Cochlear implants, the deaf culture, and ethics

A STUDY OF DISABILITY, INFORMED SURROGATE CONSENT, AND ETHNOCIDE

GLENN A. HLADÉK
Graduate student, Practical Ethics Center, University of Montana, Missoula

ABSTRACT
The use of cochlear implants in born-deaf infants addresses the issues of disability, proxy consent, and potential ethnocide of the Deaf culture. The ethical issues explored in this paper are: 1) the disability versus trait argument of deafness, 2) parents versus Deaf community in proxy consent, 3) justification for surgical intervention in a non-life-threatening condition, and 4) justification for ethnocide. Decisions for non-competent individuals should be made to assure the child of an open future, with rights that need to be protected now, so that the child can exercise them later as an adult. Cochlear implants provide the potential of an open future and are morally justified on that basis.

INTRODUCTION
The transplantation of organs was first successfully attempted in 1955. Physicians now repair or replace a variety of body parts, relegating what was once revolutionary surgery to the routine. Transplant surgery has become so successful and so widely accepted as standard medical practice, that the demand for donated organs far exceeds the supply. The ethical debate regarding these life-saving medical decisions no longer carries the emotional content that it initially did. The decision of life versus no life and the success of medical intervention has muted the debate.

Another moral/ethical debate ensues however, when biomedicine addresses the issue of quality of life, not just the preservation or extension of life. Procedures involving gene therapy, surgery in utero, and the implantation of a device to stimulate the 8th Nerve of infants born deaf are of particular interest and controversy. These interventions are specifically directed to alter, eliminate, or correct non-life-threatening conditions.

This paper will address Cochlear Implants (CI) in born-deaf children, with the emphasis on informed/surrogate consent, disability versus trait argument of deafness, and the possible demise of the deaf culture (ethnocide). The concept of a Deaf culture will be addressed initially as it frames the issue for the discussion of informed consent and autonomy.
Deaf Culture

Culture is sometimes defined as the ideas, customs, skills, and art of a given people in a given period. A common language is often accepted as necessary to share these aspects of the culture. The Deaf culture in the U.S. is comprised of a group of individuals, who are generally born deaf, and who communicate with American Sign Language (ASL). The Deaf culture is both defined and bound by these individuals' deafness and their particular language. Hearing individuals, adept in sign language, and oral speaking deaf individuals, are not generally accepted as members of the Deaf culture.

There is a long history of viewing deafness as a deficit condition. In ancient Greece deaf individuals were considered "non-persons" and killing of deaf babies was a common practice. Aristotle was quoted as saying that those born deaf "become senseless and incapable of reasoning". Roman law specified that those born deaf had no legal rights and were forbidden to marry. St. Augustine taught that the deaf were excluded from salvation on the grounds that they could not hear the word of God. The Deaf community has struggled to remove the medicalisation of deafness, to argue against the "deficit" concept of deafness, and to develop a healthy self-concept of the condition. Members of the Deaf culture celebrate their deafness, and many, if given the opportunity to hear, would choose to remain deaf because they do not see it as a disease or a disability, but rather as a difference.

The history of the severely hearing impaired or the deaf individual is replete with philosophical discussions regarding amplification, oral versus manual communication, and mainstreaming versus institutional education. Until recently technology did not allow for the early identification of hearing loss in newborns (a primary prerequisite for the successful development of speech), nor for amplification devices appropriate for born-deaf children.

Otoacoustic emissions and auditory brainstem response audiometry have only recently become technologies available to Universal Infant Hearing Screening programs. These technologies objectively identify hearing loss in the first 48 hours of life. The second technological advance is the cochlear implant (CI). The CI is an amplification system appropriate for severely hearing impaired individuals for whom traditional hearing aids provide very little benefit. There exists now the ability to identify and implant born-deaf infants with the CI, providing them with the best possible opportunity for developing speech.

The coordination of these two technologies has had a dramatic effect on the discourse of early intervention, of rehabilitation, of deafness as deficit, and of the rights of the deaf. While deafness is not eradicated by the CI, the language, education, social, and cultural ramifications of deafness have been affected significantly. The use of these technologies, with the intent to provide deaf infants with the opportunity to develop oral skills, and thus to become members of the "oral" community is considered a form of ethnocide by some members