic visits, the second most frequently used mode of communication with Deaf patients was having a family member or friend act as an interpreter (42.9%). Generally, we do not recommend using a family member or a friend to interpret a medical session. The HHS Guidance to Federal Financial Assistance Recipients states, “…with proper planning and implementation, recipients should be able to avoid most such situations [where they would need their family members to interpret]” (Health and Human Services, 2000). In addition, the Americans with Disabilities Act (ADA) of 1990 mandates that a comprehensive variety of public and private services as well as employers must be accessible to all people, regardless of disability. When interacting with people who are Deaf, this means that communication must be accessible and in most cases, the best way to ensure this is to have an interpreter instead of family members or friends. This is important for genetic counselors to understand, because family members and friends may have personal opinions and agendas that may distort the information. Additionally, non-medical interpreters may not understand the information presented to them and therefore may not relay the information back to the patient as presented by the healthcare provider. Lastly, the health literacy of Deaf individuals is generally poor (Steinberg et al., 2002; Iezzoni et al., 2004) and asking a non-trained individual to interpret medical information may add another layer of misunderstanding. Therefore, it is encouraging to see that the majority of recent genetic counseling graduates (75.7%) noted using a
certified American Sign Language interpreter as the most common mode of communication with Deaf patients.

Finally, post-training experiences may affect participants’ knowledge and attitudes. In this sample of recent genetic counseling graduates, 55.6% have not interacted with Deaf individuals outside of the workplace and 48.1% have not counseled Deaf patients. Among those who reported counseling Deaf patients, the majority do so on average of one to 10 times per year. Hence the majority of recent genetic counseling graduates in this sample have had limited interaction with Deaf individuals. Thus, it is possible that in the absence of interactions with Deaf individuals, those who received Deaf Awareness Training have not retained the knowledge gained from Deaf Awareness Training. However, those who had longer durations of training did not demonstrate greater knowledge or have a better attitude towards deaf people.

Evidence of Interest in Deaf Awareness

Approximately 80% of the participants stated that they were interested in learning American Sign Language to some extent. The most common motivation for learning ASL was being able to communicate with Deaf and hard of hearing patients. By knowing some signs, genetic counselors would be able to somewhat communicate in ASL which will help build rapport with Deaf patients. Comments provided by the research participants highlighted the fact that the language barrier may be a major factor and by learning simple words or phrases may increase trust towards health care providers. Additional motivations for learning ASL included the enjoyment of learning new languages, personal interests in American Sign Language, knowledge of ASL being a useful skill in life, and having deaf friends and family members.

Repercussions of Inadequate Deaf Awareness

Based on this study, the majority of recent genetic counseling graduates do not counsel Deaf patients. Those who do (6%), counsel an average of 1 to 10 Deaf patients per year. The limited interaction with Deaf individuals in the clinical setting, especially in genetics, may stem from the fact that
the Deaf community is still wary of our intent as health care professionals. This could potentially create a never-ending cycle, where health care professionals lack Deaf Awareness because of the limited exposure to Deaf individuals, and where Deaf individuals shy away from health care settings due to our lack of understanding of their culture. Given that this study only recruited recent genetic counseling graduates, those with more experience may see more Deaf patients. However, in the study by Enns et al., only 7.7% of the participants saw more than 10 Deaf patients a year. Since that study recruited genetic counselors of all experiences, the difference of 1.7% who said they had more interactions with Deaf patients may be accounted for by counselors who had been in clinical practice longer.

Study Limitations

This study has several limitations. First, approximately 25% of individuals did not complete the survey, leaving an effective sample size of 135. We did not perform comparisons to determine if those who did not complete the study differed in any significant way from those who completed the study. Hence, we are unable to comment on potential biases present in the study sample. Furthermore, based on this small population of genetic counselors surveyed, the study may not be fully representative of all recent genetic counseling graduates. Although this sample has similar demographics to the genetic counseling population as whole, we were unable to compare the demographics of the study sample to all genetic counselors who graduated within the last 5 years.

Those who participated were self-selecting, which also adds a response bias to the study. Individuals with a personal interest in this topic may have self-selected to take the survey, which in turn, may skew the data. Although participants are self-selected, there is no evidence that the genetic counseling program they attended influenced this, or that results are dominated by a specific program, given that programs were represented fairly equally. Additionally, in five cases, individuals who had graduated from the same program in the same year had contradicting views on whether their program offered DAT. This may be due to DAT being optional at their program, or their definition of DAT differed, despite our efforts to minimize confusion on the definition of DAT by providing a description of
what DAT involves in the survey. This study also did not address and account for external Deaf Awareness training that participants may have had.

Lastly, this study was retrospective, asking participants to look back at their graduate training and remember classes that focused on Deaf Awareness. The retrospective design of the study introduces the possibility of recall bias. By excluding genetic counselors who graduated more than 5 years ago we tried to minimize this concern, however, the details of training may still be vague.

**Implications for Genetic Counseling Training Programs**

Based on this study, it is apparent that the majority of recent genetic counseling graduates are interested in learning American Sign Language to some extent. This interest in ASL may be the stepping-stone to increasing Deaf Awareness. Even by learning the simplest of signs, genetic counselors will be able to build rapport or sign to deaf children to gain their trust and slowly bridge the gap between health care professionals and the Deaf community. By incorporating field placements within local Deaf communities, the exposures to Deaf individuals and Deaf culture may be more beneficial in attaining Deaf Awareness than the traditional Deaf Awareness training involving readings and discussions. In areas where there are limited Deaf communities, guest lectures involving a Deaf individual and an ASL interpreter may be beneficial. This will allow students to gain insight into interactions between the interpreter and the Deaf individual, while simultaneously gaining the experience of interacting with a Deaf person.

Additionally, supplementing diversity training with projects that involve role reversals such as the program implemented at the University of Rochester, School of Medicine and Dentistry called Deaf Strong Hospital (Richards et al., 1999) may be more effective in increasing Deaf Awareness by personally experiencing the difficulties of a deaf individual in the healthcare setting, students may become more Deaf Aware.
CONCLUSION

This study assessed Deaf Awareness training in genetic counseling graduate programs and investigated its impact on attitudes towards and knowledge of deafness and Deaf culture. This study is the first to describe details of Deaf Awareness training provided in graduate genetic counseling training. The majority of recent genetic counseling graduates had 1 to 2 hours of training, which primarily included readings and discussions on the genetics of deafness and Deaf community and culture. The study's findings did not provide evidence that Deaf Awareness training, as reported by respondents, had an impact on Deaf cultural competency of recent genetic counseling graduates. All participants, regardless of whether they have had or have not had training had similar attitudes and comparable knowledge of Deafness. The study however, shows an overall positive attitude towards Deaf individuals and average knowledge of deafness and Deaf culture.

Future studies could include designing alternative programs of Deaf Awareness training for genetic counseling students, and investigating the impact of their use on Deaf Awareness. This would allow us to determine whether Deaf Awareness training needs modification to be more effective, or whether it is unnecessary. Another potential project may include surveying Deaf individuals who have had genetic counseling and obtaining their opinion on whether genetic counselors have sufficient Deaf Awareness. This would also allow us to tailor our Deaf Awareness training based on what Deaf individuals feel that we, as genetic counselors lack. Lastly, additional studies may investigate knowledge of deafness and Deaf culture amongst incoming genetic counseling graduate students to identify the baseline Deaf Awareness that they possess.
REFERENCES


ACGC. (2010) Required Criteria for Graduate Programs in Genetic Counseling Seeking Accreditation by the American Board of Genetic Counseling


Alexander Graham Bell’s Memoir on the Formation of a Deaf Variety of the Human Race


APPENDIX A

Recruitment Notice

Assessing Deaf Awareness: Attitudes and Training of Recent Genetic Counseling Graduates

Did you graduate from a Genetic Counseling program within the last 5 years?

Dear members of NSGC,

My name is Honey Nagakura, and I am a 2nd year genetic counseling student at Brandeis University. I would like to invite you to participate in my research project investigating Deaf Awareness among recent genetic counseling graduates. Questions will assess graduate training, Deaf Awareness, and attitudes towards Deaf culture. The goal of this project is to evaluate Deaf Awareness training within various genetic counseling training programs, and to determine if there are associations between training and Deaf Awareness or attitudes towards Deaf culture. We are also interested in counselors' opinions on how to improve Deaf Awareness training in genetic counseling programs.

Participation in this research study is open to all individuals who:

- Are at least 18 years old or older
- Attended a Genetic Counseling Program
- Graduated from a Genetic Counseling Program in within the last 5 years
- Are members of the National Society of Genetic Counselors

NOTE: Experience with Deaf individuals is not required for participation

In the survey, when speaking of the Deaf, we are referring to pre-lingually deaf individuals.

Participation in this study is voluntary and confidential. You may discontinue participation at any time for any reason. If you wish to participate, please complete the online survey at the hyperlink below. The survey will take approximately 10-15 minutes to complete, and all data collected will remain anonymous. The survey will remain open until March 22, 2013.
APPENDIX B

Survey

Assessing Deaf Awareness- Training and Attitudes of Recent Genetic Counseling Graduates

Thank you for choosing to participate in my survey. The goal of this project is to evaluate Deaf Awareness among genetic counselors to determine if there are associations between training and experiences, and Deaf Awareness, knowledge and attitudes towards Deaf culture. We are also interested in counselors' opinions on how to improve Deaf Awareness training in genetic counseling programs. NOTE: Experience with Deaf individuals is not required for participation.

In the survey, when speaking of the Deaf, we are referring to pre-lingually deaf individuals. You are being asked to participate in an online survey for a research project conducted through Brandeis University. The University requires that you give your approval to participate in this project. To participate you must have graduated from a genetic counseling program in within the last 5 years. You must also be at least 18 years old to take this survey. Your participation in the study is completely voluntary. If you decide to participate now, you may change your mind and stop at any time, for any reason, without penalty. You can choose to not answer an individual question or you may skip any section of the survey by clicking “Next” at the bottom of the survey page to move to the next question. By clicking the "Next" button, you are consenting to participate in this study.

The following questions pertain to your experience as a Genetic Counselor.
Q1 How many years have you been practicing as a Genetic Counselor?

- Up to 1 year
- 1-2 years
- 2-3 years
- 3-4 years
- 4-5 years

Q2 What is your primary counseling setting as a Genetic Counselor? (Select all that apply)

- Adult
- Cancer
- General Genetics
- Laboratory
- Pediatric
- Prenatal
- Other (Please specify) ____________________

Q3 How long have you been at your current position?

- less than 6 months
- 1 year
- 2 years
- 3 years
- 4 years
- 5 years

Q4 In which fields have you worked? Select all that apply.

- Adult
- Cancer
- General Genetics
- Laboratory
- Prenatal
- Pediatric
- Other ____________________

The following questions address interactions with the Deaf Community:
Q5 Are you Hearing, Hard of Hearing, or Deaf?

- Hearing
- Hard of Hearing
- Deaf

Q6 Do you consider yourself part of the Deaf community?

- Yes
- Occasionally
- No

Q7 Do you have a family member who was born deaf?

- Yes
- No
If No Is Selected, Then Skip To Do you have culturally Deaf friends, ...

Q8 Which family member was born deaf? Select all that apply.

- Child
- Mother
- Father
- Brother/Sister
- Uncle/Aunt
- Grandparent
- Cousin
- Other (Please specify) ____________________

Q9 Do you have culturally Deaf friends, i.e., who identify with the Deaf community

- Yes
- I do not know
- No

Q10 Do you have deaf friends who do not identify with the Deaf community?

- Yes
- I do not know
- No
Q11 How often do you interact with deaf or hard of hearing people outside of working as a genetic counselor?

- Never
- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

Q12 Where do these interactions take place?

- At home
- Circle of friends
- Volunteering
- Work other than genetic counseling
- Other (Please specify) ____________________

Q13 Do you have deaf or hard of hearing colleagues at your workplace?

- Yes
- Not sure
- No

Q14 Do you counsel deaf patients at your current job?

- Yes
- No

Q15 How many deaf patients have you counseled in the past year?

- None
- 1-10 (~less than once a month)
- 11-20 (~2x a month)
- 21-48 (~once a week)
- More than 48 patients (more than once a week)
Q16 At which Genetic Counseling specialty did you encounter the most deaf patients?

- Adult
- Cancer
- General Genetics
- Laboratory
- Pediatrics
- Prenatal
- Other (Please Specify) ____________________
- Not Applicable

Q17 When do you ascertain your deaf patients’ preferred mode of communication?

- Inquire ahead of appointment
- Inquire at the beginning of the appointment
- Inquire during the appointment
- I do not inquire
- Never had a deaf patient

Q18 What modes of communication have you used at work to interact with your deaf patients?

- Certified American Sign Language (ASL) interpreter
- Patient’s family member or friend acts as interpreter
- Your own knowledge of ASL
- Relying on the patient’s ability to lip read
- Hand gestures
- Writing back and forth
- Never had a deaf patient
- Other (Please specify) ____________________

Q19 How often have you used a certified American Sign Language (ASL) interpreter when counseling a deaf patient whose preferred language is ASL?

- Never had a deaf patient
- Never
- Occasionally
- Most of the time
- Every time
Q20 Do you know how to secure the services of a certified ASL interpreter if needed?

○ Yes
○ No

Q21 Have you taken courses in ASL?

○ Yes
○ No

Q22 How well can you communicate in ASL?

○ Not at all
○ Poorly
○ Moderately
○ Fluently

Q23 On a scale from 1 to 5, how interested are you in learning ASL?

<table>
<thead>
<tr>
<th>Interest in learning ASL</th>
<th>No Interest (1)</th>
<th>Somewhat Interested (2)</th>
<th>Interested (3)</th>
<th>Very interested (4)</th>
<th>Currently taking ASL lessons/ Already know ASL (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
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</tr>
</tbody>
</table>

Q24 If interested in learning ASL, what motivates you to learn ASL?

The following questions address Deaf Awareness training. Deaf Awareness training may include but is not limited to understanding the difference between deaf/Deaf, the culture and language of Deaf people, how to optimize communication between deaf and hearing individuals, and the rights of the deaf individual within the healthcare setting.
Q25 Did you have any Deaf Awareness training in your genetic counseling program?

- Yes
- No

If No Is Selected, Then Skip To The Genetic Counseling Cultural Competency...

Q26 Who conducted the Deaf Awareness training?

- Genetic Counseling program instructor
- Member of the Deaf community
- Parent of a deaf child
- Child of a deaf parent
- Member of a deaf advocacy group
- Certified American Sign Language interpreter
- Other (Please specify) ____________________

Q27 What tools did your graduate program use to increase your Deaf Awareness? Please select all that apply.

- Readings
- Movies/Documentaries
- Guest Lecturers (Hearing)
- Guest Lecturers (Deaf)
- Discussions
- Field Trips
- Role Plays
- Other (Please Specify)

Q28 In the space provided please provide the name of any learning tools that you found particularly helpful (e.g. names of movies, guest lecturers, online trainings, field trip sites, etc.)
Q29 What topics were covered during the Deaf Awareness training?

- American Sign Language interpreters
- Cochlear implants
- Communicating with a Deaf individual
- Deaf community and culture
- Genetics of deafness
- Introduction to American Sign Language
- Relationship between culture and language
- Terminology and types of deafness
- Other (Please specify) ____________________

Q30 What was the duration of the Deaf Awareness training you received? (Ex. 1 hour class, 2 day training, etc.)

- 1-2 hour class
- Half a day training
- 1 day training
- 2 day training
- 3-4 day training
- 1 week long training
- 1 semester internship
- Other (Please specify) ____________________

Q31 Please describe other aspects of your Deaf Awareness training if they were not addressed in the previous questions
Q32 The Genetic Counseling Cultural Competence Toolkit was created by the 2009 JEMF award winner, Nancy Steinberg Warren to promote culturally competent genetic counseling by using online learning modules. Are you aware of the Genetic Counseling Cultural Competence Toolkit?

☐ Yes
☐ No

If No Is Selected, Then Skip To

Q33 In this toolkit, there is a module on "Risk Assessment/Inheritance/Counseling and Deaf Culture". Have you applied the "Risk Assessment/Inheritance/Counseling and Deaf Culture" module of the toolkit in your counseling practices?

☐ Have only skimmed the module, not fully explored
☐ Fully explored the module but do not think it is helpful for practice
☐ Fully explored the module and intend to apply to practice
☐ Fully explored and have applied some learning from it to practice
☐ Fully explored and fully apply it to practice
☐ Other (Please specify) ____________________

Q34 For what other purposes have you used the Genetic Counseling Competence Toolkit?

Q35 To what extent do you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>You are interested in participating in the &quot;Risk Assessment/Inheritance/Counseling and Deaf Culture&quot; online module to increase your Deaf Awareness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>You think Genetic Counseling programs should incorporate the Genetic Counseling Cultural Competence Toolkit into their graduate training.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>
Q36 For the following questions, please click on the answer that best describes your attitude towards Deaf Awareness training

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaf Awareness training was sufficient during your graduate training</td>
<td>○</td>
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<tr>
<td>Genetic counseling programs should have more emphasis on Deaf Awareness</td>
<td>○</td>
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<tr>
<td>Having Deaf Awareness training would help you become a better counselor for the Deaf.</td>
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<td>○</td>
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</tbody>
</table>
Q37 The following statements relate to deafness and Deaf culture. Please state to what extent you agree or disagree with the following statements.
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Deaf couples should receive genetic counseling to avoid having deaf children.</td>
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<td>2.</td>
<td>Deaf children should learn to speak to communicate with hearing parents.</td>
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<td>3.</td>
<td>I would like to have more deaf friends.</td>
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<td>4.</td>
<td>Deaf schools and deaf clubs create deaf “ghettos.”</td>
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<td>5.</td>
<td>Deaf people should learn speech rather than sign language.</td>
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<td>6.</td>
<td>Deaf people are handicapped.</td>
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<td>7. More research should be done to find cures for deafness.</td>
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<td>8. Deaf children should be taught in sign language.</td>
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<td>9. Hearing children of deaf parents are at risk of emotional deprivation.</td>
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<td>10. Deaf people are safe drivers.</td>
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<td>11. I would like to have more deaf colleagues.</td>
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<td>12. Deaf people should learn to lip-read.</td>
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<tr>
<td>13. Interpreters should be available for deaf people at work.</td>
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<td>14. Deaf people should automatically receive help in their home environment.</td>
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<td>15. All deaf people should be offered corrective surgery.</td>
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<td>16. Training more professionals to work with deaf clients would be a waste of time.</td>
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<td>17. Having a deaf colleague would cause problems in the workplace.</td>
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<td>18. Deaf people are physiologically impaired.</td>
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<tr>
<td>19. Deaf people should not be viewed as &quot;impaired.&quot;</td>
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<tr>
<td>20. I would like to see more deaf people at club/societies I attend.</td>
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</tr>
</tbody>
</table>
Questions 41-46 pertain to Deaf Culture in the Medical Setting. Please select the best answer to the following questions.

Q38 A cochlear implant:
- Will allow a deaf adult to immediately begin hearing and understanding oral conversations
- Destroys any residual hearing in the ear that the patient may have had
- Corrects for any type of hearing loss
- Is desired by at least 90% of deaf people
- Do not know

Q39 In a medical setting, it is the right of the deaf patient:(Select all that apply)
- To express a preference for a particular interpreter
- To be provided an interpreter by the provider
- To determine how much personal information he/she wants to disclosed in an interpreted situation
- Do not know
Q40 The hospital has arranged for you to give a presentation on an important health topic with the assistance of an ASL interpreter. The audience, which consists mainly of deaf patients, are all socializing prior to the presentation. You are ready to begin your presentation. You should:(Select all that apply)

- Stand on stage and wait patiently for the audience to settle down
- Flick the light on and off several times in order to get the audience’s attention
- Clap loudly
- As the interpreter to sign that you are ready to begin
- Do not know

Q41 In an consultation room, where would you suggest the patient and interpreter to sit?

- Place the interpreter beside the patient. The patient and the interpreter are facing the provider
- Place the interpreter beside the provider. The provider and interpreter are facing the patient
- Place the interpreter at an equal distance between the provider and the patient
- Do not know

Q42 You have a deaf couple who declines to have their newborn baby’s hearing tested. You should:

- Tell them this is required by law, and that it has to be done for their baby’s benefit
- Tell them it is their decision, but explain that this lack of knowledge will put their baby at risk
- Accept their decision
- Do not know

Q43 You go to get your patient from the waiting room. You call for your patient several times. Others in the room point to a person reading a magazine and say ”She’s deaf”. You should:(Select all that apply)

- Approach the patient and gently tap her on the shoulder
- Approach the patient and call their name louder
- Approach the patient making small gestures in her field of vision to try to get her attention
- Do not know
Q44 The following questions pertain to Deaf Culture in the Medical Setting. Please identify the following statements as either True or False.
<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Only 30% of the English language can be accurately lip read</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. You are running considerably behind schedule. Your deaf patient is waiting with his/her interpreter. The interpreter is ethically bound to wait with the patient until you are ready to see them.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. ASL is a pictorial language that produces a word-for-word translation of what is being said in English.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. The majority of hearing parents with deaf children never learn to sign.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. When communicating with a deaf patient through an interpreter, you should face the interpreter and explain to the interpreter what the patient needs to know.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Trying to help cure your patient’s deafness should be your top priority</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Because deaf people rely upon printed forms of information, their literacy is equal to or better than the general public.</td>
<td>☐</td>
<td>☐</td>
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<td></td>
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</tr>
<tr>
<td>8. A good interpreter will be able to step out of his/her interpreting role in order to explain to the provider what the patient is really trying to say.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. When there is a dominant source of light, such as a window, your deaf patient should be seated with his/her back to the light source and you should be seated facing the light source.</td>
<td></td>
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</tr>
<tr>
<td>10. For an infant, there is very little that can be done to improve an infant's hearing due to its age.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. When speaking to a deaf patient through an interpreter you should speak each word very slowly, to allow the interpreter time to sign or fingerspell your words.</td>
<td></td>
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</tr>
<tr>
<td>12. For most members of the deaf community, English is their primary language.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. When a deaf patient is hospitalized, the entire staff should be notified that the patient is deaf.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. When hiring an interpreter, the minimum time per session is two hours.</td>
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<td></td>
</tr>
<tr>
<td>15. At the end of the health care visit, the interpreter should again review the information with the patient.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
16. Early in the conversation, your patient mentions to you that he has Usher’s syndrome. This information will influence how you communicate with him.

17. Deaf patients generally do not participate in support groups such as those that help patients cope with disease or death. The main reason for this is due to the language barrier.

18. On average, deaf patients report that they are unable to convey adequate information to their doctors.

19. Less than 50% of physicians who have deaf patients use a certified interpreter.

20. Working with other minority and/or disabled population will adequately prepare a health care provider to work with the deaf.

21. 90% of deaf people have hearing parents.

22. If a child is found to have a hearing loss, you should also refer the child to an optometrist.

23. It is the patient’s responsibility to schedule the interpreter if they think one will be needed.
24. You have complicated information to communicate to a deaf patient, so it would be wise to tell the patient to bring along a friend or family member to assist with the interpretation.

25. If the patient requests an interpreter for a visit with their health care provider, it is the patient's responsibility to pay for the interpreter.

26. If a deaf patient requests an interpreter, you may ask your nurse, who has taken several semesters of ASL classes, to interpret for the consultation.

27. If you suspect hearing loss in an infant, you should make a note to recheck the infant's hearing on the next visit.

28. American Disabilities Act requires an interpreter be present whether the patient wants one or not.

Please answer the following questions pertaining to demographics

Q45 What is your gender?

- Male
- Female

Q46 What is your age?
Q47 Please select your ethnicity

- African American
- Asian
- Caucasian
- Hispanic/Latin American
- Native American
- Pacific Islander
- Other ____________________
Q48 Which Genetic Counseling Program did you graduate from?

- Arcadia University
- Boston University School of Medicine
- Brandeis University
- California State University- Stanislaus
- Case Western Reserve University
- Howard University
- Indiana University Medical Center
- Johns Hopkins Univ. / National Center for Human Genome Research
- Long Island University- C.W. Post
- McGill University
- Medical College of Virginia
- Mt. Sinai School of Medicine
- Northwestern University Medical School
- Sarah Lawrence College
- Stanford University
- University of Alabama
- University of Arkansas
- University of British Columbia
- University of California-Irvine
- University of Cincinnati College of Allied Health Sciences
- University of Colorado Health Science Center
- University of Maryland School of Medicine
- University of Michigan- Ann Arbor
- University of Minnesota
- University of North Carolina- Greensboro
- University of Pittsburgh
- University of South Carolina
- University of Texas Graduate School of Biomedical Sciences
- University of Toronto
- University of Utah Health Sciences Center
- University of Wisconsin- Madison
- Wayne State University
- Other (Please Specify)

Answer If Which Genetic Counseling Program did you graduate from? Other (Please Specify) Is Selected

Q48 Which Genetic Counseling Program did you graduate from?
Q49 What year did you graduate from your program?

- 2012
- 2011
- 2010
- 2009
- 2008
- Other ____________________

Q50 Do you have any suggestions/opinions/comments on how to increase genetic counselor’s Deaf Awareness towards the Deaf community?