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Attitudes of Deaf Adults toward Genetic Testing for Hereditary Deafness

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Summary

Recent advances within molecular genetics to identify the genes for deafness mean that it is now possible for genetic-counseling services to offer genetic testing for deafness to certain families. The purpose of this study is to document the attitudes of deaf adults toward genetic testing for deafness. A structured, self-completion questionnaire was given to delegates at an international conference on the "Deaf Nation," held at the University of Central Lancashire in 1997. The conference was aimed at well-educated people, with an emphasis on Deaf culture issues. Eighty-seven deaf delegates from the United Kingdom returned completed questionnaires. The questionnaire had been designed to quantitatively assess attitudes toward genetics, interest in prenatal diagnosis (PND) for deafness, and preference for having deaf or hearing children. The results from this study provide evidence of a predominantly negative attitude toward genetics and its impact on deaf people, in a population for whom genetic-counseling

services are relevant. Fifty-five percent of the sample thought that genetic testing would do more harm than good, 46% thought that its potential use devalued deaf people, and 49% were concerned about new discoveries in genetics. When asked about testing in pregnancy, 16% of participants said that they would consider having PND, and, of these, 29% said that they would prefer to have deaf children. Geneticists need to appreciate that some deaf persons may prefer to have deaf children and may consider the use of genetic technology to achieve this. Any genetic-counseling service set up for families with deafness can only be effective and appropriate if clinicians and counselors take into consideration the beliefs and values of the deaf community at large.



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Deafness; Genetic counseling; Genetic testing; Questionnaire; Attitudes

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