sion, stated that "the standard of care identified in this article has not been imposed by a court of law. It is the standard of care developed by geneticists and physicians. Debate as to its 'reasonableness' will have to be resolved by the medical genetics community" (Sharpe 1994*a*).

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Reply to Sharpe

To the Editor:

Mr. Sharpe correctly notes that in our article (Fitzpatrick et al. 1999) he was credited for considering the existence of a physician's duty of care toward patients (Sharpe 1994). His comments in this regard were indeed made in the context of Huntington disease, but, as we did not attribute to him *any* opinion on the duty to recontact, his position on this subject was not misrepresented, but simply omitted, from our discussion. We apologize to Mr. Sharpe and thank him for clarifying his position. The intention of our article was to report and discuss original research findings and not to present a detailed analysis of medical principles and legal obligations associated with a theoretical duty to recontact. It was our hope that our article would stimulate such a discourse, and we thank Mr. Sharpe for his insightful comments.

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The Choice to Have a Disabled Child

To the Editor:

What are the purposes of genetic testing, what are the principles guiding its use, and who should decide what tests should be available for what purposes? These familiar questions are raised in an unfamiliar context by a study reported recently in this journal (Middleton et al. 1998). Attitudes toward genetic testing were assessed among deaf people attending a conference in the United

Kingdom on issues concerning deaf people. About half the sample thought that genetic testing did more harm than good and that its potential use devalued deaf people. These attitudes were more negative than those previously reported in the general population (Michie et al. 1995). Attitudes were also more negative among those who identified equally with the deaf and hearing communities.

Of those who were interested in prenatal testing for deafness, a small proportion (4/14) said they would prefer to have deaf children. Out of the whole sample, 13/87 participants said they would prefer to have deaf children. This raises the possibility that some deaf people may consider using genetic technology to facilitate their having deaf children. Caution, however, is needed in interpreting these findings. The study sample was both small and likely to be unrepresentative of deaf people in that it comprised those attending an international conference. In addition, participants completed the questionnaires in a highly unusual social context: a conference auditorium, surrounded by mainly deaf delegates, at a conference about aspects of deafness entitled "The Deaf Nation." Two factors may have led to responses different from those that might have been given in the context of everyday living. The first factor is that the identity of being a deaf person may have been accentuated, temporarily, by being in a group of deaf people discussing deaf issues. Social categorization theory suggests that this is likely to increase the difference between the views of those within the group and the views of those not in the group (Turner and Oakes 1989). The second factor is social comparison, the perception of how others are likely to respond (Suls and Miller 1977). The views of individuals in a group have been found to shift in the direction of the group's views in order to gain approval and avoid disapproval. The social context within which the questionnaire was completed is illustrated here: "A Deaf chairwoman who introduced the question…[informed] delegates that they could make a difference to genetic services for deaf people, if they completed the questionnaire, or could exercise their right to refuse, by ignoring it" (Middleton et al. 1998, p. 1176).

Even if the attitudes reported are valid, attitudes should not be confused with behavior. What people say does not always indicate what they will do. For example, a majority of those at risk of Huntington disease said they would have a genetic test when it became available, yet only a small proportion underwent the test when it did become available (Bundey 1997). Similar findings have been found for predictive testing for cancers in both Europe and the United States (Lerman et al. 1996; Dudok de Wit et al. 1997).

With these caveats in mind, the finding that people affected by a condition have more-positive attitudes toward it than do others and also hold more-negative attitudes toward prenatal testing is supported by a large body of psychological literature. This literature shows that people with different experiences and perspectives (affected versus not affected, health professional versus lay) perceive the same condition differently: those with a condition very often perceive it as less serious than do those without the condition. For example, those found to have raised levels of cholesterol perceive this as less serious than do those with results in the normal range (Croyle et al. 1993). Parents of children with a chronic disease perceive that condition as less serious than do parents of children with other chronic diseases (Marteau and Johnston 1986). More than 80% of parents consider that their children with Down syndrome are well accepted by society, in contrast with 4% of physicians (Pueschel et al. 1986). Fewer offspring with cystic fibrosis (CF), when compared with their parents, perceive termination of pregnancy for CF as acceptable (Conway et al. 1994).

There are several possible explanations for this phenomenon of different experiences resulting in different perceptions. There is no evidence that these differences reflect differences in knowledge. They may, however, reflect a difference in the information available to individuals when asked to make a judgement (Tversky and Kahneman 1973): those living with a condition have available to them many more examples of the condition not being serious than do those not living with it. This phenomenon may also reflect minimization, a common and effective strategy for dealing with the emotions evoked by threat. In contrast to denial, there is evidence to suggest that such a strategy does not undermine practical attempts to solve a problem (Croyle et al. 1993).

How, then, should individuals be helped to make decisions about genetic testing, given these differing perspectives? There are several options. The authors suggest that those with a particular disability be treated by counselors who share that disability. To leave aside the practical problems that this would involve—requiring sets of counselors for every disease and disability—such a solution privileges the views of the affected over those of the unaffected. Would parents make better decisions if counseled by one of the 20% of the culturally Deaf who favors the birth of deaf children than if counseled by a genetic counselor who may hold less-positive views of deafness?

Another option is to give parents the choice to meet others with different experiences of, and, hence, different perspectives on, an issue. Although this latter option appears in recent guidelines in the United Kingdom on prenatal counseling (Royal College of Obstetricians and Gynaecologists and Royal College of Paediatrics and Child Health 1997), evidence is needed to determine the consequences, which may be counterintuitive. Presenting disability in a positive light may not result in more pos-

itive attitudes. In a recent study that compared the impacts of positive and negative images of children with Down syndrome, we found that presenting a photograph, regardless of whether it presented a positive or a negative image, generated more concern about the condition than presenting no photograph (Figueiras et al., in press). There is an urgent need to evaluate the cognitive, emotional, and behavioral consequences of different types of information, presented using different media and by those with different levels of experience in living with a condition.

Another important question is raised by this paper: What constitutes a legitimate request for prenatal genetic testing? Answering this raises other questions concerning the objectives of prenatal testing: Whose interests does prenatal testing serve, and what constitutes a disability? The authors state that some deaf persons may consider prenatal testing in order to have deaf children. This raises two conflicts. One concerns the objectives of prenatal testing. Is it meant to reduce disability, in which case requests for testing to ensure deaf children should not be met, or is it to offer choice, in which case such requests should be met? Views about this issue differ even among professionals in the United Kingdom. Public health specialists put more emphasis on reducing disability (e.g., Royal College of Physicians 1989), whereas the genetics community emphasizes autonomous choice (e.g., Nuffield Council on Bioethics 1993). There is also a potential conflict between the choice of parents and the opportunities and quality of life of the child in a predominantly hearing society. Parents' and children's interests may not always coincide. With the increased control provided by new genetic technologies, there is a need to ensure the widest participation of social groups in decisions about implementation. The interests of groups beyond users and providers should be incorporated, since such decisions not only reflect a society's values but, in turn, may help to shape them.

Prenatal selection for deafness has been discussed in relation to prenatal gender selection in that both are examples of using technology to "seek out and destroy" a "normal" fetus (D. C. Wertz, personal communication). Wertz reports widespread feeling among both geneticists and parents that this is a misuse of genetic technology. She suggests that it perverts the goals of medicine in order to satisfy special interests. The goals of medicine are defined as helping people to live to the fullest extent possible. This begs the question of what special interests are and why meeting them should not be a goal of medicine. Who defines what "living to the fullest extent possible" is? Some deaf parents may consider that the social advantages of sharing a Deaf culture within the family and the Deaf community outweigh the biological limitation of not hearing.

Wertz reports that the majority of 409 U.S. patients surveyed believe that a doctor should honor a parent's request for prenatal diagnosis in order to have a deaf child or a child of a specified gender (55% and 59%, respectively; D. C. Wertz, personal communication). Other surveys in the United States and Europe show that a proportion of the public is in favor of prenatal testing and selective termination for a range of conditions not considered to be diseases. For example, 25% of 147 U.S. students agreed with prenatal testing at least in some circumstances for short stature (Milner et al. 1998), and 10% of 973 citizens of the United Kingdom thought that prenatal testing with the option of termination should be available for two missing fingers (Michie et al. 1995). A 1994 U.S. survey of 1,000 members of the public and 1,084 geneticists asked whether requests for prenatal testing for gender selection should be met: just over one-third of respondees said "yes" (Wertz and Fletcher 1998). There was a belief among both geneticists and patients that withholding any service is a denial of patients' rights. However, there are considerable differences between geneticists in different countries, with only 8%–14% of U.K. geneticists agreeing that such requests should be met (a similar figure to the 16% of Middleton's sample of deaf citizens of the United Kingdom who said they would consider prenatal testing for deafness). In other countries, the figure ranged from 0% (in the Netherlands, Switzerland, and Egypt) to 90% (in Russia). Again, we should remind ourselves that these surveys only report attitudes. We do not know how such requests are actually met.

The extent to which people consider a condition to be serious depends on their culture, socioeconomic status, religion, and personal experience. These factors may differ both within a society and among different societies. In Wertz's 1994 survey, reasons given by geneticists for their views varied, with Western nations emphasizing personal autonomy and China and India emphasizing social consequences (Wertz 1995). One framework for making judgements about the use of genetic technology is not necessarily superior to another: they are different, shaped by each society's historical, cultural, and material circumstances. These circumstances determine what is beneficial and what is harmful, what is socially responsible and irresponsible, and what is autonomy. This applies to different societies as well as to different cultural and social groups within any society.

This letter started with the questions "What are the purposes of genetic testing, what are the principles guiding its use, and who should decide what tests should be available for what purposes?" Answers cannot be absolute, but must depend on the particular context within which a technology is being developed and applied. A combination of discussion, research, and developing frameworks for judgment would seem to be necessary

ingredients for the constructive development of thought and action in introducing new technologies. This is particularly the case for genetic tests used for prenatal diagnosis and selective termination of pregnancies.

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Reply to Michie and Marteau

To the Editor:

Michie and Marteau (1999 [in this issue]) make some valid points in relation to our article on attitudes toward genetic testing for deafness (Middleton et al. 1998). However, they also make some criticisms that we would like to take the opportunity to answer. Michie and Marteau point out that the study sample is likely to be unrepresentative of deaf people. It was acknowledged in our article that the study sample was biased. In fact, a culturally biased sample was chosen deliberately, since it was cultural attitudes that were of interest. Another criticism in their letter is that "participants completed the questionnaires in a highly unusual social context." Again, it was acknowledged in our article that the "responses may have been influenced by the context within which the questionnaire was distributed," and "social desirability bias" was cited as a possible confounding factor. The article was the result of a pilot study that, together with other pilot work, contributed to the design of a larger study that has ascertained the attitudes of 1,600 deaf, hard-of-hearing, or deafened adults and