

GETTING THE MESSAGE

ACROSS

Communication with Diverse Populations
in Clinical Genetics

Edited by

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1 Communicating with Clients Who Are D/deaf or Hard of Hearing

Anna Middleton and Christina Palmer

To effectively communicate, we must realise that we are all different in the way we perceive the world and use this understanding as a guide to our communication with other.

—Anthony Robbins

One child with a genetic deafness is born per thousand children (Morton & Nance 2006), making deafness one of the most common genetic conditions. However, despite this, deaf and hard-of-hearing adults very rarely access genetic counseling services, neither to discuss deafness nor other conditions running through their family (Enns, Boudreault, and Palmer et al. 2010; Middleton et al. 2010a). Many geneticists and genetic counselors assume that deaf adults are not interested in using genetic services. Research has shown that this is not the case (Boudreault et al. 2010), but deaf people face many barriers; these include problems with communication, misunderstandings about what genetic counseling is, and difficulties in arranging a referral due to anxieties about how to explain this to referring doctors, as well as worries about a lack of Deaf Awareness (see later) on the part of the health professionals (Middleton et al. 2010b).

Many healthcare professionals do not know the specific communication techniques they need to employ to converse effectively with deaf people, and this has led to a very poor experience on the part of many deaf clients; thus, interactions with the healthcare service in general are known to be severely unsatisfactory (Dye & Kyle 2001; Reeves & Kokoruwe 2005; RNID 2004; Steinberg et al. 2006). General frustrations that deaf people have with regards to the health service appear to influence their preconceived ideas about genetic services (Middleton 2009a). It is widely known that some deaf people have a distrust

of health professionals, coupled with a real anxiety about using health services. In addition to this distrust, there are often concerns about the perceived misuses of genetic testing (Middleton et al. 1998; Martinez, Linden, Schimmenti, & Palmer 2003) and an apprehension about interacting with genetic professionals. However, when given accurate information about what genetic counseling is and how to seek out a referral, deaf adults are keen to connect with genetic services (Middleton et al. 2010a).

This chapter aims to offer practical information to help genetic professionals engage effectively with deaf clients. It covers background information about deafness and its impact on individuals and families. It shows how to prepare for a consultation, what sort of interpreter should be arranged, how to book an interpreter, and what sorts of issues are important to deaf people within a genetic consultation. Finally, it covers Deaf Awareness and how communication should be facilitated so that accessibility and communication are optimal for the deaf client.

BACKGROUND

Clients Who are Deaf or Hard of Hearing

Deafness can be highly variable and can affect individuals in different ways. Someone with an audiogram classification in the profound or a severe range would normally find it challenging to hear conversational speech. The terms *profound*, *severe*, *moderate*, and *mild* “deafness” have precise audiological definitions that describe the level of hearing loss with respect to sounds used in conversational speech (Prosser & Martini 2007). Hearing impairment may change over time or may be static. Individuals can be deaf due to a variety of reasons; the most common gene that plays a part in nonsyndromic deafness is *GJB2*, also known as Connexin 26 (this latter term refers to the protein made by the *GJB2* gene). This (typically) recessive gene has a carrier frequency of approximately 1 in 33, and homozygotes for *GJB2* (as well as biallelic carriers for *GJB2/GJB6*) usually have a severe-profound, congenital hearing loss, although some individuals have audiograms that fall in the mild or moderate range (Smith & Van Camp 2010). Because the focus on this book is on communication within a clinic, no further attention will be given here to the genetic causes of deafness or to a clinical overview; the interested reader is directed to comprehensive texts provided by experts in the field, such as Smith and Van Camp at the GeneReviews section of the www.genetests.org website.

Terms That Deaf People Use to Describe Themselves

There is often disparity in the terminology linked with deafness, largely because people with hearing loss and health professionals and academics use different terms to describe similar concepts (Grundfast & Rosen 1992).

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“Hearing impaired” has a precise medical description, as defined by the International Classification of Functioning, Disability, and Health (Stephens & Danermark 2005) and, as such, is often used by health professionals. However, many deaf people themselves do not like this term because it has a negative connotation (as if the person him- or herself were defective or “impaired”). It is therefore not seen as politically correct, and several professional organizations (such as the Royal National Institute for Deaf People [RNID] in the United Kingdom) and representatives for deaf people have dropped the use of this term. Therefore, within a genetic consultation, direct communication with a deaf client should not involve use of the term “hearing impaired” unless the client him- or herself uses it.

There has been a push recently to avoid using a medical condition to describe a person (e.g., “the breast cancer client”). It is seen as more politically correct to refer to the person first and the condition second (e.g., “the client with breast cancer”). This phraseology does not completely translate to deafness because the term “deaf” can often be linked to identity (as will be shown later, in sections on medical versus cultural identity). For example, it is still perfectly acceptable and indeed preferable to use the descriptor “deaf people” rather than “people with deafness.” However, for those who don’t perceive themselves as deaf but more as having started out hearing and lost some or all of this function, then the phrases “person with hearing loss,” “person who is partially hearing,” “person with hearing impairment” are acceptable (see Figure 1.1).

Often, the term “deaf” (written with a lowercase d) is used generically to refer to all those with a hearing loss, including those who were born deaf as well as those who began life hearing and have lost this over time. In this chapter, the term “deafness” and “deaf people” is used collectively to refer to people with any level and perception of hearing loss.

Medical or Cultural Model?

Medical Model

- The medical model perceives deafness as a medical problem or pathology due to a deficit within the ear that needs to be treated with a hearing aid or cochlear implant. Health professionals (e.g., audiologists and ear, nose, and throat [ENT] surgeons) traditionally work within the medical model and may assume that the deaf client wishes to be treated or cured of his or her deafness. However, genetic professionals need to be aware that deaf clients coming for genetic counseling may not perceive their deafness from the medical model.
- People who perceive their hearing loss from the medical perspective usually use spoken language and identify more with the Hearing World (also termed “culturally hearing”). They also may believe that they have a disability and, within

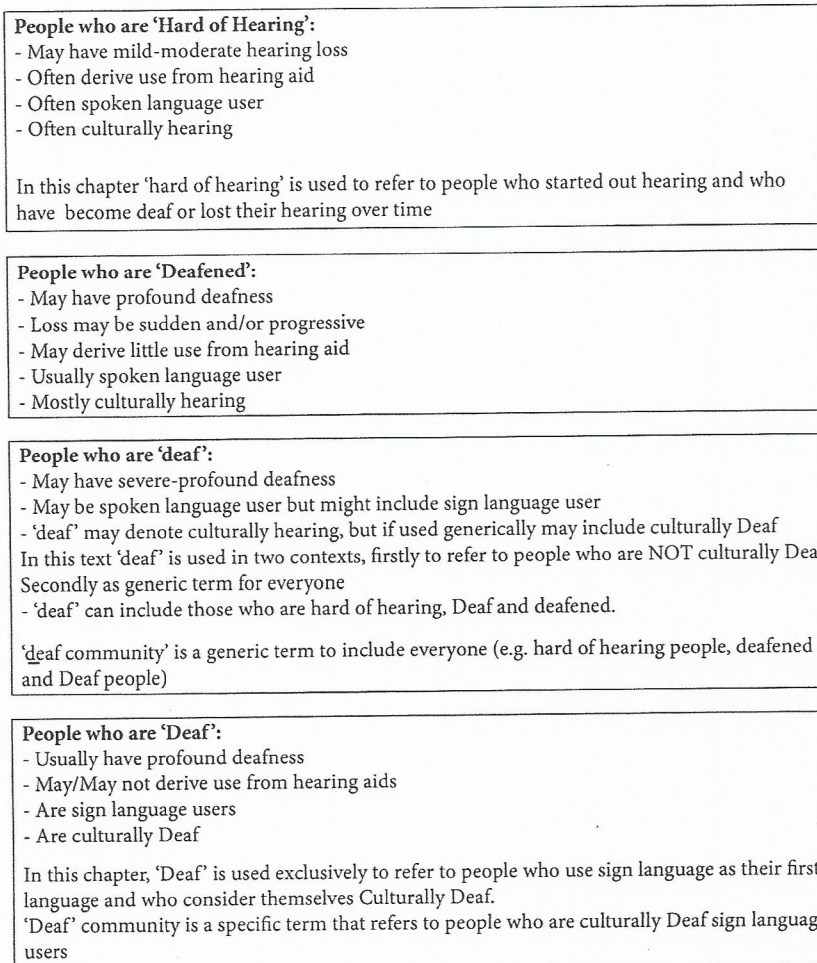


FIGURE 1.1 Terminology and Broad Descriptors.

a genetic counseling context, may be keen to avoid passing on deafness to their children.

Cultural Model

- The cultural or linguistic model determines that deafness is a way of life rather than a medical problem that requires treatment.
- People who are culturally deaf use signed language as their preferred communication and often refer to themselves as Deaf (written with an uppercase D) (Padden & Humphries 2005); these clients define themselves as part of the Deaf community or Deaf World. They may believe that they do not have a disability, but that society disables them. Within a genetic counseling context, they may not mind passing on deafness to their children.

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- When several members of the same family have deafness and use sign language as their preferred language, a strong Deaf identity often develops. It is thought that 90% of culturally Deaf adults have a Deaf rather than a hearing partner (Schein 1989); 70% of D/deaf couples who have only deaf children are believed to be deaf because of changes to the GJB2 gene (Nance et al. 2000).
- The “Deaf culture” is worldwide, and there are many active Deaf communities, for example, in the United States, United Kingdom, Australia, Canada, Germany, Sweden, the Netherlands, and elsewhere.

Different Perceptions of Deafness

- A person who is hard of hearing or deafened will usually perceive his or her deafness from the medical model and will usually use spoken language, lipreading, and written forms to communicate. He or she may feel incredibly disabled by the hearing loss and may have to make significant practical and emotional adjustments in his or her life to adapt to this.
- A person who considers him- or herself culturally Deaf may reject the medical model of deafness; he or she usually uses a National Sign Language (e.g., British Sign Language [BSL] or American Sign Language [ASL]) to communicate, with some lipreading; because spoken English is a second language, some may prefer not to use written/read English. These individuals often feel pride attached to their deafness and, in many circumstances, express a preference to being deaf rather than hearing (Ladd 2003).

Different Ways Deaf People Communicate

Deaf and hard-of-hearing people can use several different methods of communication. These include (but are not limited to) speech; National Signed Language (e.g., BSL, ASL); Signed Supported Spoken Language (SSSL), which translates spoken language into sign language using the same word order and structure as the spoken language (e.g., Signed Supported English); lip- or speech-reading; and written notes.

Spoken Language

The vast majority of hard-of-hearing and deafened people use spoken language. Within this, they may rely heavily on lipreading and a strong level of Deaf Awareness on the part of the person with whom they are communicating (Middleton et al. 2010b). Conversely, lipreading for a profoundly deaf person who has never heard sound can be incredibly challenging (Barnett 2002). It is possible for different words to look the same to a person who is lip-reading; this is because in spoken language it is the sound made within the throat (which is thus invisible to the viewer) that

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Mr. and Mrs. Brown said that they would like a “communication supporter” called a “lip-speaker” at their consultation. They had worked previously with a lip-speaker they liked, and they provided the name and contact details so that the genetic counselor could contact her. The genetic counselor booked this lip-speaker and sent her details of the sorts of issues that would be discussed in the consultation, together with an explanation of some genetic terminology she would be using. The genetic counselor arranged to meet the lip-speaker 20 minutes prior to the consultation, so that they could arrange the chairs appropriately in the room in relation to the light and also have a chat about how the genetic counselor would conduct the session. The genetic counselor asked the lip-speaker to speak to the receptionist for the clinic and to make arrangements to be brought over to the reception as soon as Mr. and Mrs. Brown made themselves known. This meant that the lip-speaker would be able to sit with Mr. and Mrs. Brown and their children in the waiting area and alert them when the genetic counselor was ready to see them. When the genetic counselor called out their names, the Brown family was prompted by the lip-speaker that it was their turn, and the family came into the consultation room. The session started with the family checking that the seating arrangements were suitable for them; the lip-speaker sat to the genetic counselor’s side, so that all the family could lip-read the genetic counselor and look to the lip-speaker easily for prompts. The genetic counselor conducted the session, and the lip-speaker mouthed the English clearly together with finger-spelled letters for individual words. The genetic counselor took her time, took care not to use jargon, and repeated and rephrased what she said, because this is particularly useful for lipreading. She also paused between changes in topic and checked periodically that the lip-speaker was keeping up. Effective communication was delivered in speech via the support of the lip-speaker, and the deaf family was able to engage fully in their genetic counseling consultation because of this.

Note: In the United States, deaf individuals who prefer to use speech might use TTY service or MSN Messenger service for direct communication with their genetic counselor.

National Sign Language

National Sign Languages (NSL) have their own systems of grammar and sentence construction that is different from—and not a literal translation of—spoken languages (Fischer & Hulst 2003). National Sign Languages vary among countries; for example, the sign language in the United States is different from BSL; there are also regional dialects within countries. A person using an NSL would not usually use his or her voice to speak at the same time, but he or she may mouth some individual words. This is different from SSSL, in which the signing is based literally on the spoken language. People who are culturally Deaf would usually use an NSL rather than a SSSL.

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Sign Supported Spoken Language

For deaf children born into hearing families, an emphasis may be placed on developing spoken language. These deaf children also may learn to sign via SSSL because SSSL has the same sentence construction as spoken language. SSSL may also be used by deaf and hard-of-hearing people who would not consider themselves culturally Deaf but who span the Deaf and Hearing Worlds. Sign language interpreters often are trained to recognize whether a deaf individual is using SSSL (a coded form of spoken language) or an NSL (a signed language) and will adapt their signing and voicing accordingly.

Reading/Writing

Deaf people who use NSLs may find reading and writing more difficult than do SSSL users because the written form of a language has the same sentence construction as SSSL, rather than NSL. Thus, it may not be helpful to use written notes with an NSL user (although in some cases, for the sake of confidentiality, an NSL user may prefer using written notes rather than a sign language interpreter as a means of communication with a healthcare provider—it is important to ascertain a Deaf individual's preferred mode of communication prior to an appointment). It also means that written text by an NSL user may give the impression that English is a second language (which, of course, it is!); for example, sentences may contain differently ordered grammar or spelling mistakes. It is very important to realize that this is in no way indicative of intellectual ability but is rather a symbol of difficulties in receiving the most suitable education to facilitate multilingual achievement. Where written material is the only available medium, it is important to have this structured in "Plain English" for sign language users, and there are companies that specialize in this work. Plain English is a written form of English in which care has been taken to reduce sentence size, restrict the use of jargon, and avoid legal-speak. The British government places particular emphasis on the fact that all publications produced for the lay person be written in lay language that is easy to understand.

Where possible, written materials (e.g., clinic information) should be translated into sign language with captioned text and offered in an electronic form (e.g., on DVD). Consideration also needs to be given to the way consent forms and family history questionnaires are formulated and could also be delivered in a signed electronic format.

Genetic Counseling Isn't Always About Deafness

A client with hearing loss may come for genetic counseling for the same reasons that hearing clients do, so genetic professionals need to remove the common

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Thoughts from Deaf Clients About Genetic counseling

When deaf and hard-of-hearing people were asked what they thought genetic counseling is, there tended to be two camps—those who thought it must involve some kind of therapeutic counseling for mental health issues, and those who thought it must involve prenatal testing for deafness with recommended selective abortion (Middleton et al. 2010a).

The power of this latter issue should not be underestimated because it may hinder engagement with genetic services. For example, a deaf client may decline a prenatal test for Duchenne muscular dystrophy because he or she wrongly assumes that deafness will also be tested for at the same time.

It is, therefore, incredibly helpful to start any genetic counseling consultation with a brief description of what the consultation will entail and what the genetic counseling process involves (see Box 1.2).

Box 1.2 Case Study 2: Working with Assumptions About Genetic Counseling

Mrs. Smith is profoundly deaf. She is also culturally Deaf and British Sign Language (BSL) is her first language. She does not wear a hearing aid nor have a cochlear implant, and her lipreading skills are adequate, but she finds it difficult to fully comprehend a full conversation via lipreading. Mrs. Smith is pregnant and, on the routine 20-week scan, it was found that the fetus had echogenic bowel, together with other features that could be indicative of cystic fibrosis. The prenatal genetic counselor became involved with Mrs. Smith because she was referred to discuss cystic fibrosis and the pros and cons of having a diagnostic chorionic villus sampling (CVS) (the center she went to routinely performed CVS throughout pregnancy, not just in the first trimester). The genetic counselor was informed by the referring obstetrician that Mrs. Smith is Deaf and preferred to be contacted via text on her mobile telephone. The genetic counselor sent a text to Mrs. Smith to ask what sort of interpreter she preferred and whether she had any preferences for who was booked. Mrs. Smith said that she needed a BSL interpreter and that anyone from the Signature website (U.K. based) would be appropriate. Mrs. Smith also said that, because she could access e-mail on her phone, she would prefer to continue the conversation via e-mail so that more could be discussed. Over the next two days, arrangements were made via e-mail for the consultation and the interpreter. The genetic counselor was careful to compose short messages about what would be discussed in the clinic (e.g., a discussion about the ultrasound findings and the possibility of additional testing), because this text-based communication was in written English—not Mrs. Smith's first language—and thus there was room for possible misunderstanding. The genetic counselor was also aware that Mrs. Smith may be very nervous about undergoing prenatal testing and may wrongly assume

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that deafness would be tested for. This hunch was correct, and, within the consultation, Mrs. Smith revealed that she had reservations about going ahead with prenatal genetic diagnosis for cystic fibrosis and wanted additional reassurance that deafness would not be tested for. She was particularly suspicious that the obstetricians would encourage a termination of pregnancy if the baby was thought to be deaf. The genetic counselor was able to reassure Mrs. Smith that this would not happen; by facilitating Mrs. Smith's preferred communication channels (text, e-mail, interpreter), the genetic counselor was able to address many of Mrs. Smith's fears and preconceived ideas about the process of genetic counseling.

Note: Although this example focuses on a British Deaf client, the essential point about the importance of facilitating the preferred communication channels holds worldwide. In many countries (e.g., Britain, United States), it is a legal requirement that sign language interpreters be available when requested by a deaf client. Moreover, a genetic service can build rapport and illustrate Deaf Awareness by asking a sign language user if he or she has a preference for a specific sign language interpreter or agency when booking a sign language interpreter. If a genetic service or medical center has a sign language interpreter on staff, this should be explained in advance to the Deaf client so that he or she understands why the genetic counselor or genetic staff did not ask for suggestions.

PREPARING FOR THE CONSULTATION

Disability legislation in a variety of countries (for example, the Disability Discrimination Act in the United Kingdom; the Americans with Disabilities Act in the United States) decrees that it is the service provider's responsibility to ensure that appropriate measures are taken to enable equal access to services for deaf and hard-of-hearing clients; the service provider also must cover the cost of this.

One way to ensure equal access is to employ the services of a Deaf Awareness or Deaf Equality consultancy service (usually run by Deaf advocates who are able to advise on the most appropriate way to deliver services) to assess what is available and make recommendations. Cultural awareness is another important aspect of genetic services for Deaf clients. Genetic services providers, including genetic counselors, can develop cultural awareness through a series of Deaf culture workshops and by developing ties with local and national Deaf organizations.

The Clinic Booking Process

Any clinic booking process that relies on the client phoning the hospital or service to book or confirm an appointment is difficult for a deaf or hard-of-hearing client.

Communication with deaf clients needs to be adapted; this can be done using e-mail, texting, or through online messenger services (e.g., MSN Messenger) (Baldwin et al. 2011; Withrow et al. 2009).

The Waiting Room

Waiting for your name to be called out prior to a consultation is one of the most stressful events for a deaf client: thousands of health service appointments have been missed because the deaf person didn't hear his or her name being called. When the deaf client arrives for his or her appointment, the reception staff need to know that they must adapt their communication style. Staff should be encouraged to take a Deaf Awareness training course: they need to speak clearly, use good Deaf Awareness skills (see later), and inform the client how he or she will know when it is his or her turn for the appointment. Several different methods can work. A visual board that displays the client's name (either written or electronic) and where to go can be useful. However, as with calling out a client's name, this does breach confidentiality. Alternatively, each client could be given a number on a piece of paper, and the genetic counsellor can then hold up the number corresponding to the client when it is his or her turn. Since clinic clients generally must sign in when they arrive at the clinic, another option is for the staff to be aware of the day(s) on which a deaf client has an appointment. Staff can meet the deaf client as he or she signs in, walk over to the deaf client when it is his or her appointment time, and walk him or her to the assigned clinic room. Another option is to use a vibrating pager, which the client holds while waiting; it vibrates when it is his or her turn. This latter method is particularly appropriate for deaf clients because it doesn't rely on them keeping a very firm look out for visual cues; it means they can relax while they are waiting. For hearing aid users, the inclusion of an induction loop is pivotal.

It is also very important to appreciate that deaf clients cannot easily communicate if they cannot easily see—sending them off to a busy waiting room with plants, tables, and people standing around can be incredibly stressful if they cannot easily view the visual notice board or genetic professional who has come to get them. Simple things like moving chairs so that they face the space where the genetic professional will stand can make all the difference.

Observations of the Deaf Client Before the Consultation Starts

Seeing a hearing aid on a deaf client may offer some clues as to how he or she prefers to communicate. It is possible that he or she utilizes his or her residual hearing and thus will use lipreading and spoken language. Alternatively, he or she may be a

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sign language user predominantly but gain some helpful cues from the hearing aid (but not enough to actually “hear” a conversation in its entirety). It should not be assumed that, if no hearing aid is seen, the client is not deaf; such clients may be sign language users and gain no useful benefit from a hearing aid.

Timing of Consultations

The time taken for a routine genetic counseling consultation could be doubled for a deaf client. When an interpreter is used, time needs to be allowed for the interpreter to listen to what is being said and translate this into sign language, for the deaf client to watch this and then respond in sign language, and for the sign language interpreter to translate the response into spoken language. The messages being delivered by the genetic counselor need to be repeatedly rephrased and delivered in different ways, to allow the deaf client the chance to overcome inevitable obstacles with lip-reading or to allow the sign language interpreter the chance to overcome inevitable obstacles with translating genetic and medical terminology (unfamiliar to most interpreters) into sign language.

It is usual and natural for consultations to take more time with deaf and hard-of-hearing clients. It is also necessary to allow for a short break during a consultation. This is because it is particularly tiring following a translated conversation, as well as trying to lip-read and also sometimes deal with distracting ambient noise at the same time. Genetic counselors should also be aware that many deaf and hard-of-hearing people have tinnitus (ringing in the ears) that can be incredibly distracting and also can make stressful situations even worse with regards to being able to concentrate.

Preferences for Communication in a Clinical Setting

Research has shown that many deaf sign language users prefer their healthcare consultations to be delivered in sign language, preferably by a signing health professional or, if that is not possible, then via an interpreter (Baldwin et al. 2011; Dye & Kyle 2001; Middleton et al. 2010b; Withrow et al. 2009). However, if a signing health professional is not available, some deaf sign language users will prefer their healthcare consultations to be conducted using written communication rather than via an interpreter. This is because they do not wish to have a third party (sign language interpreter) privy to their medical information; they prefer to keep their medical information between themselves and their healthcare provider. Sign language users are usually resistant to consultations delivered only in speech, and it is the clinicians’ responsibility to ensure that the appropriate methods of communication (e.g., interpreters) are in place.

Hard-of-hearing spoken language users are accepting of consultations in speech but only if there is a good level of Deaf Awareness on the part of the genetic professional (Middleton et al. 2010b); this may mean also using handwritten notes and electronic note-taking, and time needs to be allowed for the client to switch his or her gaze from reading the written notes and to the genetic professional for lipreading.

Types of Interpreter and Communication Support

Information can be interpreted in several different ways, depending on the preferences of the deaf or hard-of-hearing client. An *interpreter* will turn an NSL or SSSL into spoken language, and spoken language into an NSL or SSSL. A *communication support professional* (e.g., a *lip-speaker*) will turn spoken language into clear spoken language accessible to both the hearing health professional and the deaf or hard-of-hearing client. A *speech-to-text reporter* (STTR) and *voice-to-text software* convert speech into written text (available on many computers and smart phones). *Deaf relay interpreters* work with hearing interpreters; they convert the sign language used by the hearing interpreters into a tailor-made sign language for the deaf client. As an example, a deaf interpreter fluent in BSL would be used for a deaf client whose native language is BSL but is receiving genetic services in the United States via a hearing interpreter trained in ASL. All these services can be available in person or via an online service.

For some individuals, expressive and receptive language will be the same. Others may prefer to express themselves through spoken language but receive information in a signed language.

Before the consultation begins, it is most helpful to ask the deaf or hard-of-hearing client what form of communication support they prefer. They may also have a particular person whom they prefer to work with, or, alternatively, a particular gender of interpreter (e.g., if the consultation will involve a physical examination). Interpreters are often well known in the Deaf community and may also be hearing children of deaf parents themselves; thus, it is distinctly possible that the deaf client may know the interpreter socially and may feel quite strongly about working with (or not with) certain interpreters.

It is not thought good practice to allow a younger child or relative to be used as an interpreter. It is always the responsibility of the genetic service to pay the cost of the interpreter, as well as travel expenses and booking fee (if there is one). For a more comprehensive overview of the different types of interpreters available see www.signature.org.uk (in the United Kingdom), www.rid.org (in the United States), and www.deafau.org.au (in Australia).

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COMMUNICATION IN THE CONSULTATION

Working with Interpreters

Once the most appropriate interpreter or communication support person has been booked, it is important to put aside some time, ahead of the consultation, to speak with them about the content of the consultation. Ideally, this would happen several days before meeting in person, but when this isn't possible, it should definitely be scheduled for at least half an hour before the consultation. This is because the interpreter needs to have time to practice how he or she will relay certain concepts, and it is also likely that he or she will want to double-check meanings and intentions with the genetic professional to make the communication as clear as possible. With a complicated subject like genetic, it is imperative that the genetic counselor spends time explaining the biology behind, for example, inheritance patterns, so that the interpreter can prepare what sort of visual metaphors he or she may use and check these out. It is often helpful to send diagrams or explanations ahead of the consultation. If bad news is going to be given, then it is helpful to give the interpreter some warning of this—not necessarily to give the news before the client receives it, but to forewarn the interpreter of the sorts of issues that may arise so that he or she is not caught off guard. An important balance must be struck between preparing an interpreter for a session and ensuring that the interpreter does not receive distinctly personal information about the deaf client before the deaf client receives that same information. This balance should be rigorously respected; otherwise (1) it is possible that the information will affect the interpreter's demeanor and disrupt the healthcare professional's plan for conducting the session, and (2) if the deaf client decides to cancel the appointment, then the interpreter is left knowing something very significant about the deaf client without that deaf client's knowledge, which could create ethical dilemmas.

Sometimes, the client may prefer for the interpreter to meet him or her in the waiting area and come into the clinic with the client. Thus, it is imperative that decisions are made about what preparation the interpreter needs and what the client expects so that all are clear on what will be happening. When the interpreter and client are present in the consultation room, there will likely be a discussion about the seating and how this is positioned in relation to the light; chairs may be moved around and it is up to the genetic counselor to make sure that everyone is seated in a position where he or she can easily be seen by both interpreter and client.

It is important for the genetic counselor not to assume that every message he or she wishes to relay through the interpreter is actually relayed word for word and with the same intonation and tone intended. There is nearly always some difficulty encountered at some point. It is therefore important not to speak too fast and to keep an eye on the interpreter to check that he or she appears to be keeping up. It is also important to pause frequently to allow time for the interpreter to catch up and

also to pause between changes in topic so that the interpreter can indicate to the deaf client that a new set of information is on its way.

It is important for the genetic counselor to “control” the session. If the client needs comforting, it is for the genetic counselor to do this, not the interpreter.

Sign language interpreters will also interpret other people’s conversations or sounds (e.g., telephone, music) if they hear it. Since hearing people have access to these “extraneous” sounds, it is perfectly acceptable for deaf people to also have access. Thus, if a genetic counselor’s phone rings in the middle of the session, and she chooses to answer it and have a conversation, the interpreter will alert the deaf client that the phone is ringing and will interpret what the genetic counselor is saying over the phone (which is no different from a hearing client having access to the genetic counselor’s phone conversation), even though this conversation has nothing to do with the current session.

The process of interpreting means that the interpreter makes sense of what the client is expressing; this may mean that sometimes the interpreter “fills in the gaps” as he or she translates what he or she thinks the deaf client is expressing. Although this always involves a level of intuition and empathy, there are also occasions when what the Deaf client is expressing is not well understood by the interpreter. It is also distinctly possible that what the Deaf client is expressing is incoherent or muddled (e.g., if he or she has a mental health issue); thus, the interpreter will often have to make an immediate judgment on whether to express his or her own interpretation of what is being communicated, whether he or she interprets “a flavor” of this, or whether a literal translation (that may make no sense) is most appropriate. For these reasons, it is therefore vitally important to have a debriefing session with the interpreter after a consultation, to check that the interpreter was satisfied with the exchange of language and that there was nothing missing.

Booking an Interpreter

There is no universally recognized register of interpreters; however, most countries will have their own accredited organizations for interpreting, and so it is helpful to do an Internet search to learn about the accreditation requirements in a specific country. Many hospitals will have access to particular interpreting agencies; however, since a different interpreter is usually sent for each assignment, many health professionals prefer to establish their own network of interpreters that they like to work with. Limiting the pool allows chosen interpreters an opportunity to build expertise.

A consultation that is likely to last more than an hour may require two interpreters; they usually work for 20–30 minutes and then swap over.

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It is important to allow several weeks to book an interpreter to attend a consultation in person. However, it is possible to gain access to instant, live online BSL interpreting via the Internet, for example at www.signtranslate.com. If an online interpreter is required, the same rules apply in that it is important to allow time to prepare the interpreter for the language and concepts that will be discussed in the consultation. When booking an interpreter, the following information will be required: nature of consultation (medical), number of deaf people and number of hearing people in the consultation, where the consultation is (directions to be sent), the content of the consultation (preparation material to be sent, such as explanations of what recessive inheritance is and an overview of the topics for discussion), who the deaf client(s) is, how long the consultation will last, where exactly to meet (e.g., in the waiting room with the deaf client or the clinic room before the deaf client arrives, etc.).

The following is from the British Deaf Association guide on working with interpreters (British Deaf Association 2005, www.bda.org.uk):

- “Talk directly to the Deaf person. Correct: ‘Did you have trouble finding us today?’ Incorrect: ‘Please ask if s/he had trouble finding us today?’
- The spoken side of the interpretation is called the ‘voice-over’ and will always be in first person, e.g.: ‘I had no trouble finding you; your directions were very clear.’ The Deaf person is ‘speaking’ with the interpreter’s voice.
- Look at the Deaf person and not the interpreter. Maintaining good eye contact will reinforce the feeling of direct communication.
- The interpreter will not take part in the discussion, and is impartial. During the communication, do not ask an interpreter for their opinion or advice.
- The interpreter relays what they hear, so the Deaf person has full access to all communication. Do not say anything you don’t want everyone to know!
- The interpreter will interrupt if they need something to be repeated or clarified. Equally, if you are not sure of something, you can ask the Deaf person to repeat or rephrase it. If you think the interpreter may have misunderstood or missed something, it’s fine to ask to go back and find out for sure.
- Position the interpreter close to the main speaker if possible, and clearly visible to the Deaf person. The interpreter should be well lit, but not from behind—so do not put them in front of a bright window!
- Don’t be put off if the Deaf person doesn’t watch you when you are talking, because they’ll be watching the interpreter.
- The interpreter can only listen to or watch one person at a time, so—as with any communication—it is important to take turns and not talk over each other.
- Speak clearly at your normal pace. Interpretation is almost simultaneous, but there will be a slight delay as the interpreter picks up the meaning of a phrase. If you usually speak very quickly, you may need to slow down a little (the interpreter can advise you). Allow time for Deaf people to respond or ask questions.

- Afterwards, as part of the feedback process, check with the Deaf person whether interpreting arrangements were satisfactory, and whether they would be happy to use the same interpreter again. If you have suggestions for improvement, tell the interpreter or the agency.”

Deaf Awareness

“Deaf Awareness” is the conscious attention given to making sure that communication is appropriate and sensitive to the deaf client’s needs. This means adapting one’s communication style to the individual client—all deaf and hard-of-hearing people are different and may have slightly different needs. For example, an elderly hearing aid user might find it helpful if his or her genetic professional slowed down his or her speech and also raised it slightly. Conversely, this is unlikely to be at all helpful for someone who is good at lipreading and who has a finely tuned hearing aid—the slowed speech distorts lipreading and the hearing aid warps the sound if it is too loud. The following text gives details of good Deaf Awareness for sign language and spoken language users (see Figures 1.2 and 1.3).

Training Recommendations for Staff Working in Genetic Services

- Substantial Deaf Awareness training is recommended for at least one member of administration staff and one member of clinical staff in each genetics department. This training should be offered by someone who is deaf, or if this is not feasible, training should have significant input from someone who is deaf.

Greeting	Welcome the client with a sign-language greeting (or ask the client to teach you one) Ask the client how best to communicate with him or her
Environment	Room is well lit, and the light is not shining in the client’s eyes People are positioned so that the client who is deaf can see the doctor and the interpreter
Expressive communication	Work with a qualified interpreter Speak to the client, not the interpreter Topic changes are stated explicitly Note writing and written materials may have limited usefulness Ask the client periodically about the quality of the communication Ask the client for periodic summaries to check accuracy of communication
Receptive communication	Look at the client while listening to the interpreter When uncertain, ask the client (not the interpreter) for clarification Summarise the client’s story to check accuracy (Barnett 2002, p696)

FIGURE 1.2 Deaf Awareness for Deaf Sign Language Users.

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Greeting	Ask the client how best to communicate with him or her
Environment	Background noise is minimized [Health professional's] face is well lit
Expressive communication	Eye contact is established before speaking View of mouth is not obscured (by hands, pens, charts etc) Adjust voice pitch if this helps Topic changes are stated explicitly Repeat information that is not understood. Rephrase if it is still not understood Use assistive listening devices (e.g. hearing aids, note-takers) if they help Note writing may be helpful Ask the client periodically about the quality of the communication Ask the client for periodic summaries to check accuracy of communication
Receptive communication	When uncertain, ask the client to repeat or clarify Repeat the client's statement to confirm comprehension If still unclear, note writing may help Summarise the client's story to check accuracy (Barnett 2002, p695-6)

FIGURE 1.3
Deaf Awareness for Hard-of-Hearing Spoken Language Users.

- All genetic professionals who regularly see deaf and hard-of-hearing clients (e.g., on a monthly basis) should have Deaf Awareness training.
- At least one member of the genetic team frequently seeing deaf sign language users (e.g., as part of a specialist deafness clinic, perhaps on a monthly or even weekly basis) should undertake NSL training at least to a basic level.
- Genetic professionals who specialize in working with deaf clients and who frequently see deaf sign language users should aim for fluency in their NSL and be able to deliver a consultation in NSL (Middleton 2009b).

Marking of Medical Records

Medical notes should be clearly labeled with the communication needs of a deaf or hard-of-hearing client. This may mean printing in bold on the front page or the notes or adding an auto-alert to electronic records that indicates the client is, for example, “profoundly deaf,” “uses British Sign Language,” and “prefers to use Mr. X, BSL interpreter from Y agency (telephone number ...).”

Use of Language

Value-laden terms should not be used to give deafness a negative connotation (e.g., avoid “mutation,” “abnormal,” “normal,” be sensitive to words like “risk”). Words such as “chromosome,” “gene,” and “DNA” may need to be finger-spelled and have

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a definition applied. This is why it is helpful for the interpreter to have been given the opportunity to learn for him- or herself what these terms mean before the consultation; they can then think creatively about how they will describe this in sign language.

Taking a Family History

Deaf children growing up in hearing families often miss out on incidental conversations that occur within the family because of communication difficulties. This means that they may have a lack of knowledge about relatives and their medical conditions. Therefore, when taking a family history, it may be necessary to get permission to call hearing relatives to gather more information (Israel & Arnos 1995). Other options from our experience are (1) ask the deaf client to ask his or her hearing relatives to assist in filling out a family history questionnaire, and (2) ask the deaf client to text his or her hearing relatives with family history questions as they arise during the genetic counseling session. Many deaf individuals use text messaging for communicating with family and friends.

Asking About a Family History of Deafness

Genetic counselors who want to take down a family history of deafness from a deaf client will usually need to explain carefully why this is necessary. Some deaf clients are sensitive to being asked about their family, given that, in the past, this information was used against them in the name of eugenic practices. A suspicion about this still remains (Middleton et al. 2010a). However, once the deaf client is reassured as to why it is important to ask about his or her family history of deafness, many individuals are interested in describing their family to, and sharing family stories with, the genetic counselor.

An Inappropriate Focus on Deafness

Iezzoni et al. (2004) interviewed deaf and hard-of-hearing people on their views about the healthcare system. They reported that “respondents wondered why physicians repeatedly question them about what caused their deafness when hearing is irrelevant to their current health concerns” (Iezzoni et al. 2004, 358).

Research has shown that deaf clients are sometimes fed up that they are repeatedly asked about their deafness and also about deafness in their family. This is particularly important for deaf clients who have been referred for genetic counseling to discuss an issue unrelated to deafness.

Genetic counselors should be respectful of the fact that many deaf people do not see their deafness as a medical problem that needs to be explored.

Visual Aids

Deaf and hard-of-hearing people use of diagrams and visual aids in genetic counseling is

Emotional Is

Deafness can be a source of grief or perspective on life. Some deaf people experience “audism,” a form of discrimination like someone who experiences this as a higher risk than hearing people (Health 2005). Many deaf people are surprised if their responses.

It is likely that deaf people communicating with hearing people use basic communication difficulties.

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Visual Aids

Deaf and hard-of-hearing people tend to be very “visual” and respond well to the use of diagrams, animations, and hand signals (e.g., one hand to indicate a recessive gene and another to indicate a dominant gene). Incorporating visual aids into a consultation is vitally important for deaf clients.

Emotional Issues to Consider in a Consultation

Deafness can be very disabling to a person, irrespective of his or her positive attitude or perspective of deafness. Most deaf and hard-of-hearing people have experienced “audism,” a form of discrimination based on an individual’s ability to hear or behave like someone who hears (Bauman 2004), at some point in their lives, and many experience this bias on a daily basis. It is known that deaf people generally have a higher risk than hearing people of having mental health issues (Department of Health 2005), likely as a result of audism, and therefore allowance must be made within any consultation for emotional fragility. The genetic counselor must not be surprised if there are sometimes frustration and seemingly overactive emotional responses.

It is likely that the deaf client will have previous negative experiences of communicating with health professionals, and this may mean that he or she is defensive or aggressive in anticipation of poor service again. It can also help to use basic counseling skills, such as acknowledging openly some of the obvious difficulties.

For example, by saying things like “I can see you are really frustrated; however, I’m going to try really hard to understand what is going on for you” or “I can understand that you are fed up with health professionals; help me to learn what I need to do to help you.”

Post-Clinic Letters

Genetic counselors will need to adapt the standard post-clinic letter for deaf and hard-of-hearing clients. This needs to be written in Plain English for deaf people so that when it is read they can easily translate it into sign language. Alternatively, information delivered directly in sign language and provided electronically would be best practice for Deaf clients (although not appropriate for hard-of-hearing non-sign language users). An online search will easily locate specialist companies that can translate client letters from standard written English into Plain English for Deaf people, as well as into sign language on DVD. Such work can often be completed within 24 hours. Alternatively, online resources of genetic information

delivered in sign language can be accessed via the Internet. For example, the University of Manchester has produced video in BSL that describes different inheritance patterns and also provides information about genetic deafness. This can be viewed at <http://sites.mhs.manchester.ac.uk/what-is-genetic-counselling/>. By 2013, the website DeafMD.org will have cancer genetic information available in ASL (see Box 1.3).

Box 1.3 Case Study 3: Genetic counseling Delivered Visually

Roberto and his wife Maria attend a genetic counseling consultation in London. They are both profoundly deaf, and their first language is British Sign Language (BSL). Their genetic counselor, Alison, is not familiar with BSL and so established prior to the session that the couple prefers a BSL/English interpreter. Alison booked a local freelance worker who is a full member of the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD) (she checked through the Signature website), thereby ensuring that a qualified and trained professional would provide interpreting for the session. Alison has already had a long chat with the interpreter on the phone to discuss the sorts of genetic terminology she will be describing in the consultation and how she plans to structure the session. They have discussed how the interpreter plans to sign particular concepts, such as “dominant inheritance” and “gene alteration.” Alison has also given the interpreter a basic biology lesson on what DNA is, as well as what is meant by “gene,” “chromosome,” and “genome.” In addition, she has sent some written information and drawings in a post to the interpreter. Alison has also provided information about the room they will be using and how the light is positioned, and has already given some thought to appropriate seating arrangements. In the consultation, Roberto and Maria ask for information about the chances of having deaf children. It is clear to Alison that there is a dominantly inherited, genetic deafness on Roberto’s side of the family and an environmental cause to Maria’s deafness. Alison first defines the terms she is going to use—“genome,” “chromosome,” “gene,” and “DNA”—and shows the couple pictures of these using a library metaphor—the DNA represents the words in a book, each individual book represents a gene, each shelf of books represents a chromosome, and a set of shelves represents a genome. She checks that the couple are following her and asks several times for them to give feedback on what she is saying, so that she can check their understanding. When Alison describes dominant inheritance, she draws on a piece of paper, being careful to not talk at the same time so that the couple can watch her draw. When they look up she describes what she has drawn. To reinforce the points she is making, she also describes dominant inheritance using her two hands to represent two genes; she moves her hands to indicate one gene being passed on and the other not. The interpreter also uses the same nomenclature. Alison asks Roberto

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and Maria to summarize their understanding of the genetic terminology and also asks them to draw out the inheritance pattern. At the end of the consultation, Alison gives the couple a DVD containing a National Sign Language (NSL) version of the department leaflet “What Is Dominant Inheritance?” so that they have a signed record of the information.

Comment

Alison has used four different visual methods to relay information—pre-printed pictures, live drawing, hand signals, and a DVD summary. This has all been delivered in sign language, with several opportunities to repeat and rephrase the different concepts. The couple’s understanding has also been checked throughout the consultation. In England, Wales, and Northern Ireland a list of NRCPD-registered interpreters can be found at www.signature.org.uk. In the United States, a list of certified interpreters can be found through www.rid.org.

Case study taken from Middleton (2009b).

SUMMARY

This chapter has offered an insight into those issues of relevance and importance to deaf and hard-of-hearing people and described the sorts of preparation that genetic professionals should make for consultations involving this client group.

- Deafness can be perceived in different ways, and this can have an impact on how a consultation should be delivered.
- The different forms of communication require counselors to choose the most appropriate interpreters for each individual client.
- The unique historical context of eugenics and deafness, and its potential impact on modern-day consultation, is of particular significance to genetic counseling for deaf people.
- Much work needs to be done before and during a consultation to meet the communication needs of the deaf client.

At present, deaf and hard-of-hearing clients rarely access genetic counseling services, not due to disinterest but due to barriers that prevent access. Once these access issues are addressed—and numerous research studies across the world are providing the evidence to help unravel these—then more deaf and hard-of-hearing clients will seek genetic counseling. It is, therefore, vital that genetic professionals are adequately prepared to work sensitively with this client group.

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