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# Examining the Relationship Between Genetic Counselors' Attitudes Toward Deaf People and the Genetic Counseling Session

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**Abstract** Given the medical and cultural perspectives on deafness it is important to determine if genetic counselors' attitudes toward deaf people can affect counseling sessions for deafness genes. One hundred fifty-eight genetic counselors recruited through the National Society of Genetic Counselors Listserv completed an online survey assessing attitudes toward deaf people and scenario-specific comfort levels discussing and offering genetic testing for deafness. Respondents with deaf/Deaf friends or who work in prenatal or pediatric settings had more positive attitudes toward deaf people than those without deaf/Deaf friends or those working in 'other' settings. More positive attitudes

toward deaf people correlated with higher comfort level *talking* about genetic testing for the two scenarios involving culturally Deaf clients; and correlated with higher comfort level *offering* genetic testing to culturally Deaf clients wishing to have a deaf child. Attitudes and comfort level were not correlated in the scenarios involving hearing or non-culturally deaf clients. These results suggest that genetic counselors' attitudes could affect information provision and the decision making process of culturally Deaf clients. Cultural sensitivity workshops in genetic counseling training programs that incorporate personal interactions with culturally Deaf individuals are recommended. Additional suggestions for fostering personal interactions are provided.

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Deaf culture · Hearing impaired · Hearing loss

## Introduction

Since the discovery of *GJB2*, the gene that encodes for the connexin 26 protein (Denoyelle et al. 1997) and accounts for up to 50% of nonsyndromic sensorineural deafness in some populations (Kenneson et al. 2002), the number of hearing and deaf individuals seeking genetic counseling and testing for deafness for diagnostic, carrier, and prenatal purposes is anticipated to increase (Withrow et al. 2009). However, deaf and hearing individuals' attitudes toward, and use of genetic information related to deafness can vary considerably due to different cultural and medical perspectives on what it means to be deaf (Brunger et al. 2000; Burton et al. 2006; Dagan et al. 2002; Guillemain and Gillam 2006; Martinez et al. 2003; Middleton et al. 1998; Steinberg et al. 2007; Stern et al. 2002; Taneja et al. 2004;

Withrow et al. 2008). Currently unknown is the extent to which the attitudes of genetics professionals toward deaf people play a role in the use of genetic information for deafness. However, there is evidence that attitudes and biases can influence both content and presentation of information relevant to decision-making (Shiloh 1996; Shiloh and Sagi 1989; Tversky and Kahneman 1981) and the options that health care providers offer (Bach and Tilton 1992; Ormond et al. 2003; Rebagliato et al. 2000; Shaw et al. 1977). Thus, it is important to determine if genetics counselors' attitudes toward deaf people can affect genetic counseling sessions.

Many deaf individuals consider themselves to be part of a linguistic and cultural minority group (Johnson and Erting 1989; Lane 2005; Padden and Humphries 2005). Just like any other culture, Deaf<sup>1</sup> culture has its own customs, values, history, beliefs and traditions, and a large fraction of this group marry from within the cultural group (Lane 2005; Padden and Humphries 2005). The degree of hearing loss does not necessarily determine cultural identity for members of the Deaf community (Israel et al. 1992). Instead, the strongest determinant of cultural identity is the linguistic preference of a signed language, e.g., American Sign Language (ASL) (Lane 1992), and it is estimated that ASL is the linguistic preference for up to half a million individuals in the United States (Mitchell et al. 2006). In contrast to most ethnic and minority groups, however, most members of the Deaf community are not part of the community from birth; instead they join later in life (Lane 1992). This phenomenon is explained by the fact that 90–95% of deaf people are born to hearing parents (Mitchell and Karchmer 2004; Schein and Delk 1974) and learn about Deaf culture in places outside of their hearing families, such as deaf schools or social gatherings (Padden and Humphries 2005). The exception occurs with the birth of a deaf child into a deaf family which enables continuation of Deaf culture from within the family (Bauman 2005; Lane and Grodin 1997). Most importantly, the Deaf community considers being deaf a linguistic and cultural characteristic worthy of preservation and not a medical condition requiring treatment (Christiansen 1991; Lane and Grodin 1997; Middleton et al. 1998).

The medical perspective of deafness is pervasive among most hearing individuals as well as some deaf individuals, particularly late-deafened individuals who had been part of the majority culture from birth, i.e. the hearing society

(Lane 1992). This perspective views deafness as a pathology which requires remediation particularly targeted toward facilitating oral speech and using residual hearing (Lane and Grodin 1997).

Currently there are no empirical data on genetic counselors' attitudes toward deaf people. Since virtually all genetic counselors are hearing, there have been efforts by several genetics professionals to educate genetic counselors about the provision of genetic counseling to deaf people (Arnos et al. 1992a, b; Israel et al. 1992). From a social psychology perspective, however, members of the Deaf cultural and linguistic minority group form an 'out-group' relative to hearing individuals (Cooper et al. 2003; Johnson and Erting 1989). Based on the contact hypothesis, *personal interactions* between groups is a key component for developing, maintaining, or changing attitudes toward the groups (Dovidio et al. 2003). Hence, it may be difficult for genetic counselors to understand Deaf culture without direct interactional experience with that culture or its members. This lack of contact between groups could greatly impact genetic counselor's attitudes toward deaf people and affect relationships between genetic counselors and their culturally Deaf clients.

A recent study with mental health providers supports the contact hypothesis with respect to attitudes toward deaf individuals (Cooper et al. 2003). In that study, greater amount of contact with deaf individuals of 'equal and higher social status' related to more positive attitudes toward deaf people among mental health providers. Studies regarding application of the contact hypothesis with medical students and individuals with disabilities have found that the more contact medical students had with people with disabilities, the more positive their attitudes were toward people with disabilities, and the more comfortable they felt with their interactions (Tervo et al. 2002, 2004). Although these latter findings are important, comparison with the disability literature is not meant to imply that deafness is solely viewed as a disability, because it is also part of a cultural and linguistic framework. Comparison with the disability literature is further limited by empirical evidence that the structure of attitudes toward deaf people differs from the structure of attitudes toward people with disabilities (Kiger 1997).

These prior studies of the contact hypothesis in other health professions suggest that genetic counselors' attitudes toward deaf people will depend in part on having personal and professional contact with deaf individuals, and that their attitudes will affect their level of comfort in their interactions with culturally Deaf clients. However, empirical data are needed to address these questions because the strong philosophy of non-directive counseling and empathy in genetic counseling (McCarthy Veach et al. 2003; Weil et al. 2006) might serve to subjugate genetic counselors'

<sup>1</sup> Deaf written with a lowercase 'd' refers to the audiological condition of not hearing and includes individuals with any type of hearing impairment, whereas Deaf written with an uppercase 'D' refers to a particular group of deaf people who share a language (sign language) and a culture, referred to as part of the Deaf-world or the Deaf community.

attitudes toward deaf people in favor of supporting the values of the culturally Deaf clients. Some evidence to support this phenomenon also exists. Ormond et al. (2003) surveyed 85 health care trainees, including genetic counselors, and reported that 75% felt comfortable working with patients with disabilities, *despite* limited personal and professional contact with individuals with disabilities, demonstrating a focus on the patient's views and values. The extent to which these results apply to a cultural and linguistic minority group can only be determined through empirical study.

The current research study aims to examine genetic counselors' general attitudes toward deaf people, and to describe the relationship between these attitudes and the genetic counseling session using the framework of the contact hypothesis. We hypothesized that genetic counselors with greater contact with deaf/Deaf individuals will have more positive attitudes toward deaf people, and that positive attitudes toward deaf people will be associated with greater comfort discussing and offering genetic testing for deafness with culturally Deaf clients.

## Materials and Methods

### Sampling Frame

The study sample was ascertained from members of the National Society of Genetic Counselors (NSGC) through their general electronic Listserv during the period of 2/07/08 — 3/07/08. Individuals were eligible to participate if they were (1) trained genetic counselors, (2) an NSGC full member, and (3) a part of the NSGC general Listserv. Approval of the study was obtained through the Institutional Review Boards at the California State University of Northridge and the University of California, Los Angeles.

### Questionnaire Development and Measures

A self-administered online survey was developed to test the hypotheses. The survey was pilot tested with 14 genetic counseling students for time required to complete the questionnaire and to assess its content and clarity. Revisions were made based on this pilot test. The first section solicited basic demographic information, information on primary counseling setting (prenatal, cancer, general genetics, pediatric, adult, other), number of years employed as a genetic counselor, number of times in the past year genetic testing for deafness was discussed with hearing or deaf clients in a clinical setting, personal or professional contact with deaf/Deaf individuals (as family members, friends, clients) and familiarity with Deaf culture and ASL. Two items assessed exposure to information on the genetics of

deafness and information about Deaf culture in their genetic counseling training program.

The second section contained the Attitudes To Deafness Scale (Cooper et al. 2004) which consists of a set of 22 statements about deaf people which encompass equality, ability, cultural and linguistic issues (Table 1). The scale, which was developed in England to measure health professionals' general attitudes toward deaf people, includes eight positive statements and 14 negative statements. Items are rated on a six-point Likert scale from 1 to 6 anchored by the labels strongly agree and strongly disagree, with no neutral point, and item responses are summed to produce a total attitude score. The theoretical range of scores is 22–132 with higher scores indicating more positive attitudes toward deaf people compared to lower scores. Content validity was established through the process of item development and through the process of selecting the final 22 items pertinent to the attitude construct. Importantly, item development was, in part, based on input from a focus group comprised of deaf individuals who described their experiences with hearing people's attitudes toward deafness and deaf people, thereby adding to the content validity to the scale items. The initial set of 60 items was then subject to a multi-step item analysis (based on responses to the items from a sample of mental health providers) to identify the subset of items that most effectively distinguished responders with a positive attitude toward deaf people from those with a negative attitude. Cronbach's alpha for the final 22 items was 0.71 (Cooper et al. 2004), suggesting strong internal reliability of the scale items and supportive of the scale's content validity. The instrument was developed for use with all human service professionals working with deaf people (Cooper et al. 2004) and was previously used to evaluate mental health providers' attitudes toward deaf people in the context of the contact hypothesis (Cooper et al. 2003). Pilot-testing in an American sample of genetic counseling students, and review of items by a Deaf co-author, did not identify any problems understanding or responding to these statements.

The third section contained scenarios and assessed genetic counselors' comfort level with genetic testing for deafness. Five scenarios were developed by the investigators using familiar or anticipated counseling situations (Appendix). Scenarios varied the age of the client, clinic setting, family constellation of deafness, cultural affiliation, and reason for pursuing genetic counseling and testing (see Table 2) as follows: "Scenario 1" describes hearing parents and a deaf child in a pediatric setting wanting to know why their child is deaf and the recurrence chance for future pregnancies; "Scenario 2" takes place in a prenatal setting and describes a hearing couple with a family history of deafness who want a hearing child and are interested in prenatal testing; "Scenario 3" describes non-culturally deaf

**Table 1** Attitudes To Deafness Scale

## Positive attitude statements

- att3: I would like to have more deaf friends.
- att8: Deaf children should be taught in sign language.
- att10: Deaf people are safe drivers.
- att11: I would like to have more deaf colleagues.
- att13: Interpreters should be available for deaf people at work.
- att19: Deaf people should not be viewed as “impaired.”
- att20: I would like to see more deaf people at club/societies I attend.
- att22: Deaf people have their own culture.

## Negative attitude statements

- att1: Deaf couples should receive genetic counseling to avoid having deaf children.
- att2: Deaf children should learn to speak to communicate with hearing parents.
- att4: Deaf schools and deaf clubs create deaf “ghettos.”
- att5: Deaf people should learn speech rather than sign language.
- att6: Deaf people are handicapped.
- att7: More research should be done to find cures for deafness.
- att9: Hearing children of deaf parents are at risk of emotional deprivation.
- att12: Deaf people should learn to lip-read.
- att14: Deaf people should automatically receive help in their home environment.
- att15: All deaf people should be offered corrective surgery.
- att16: Training more professionals to work with deaf clients would be a waste of time.
- att17: Having a deaf colleague would cause problems in the workplace.
- att18: Deaf people are physiologically impaired.
- att21: Having a deaf friend would be difficult.

Scale reported in its entirety as described in Cooper et al. (2004). ‘Deaf’ is capitalized at the beginning of a statement as per grammatical rules, and in that case does not imply culturally Deaf. Attitude statements are preceded by an acronym for ease of reporting results

parents in a prenatal setting interested in prenatal testing for preparation for cochlear implants if they have a deaf child; “Scenario 4” describes culturally Deaf parents and their Deaf children in a pediatric setting interested in genetic testing to learn why they are deaf; and “Scenario 5” takes place in a prenatal setting and describes a culturally Deaf couple who would like a deaf child and are interested in prenatal testing.

Three questions followed each scenario. The first two questions asked the respondents to rate how *comfortable* they would be *talking* about genetic testing based on the scenario and how *comfortable* they would be *offering* genetic testing for deafness based on the scenario. Response categories for both items used a five point Likert scale from 1 to 5 anchored with labels comfortable and uncomfortable. The third question for each scenario asked,

on a *personal* level, if the respondent thought the family in the scenario should be offered genetic testing for deafness. The response categories for this item were “yes,” “no,” and “unsure”. For the purposes of this study, we use the words ‘talking’ and ‘offering’, even in the context of a counseling scenario with deaf clients who use sign language, but it is important to note that a conversation with a culturally Deaf client would be in sign language rather via speech, either directly or with a third-party such as a certified sign language interpreter.

## Statistical Plan

Descriptive statistics were computed for each item in the survey for descriptive purposes and to identify potential outliers and missing data. An attitude toward deaf people

**Table 2** Overview of Scenarios

Scenario	Clinical setting	Clients	Members of Deaf culture?	Reason for genetic testing
1	Pediatric	Hearing parents with a deaf child	No	Recurrence chance
2	Prenatal	Hearing couple with family history of deafness	No	Want hearing child
3	Prenatal	Deaf parents	No	Preparation for cochlear implant
4	Pediatric	Deaf parents and deaf child	Yes	Etiology of family’s deafness
5	Prenatal	Deaf couple	Yes	Want deaf child

score (attitude score) was computed for each respondent based on their responses to the Attitudes To Deafness scale following the method described in Cooper et al. (2004). In the case of a missing scale item, the group average for that item was used in order to develop an overall score (Little and Rubin 1989). The attitude score and the outcome variables related to talking about and offering genetic testing were treated as quantitative variables, and the outcome variable related to personal feelings about offering genetic testing was treated as a categorical variable. ANOVA and Pearson-product-moment correlation analyses were performed to identify factors related to attitudes toward deaf people, and to examine the relationship between these attitudes and the three main outcome variables related to discussing and offering genetic testing. Separate analyses were performed for each scenario and outcome variable, using SAS version 9.1 (SAS 2002). An alpha of 0.05 was used to determine statistical significance. Corrections for multiple testing were not made.

## Results

### Descriptive Statistics

#### *Sample Characteristics*

A total of 179 certified genetic counselors participated in the study for a response rate of 9.8% based on a total of 1,829 NSGC full members reported in the 2006 Professional Status Survey (Parrot and Del Vecchio 2007). This response rate is a conservative estimate because it assumes that all NSGC full members in the 2006 survey receive ListServ messages. After excluding questionnaires from 21 subjects due to substantial missing data, questionnaires from 158 subjects were available for analyses.

The demographic characteristics of the sample are described in Table 3. The sample is reflective of the general population of NSGC members on four characteristics: ethnicity, age, years employed as a genetic counselor, and primary clinical setting (Parrot and Del Vecchio 2007). For analysis purposes, clinical setting was re-categorized as prenatal, pediatrics, and other (cancer, general genetics, adult, other); number of deaf clients was dichotomized into  $\leq 10$ /year and  $> 10$ /year; and years of employment was dichotomized into  $\leq 5$  years and  $> 5$  years.

#### *Attitudes To Deafness Scale*

Cronbach's alpha in this sample was 0.61, providing evidence that this scale is appropriate for use in an American sample. The average attitude score for the sample was 98.3 (SD=10.9; min=61, max=127), and the average

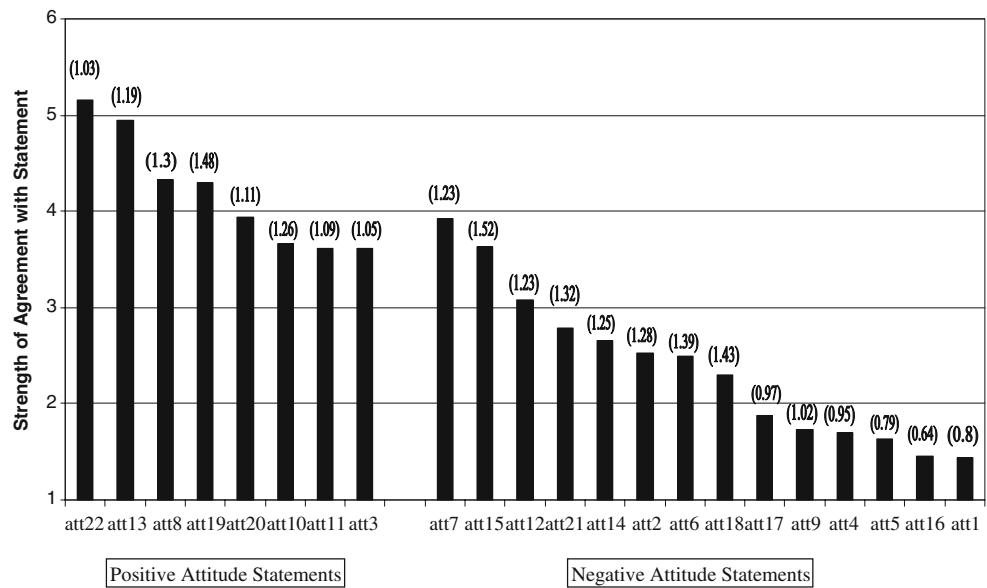
**Table 3** Sample Demographics

N	158
Female	99.4%
Average age (SD)	33.7 (8.0)
Caucasian	93.7%
Hearing	98.7%
$\leq 5$ years employed as genetic counselor	56.1%
Clinic setting	
Prenatal	46.5%
Pediatric	21.9%
Other (cancer, adult, general)	31.6%
$\leq 10$ deaf clients/year	92.3%
$\leq 10$ times per year discuss genetic testing for deafness	86.7%
Frequently assess culture of deaf clients	27.3%
Deaf community member	0%
ASL fluency	
Not at all	70.1%
A little	29.3%
Fluent	0.6%
Personal interactions	
Deaf relatives	7.6%
Deaf friends	15.9%
Culturally Deaf friends	8.3%
Training program	
Included genetics of deafness	89.2%
Included Deaf culture information	70.3%

response and standard deviation for each attitude statement are graphed in Fig. 1. Positive attitude statements are grouped on the left and negative attitude statements are grouped on the right side of the figure. In general the respondents agreed more with the positive statements and agreed less with the negative statements. However, in both domains there was variability in the strength of agreement across items. Among the positive statements, the items receiving the highest average score (and indicative of moderate to strong agreement) were att22 ("Deaf people have their own culture", mean=5.2) and att13 ("Interpreters should be available for deaf people at work", mean=4.9), whereas the items with the lowest average score (and indicative of mild-moderate agreement) were att10 ("Deaf people are safe drivers", mean=3.7), att11 ("I would like to have more deaf colleagues", mean=3.6), and att3 ("I would like to have more deaf friends", mean=3.6). Among the negative statements, the items with the lowest average score (and indicative of strong disagreement) were att16 ("Training more professionals to work with deaf clients would be a waste of time", mean=1.5) and att1 ("Deaf couples should receive genetic counseling to avoid having deaf children", mean=1.4), whereas the items with the highest average score (and indicative of mild-moderate agreement) were



**Fig. 1** Average Agreement for Attitude Statements with (SD), Where 1 Corresponds to Strongly Disagree and 6 Corresponds to Strongly Agree. Note that Fig. 1 Represents the Original Raw Survey Data Before the Negative Attitude Statements were Reverse Scored for Computation of the Total Score.



att7 (“More research should be done to find cures for deafness”, mean=3.9) and att15 (“All deaf people should be offered corrective surgery”, mean=3.6).

*Scenario Responses*

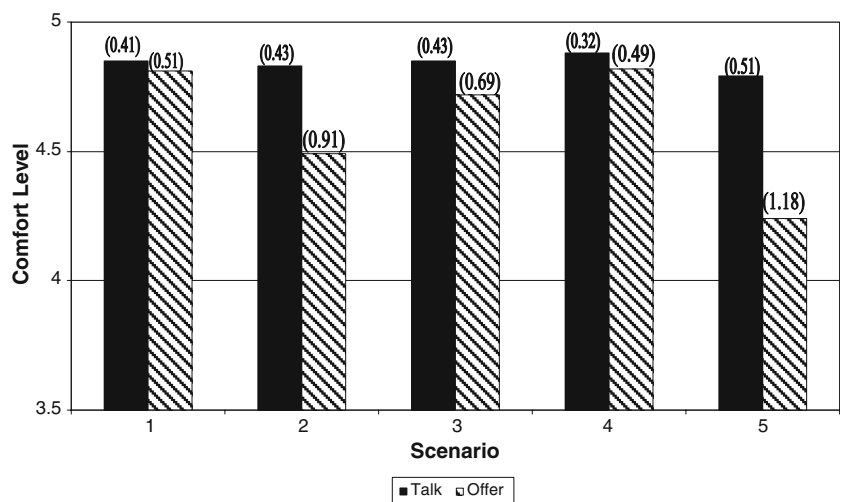
The respondents’ average comfort levels regarding *talking* about and *offering* genetic testing for deafness for each scenario are graphed in Fig. 2. The average comfort level *talking* about genetic testing in each scenario was high, ranging from 4.79 to 4.88 on a 1–5 scale. More variability was observed in the comfort level *offering* genetic testing, where average levels ranged from 4.82 for scenario 4 to 4.24 for scenario 5 on a 1–5 scale. Inspection of Fig. 2 also reveals that the average comfort levels when *offering* genetic testing for two of the three prenatal scenarios (scenarios 2 and 5) were lower compared to the other scenarios.

Respondents were also asked if, on a *personal* level, they thought the family in each scenario should be offered genetic testing. For each scenario, the majority of the participants indicated that they felt that genetic testing should be offered, although some variability was seen among the scenarios (scenario 1, yes=97%; scenario 2, yes=91%; scenario 3, yes=97%; scenario 4, yes=95.5%; scenario 5, yes=79%). Due to insufficient variability, subsequent analyses focus only on personal feelings about scenario 5.

Factors Related to Attitudes Toward Deaf People

We tested the hypothesis that attitudes toward deaf people would in part be explained by factors related to contact with deaf individuals. Consistent with this hypothesis, we found a statistically significant associa-

**Fig. 2** Mean Comfort Level When Discussing Genetic Testing for Deafness (Talk) and Offering Genetic Testing for Deafness (Offer) with (SD). Comfort Level Ranges from 1 (Uncomfortable) to 5 (Comfortable).



tion between scores on the Attitudes To Deafness scale and having deaf/Deaf friends ( $F_{1,156}=9.3$ ,  $p=0.003$ ). Also consistent with this hypothesis, respondents with deaf/Deaf friends (mean=104.2, SD=11.9) had higher mean attitude scores (thus indicating more positive attitudes toward deaf people) than respondents without deaf/Deaf friends (mean=97.2, SD=10.4). However, there was no significant association between attitudes toward deaf people and number of deaf clients ( $\leq 10$  per year vs.  $>10$  per year) ( $F_{1,154}=2.14$ ,  $p=0.15$ ).

We also examined the relationship between attitudes toward deaf people and clinical setting, exposure to Deaf culture, years of employment, and age, in order to identify additional factors that explain variability in the attitudes scores. One-way ANOVA demonstrated a non-significant trend suggestive that attitudes toward deaf people are related to clinical setting ( $F_{2,152}=2.7$ ,  $p=0.07$ ). Respondents working in prenatal (mean=99.8, SD=10.2) or pediatric settings (mean=99.7, SD=10.7) had nearly identical mean attitude scores, which were higher and indicative of more positive attitudes toward deaf people, than those working in 'other' settings (mean=95.4, SD=11.9). However, attitudes toward deaf people were not related to instruction on Deaf culture in graduate school ( $F_{2,155}=1.86$ ,  $p=.16$ ), years of employment ( $F_{1,155}=.07$ ,  $p=0.79$ ), or age ( $r=0.02$ ,  $p=0.83$ ).

#### Relationship Between Attitudes Toward Deaf People and Genetic Counselors' Comfort Levels

We tested the hypothesis that positive attitudes toward deaf people would be associated with greater genetic counselor comfort level when discussing and offering genetic testing with culturally Deaf clients by computing correlations between attitude score and comfort level when *talking* about and *offering* genetic testing for deafness for each of the five counseling scenarios. Results supported our hypothesis and revealed that more positive attitudes toward deaf people correlated with greater level of comfort *talking* about genetic testing in the two scenarios involving culturally Deaf clients (scenarios 4 and 5); and conversely, less positive attitudes toward deaf people correlated with lower levels of comfort *talking* about genetic testing with culturally Deaf clients in these scenarios. Specifically, a statistically significant positive correlation was found between attitude score and comfort level when *talking* about genetic testing in scenario 5 ( $r=0.18$ ,  $p=0.02$ ) and a non-significant positive trend was noted between attitude score and comfort level when *talking* about genetic testing in scenario 4 ( $r=0.12$ ,  $p=0.14$ ). A nearly statistically significant positive correlation was also found between attitude score and comfort level when *offering* genetic testing for scenario 5 ( $r=0.15$ ,  $p=0.06$ ), revealing that more positive attitudes toward deaf people correlate with greater

comfort offering genetic testing to a culturally Deaf couple who wishes to have a deaf child.

There was no correlation between attitudes toward deaf people and genetic counselors' comfort level talking or offering genetic testing for the three scenarios involving hearing or non-culturally deaf clients (all remaining p-values  $>0.30$ ).

We also examined the relationship between attitudes toward deaf people and personal feelings regarding offering genetic testing for deafness, as personal feelings may be another indicator of genetic counselors' comfort level with deaf clients. However, this analysis could only be performed with scenario 5 (culturally Deaf couple wishing to have a deaf child) due to insufficient variability in responses to the personal feelings item for the remaining scenarios. Although not statistically significant ( $F_{2,155}=1.7$ ,  $p=0.18$ ), we observed the hypothesized trend suggesting that respondents with less positive attitudes toward deaf people are less personally comfortable with the idea of offering genetic testing to culturally Deaf couples who wish to have a deaf child than respondents with more positive attitudes toward deaf people. In this scenario, the mean attitude score for respondents indicating that they did *not* personally feel that genetic testing should be offered (mean=94.5, SD=14.5) was *lower* than the mean attitude score for those who personally felt that genetic testing *should be* offered (mean=97.9, SD=10.3) or those who were *unsure* about their feelings (mean=101.6, SD=12.6).

## Discussion

Due to the differences between the cultural and medical perspectives on deafness and the advances in genetic testing for deafness, many ethical, social, and clinical issues arise for genetic counseling professionals who interact with deaf individuals in their clinics. One issue is whether genetic counselors' attitudes toward deaf people can affect the genetic counseling session and the decisions made by clients. The purposes of this study were (a) to examine genetic counselors' attitudes toward deaf people and identify factors related to these attitudes, and (b) to examine the relationship between genetic counselors' attitudes toward deaf individuals and their comfort level while discussing and offering genetic testing for deafness with deaf/Deaf and hearing clients. This study is important for two reasons. First, although deaf adults, including culturally Deaf adults, very rarely attend genetic counseling (Israel et al. 1992; Martinez et al. 2003; Middleton et al. 2008), referrals for deaf adults to meet with genetic counselors are likely to increase in the future as knowledge about genetic testing and the potential benefits of genetic counseling increases. Therefore even if genetic counselors are not



currently familiar with deaf issues, and how attitudes toward deaf people may affect genetic counseling sessions, they will need to be familiar with these topics in the future. Second, although our focus is on genetic counselors and deaf clients, the methodology presented here, including the contact hypothesis, can be applied to research about other human characteristics or conditions to further illuminate interactions between genetic counselors and their clients.

We used the Attitudes To Deafness scale (Cooper et al. 2004) to measure genetic counselors' general attitudes toward deaf people. This scale is composed of eight positive and 14 negative statements about deaf people or deafness. It was previously validated in a sample of British mental health providers and found to be internally consistent (Cronbach's  $\alpha=0.7$ ) (Cooper et al. 2004), and in this sample of predominantly American genetic counselors it was also found to be internally consistent (Cronbach's  $\alpha=0.61$ ).

An examination of individual scale items in Fig. 1 reveals strong agreement with "Interpreters should be available for deaf people at work" (att13) and "Deaf people have their own culture," (att22) and strong disagreement with "Training more professionals to work with deaf clients would be a waste of time" (att16). Not only do these results suggest that respondents value equal access to information and communication in the work and healthcare settings, but they reveal an understanding that professionals would benefit from training in order to better serve deaf clients. The latter point may reflect respondents' recognition that Deaf individuals have their own culture, and thus responses regarding more professional training may reflect an interest in learning more about this culture. Although 70% of respondents indicated receiving instruction on deafness and Deaf culture in their training program, the current research did not assess the type or duration of training in Deaf culture or the genetics of deafness.

There was much weaker agreement for the positive attitude items "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). These results warrant more investigation because they may be tapping into perceptions of relationships between deaf and hearing people and the persistence of myths about deaf people. In terms of relationships between deaf and hearing people, it is possible that the neutral-weak agreement responses regarding the desire for more deaf friends or deaf colleagues reflects respondents' perceptions of deaf people or perceptions about communication with deaf individuals. The latter point illustrates that fluency in sign language and/or availability of interpreters are important for relationships between deaf and hearing people, and is consistent with respondents' agreement that "Interpreters should be available for deaf people at work" (att13). Weak agreement with

the statement about deaf drivers suggests that myths about deaf individuals persist since several studies have shown that the safety and performance records of deaf drivers and hearing drivers do not significantly differ (Finesilver 1962; Roydhouse 1967; Wagner 1962; Ysander 1966). It is also possible that the phrasing of these items was awkward for respondents, and that a neutral response would be most natural. However, pilot-testing did not reveal problems with the phrasing of these items.

In this sample, there was a mild-moderate agreement that "More research should be done to find cures for deafness" (att7) and "All deaf people should be offered corrective surgery" (att15). Although it is possible that agreement with these two items reveals a lack of awareness of Deaf culture and its values, it is also possible that genetic counselors have an understanding and knowledge of both the medical and cultural models of deafness that is not easily captured by responses to these two items. For example, a person can feel that there should be a cure for deafness that will help people who are hard of hearing, deafened or who were hearing once and who have lost their hearing, and this would not imply that they do not also feel compassion and respect for the Deaf community. It is also important to notice that the language used in the second item is not necessarily saying that all deaf people should *have* corrective surgery, it is merely saying that it should be offered, which is consistent with the non-directive nature of genetic counseling. Genetic counselors' agreement with this statement suggests that they believe that all options with regard to medical management should be offered to deaf individuals. Because of this, agreement with that statement may not necessarily mean the respondents have less positive attitude toward deafness. Instead, it may mean that they want deaf individuals to make fully informed decisions regarding management, whether that is pursuing medical intervention or not. However, this research did not address actual counseling sessions, and so additional research is needed to determine whether or not genetic counselors generally offer all options when counseling deaf individuals, including information about the Deaf community, Deaf culture, and ASL, or if genetic counselors only offer all options with respect to medical management.

The results of this study are the first empirical evidence that genetic counselors vary in their attitudes toward deaf people based on the Attitudes To Deafness scale. Attitude scores ranged from 61 to 127, with average of 98.3 and standard deviation of 10.9. We used the framework of the contact hypothesis to identify factors related to genetic counselors' attitudes toward deaf people based on their Attitudes To Deafness scores. The contact hypothesis posits that more contact between hearing and deaf individuals of equal or higher social status creates more positive attitudes towards deaf individuals (Dovidio et al. 2003). Based on

this hypothesis, we predicted that the variability in attitudes toward deaf people would in part be explained by contact with deaf individuals. In this sample, ~16% reported having deaf friends, ~8% reported having culturally Deaf friends, and ~8% reported providing genetic counseling to more than ten deaf clients per year. Consistent with the contact hypothesis, our results demonstrated that respondents with deaf/Deaf friends (who are presumably of at least equal social status) hold more positive attitudes toward deaf people than those with no deaf/Deaf friends. However, there was no relationship between attitudes toward deaf people and number of deaf clients per year. Together, these findings are consistent with a recent study of mental health providers in the United Kingdom which found that their attitudes toward deaf people (based the same Attitudes To Deafness scale used in the current study) were associated with the amount of contact with deaf people of equal and higher social status, but not associated with total amount of contact with deaf people (Cooper et al. 2003).

There was no relationship between attitudes toward deaf people and years of employment, age, or instruction on Deaf culture in graduate school. These results differ from those reported in Cooper et al. (2003) where younger participants or those with training in deafness had more positive attitudes than older participants or those without training in deafness. Since both samples were of similar age range and mean age, it is unclear why the two studies produced conflicting results with respect to the effect of age on attitudes toward deaf people. However, it is possible that the discrepancy in the effect of instruction or training in deafness/Deaf culture on attitudes toward deaf people is explained by differences in the form and content of instruction between the UK and the US. This is an intriguing idea, and suggests that research on the effect of different methods for providing education on deafness/Deaf culture on genetic counselors' attitudes toward deaf people is warranted. In light of the findings in Cooper et al. (2003) and the current study that *personal interactions* between deaf and hearing individuals are significantly related to positive attitudes toward deaf people, it seems that genetic counseling training modules that include interactions between deaf/Deaf and hearing individuals should be considered. Because our findings suggest that attitudes toward deaf people specifically correlate with comfort levels with culturally Deaf clients, interactions with culturally Deaf individuals may be particularly important. Interactions could be facilitated in several ways: (1) by inviting professionally trained members of the Deaf community to conduct educational workshops in genetic counseling training programs and at genetics-related professional meetings such as the Annual Education Conference of the National Society of Genetic Counselors; (2) by inviting members of the Deaf community to observe

genetics case conferences and to hold follow up discussions with genetic counselors/students; and (3) by contacting representatives of the National Association for the Deaf to initiate projects that would require Deaf individuals and genetic counselors/students to work together. It would be valuable to build in an assessment of these activities, particularly in terms of effect on genetic counselors' attitudes toward deaf people.

We unexpectedly found a trend that suggested that clinical setting may be associated with attitudes toward deaf people. Specifically, respondents working in prenatal or pediatric settings held more positive attitudes toward deaf people than those working in 'other' settings, i.e., cancer, adult, general, and other. One possible explanation is that some settings offer more opportunity for interaction with deaf individuals than other settings. However, our data do not provide strong support for this explanation as 10.6% of genetic counselors working in 'other' clinical settings reported counseling >10 deaf clients per year compared to 14.7% of pediatric counselors and 2.3% of prenatal counselors. Another possible explanation for this finding is that genetic counselors working in prenatal and pediatric settings are more exposed to ethical discussion and debate surrounding prenatal diagnosis for deafness and selective termination of pregnancy (TOP), as this is a relatively common example used for discussion of ethical and moral dilemmas. Furthermore, such discussion usually involves input from the Deaf community and their views, hence it is possible that prenatal and pediatric genetic counselors have more exposure to the cultural view of deafness by virtue of these discussions that pertain to their practice setting. In contrast, genetic counselors working in other settings may have less exposure to discussion regarding prenatal diagnosis for deafness and selective TOP, have less awareness of the input from the Deaf community on these issues, and hence have less exposure to the cultural view of deafness. Further research is needed to understand the relationship between clinical setting and attitudes toward deaf people.

We also hypothesized that a more positive attitude toward deaf people would correlate with being more comfortable discussing and offering genetic testing for deafness with culturally Deaf clients. To assess this hypothesis, scenarios were presented with questions addressing comfort level when discussing and offering genetic testing. Scenarios varied the client presenting to clinic, the client's cultural affiliation and their reason for referral to genetics counseling. Evidence was found to support this hypothesis in the two counseling scenarios involving culturally Deaf clients. Specifically, higher attitude scores, indicative of more positive attitudes toward

deaf people, were significantly correlated with greater levels of comfort when *talking* about pediatric genetic testing with culturally Deaf parents and their deaf child (scenario 4) and when *talking* about and *offering* prenatal genetic testing for deafness with a culturally Deaf couple wishing to have a deaf child (scenario 5). In contrast, there were no significant correlations between attitudes toward deaf people and comfort level in counseling scenarios involving hearing or non-culturally deaf clients. Overall, the results of this study suggest that genetic counselors' attitudes toward deaf people may influence their level of comfort when interacting with culturally Deaf clients. This is an important finding because there is evidence that attitudes and biases can influence both content and presentation of information relevant to decision-making (Shiloh 1996; Shiloh and Sagi 1989; Tversky and Kahneman 1981) and the options that health care providers offer (Bach and Tilton 1992; Ormond et al. 2003; Rebagliato et al. 2000; Shaw et al. 1977). Additional research is needed to determine (1) the extent to which genetic counselors' attitudes toward deaf people correlate with other types of counseling scenarios involving deaf clients, e.g., clients with adult-onset deafness, deaf or hearing clients for whom pregnancy termination is not an option, and (2) if genetic counselors' attitudes and comfort levels during counseling sessions with culturally Deaf clients can affect the way information is presented and the client's decision making process.

On average, our results suggest that genetic counselors are generally very comfortable with the information provision aspect of genetic counseling for deafness, as evidenced by the high level of comfort expressed by respondents when *talking* about genetic testing for deafness with clients in these five scenarios. However, our results also reveal that respondents' level of comfort when *offering* genetic testing for deafness depended on the reason for testing. On average, respondents were *less* comfortable offering genetic testing in situations involving prenatal testing for hearing status, regardless of cultural affiliation of the parents, compared with scenarios involving pediatric genetic testing or prenatal testing for preparation of a cochlear implant. This result suggests that genetic counselors may see deafness as a condition where prenatal diagnosis is not necessary because it is not a life-threatening condition, and termination based on hearing status may be viewed as a radical decision by some and certainly controversial within the Deaf community. In fact, because TOP for deafness is controversial and there is no consensus of opinion on whether it is 'acceptable' to offer it or not, genetic counselors may feel very nervous about being involved in such counseling sessions, and this may also help to explain the lower level of comfort offering genetic testing in the prenatal scenarios compared to the pediatric scenarios. Several empirical studies of consumer

attitudes toward prenatal diagnosis for deafness reveal a moderate level interest in prenatal diagnosis for deafness for purposes of preparation, but few consumers have indicated that prenatal diagnosis would be used for termination purposes (Brunger et al. 2000; Burton et al. 2006; Dagan et al. 2002; Guillemin and Gillam 2006; Middleton et al. 2001; Withrow et al. 2008).

The majority of the sample personally felt that the families in all of the scenarios should be offered genetic testing, a finding which may relate to the non-directive philosophy of genetic counseling. However, there was also evidence that in some situations attitudes toward deaf people can influence genetic counselors' personal feelings about genetic testing for deafness. Specifically, although it did not reach statistical significance in this sample, we found that genetic counselors with less positive attitudes toward deaf people were less likely to feel that prenatal genetic testing for deafness should be offered to culturally Deaf parents who wish to have a deaf child compared to genetic counselors with more positive attitudes toward deaf people. To date there is no evidence that this will be a common genetic counseling scenario because of evidence from survey responses that the majority of culturally Deaf individuals do not have a preference for deaf or hearing children or an interest in prenatal diagnosis for hearing status (Middleton et al. 1998, 2001; Stern et al. 2002). However, the finding that attitudes toward deaf people manifest in this specific scenario may explain the current controversy over the proposed amendment to United Kingdom's Human Fertilization and Embryology Act 1990 (Clause 14 (4)(9)) (Emery et al. 2008), which if enacted would specifically prohibit the use of pre-implantation genetic diagnosis for the selection of a deaf embryo.

There are several limitations to this study. First, the response rate for this survey is 9.8%. One concern with a low response rate is response bias. However, our sample demographics were similar to those of the NSGC member population with respect to gender, age, ethnicity, years employed as a genetic counselor, and primary clinical setting (Parrot and Del Vecchio 2007), reducing the potential effects of response bias on our results. A related concern is that the sample size may not have been large enough to detect significant associations with attitudes toward deaf people. Therefore, additional research with larger samples is needed to replicate and extend these findings, particularly in light of the multiple statistical tests performed in this study.

Another potential limitation is the lack of diversity in the sample, which was found to be mainly hearing (98.7%), Caucasian (93.7%), and female (99.4%). However, because this lack of diversity is a reflection of the general lack of diversity in the genetic counseling profession rather than a recruitment bias, this does not constitute a serious limitation

to our study. Rather, this limitation reveals the importance of increasing the cultural diversity in the genetic counseling profession, which can be done through recruitment and training of individuals from this cultural and linguistic minority group into the genetic counseling field. Recruitment of deaf individuals whose linguistic preference is ASL is particularly important in light of the finding that 0.6% of our study sample considered themselves fluent in this language.

A third limitation involves the Attitudes To Deafness scale. This scale was originally used to assess mental health providers' attitudes toward deaf people, thus raising questions about the validity of the scale for non-mental health providers. However, the intention of the creators of this scale was to develop an instrument that would apply to all human service professionals working with deaf people (Cooper et al. 2004), and so should be applicable to genetic counselors. In this sample of genetic counselors, Cronbach's alpha was 0.61, which is lower than reported in original investigations of the scale (Cronbach's  $\alpha=0.7$ ), but still quite respectable and indicative that the items are performing as intended. While every attitude scale has its limitations, this scale has been shown to have content validity and internal reliability. That said, future research is needed to further evaluate and possibly refine measures of attitudes toward deaf people. In addition, this study did not include a scenario that explicitly described a client with adult-onset deafness, nor were respondents asked to describe the audiologic status of the deaf individuals with whom they have had contact. More research is needed to determine if audiologic status of deaf clients or deaf friends provides explanatory value for genetic counselors' attitudes toward deaf people.

Another limitation of this study is that the outcome data are based on self-report. Hence, the extent to which reported attitudes and feelings of comfort predict genetic counselors' actual behaviors with culturally Deaf clients is unknown. Research on real genetic counseling sessions with culturally Deaf clients clearly is warranted in order to understand whether attitudes toward deaf people have an impact on the genetic counseling session. Finally, although our primary outcome variables were based on comfort levels while 'talking' about and 'offering' genetic testing, a conversation with a culturally Deaf client would be in sign language rather than via speech, and the impact of conducting a counseling session through an interpreter may add another dimension to genetic counselors' assessments of comfort level that was not explicitly measured in this study.

In conclusion, this study demonstrates that the majority of genetic counselors have limited personal or professional interactions with deaf individuals, that contact with deaf/Deaf individuals is associated with more positive attitudes

toward deaf individuals, and that a more positive attitude toward deaf people correlates with a higher comfort level with culturally Deaf clients when discussing and offering genetic testing for deafness for diagnostic and prenatal purposes. These results have implications for both genetic counselors and their culturally Deaf clients because variability in genetic counselors' attitudes toward deaf people may make culturally Deaf clients feel uncomfortable and perceive that their culture is not valued by genetics professionals. In turn, these feelings may influence the client's discussions in counseling sessions and decisions made regarding testing and medical management. Future research is warranted on genetic counselors' attitudes towards deaf people and its effect on genetic counseling sessions in order to better understand how to augment training programs and to better understand how genetic counselors as a whole can better serve the Deaf community. In this regard, developing research protocols that examine real genetic counseling sessions with deaf/Deaf clients will be essential.

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## Appendix

### Scenario 1

Jennifer, a 2-year-old, congenitally deaf female has been referred to your clinic by her pediatrician who mentioned the possibility of a certain gene change that could have caused her deafness. She was determined to have a moderately severe sensorineural deafness at birth and does not appear to have any medical conditions or birth defects. Her parents, Susan and Daniel, do not have a history of deafness, nor do they know of anyone else in their family who is deaf. They are thinking about having another child and would like to know if Jennifer's deafness is genetic and if it will occur in future pregnancies.

### Scenario 2

Heather is a 28-year-old woman who is 11 weeks into her first pregnancy. Her husband Greg, 32, has attended today's session with her. After taking a family history and discussing with the couple their reasons for wanting to



see a genetic counselor, you learn that multiple members of Heather's family and Greg's family are deaf. Neither Heather nor Greg have any signs of deafness and have had their hearing tested within the past year. Heather and Greg are wondering if the deafness in their families is something that could occur in this pregnancy. They inform you that they are hoping for a hearing child and are interested in genetic testing for deafness for this pregnancy because of their family history.

#### Scenario 3

Robert and Betty, who are both deaf, have also come to your clinic today to discuss genetic testing for deafness. Betty is currently 15 weeks pregnant with her second pregnancy. They have a 12 year old daughter, Lisa, who is deaf. Lisa has a cochlear implant and Robert and Betty decided to place Lisa in a mainstream hearing classroom. Various members of Betty's family are deaf, but no other members of Robert's family are deaf. Betty has previously had genetic testing and a deafness-causing variant was found. Robert has not had any genetic testing. Betty and Robert are interested in genetic testing to determine the hearing status of the pregnancy so that they can prepare for cochlear implantation if the child has inherited Betty's deafness-causing variant.

#### Scenario 4

Claire and Lucas, both 37 years old, have brought their 9 year old son, Brandon, in to clinic. All three family members present at today's session are deaf and a sign language interpreter is used during the counseling session. Claire and Lucas have three other children ranging from 10 months to 7 years who are also deaf. All three of the school aged children attend a school for the deaf and are taught solely in sign language. Lucas heard about the possibility of genetic testing for deafness through a school newsletter stating the pros and cons of the testing. Claire and Lucas want more information of this type of testing before making a decision regarding genetic testing to find a cause for the family's deafness.

#### Scenario 5

Virginia, who is 17 weeks pregnant, and Craig, both of whom are deaf, are interested in prenatal genetic testing for deafness. Virginia states that she previously had genetic testing that revealed an autosomal recessive form of deafness. Craig, who has also had genetic testing for his deafness, is a carrier for the same autosomal recessive form of deafness that Virginia has. You explain to Virginia and Craig that there is a 50% chance of having a deaf child and

a 50% chance of having a hearing child. Through the discussion of this information the couple states that they are hoping for a deaf child and would like to pursue prenatal genetic testing for deafness.

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