

ANNA MIDDLETON, STEVEN D. EMERY,  
AND GRAHAM H. TURNER

# Views, Knowledge, and Beliefs about Genetics and Genetic Counseling among Deaf People

OUT OF THE one in five hundred children born with moderate-to-profound, congenital, or early-onset deafness, more than 50 percent have this condition due to a genetic cause (Morton and Nance 2006). Therefore, within the UK there are under a hundred thousand people with a genetic or an inherited form of deafness or hearing loss; within the United States this number reaches several hundred thousand. Several hundred genes involved with deafness have been identified (Smith and Van Camp 2009), and it is now possible for Deaf and hard of hearing adults to explore the genetic basis of their deafness and find out what the chances are of passing this on to their children.

One health service offered by geneticists and genetic counselors is genetic counseling, which presents information to clients about the risk of inheriting or passing on various genetic disorders (McCarthy Veach, LeRoy, and Bartels 2003). The vast majority of consultations contend with serious, life-threatening conditions. For example, people may wish to know whether they are at risk for inheriting an ag-

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Anna Middleton is Consultant Research Genetic Counsellor and Research Fellow at Cardiff University, UK. Steve Emery is a Research Fellow at the University of Bristol, UK. Graham Turner is Chair of Interpreting and Translation Studies at Heriot-Watt University, UK.

gressive form of breast cancer that has affected several of their close relatives. Or a couple may wish to have a genetic test done on their embryos because they wish to avoid a genetic condition that their previous child died from. Deaf adults very rarely utilize genetic counseling services either to discuss any medical conditions in their family that they may be concerned about or to discuss issues relating to deafness (personal communication from three regional genetics services in the UK).

Genetic counseling not only offers medical and technical information about a client's genetic makeup but also pays specific attention to the delivery of such information in a nonjudgmental and supportive environment (Djurdjinovic 1998; Skirton and Patch 2002; McCarthy Veach, LeRoy, and Bartels 2003). There is also no underlying agenda to reduce all disability in society via the use of genetic counseling: Genetics professionals aim to be nondirective and do not have predetermined ideas on the decisions that clients should or should not make (McCarthy Veach, LeRoy, and Bartels 2003).

Deaf clients may wish to attend genetic counseling to discuss their family history of deafness, and the different personal perspectives they have about the significance of deafness will direct the focus of their consultation (Arnos, Israel, and Cunningham 1991). For example, hard of hearing, spoken language users who have a childhood-onset, progressive hearing loss may feel strongly that they do not wish to pass their hearing loss on to their children. With this in mind, they may attend genetic counseling to investigate the chances of this happening and to ask whether they can have a test in pregnancy for the genes for deafness. On the other hand, a Deaf couple who use a signed language and are proud of having several generations of deafness in the family may be interested in genetic counseling to understand the exact genetic basis of the deafness, just for information's sake. It is known that deaf people often choose to have a deaf partner (Schein 1989). Such partnerships maintain the high frequency of deafness-causing genes in society (Nance, Liu, and Pandya 2000), and indeed some deaf people are excited about using genetic testing so that they can learn whether they and their partner have an increased chance of having deaf children (Middleton 2006). Deaf and hard of hearing people may also wish to attend genetic counseling to discuss issues entirely unrelated to deafness.

When offered an opportunity to discuss their family history of deafness, many deaf adults reported that they would be interested in knowing more about why they were deaf and what the chances were of passing this on (Withrow et al. 2008).

Potential clients are free to decide for themselves whether to access genetic counseling services. We ourselves do not have an underlying assumption that all deaf people should participate in genetic counseling. An informed decision about whether to initiate a referral can only be made if a person has internalized accurate information about what genetic counseling is. Genetic science is an example of new technologies that are constantly being introduced within institutional and policy structures, and these, combined with the linguistic complications of having to negotiate communication challenges, present considerable barriers to the participation of lay people. It is well known that deaf people miss out on general health-related information that is available to hearing peers through overheard conversations with family, incidental chat, and TV or radio programs (Rogel 2008). Therefore, for them, information and knowledge about health issues may be lacking (Barnett 2002), and this can be applied to knowledge about genetic counseling. Nonetheless, the issue of genetics in relation to eugenics has been discussed extensively within Deaf studies in significant work by scholars such as Harlan Lane, Paddy Ladd, Carol Padden, and Tom Humphries (Lane 1984; Ladd 2003; Padden and Humphries 2005). Each of these seminal texts makes a link between modern genetic services and the eugenic practices of the past—a link from which today's practicing genetic counselors and geneticists would carefully distance themselves. However, because of these discussions there may be a heightened awareness of genetics and some of the implications of the technology; this may mean that deaf and hard of hearing groups have had more exposure to the ideas behind genetics than the lay public in general.

Research that has looked at views of deaf adults has considered specifically attitudes toward genetic testing for deafness (Middleton, Hewison, and Mueller 1998, 2001; Stern et al. 2002; Taneja et al. 2004; Guillemin and Gillam 2006; Withrow et al. 2008), attitudes toward the provision of genetics services (Withrow et al. 2008), and

attitudes toward newborn screening for deafness (Burton et al. 2006). However, after extensive searching of the literature, we have found no studies that have explored the knowledge and understanding that deaf people have about genetic counseling itself.

Previous research by Anna Middleton has indicated that deaf adults may feel threatened by the use of genetics technology and have negative views about the perceived impact of genetic testing on deaf people (Middleton, Hewison, and Mueller 1998, 2001). Recent legislation introduced into the UK, the Human Fertilisation and Embryology Bill (2008), may add to such fears (see the article by Emery, Middleton, and Turner in this issue). These therefore may help explain why few deaf adults are involved in genetic counseling services. However, we feel that this may represent only part of the picture and hypothesize that there is likely to be an interplay of many factors. Within this article we explore two of the key factors relating to views about what genetic counseling is and attitudes toward new discoveries in genetics.

## Methodology

### *Ascertainment of Participants*

Participants were recruited for the study among the readership of two British magazines for Deaf and hard of hearing people, *Sign Matters* (now named the *British Deaf News*) and *Hearing Concern* (now named *Hearing Matters*). *British Deaf News* is published by the British Deaf Association and is particularly targeted at sign language users in the UK. In parallel, *Hearing Concern* was published by a charity of the same name and was directed at Deaf and hard of hearing people. In 2006 all copies of one issue of both magazines (i.e., 5,250 total copies: *Sign Matters*, 1750; *Hearing Concern*, 3,500) included both a questionnaire and an invitation to participate in the study.

### Sample Size and Structure

A total of 1,098 people returned a completed questionnaire. Participants defined themselves as deaf, Deaf, hard of hearing, hearing im-

paired, deafened, or having a specific level of hearing loss. They included those who were born deaf, those who had lost their hearing in childhood, and those who had progressive, adult onset hearing loss, as well as those who had lost their hearing as they approached midlife (e.g., at least fifty years of age). No hearing people participated. Participants could also indicate whether they identified more with the Deaf community, hard of hearing community, mainstream hearing society, or all communities or did not feel part of any community.

Ninety-nine questionnaires were discarded from the analysis because they were either unintelligible or returned too late for coding. In addition, 426 questionnaires were returned by participants who were over the age of seventy when the questionnaire was completed. This group was the most likely to give incomplete answers or to skip questions entirely and were also the most likely to indicate a level of uncertainty about the relevance of the study to them. In reality, attendance at genetic counseling clinics is unusual for people over the age of seventy. We therefore excluded those older than seventy from the analysis; the remaining sample size for the study was 573. The Multicentre Research Ethics Committee approved the research.

### *Questionnaire*

A thirty-two-item, nonstandard questionnaire was designed for use with Deaf and hard of hearing participants, some of whom use spoken language, while others use sign language. It was based on themes identified as important by the research steering group (consisting of deaf, Deaf, hard of hearing, and hearing academics, health professionals, and lay people).

Careful attention was given to sentence construction and ease of translation into British Sign Language (BSL). The questionnaire was generated after a review of the medical, social sciences, and Deaf studies literature. The question format, content, and structure were scrutinized in various ways, considering plain English scores and checking for face validity, perceived reliability, and readability. Native Deaf sign language users, hard of hearing, spoken language users, teachers of

Deaf people, and experts in sign language studies all participated in the pilot work for the questionnaire design.

The questionnaire was introduced with a very basic overview of genetic counseling. The questions then ascertained views about new discoveries in genetics and knowledge of genetic counseling. This article explores these two issues. The remainder of the questionnaire covered other issues relevant to genetic counseling and will be explored in forthcoming work. Participants could indicate on the questionnaire whether they were willing to be interviewed in British Sign Language to explore their views in greater depth.

#### *Analysis of the Questionnaires*

All of the questionnaire data were coded by a statistician and entered into the software package SPSS 14.0. Descriptive statistics involving cross-tabulations and chi-squared analysis were used. Within the quantitative data analysis, we made comparisons between participants who use sign language as their first or preferred language and those who use spoken language as their mode of communication.

Participants were able to give open, free-text comments in the written questionnaire; these were coded and categorized. The method of using free-text comments in qualitative genetic counseling research is well established (Phelps et al. 2007). The analysis was initiated by open coding and then further refined by axial coding (Flick 2006). Quotes from the free-text comments are given in quotation marks in the results section, whereas quotes from the interview transcripts are given in italics.

#### *Questions of Interest in the Structured Questionnaire*

We focus the data analysis here on the following issues:

1. Views about New Discoveries in Genetics  
Participants were asked to pick one or more adjectives that described how they felt about new discoveries in genetics. The list contained four neutral words, four negative words, and four positive words.
2. Knowledge of and Views about Genetic Counseling

This was measured by agreement or disagreement with the following statements: “I didn’t know what genetic counseling was before reading this questionnaire,” “I don’t know specifically how to get genetic counseling,” “I think genetic counseling aims to reduce deafness in society,” “I don’t think there should be genetic counseling for deafness.”

### *Interviews*

The interviews were conducted with a Deaf researcher in BSL throughout the UK in 2007 and 2008, with digital video recording. Seventy-five participants indicated on the written questionnaire that they would be willing to be interviewed in BSL. Sixty-four participants were selected for interviews; they were chosen if their questionnaire answers indicated that they were likely to have a genetic deafness. Of those, thirty were actually interviewed (the others later declined, were not contactable, or withdrew). A hearing person familiar with the professional requirements of translating signed data into written text from academic projects produced written transcripts from the video interviews.

### *Analysis of Interview Data*

The interviews were analyzed twice. The first analysis was conducted by a hearing researcher using the written, translated transcripts. Here a thematic analysis was performed (Miles and Huberman 1994), starting with an open coding procedure (Strauss and Corbin 1990) and then refining with axial coding (Flick 2006). The second analysis, using the original BSL data, was carried out by the Deaf researcher who conducted the interviews. Within this article we present the findings from the hearing researcher’s analysis, and here we have chosen to select quotes that support the quantitative data. A much more in-depth, qualitative analysis that includes a discussion of deviant cases will appear elsewhere.

## Results

TABLE 1. Background Information about the Participants

		Mode of Communication		
		Deaf sign language users	Hard of hearing, spoken language users	Total
Q: Do you feel part of the Deaf or hearing community?	Deaf community (i.e., Deaf culture)	188 (82.5%)	51 (15%)	239 (42%)
	HOH community/mainstream hearing society/don't feel part of a community	40 (17.5%)	294 (85%)	334 (58%)
	Total	228 (100%)	345 (100%)	573 Chi-square = 258 df = 1, $P \leq 0.001$
Age	childbearing years (16–43 years old)	100 (44%)	55 (16%)	155 (27%)
	middle age (44–69 years old)	128 (56%)	290 (84%)	418 (73%)
	Total	228 (100%)	345 (100%)	573 Chi-square = 52 df = 1, $P \leq 0.001$
Q: Are you male or female?	Male	88 (39%)	79 (23%)	167 (29%)
	Female	139 (61%)	266 (77%)	405 (71%)
	Total	227 (100%)	345 (100%)	572 Chi-square = 17 df = 1, $P \leq 0.001$

Note. Figures in parentheses denote percentages within columns.

Q: Which of the given words best describe how you feel about new discoveries in genetics? (check as many as you like)

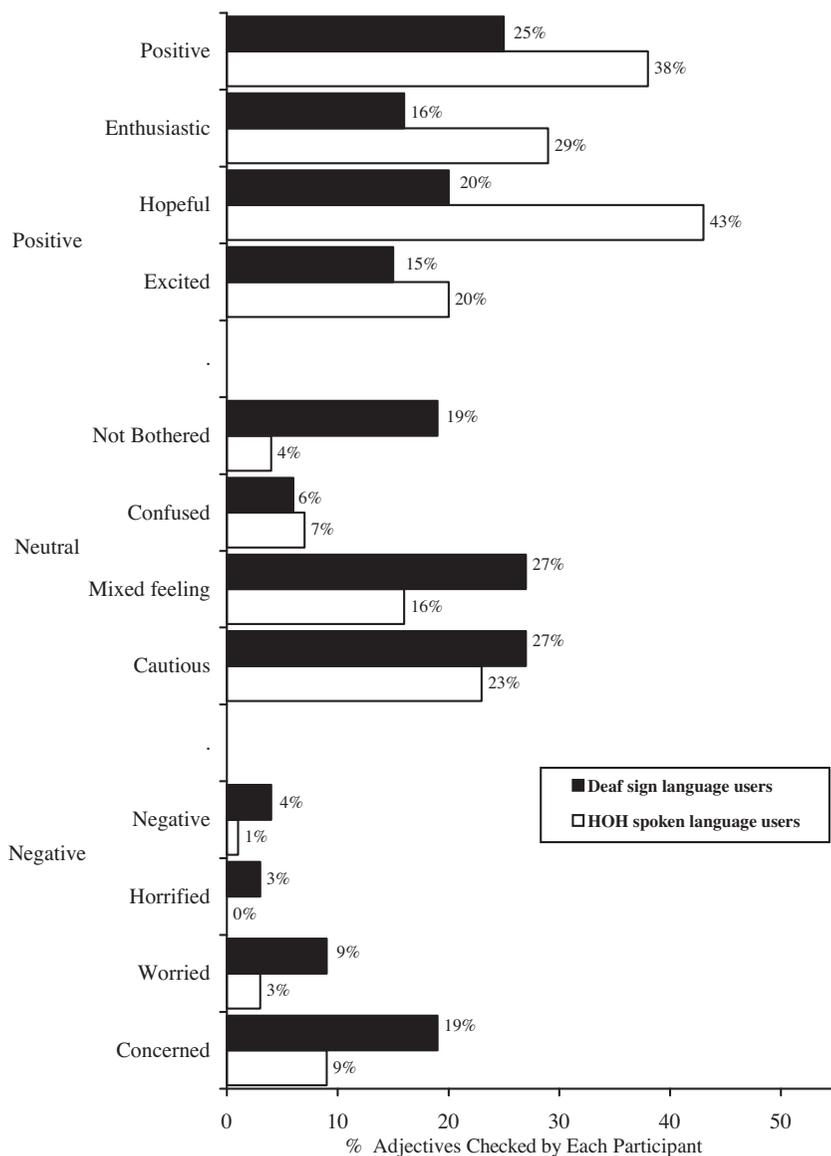


FIGURE 1. Views about new discoveries in genetics.

*Written Comments That Supplement the Answers Shown in Figure 2*

Some people commented that they were comfortable with new discoveries in genetics that apply to “disability,” presumably to help cure serious diseases; however, they were not so comfortable with this technology when applied to deafness. They also intimated that deaf people had been excluded from consultation about this:

“I think it good for other disabilities but not for deafness.”

(Deaf sign language user, identifies with the Deaf community, age 58, male)

“Major concern is that genetics will be used for the wrong reason—without full consultation with people who are already affected by the genes, e.g., deaf.”

(Deaf sign language user, identifies with the Deaf community, age 61, male)

One person indicated that genetic technology could be used to create more deafness (presumably via the selection of embryos with the genes for deafness), and another stated that he was considering IVF and was choosing to have egg donation from a Deaf friend:

“Excited is to create more deaf people! Also for medical research, e.g., cancer, heart, etc.”

(Deaf sign language user, identifies with both the Deaf community and the hearing world, age 51, male)

“I am . . . in the final stages of consideration of conceiving a child [via assisted reproductive technology] with a female friend who is Deaf, too.”

(Deaf sign language user, identifies with the Deaf community, male)

Several people indicated that caution was needed when considering new discoveries in genetics and that there was potential for harm, as well as good:

“I am interested to see what’s going on in genetics but have mixed feelings about it as it is a double-edged sword.”

(Deaf sign language user, identifies with the Deaf community, age 29, female)

“Controls need to be in place.”

(deaf spoken language user, identifies with the Deaf community and the hearing world, age 48, male)

Others felt positive about new discoveries in genetics and hoped that one day there would be a cure for deafness:

“Very interested in the recent genetic, stem-cell therapies being developed for treatment and restoration of certain disorders. Whether this [*sic*] stem cells could be used to repair or restore damaged or defective nerve damage or genetically impaired hearing, would be something I would consider to restore hearing to a near normal level.”

(person with hearing impairment who uses a mixture of sign and spoken language, age 53, male)

“I am excited by genetics as a whole because I believe one day deafness can be eradicated [*sic*] using genetic engineering. My deafness was caused by the hair cells, which one day might be regrown using genetics.”

(deaf spoken language user, identifies with the hearing world, age 56, male)

Several people suggested that they did not know enough about new discoveries in genetics to comment on this:

“Not an area I know much about.”

(hard of hearing, spoken language user, identifies with the Deaf community and the hearing world, age 58, female)

“Don’t know enough about new genetic discoveries to have an opinion.”

(hard of hearing, spoken language user, identifies with the hearing world, age 30, female)

TABLE 2. Knowledge of and Views about Genetic Counseling

Q: The following list gives opinions that you might have about genetic counseling. You don't have to know anything about this to take part. Please check those below if they fit your own opinions.	Mode of Communication		
	Deaf sign language users	Hard-of-hearing, spoken language users	Total
"I didn't know what genetic counseling was before reading this questionnaire."	99 (45%)	175 (52%)	274 (49.5%)
"I did know what genetic counseling was before reading this questionnaire."	121 (55%)	159 (48%)	280 (50.5%)
Total	220 (100%)	334 (100%)	554 Chi-square = 2.9 df = 1, P = 0.09
"I don't know specifically how to get genetic counseling"	157 (75%)	274 (84%)	431 (80%)
"I know specifically how to get genetic counseling."	52 (25%)	53 (16%)	105 (20%)
Total	209 (100%)	327 (100%)	536 Chi-square = 6 df = 1, P = 0.01
"I think genetic counseling aims to reduce deafness in society."	63 (29%)	89 (27%)	152 (28%)
"I don't think genetic counseling aims to reduce deafness in society."	62 (28%)	80 (24%)	142 (26%)
"I'm not sure."	94 (43%)	162 (49%)	256 (46%)
Total	219 (100%)	331 (100%)	550 Chi-square = 2 df = 2, P = 0.4
"I don't think there should be genetic counseling for deafness."	30 (14%)	9 (3%)	39 (7%)
"I think there should be genetic counseling for deafness."	97 (45%)	221 (66%)	318 (58%)
"I'm not sure."	90 (41%)	102 (31%)	192 (35%)
Total	217 (100%)	332 (100%)	549 Chi-square = 38 df = 2, P ≤ 0.4001

Note. Figures in parentheses denote percentages within columns.

General comments about genetic counseling were made. Several participants made the link between genetic counseling and abortion for deafness—as if the two were synonymous:

“One needs to be cautious over genetic counseling . . . the subject of abortion is a thorny one—what genetic defects in unborn babies call for abortion?”

(Deaf sign language user, identifies with the Deaf Community and the hearing world, age 61, male)

“I do not agree with genetic counselling [*sic*] because had my parents used counselling [*sic*] I might not be here.”

(deaf spoken language user, identifies with the hearing world, age 56, male)

Participant 177: *People will go to genetic counselors, find that they're carrying a deaf child, and abort them. There are so many hearing parents; they don't know about deafness, they don't sign, they'll just have abortions if they find out their child might be deaf, and so the Deaf community will dwindle. I'm suspicious of that. I don't want that to be a tool for abusing the Deaf community. That worries me.*

(Deaf sign language user, identifies with the Deaf community, age 30, female)

Others took this a step further and implied that genetic counseling has an overt eugenic agenda, and they expressed their fear surrounding this:

“Genetic counseling is only a polite term for ridding the world of deaf + hard of hearing people. What do you want? A pure Ayrian [*sic*] race? We had one Hitler last century. We don't need anymore, thank you!”

(hard of hearing, spoken language user, identifies with all communities, age 48, female)

Interviewer: *Do you think that the Deaf community and deaf people have a general fear of genetics?*

Participant 1061: *I think as deaf genetics develops there'll be more and more parents who, if they discover that there might be deafness that*

*can be passed on in their families, will want to prevent that and will either not reproduce or will have an abortion, and that might wipe out future generations. Deaf people are frightened of that. They want things to be left as they are, normal. There are always fluctuations in the deaf population, but they don't want to see a great reduction in the population or for it to be wiped out. They are frightened of that, I think.*

(Deaf sign language user, identifies with the Deaf community, age 51, female)

Participant 82: *I think there's a fear around genetics because of the possibility of influence and that that might stop deafness altogether.*

Interviewer: *Okay, in the future?*

Participant 82: *I think that they will identify the gene for deafness, and they'll want to eradicate that so that it won't get passed down. So there'll be no more deaf children in the end.*

Interviewer: *So you mean you think that deaf people fear that could happen in the future?*

Participant 82: *Yes. That's what I think, yes.*

(Deaf sign language user, does not identify with any community, age 52, female)

Others thought “genetic counseling” was the same as “therapeutic” counseling or were unclear as to how the concept of “counseling” was connected with genetics:

Participant 320: *If people were all right before, then they start getting mental health issues, should they go to a genetic counselor? Will that make them better?*

Interviewer: *Okay . . .*

Participant 230: *Will that improve things? They could find out what was wrong; access or family matters or something personal, and that might make it better.*

Interviewer: *No. That's not genetic counseling.*

Participant 230: *It's not? Okay. That's different then.*

Interviewer: *I think what you mean is counseling. A counseling service might be able to provide that. Deaf people with mental health issues can go along to counseling and get better, but genetic counseling is different.*

Participant 230: *It's different? Right.*

(Deaf sign language user, identifies with the Deaf community, age 41, male)

Interviewer: *What's your impression of genetic counseling? What do you think it might be?*

Participant 289: *My understanding of it is that the counselor does some research into whatever the genetic issue is, into those genes, and perhaps if someone doesn't want to have a deaf or a hearing child, they offer the opportunity to find out whether that is likely, whether it will be passed on. I imagine. But my conception of genetic counseling and what it is really is that it's to do with genetics—that bit is clear—but the counseling part I'm less sure about. I'm not sure how the genetics and the counseling come together.*

(Deaf sign language user, identifies with the Deaf community and the hearing society, age 50, male)

When asked what they thought the reason was for lack of referrals to genetic counseling, several participants felt that deaf people just do not have enough information about what genetic counseling is and how to obtain a referral.

Interviewer: *Very few people have been referred to genetic counselors to discuss issues. Why do you think that is? Deaf people, I mean.*

Participant 108: *I think it's a lack of information.*

Interviewer: *[nods]*

Participant 108: *People don't know that there are genetic counselors out there. We've never seen them. So we wouldn't know where to*

*go if we needed one. Perhaps you'd ask your GP [general practitioner] to refer you to one, but I don't know.*

(Deaf sign language user, identifies with Deaf community, no age given, female)

Interviewer: *[How do you get genetic counseling?]*

Participant 1061: *I'm not sure whether you'd go to your GP or somewhere else. I'm not sure. There's not enough information or publicity around about where deaf people can go for any genetics service.*

(Deaf sign language user, identifies with the Deaf community, age 51, female)

Others had very accurate ideas about what genetic counseling is:

Interviewer: *What did genetic counseling mean to you?*

Participant 930: *It's not counseling as such; it's more finding out about your genetic background and finding out for yourself what the possibilities are of you developing various diseases—whether they might develop in later life or whether they might be passed on to your children. That's what the counseling's about. It's about finding out more about your genetic makeup.*

(Deaf sign language user, identifies with the Deaf community, age 46, male)

Interviewer: *What's your impression of genetic counseling? What do you think it might be?*

Participant 33: *My understanding of it is that the counselor does some research into whatever the genetic issue is, into those genes, and perhaps if someone doesn't want to have a deaf or a hearing child, they offer the opportunity to find out whether that is likely, whether it will be passed on. I imagine.*

(Deaf sign language user, identifies with the Deaf community, age 29, male)

Finally, one participant indicated that he had learned about genetics via the deaf media:

Interviewer: *Was there anything about genetics in particular that interested you in this research?*

Participant 155: *Yes. Yes. Yes. I'm trying to remember—I think it was about nine years ago—I was looking at an issue of British Deaf News. . . . I was reading through it, and it was talking about what was happening in America—always the future for us here—and they were having a conference, no, not a conference . . . erm . . . it was the [British Deaf Association] conference over in Belfast.*

Interviewer: *Oh yeah?*

Participant 155: *And they were having an open debate. A well-known Deaf person stood up on the platform and said, “20, 21, or 25 years in the future deafness will have been wiped out by genetics.”*

Interviewer: *Wow.*

Participant 155: *I watched that, and it made my blood boil. But I wasn't sure whether it was true.*

(Deaf sign language user, identifies with Deaf community, age 46, male)

## Discussion

This study aimed to assess the views, knowledge, and beliefs about genetics and genetic counseling expressed by a sample of Deaf and hard of hearing people from the UK. We explore these in this section and draw the conclusion that they are likely to play a part in influencing the uptake of genetic counseling services.

We chose to involve a mixed sample of Deaf and hard of hearing people in the research, including those who use sign language as their first language and also those who use spoken language. All of the participants would be eligible to receive a referral for genetic counseling if they wanted to explore the relevance of a particular genetic condition (not necessarily deafness) as genetic counseling services are available to anyone. The sample of sign language users consisted of a majority who identify with the Deaf community (i.e., they perceive their deafness from a cultural or linguistic perspective [Padden 1980;

Ladd 2003]), which embraces deafness and celebrates sign language. The group of hard of hearing, spoken language users consisted of a majority who identify with the mainstream, hearing society or with other hard of hearing people and who therefore regard deafness within a medical frame of reference, which sees deafness as a hindrance to be treated.

Figure 1 shows that Deaf sign language users are more likely to identify neutral or negative words as describing their feelings about new discoveries in genetics, while hard of hearing, spoken language users are more likely to choose positive words. This is entirely consistent with the results from previous work more than ten years ago, which used the same question with a very similar study sample of Deaf and hard of hearing people (Middleton 1999). Deaf people who do not see their deafness as a disability have a certain sense of foreboding about genetics; this is reflected in both the quantitative and the qualitative findings and has been consistent over time. It is the hard of hearing, spoken language users who feel most positive and hopeful for the future use of genetic science. These opposing perspectives of genetics appear to be directly linked to opposing views about deafness. Interestingly, only a few culturally Deaf respondents acknowledged that genetic technology would not necessarily be applied only to the medical model of deafness—advances in the technology *could* mean that people could use it to select *for* deafness (“create more deaf people!”). The participant who indicated that he was considering using assisted reproductive technologies to have a child and that both he and the egg donor are Deaf shows how it is possible to engage with the use of technology. With this particular case, we are not suggesting that this couple is hoping deliberately to create a deaf child; it is likely that the choice of donors is based on the relevant individuals in a holistic sense rather than depending entirely upon deafness as the only pertinent factor.

With regard to knowledge about genetic counseling, before completing the questionnaire there was no significant difference between sign language users and spoken language users. Approximately half of each group stated they knew what genetic counseling was before reading the questionnaire. This was supported by the qualitative data, which indicate that several participants have a good understanding of

genetic counseling (even if they seemed to be guessing or implied that they were unsure). We are unable to compare our figures on knowledge about genetic counseling as expressed by participants prior to completing the questionnaire directly with other studies as there are no comparable studies. However, drawing upon anecdotal experience gained while working in a genetic counseling clinic and also from looking at the limited research data, we would say that most people who come to the clinic have little awareness of what genetic counseling actually entails. Therefore, within our study, the fact that half of the sample indicated that they knew what genetic counseling was could be considered quite high (i.e., this group claims greater knowledge than most members of the lay public). It is possible that participants did not want to give the impression of “not knowing” as they did not want to appear ignorant, or it may be that they genuinely did have more of an awareness. Issues that link genetics and deafness have been discussed in the deaf and hard of hearing media (e.g., in *SeeHear* and *SignOn*, UK television programs for deaf people), as well as through articles in the *British Deaf News* and *Hearing Concern*; therefore, it may be that these groups are more aware of the relevant issues than their hearing peers. Alternatively, it is possible that the people who self-selected to participate in the study did so because they already had a prior interest in and knowledge about genetics.

Two-thirds of the sample were either unsure or (correctly) did not think that the aim of genetic counseling was to reduce deafness in society, and a majority thought that there should be genetic counseling for deafness. Significantly more of those who thought this were hard of hearing, spoken language users as opposed to Deaf sign language users. These results imply that Deaf and hard of hearing people have some knowledge of genetic counseling and do not automatically leap to the assumption that its aim is to reduce deafness in society. The qualitative data show that some participants are quite aware of genetic technologies (e.g., “very interested in the recent genetic, stem-cell therapies”) and that others have accurate views of genetic counseling.

However, the issues of prenatal testing and termination of pregnancy for deafness were still raised by several people—and not just those who identify with the Deaf community (Middleton, Hewison, and Mueller 1998). Fears and expressions of caution about the “misuse” of

genetic counseling (i.e., with respect to enabling couples to select against deafness) were voiced several times by both Deaf sign language users and hard of hearing, spoken language users. Several people made a strong connection between genetic counseling and this potential situation, and yet the vast majority of genetic counseling consultations are not for deafness. Even in those that are about deafness, the issue of prenatal testing for deafness is not, in our experience, raised by either the counselor or the client (personal communication from practicing genetics counselors in Leeds, Cambridge, and Cardiff).

As the authors of this article, we feel it is important to state that it is not our intention to create a power differential between the health professional who supposedly knows a lot about genetics and the deaf client who knows nothing. We are not implying this, and we do not have any evidence to support this. All potential users of genetic services draw upon the collection of their life experiences, and it is vital for genetic counselors and geneticists to put neither judgment nor value on whether their views are “right” or “wrong.” We hope that, among other outcomes, this research will demonstrate to genetic counselors that they must not assume that they and their clients walk into a clinic with the same expectations of the consultation.

The majority of both sign language users and spoken language users did not know specifically how to get genetic counseling. In the UK, a referral to genetics services can usually be obtained from one’s general practitioner or family doctor or from a hospital specialist such as an audiologist; an ear, nose, and throat (ENT) physician; or a pediatrician. Self-referrals are also possible, so clients may contact the genetics department directly and ask to be seen. An array of research makes it clear that many Deaf and hard of hearing people have experienced an appalling lack of deaf awareness in the health professionals they have seen when using medical services (Harmer 1999; Munoz-Baell and Ruiz 2000; Ubido et al. 2002; Iezzoni et al. 2004; Meador and Zazove 2005; Steinberg et al. 2006): This in itself is likely to have contributed to the decreased utilization of health services. In addition, many Deaf people do not frequently use medical services that have to do with deafness, such as audiology and ENT, as there is neither need nor interest, and so a discussion in such a context about a referral for genetic counseling is very unlikely to occur.

As the introduction states, institutional and policy structures—how does one actually *get* a referral to a genetics counselor, for example?—are inevitably made even more complex by the linguistic complications of having to navigate communication challenges with health professionals. Managing to engage with the health service infrastructure presents considerable barriers. In other words, while the availability of genetic counseling seeks, in theory, to facilitate “handling innovation in a responsible and ethical way” (as Ernst Thoutenhoofd puts it in his introduction to this issue), the “collective interest” (*ibid.*) served by public engagement with such services is too often in danger of being thwarted at the very first hurdle.

Approximately one-third of the study sample feels that one of the aims of genetic counseling is to reduce deafness in society. The implication of this statistic is that participants believe that genetic counselors and geneticists are expected to put pressure on families to make certain choices to prevent deaf children from being born. This should not happen within today’s genetic counseling services as their whole ethos is no longer about reducing disability in society but about enabling individuals to make personal choices that are right for them (Clarke 1990). Critics of the process would argue that it is never possible to be truly nondirective (Kessler 1992); however, with good communication and counseling skills, genetics professionals will be able to help clients to make their own decisions. The difficulties that some professionals have in achieving nondirective goals are “largely due to the inadequate and ineffective application of basic counseling skills” (Kessler 2001).

### Concluding Remarks

Genetic science is undoubtedly a social problem. This article explores one aspect of the realization of this principle: the absolutely fundamental issue of simply bringing the counselor and the counseled *together* and doing so with a shared understanding of what their dialogue is about, what it is for, and what it *means*.

There is currently no clear evidence that adequately explains why this potential consumer group accesses genetic counseling services so infrequently, but from our research findings we can make some pos-

sible suggestions as to why this is the case. It is possible that Deaf and hard of hearing people are either not aware of genetic counseling services or else misunderstand their aims. Some have said that they will not seek genetic counseling because they worry that they will be told not to have children (Israel 1995)—something that should not happen within modern genetics services. One other reason could be that Deaf and hard of hearing people are not aware that their deafness could be genetic. There may also not be a priority attached to genetics issues, given social exclusion and other more pressing matters that deaf people may feel they need to address. Deaf people may have been reluctant to avail themselves of genetic counseling services, having assumed that there would be little Deaf awareness among the clinical staff, or limited access to BSL interpretation or to consultations in a signed language. Such possibilities are being explored in our current research.

At this stage, our hypothesis from data such as those presented here is that Deaf and hard of hearing people do not use genetic counseling services probably because they do not know how to access them rather than because they do not know they exist or have strong misconceptions about the aims of genetic counseling. Nevertheless, significant numbers of people still have misunderstandings about what genetic counseling offers. Our data show that it is more likely to be lack of knowledge about the process of obtaining a referral that is important than lack of knowledge about what genetic counseling actually means. We know that hearing people also have a similar lack of knowledge about genetic counseling (Harris 1997; Bernhardt, Biesecker, and Mastromarino 2000; Prothero 2006), and even some health professionals lack understanding (Tomatir et al. 2006; van Langen et al. 2003), and yet this does not seem to prevent them from accessing services. Access to genetics services is influenced by a number of complex factors: Knowledge about genetics is likely to be only part of this picture.

We have argued here that, as far as questions of purpose and significance are concerned, Deaf and hard of hearing people are, more often than one might expect, closer to this shared starting point than might be anticipated. Not only, one might provocatively argue, is this a situation in which the world finds it easier not to *understand* deaf people—as Padden and Humphries (2005) have suggested—but it is also one where one might be drawn to conclude that society is not

willing, in fact, to *engage* with deaf people. Breaking down such barriers and addressing the tacit reluctance to do so are surely also part of the project that Thoutenhoofd here describes as “monitor[ing] the participation of deaf people in this transformation of the existing knowledge systems.”

In a context where deaf experiences are so often conceived as presenting medical problems for society, this issue offers a stark illustration of a different perspective that will be familiar to many readers. As the articles in this issue suggest, we are not on medical territory here: The science is a social problem; the service provision is a social problem; and accessing that provision is a social problem. However, the Deaf and hard of hearing people themselves are not a social problem here—let alone a medical one. Even though they are directly, personally, and collectively threatened by the technology of genetics, they are nonetheless willing to face its implications and respond to them honestly and directly.

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### Notes

1. Terminology: We use an uppercase D in “Deaf” to refer to people who identify with the Deaf community and who consider themselves culturally Deaf (thus, in the UK, these people use British Sign Language as their first or preferred language and have a positive identity attached to being deaf). The term *hard of hearing* is used to refer to people who identify with the hearing world and who use spoken language rather than sign language. We often use the term *deaf* in a general, all-inclusive way to refer to people with *any* audiological level of deafness and also *any* stance with respect to deafness (i.e., to include those who identify with the Deaf community, as well as

those who identify with the hearing world). We make comparisons between the Deaf community (consisting of people who use BSL and do not perceive their deafness from a medical perspective) and the hearing world (consisting of the mainstream hearing society, where spoken language is the main form of communication and the majority perceive deafness as a medical condition that requires treatment, e.g., through a hearing aid or cochlear implant). This term also includes people who might refer to themselves as “deafened” or “hearing impaired.”

2. Conversation with Clinical Director at the Yorkshire Regional Genetics Service, St James’s Hospital Leeds, UK, 1/09/98. Conversation with the Clinical Director at the East Anglia Regional Genetics Service, Addenbrookes Hospital, Cambridge, UK, 1/11/01. Conversation with the Clinical Director at the All Wales Medical Genetics Service, University Hospital of Wales, Cardiff, UK, 1/12/05.

3. The lead author has worked as a genetic counselor in a clinical capacity at the Yorkshire Regional Genetics Service, St. James’s Hospital, Leeds, UK and at the East Anglia Regional Genetics Service, Addenbrookes Hospital, Cambridge, UK. The lead author has also worked in a research capacity at the All Wales Medical Genetics Service, University Hospital of Wales, Cardiff. In these three roles information was gained via personal communication with colleagues between the years 1995–2009.

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