

Deaf culture, cochlear implants, and elective disability.

Tucker, Bonnie Poitras. "Deaf culture, cochlear implants, and elective disability. " The Hastings Center Report. 28.n4 (July-August 1998): 6 (9). Expanded Academic ASAP. Gale. University of Washington. 2 Oct. 2007

<<http://find.galegroup.com/itx/infomark.do?&contentSet=IAC->

[Documents&type=retrieve&tabID=T002&prodId=EAIM&docId=A21195461&source=gale&srcprod=EAIM&userGroupName=wash_eai&version=1.0](http://find.galegroup.com/itx/infomark.do?&contentSet=IAC-Documents&type=retrieve&tabID=T002&prodId=EAIM&docId=A21195461&source=gale&srcprod=EAIM&userGroupName=wash_eai&version=1.0)>.

Abstract:

The use of cochlear implants, especially for prelingually deafened children, has aroused heated debate, Members and proponents of Deaf culture vigorously oppose implants both as a seriously invasive treatment of dubious efficacy and as a threat to Deaf culture. Some find these arguments persuasive; others do not. And in this context arise questions about the extent to which individuals with disabilities may decline treatments to ameliorate disabling conditions, When they do so, to what extent may they call upon society to provide supportive services and accommodations?

Full Text: COPYRIGHT 1998 Hastings Center

During the past decade, a growing concept I of Deaf culture has taken root. Under this concept, people who cannot hear are viewed as either deaf (with a small d) or Deaf (with a capital D). Persons who view themselves as deaf are those who, although impaired in their ability to hear, have assimilated into hearing society and do not view themselves as members of a separate culture. People who call themselves "Deaf," however, view and define deafness as a cultural identity rather than as a disability for some purposes; they insist that their culture and separate identity must be nourished and maintained.[1]

A cochlear implant is a surgically implanted device that is capable of restoring hearing and speech understanding to many individuals who are severely or profoundly deaf. Numerous studies show both the ability of profoundly deaf individuals to hear speech with cochlear implants and the ability of implanted deaf children to develop age-appropriate spoken and receptive language skills.[2] As reported in May 1998 to the Advisory Council of the National Institute on Deafness and Other Communication Disorders: "It has now been demonstrated that the long-term benefits of cochlear implants in children are not limited to speech recognition but extend into dramatically improved language learning and language skills." [3] In a recent survey, parents of 176 implanted children perceived that: (1) 44 percent of the children had greater than 70 percent open speech discrimination (using sound alone with no visual clues), (2) 61 percent of the children had greater than 50 percent open speech discrimination, and (3) 84 percent of the children had greater than 40 percent open speech discrimination.[4]

Because cochlear implants have the potential to ameliorate or eliminate ramifications of deafness, they are opposed by Deaf culturists, who view efforts to "cure" deafness or ameliorate its effects as an immoral means of killing Deaf culture.

The theory of Deaf culture is primarily premised on a shared language--American Sign Language (ASL). Individuals who communicate via ASL clearly do speak a different language. American Sign Language is visual rather than spoken, with its own syntax and grammar. ASL is quite different from

signed English, which involves signing each English word as it is spoken, using English grammar and structure. In addition, some members of the Deaf cultural community claim to be part of a separate culture as a result of attending segregated (often residential) schools for Deaf children,[5] or as a result of their participation in Deaf clubs or wholly Deaf environments in which they socialize or work.

According to the leaders of the National Association of the Deaf (NAD), Deaf people like being Deaf, want to be Deaf, and are proud of their Deafness. Deaf culturists claim the right to their own "ethnicity, with [their] own language and culture, the same way that Native Americans or Italians [or blacks] bond together." [6] They claim the right to "personal diversity," which is "something to be cherished rather than fixed and erased." In short, they claim the right to their "birthright of silence."

Many individuals who are deaf, however, do not agree that these facts give rise to a true culture. The now deceased Larry G. Stewart, a leading member of the signing deaf community (a strong proponent and user of sign language), noted that "[D]eaf culture' was not discovered; it was created for political purposes. The term has yet to be satisfactorily defined." [7] Dr. Stewart went on to say that "[i]n the larger sense of world cultures, the meaning of culture is so powerful and complex that to apply it so narrowly to a group of highly diverse deaf American citizens, whose members are as heterogeneous as the general population, simply makes no sense" (p. 129).

Although Deaf culturists equate being deaf to being a member of a racial or tribal minority, many deaf people find the analogy nonsensical. Deaf people lack one of the five critical senses. True deaf people such as this author are physically incapable of talking on the telephone alone. We have to use the phone with the aid of a third party--an interpreter or a relay service, both of which present extremely awkward situations. Most of us would love to be able to pick up the telephone and make a personal or business call when and how we feel like it without having to scramble to find an interpreter and without having to make the call with a third person privy to every word. We'd like to be able to go to a movie or a play regardless of whether captioning or interpreters are available. We'd like to be able to participate in group conversations, to hear the conversation at the dinner table. We'd like to be able to hear music; to hear our children and grandchildren laugh and cry; to listen to the radio when we are driving; to have a car phone; to be able to use the drive-up window at McDonald's; to hear the announcements at the airport; to be able to talk to the person in front of or behind us on a hiking trail; to be able to go to a professional meeting on the spur of the moment; to be able to get any job we want without having to consider how our deafness will interfere with the job duties. We'd particularly like to hear our own voices and to be able to control the tone and pitch and loudness of our voices. The list is endless. Why would any human being want to deny such pleasures to herself or her children?

Many members of the Deaf cultural community strongly desire to have Deaf children, who will be a part of their parents' Deaf culture. Some expectant Deaf parents visit geneticists for the purpose of determining whether their children are likely to be born deaf. As explained by Jamie Israel, a genetic counselor at Gallaudet University's genetic services center, "[m]any of our [Deaf] families are not interested in fixing or curing deaf genes . . . [m]any... couples come in and want... [D]eaf children." [8] If their children are not likely to be born deaf, Deaf parents may choose not to have children, or to abort children in gestation, just as hearing or deaf people who determine through genetic research that their children are likely to be born deaf may choose not to have children or to abort children in gestation.

The desire of parents to have children who will be like them and fit into their world is certainly understandable. But most parents want more for their children than they have. While this author's parents, for example, never went to college, they wanted all their children to have that opportunity. Similarly, although we cannot hear, most people who are deaf want our children and grandchildren to have that ability.

Dena S. Davis notes that "the primary argument against deliberately seeking to produce deaf children is that it violates the child's own autonomy and

narrows the scope of her choices when she grows up; in other words, it violates her right to an `open future.'"[9] Insisting that children who are deaf be raised in a Deaf cultural community denies these children the right to choose for themselves whether to accept or reject the larger hearing world.

Deaf culturists argue that parents should not make decisions about cochlear implants for their deaf children, that the children should be allowed to make such decisions for themselves when they are old enough to do so. However, experience has proven that early implantation is necessary for maximum efficacy of a cochlear implant. Thus, waiting ten or fifteen years to make the decision for a child to have a cochlear implant is the same as deciding that the child will not have an implant. If a child who is deaf is going to learn to talk, he or she must begin learning at a very early age. A person who is deaf does not learn to speak at the age of twelve or older, the age at which the child is arguably old enough to decide for herself how she wants to live her life. But a child who is deaf who learns to speak and is part of the hearing world during childhood can learn to sign later in life and join the Deaf world.

Many of the leaders of the Deaf culture movement can speak, as a result of early oral training (or in a few cases because they became deaf later in life), and the majority of those leaders know perfect English--although they know ASL as well. Indeed, it is their oral skills that have enabled them to argue for Deaf isolationism so persuasively. Many of these leaders of Deaf culture, however, do not want today's deaf children to learn spoken English. Rather, they believe that spoken English should be rejected by Deaf people, and that Deaf people should use only ASL as their mode of "spoken" (actually signed) language. This is known as the "bi-bi," or "bilingual-bicultural" approach.[10] Under this approach, Deaf children are to learn ASL only, and not spoken or signed English. Bi-bi advocates believe that children who are deaf should be taught their "natural language" of ASL, which they consider to be the "birthright of all deaf children" (p. 60). Their rationale is expressed as follows:

Natural sign not only serves deaf
children as a means of communication
between other sign language
users but can support intellectual
development and the acquisition
of ideas in the same way
that spoken language serves hearing
people. It is, therefore, a folly,
say bilingualists, to create an artificial
sign system, such as SE

[signed English] when a bona

fide sign language already exists. It

is not only a folly but, say most

supporters of bilingualism, a

moral crime to attempt to force

young deaf children to do something

they cannot do, that is, learn

spoken language as a first language

.... (p. 63)

The contention on the part of the Deaf culture movement that children who are deaf are unable to "learn spoken language as a first language" is, of course, belied by the thousands of deaf children, including this author, who have learned spoken language as a first (and in many cases only) language. Nevertheless, advocates of biculturalism espouse the view that once a child who is deaf has acquired a strong "natural" language (ASL), the child can then be taught written (but not spoken) English as a second language. What biculturists do not explain, at least in any satisfactory manner, is why even if one accepts the proposition that sign language is more natural to deaf children than speech, learning ASL is more "natural" than learning signed English. Nor do biculturists explain why a child who is deaf should have to struggle with learning to read and write English as a second language, when even if the child is taught to sign only, it would be so much easier for the child to learn and sign English, and then apply those English signing skills when learning how to read and write.

The leaders of Deaf culture who espouse the most radical interpretation of the "bi-bi" movement and want to deny children who are deaf both spoken and signed English, would deny deaf children the very skills that allow many of the Deaf culture leaders to perform successfully in this hearing world. One oral deaf leader, Kevin Nolan, noted that "nearly all" the Deaf culture leaders he knows "have had the benefit of early oral education." [11] Mr. Nolan asks:

Why should they deny children

who are deaf the opportunity to

realize the same oral successes that

they themselves have experienced?

. . . Having benefited from oral

education in their own childhoods,

why do they . . . deny their oral

backgrounds--those very backgrounds

that helped them to become

the leaders that they are

today? (p. T3)

When this author and many of the leaders of the Deaf culture movement were growing up, technology was very limited. Most people of our generation (born at least between 1940 and 1960) who are profoundly deaf were not able to obtain much, if any, benefit from hearing aids. (This author, for example, has never been able to wear a hearing aid.) The times have changed, drastically! Technology has vastly improved. Today's deaf children are able to wear much-improved hearing aids or to have cochlear implants. And the technology is still improving rapidly. It is very likely that in ten to fifteen years, perhaps less, cochlear implants will have improved to the point where almost all children who are deaf could benefit very substantially from an implant.

Deaf culture advocates, however, are strongly opposed to research geared at "curing" deafness and are particularly opposed to placing cochlear implants in children. They assert that members of their minority group "are in no more need of a cure for their condition than are Haitians or Hispanics." [12] To many members of the Deaf cultural community, cochlear implants represent "the ultimate denial of deafness, the ultimate refusal to let deaf children be Deaf" (p. 40). As stated by Roz Rosen, former president of NAD, since "[h]earing is not a life or death matter... [it is] consequently not worth the medical, moral and ethical risk of altering a child." [13] In accord with this reasoning, Deaf culturists have strongly criticized the National Institute of Health's National Institute on Deafness and Other Communication Disorders, which gives federal grants for research geared at the prevention and treatment of deafness and other communication disorders. [14]

Gallaudet students and their families or friends have informed this author that cochlear implants are greatly frowned upon at Gallaudet, and that implanted individuals who attend Gallaudet are usually pressured (often by their peers rather than by staff or faculty members) to remove them or at least not to wear their processors. As one reporter succinctly stated:

As anyone at Gallaudet knows, a

student with a [cochlear implant]

device . . . runs the risk of being
shunned. "I have some friends
with implants," says Scott Mohan,
a sixth generation deaf senior at
Gallaudet. "They just don't use
them anymore."
"You can understand why," says
Keith Muller, Executive Director
of the League for the Hard of
Hearing in New York City. "Kids
who try to speak in deaf schools
are ridiculed. And the greater their
oral success, the more they are
criticized." [15]

The hatred with which Deaf culturists view cochlear implants is expressed in the ASL sign for a cochlear implant, which contains a two-fingered stab to the back of the neck, indicating a "vampire" in the cochlea.

One individual seeking information about cochlear implants sent a list of questions to selected cochlear implant recipients and parents of children with cochlear implants. [16] Questions asked included the following:

- 1) Do you think that having a
cochlear implant takes away your

Deaf pride?

2) Do you think that cochlear implants

remove you as a member of

Deaf culture?

3) Do you think that cochlear implants

are a way for hearing people

to break down Deaf society?

4) Do you think that a person

should be allowed to choose

whether or not to have a cochlear

implant or should it be left up to

the parents to decide? (Take into

consideration that the longer you

wait, the less likely it is that [the

implant] will work).

At least several recipients of that questionnaire were angered by these questions. The responses of three individuals are illustrative.

To the question about whether cochlear implants take away "your Deaf pride," one respondent, Bill Boyle, noted, "... what the hell is deaf pride? Proud not to hear your child's voice, pianos, the birds in the trees? That's not pride, it's bull-headedness and selfishness I feel the implant enhances my pride. I am proud to be overcoming what was considered a severe handicap, proud to be part of the community as a whole, not to a `club' of narrow minded people." [17]

To the question about whether cochlear implants "remove you as a member of Deaf culture," another recipient, Melissa Chaikof, responded:

If the cochlear implant has removed

my daughters from "[D]eaf

culture," and it probably has, then

that is fine by me. The [D]eaf culturists

opportunities in life are so

limited, and my daughters' are

not. Furthermore, it has been the

choice of those in the "[D]eaf culture"

to exclude those with implants

from their group[18]

To the question about whether cochlear implants are a way for hearing people to break down Deaf society, Ms. Chaikof stated: "In obtaining implants for our daughter, we did not have the ulterior motive of `breaking down Deaf society.' If that is an indirect result... [m]y concern for my daughters' futures is far greater than for the future of `Deaf society.'"

The three respondents replied to the question about whether a person should be allowed to choose whether to have a cochlear implant or whether parents should make that decision as follows:

(i) Mildred Oberkotter replied:

"for young children, it is essential

that parents choose what is best

for their child's interest and [the

child's ability to] function in

his/her culture in which s/he is
born. So much time and possible
maximum value would be lost in
language and auditory development
if and when the child is cognitively
ready to make such a decision
for him/herself." [19]

(ii) Melissa Chaikof replied: "I
absolutely think that the decision
as to whether or not to implant
should be in the hands of the parents
. . . and the implant team.

Some children and some families
make better candidates. For example,
one implant team here will
not implant children in total communication
[sign and some speech]
or manual [sign language only]

programs . . . [T]he kids whose

parents are committed to an auditory-verbal

approach [learning to

listen], as we are, stand a very high

chance of success."

(iii) Bill Boyle replied: "If this

[question] is about children, it is

an enormous responsibility for the

parents to decide. But--it is a decision

[for] the parents who truly

believe that their decision will be

in the best interest of their child,

and not a decision [for] NAD or

others to decide. Yes, the longer

you wait, the less benefit, so leave

the parents alone and let them

decide"

While vehemently proclaiming the right to preserve their Deaf cultural heritage and denouncing those who choose to alleviate--to the maximum extent possible--their deafness or their childrens' deafness, members of the Deaf cultural community are strong activists for the promulgation of laws protecting persons with disabilities, such as the Americans with Disabilities Act. They vigorously advocate for the provision of special services to alleviate the effects of deafness. The Deaf cultural community, for example, is opposed to educating children who are deaf in mainstream classrooms but insists that

such children should be placed in segregated schools for the Deaf so that they may become full-fledged members of the Deaf cultural society.

The costs of special schools for children who are deaf are high. One study estimated that the yearly cost of educating one child in a residential school for the deaf is \$35,780 and educating one child in a self-contained class for the deaf (in a public school) is \$9,689, compared to only \$3,383 to educate the same child in a regular classroom.[20] The fiscal year 1997 budget for the Phoenix Day School for the Deaf in Phoenix, Arizona (a nonresidential school), for example, was nearly \$5.8 million to educate approximately 230 children. Special colleges for deaf students are equally expensive. The 1995 federal budget for Gallaudet University's college programs for deaf students was \$54.2 million; the 1995 federal budget for college programs for deaf students at the National Technical Institute for the Deaf in Rochester, New York was \$42.7 million.

Other services to alleviate the effects of deafness are also costly, such as relay services mandated by ADA Title IV. In 1995, the Arizona relay service, a relatively small service, employed approximately 140 to 160 relay operators--plus administrative and technical personnel--and processed approximately 60,000 calls per month. The cost for this service to Arizona telephone users was approximately \$300,000 per month, or \$3.6 million per year, not to mention the expenditure of hundreds of thousands of dollars to purchase the necessary equipment for the service to operate.

Other examples include the costs of interpreters and captioning. Interpreter fees for deaf people range from \$20 to \$40 per hour in most cities (more in some), and almost all interpreting agencies require payment of at least a two-hour minimum fee. In some cases, interpreters will be paid for a half day's work even when only one hour or less of the interpreter's time is required. Further, most interpreting agencies insist that two interpreters be hired to interpret for any period longer than one hour, or in some cases two hours, due to the need for the interpreters to switch off every twenty minutes. Real-time captioning may be even more expensive. The average cost of a real-time stenographer ranges between \$40 and \$100 per hour, assuming the reporter provides his or her own equipment.

It is estimated that deafness costs society "\$2.5 billion per year in lost workforce productivity; \$121.8 billion in the cost of education; and more than \$2 billion annually for the cost of equal access, Social Security Disability Income, Medicare, and other entitlements of the disabled." [21]

All of these expenditures are necessary today to allow many persons who are deaf to take their rightful place in society. Currently, therefore, the majority of Americans, including our representatives in Congress, rightfully endorse these expenditures. But the right of deaf persons to receive costly assistance is not unlimited. While society has moral and ethical obligations to persons who are deaf, people who are deaf also have moral and ethical obligations to society: with rights come responsibilities. To fulfill their obligations and responsibilities, people who are deaf should support, rather than protest, research to ameliorate or eliminate deafness, and agree to accept full responsibility for the ramifications of chosen deafness or the refusal to take reasonable steps to modify the ramifications of their deafness.

When most deafness becomes correctable, which for many people has already occurred and for others may well happen in the near future, an individual who chooses not to correct his or her deafness (or the deafness of his or her child) will lack the moral right to demand that others pay for costly accommodations to compensate for the lack of hearing of that individual (or his or her child). In this age of budget crises and cries for tax reform, when there is talk of, and some action with respect to, the need to cut funding for welfare, Medicaid, Social Security, federally supported food banks, and other social welfare programs, it is unrealistic, at best, to expect society to fund expenditures that could be eliminated. At worst, such an egocentric approach appears to give credence to Philip Howard's *Death of Common Sense*. [22]

A primary criticism of this approach is that it leads to a slippery

slope. If we force people who are deaf either to correct their deafness to the extent possible or to forgo public and private benefits, what else will we force people to do in the name of common sense? If prospective parents choose to bear a child whom they know will be born deaf, will we label that as a form of willful deafness and deny the child accommodations? While recognizing the slippery slope, this author believes that lines can be drawn. Forcing a person to choose between surgery and accommodations, for example, is not analogous to forcing parents to choose between abortion and the right of their deaf children to receive appropriate accommodations. Abortion is the prevention of life; surgery is not, despite the contention that it will lead to the end of Deaf cultural life.

Another criticism of this argument is that no individual should be required to have surgery or any other invasive bodily procedure. In response to the irrefutable fact that every person always has the right to refuse any treatment, Deaf culturists assert that a person who is deaf will be given no real choice because accommodations for deafness will not be available as a result of that choice.

In our society, however, individuals are always obligated to assume responsibility for their choices. In the legal context, for example, one who suffers physical injury due to the negligence of another may sue the negligent actor for damages, but recovery for permanent injury is not permissible if the injury could be eliminated by reasonable measures.[23] As one court stated, it is "well established that the plaintiff in a personal injury case cannot claim damages for what would otherwise be a permanent injury if the permanency of the injury could have been avoided by submitting to treatment by a physician, including possible surgery, when a reasonable person would do so under the same circumstances." [24]

Whether submitting to surgery is a "reasonable measure" depends on the circumstances. We must look to the risk of the surgery, the pain involved, the probability of the surgery having successful results, the cost of the surgery, and the amount of effort to be expended by the person having the surgery to obtain successful results.[25] Then we must weigh those considerations against the consequences of not having the surgery.[26]

When cochlear implants have a high probability of significant success for all deaf people who are candidates for an implant, a court would be likely to hold that an individual who became deaf due to the fault (tort) of another (a tortfeasor) could not recover from the tortfeasor for a permanent injury (permanent deafness) if that individual refuses cochlear implant surgery. The deafened individual could not be required to have surgery, of course. Similarly, an injured person who refuses possible surgery due to religious or other personal reasons cannot be compelled to have surgery. Having made that choice due to religious or personal reasons, however, an individual can not usually recover damages for the now permanent injury, despite the fact that, absent the tortfeasor's negligence, the injury would not have existed. A similar reasonable principle may apply with respect to people who choose to remain deaf when a choice is possible, or who choose not to alleviate many of the ramifications of their deafness.

Currently, the Americans with Disabilities Act (ADA) and other laws preventing discrimination on the basis of disability[27] do not provide that people with "voluntary" disabilities are not protected by those laws, nor, for the most part, have the laws been interpreted in such a manner.[28] We do not look to "how" an individual became disabled when deciding whether society will assist that individual to prevent discrimination. How an individual became disabled, however, is different from asking whether an individual has taken--or will take--all reasonable efforts to eliminate or mitigate the effects of that disability.

In the not so distant future, courts may begin to decline to apply disability antidiscrimination laws to individuals who refuse to take reasonable efforts--including surgery--to eliminate, or at least minimize, the effects of their disabilities. This is particularly true when disabilities such as blindness or deafness are at issue, because it is difficult and expensive to provide accommodations for individuals with such disabilities. But the same concept should

apply to all disabilities. By way of example, if a person with manic depression refuses to take medication that would alleviate the symptoms of that disability (medication that meets the test of reasonableness), should an employer be expected to provide that individual with flexible and shorter work hours, release from certain job duties, or other accommodations to his or her chosen manic depression? Not in the opinion of this author.

Today, there is a tremendous backlash against laws such as the ADA. Some members of society, particularly the business sector, view the ADA as providing "special benefits" to people with disabilities;[29] those individuals and entities do not understand that the ADA is intended simply to level the playing field for people with disabilities, to allow them the opportunity to take part in mainstream society. The ADA does not provide "special benefits" for people with disabilities. For example, providing an interpreter or a special typewriter telephone (and a relay service) for an employee who is deaf is not a "special benefit;" rather it is an accommodation (that must be provided only when it is reasonable for the employer to do so) to allow the deaf person to take part in the work force to the same extent that a hearing person is already able to do so (without accommodation).

The United Kingdom's recently enacted Disability Discrimination Act of 1995 (DDA) already recognizes this concept to some degree. Under the U.K.'s DDA, an individual is deemed to be disabled, even if the disability is controllable by medication or other medical treatment, if the disability would have a substantial effect on the individual's ability to carry out normal day-to-day activities without the medication or medical treatment. Practical exceptions are noted, however.

For example, this rule does not extend

to those with impaired sight

where the impairment is correctable

by spectacles or contact

lenses or by some other prescribed

method, whether or not those aids

are in fact used. This exception reflects

the fact that the correction of

impaired sight by spectacles and

contact lenses is usually so effective

that "people who wear spectacles

or contact lenses would not

generally think of themselves as

disabled."[30] (emphasis added)

The U.K.'S DDA provides that the Secretary of State may issue regulations making other exceptions (in addition to the exception dealing with certain vision impairments) to the rule dealing with disabilities and corrective medical treatment. The DDA's annotations offer one illustration of such a regulation that might be enacted:

For example, at the moment, people

wearing hearing aids will be

covered by the definition because

hearing aids usually provide only a

partial correction of a disability.

Those people are still usually, and

should be, seen as disabled. But if

at some future date, as a result of

improved technology, hearing aids

became as completely effective as

spectacles or contact lenses are

today, it might be appropriate to

exclude people in that situation

from the general definition of disability.

(pp. 50-8,9)

The United States Equal Employment Opportunity Commission (EEOC), which is responsible for enforcing the employment section (Title I) of the ADA, also takes the position that the determination whether an individual's physical or mental impairment "substantially limits a major life activity" (as required to fall within the definition of a person with a disability under the ADA) should be made without considering the effects of medical treatment on the individual.[31] The EEOC has not noted exceptions to that rule, as has the U.K.'s DDA. Nevertheless, even absent such exceptions, several courts have disagreed with the EEOC, and have refused, for practical reasons, to hold that a physical impairment that is correctable by medical treatment constitutes a disability under ADA Title I.

For example, the EEOC's regulations state that an insulin-dependent diabetic is disabled for ADA Title I purposes if the only way the individual can perform major life activities is with the aid of insulin (without insulin the individual would lapse into a coma). In *Coghlan v. H. J. Deinz Co.* the court disagreed with that reasoning, holding that the EEOC's interpretation contradicts the express language of the ADA, because "an insulin-dependent diabetic who takes insulin could perform major life activities would therefore not be substantially limited" in the ability to perform such activities, and is therefore not disabled within the meaning of Title I of the ADA.[32]

Other courts have also disagreed with the EEOC's reasoning. These courts seem troubled by the need to give special protection to individuals whose physical or mental impairments (otherwise considered disabilities) are completely correctable, even though in the cases cited the plaintiffs were receiving appropriate medical treatment and were not seeking accommodations for problems alleviated by such medical treatment. Indeed, in at least one case a court held that an individual who refused to submit to surgery that would have remedied a physical impairment could not claim protection under ADA Title I. In *Pangalos v. Prudential Insurance* the court held that an individual's severe ulcerative colitis did not constitute a covered disability under the ADA because it could have been remedied by a colostomy, a surgical procedure the individual refused to have.[33]

It seems likely that in the future more courts will hold that the law does not require that an individual with a physical impairment be provided with accommodations which would not be necessary if the individual would obtain reasonable medical treatment that would obviate the need for such accommodations. If courts routinely accept an individual's refusal of reasonable medical treatment, and require the provision of accommodations to level the playing field for that individual, the social and political mood and climate with respect to laws such as the ADA is likely to deteriorate. Members of the public, including politicians, are likely to ask: why should the public and private sectors be required to spend money to provide accommodations for a person whose disability is correctable, when correcting the disability would in itself help to level the playing field for that person?

This is not to say, however, that people who are deaf and have cochlear implants, or other people with disabilities who accept mitigating medical intervention, should not be protected in any fashion by laws such as the ADA. This author agrees that such individuals may still be illegally discriminated against. Suppose, for example, that an employer refused to hire a deaf person simply because that person was deaf and had a cochlear implant. Such conduct should be held to violate the ADA. This type of situation is quite different from requiring the provision of costly accommodations that would not be necessary if reasonable medical intervention was accepted. It is crucial that we distinguish between the two types of situations.

Moreover, the argument that those who refuse cochlear implants for themselves or their children should not demand costly accommodations necessitated by deafness has validity only to the extent that cochlear implants are financially accessible. Cochlear implants themselves are not inexpensive--it is estimated that in the United States the cost of an implant, including necessary rehabilitation and training, approximates \$40,000. Presently, most (but not all) insurance companies cover the bulk of this cost;[34] in other circumstances state-funded medical programs for low-income families or individuals

cover the cost; in still other circumstances organizations such as HEAR in Denver have donated or obtained funds to cover the costs of cochlear implants. To the extent that an implant is not available due to financial constraints, an individual has not made a choice to remain deaf (or to have her child remain deaf) and may yet demand accommodations for her (or her child's) deafness. It makes a lot more sense for society to be required to fund cochlear implants to eradicate the effects of deafness, however, than for society to be required to fund the never-ending costs associated with uncorrected lifelong deafness.

Cochlear implants do not, and likely will not, eliminate deafness altogether. An individual who has an implant is still deaf. The difference is, however, that the ramifications of deafness are significantly reduced. At the present time, it is known that most children, and people who become deaf later in life and have memory of normal hearing, do very well with cochlear implants, thus reducing (if not eliminating) the need for special schools, interpreters, and other costly accommodations. Such individuals who refuse today to have cochlear implants, yet demand costly accommodations, should, in this author's opinion, be viewed as acting unethically.

In spite of all that is said above, it is impossible not to recognize the source and validity of the anger, hostility, and solidarity expressed by the Deaf culturists who choose to reject hearing society and who do not wish to be "hearing" to any degree. Any individual with any compassion who knows anything of the history of people who are deaf must understand how the concept of Deaf culture came into existence. Many people who are deaf continue to live as second class citizens, as indicated not only by the rejection of deaf people by most hearing people but by the facts that:

The average deaf person today

reads at a fourth grade level. One

in three drops out of high school.

Only one in five who starts college

gets a degree. Deaf adults make 30

percent less than the general population.

Their unemployment rate

is high, and when they are employed,

it is usually in manual jobs

such as kitchen workers, janitors,

machine operators, tailors and carpenters,

for which a strong command

of English is not required ...[35]

Rejecting hearing society, technology that will alleviate the ramifications of deafness, and the potential eradication of most deafness, however, is not the solution to the problems of deaf people. Rather, deaf people with cochlear implants, particularly children, have a wealth of opportunities and potential life experiences available to them. To deny such opportunities based on theories of segregation is indeed illogical.

References

- [1.] For an article explaining the viewpoint of Deaf culture, see Edward Dolnick, "Deafness as Culture," *Atlantic* 272, no. 3 (1993): 37-53.
- [2.] See, for example, Susan B. Waltzman, Noel L. Cohen, Railey H. Gomolin, Janet. E. Green, William H. Shapiro et al., "Open-Set Speech Perception in Congenitally Deaf Children Using Cochlear Implants," *American Journal of Otology* 18, no. 3 (1997): 342-49; "Progress Report, Outcomes for Paediatric Cochlear Implantation in Nottingham: Safe Effective--Efficient," Nottingham Paediatric Cochlear Programme, University Hospital NHS Trust, Queens Medical Centre, Nottingham, England (May 1997); T. A. Zwolan, P. R. Kileny, S. A. Telian, "Self-Report of Cochlear Implant Use and Satisfaction by Prelingually Deafened Adults," *Ear & Hearing* 17, no. 3 (1996): 198-210; Amy M. Robbins, "Implanted Children Can Speak, But Can They Communicate?" Paper Presented at the Sixth Symposium on Cochlear Implants in Children, University of Miami School of Medicine, Miami, Florida, February 1996; N. M. Young, J. C. Johnson, M. B. Mets, T. C. Hain, "Cochlear Implants in Young Children with Usher's Syndrome," *Annals of Otology Rhinology & Laryngology Suppl.* 166, No. 9, Part 2 (1995): 342-45; Anne E. Geers and Jean S. Moog, eds., "Effectiveness of Cochlear Implants and Tactile Aids for Deaf Children: The Sensory Aids Study at Central Institute for the Deaf," *The Volta Review* 96, no. 5 (1994).
- [3.] Report of Dr. Robert E Naunton, Director, Division of Human Communications, National Institute of Deafness and Other Communication Disorders, 7 May 1998 (in the author's files).
- [4.] Bonnie E Tucker, *Cochlear Implants: A Handbook* (Jefferson, N.C.: McFarland & Co., 1998, forthcoming).
- [5.] The vast majority of deaf children in the United States no longer attend such schools; the Individuals with Disabilities Education Act--enacted in 1973 for the purpose of providing children with disabilities with a free appropriate public education, primarily alongside children without disabilities has resulted in sharp declines in special school enrollments. See, for example, Felicity Barringer, "Pride in a Soundless World: Deaf Oppose a Hearing Aid," *New York Times*, 16 May 1993.
- [6.] Roslyn Rosen, "President Rosen on Cochlear Implants," *NAD Broadcaster*, December 1992, p. 6; see also, "The President Signs On," *NAD Broadcaster*, January 1991, p. 3.
- [7.] Larry G. Stewart, "Debunking the Bilingual/Bicultural Snow Job in the American Deaf Community," *A Deaf American Monograph* 42 (1992): 129-42.

- [8.] Abigail Trafford, "The Brave New World of Genetic Planning," Washington Post, 15 November 1994.
- [9.] Dena S. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," Hastings Center Report 27, no. 2 (1997): 715, at9.
- [10.] See, for example, Wendy Lynas, Communication Options in the Education of Deaf Children (London: Whurr Publishers, 1994).
- [11.] Kevin Nolan, "Communication Chores: A Parent's Perspective," Clarke Speaks (Winter/Spring 1997): T3.
- [12.] Dolnick, "Deafness as Culture," p. 37.
- [13.] Rosen, "President Rosen on Cochlear Implants."
- [14.] The author is a member of the National Advisory Council to the National Institute on Deafness and Other Communication Disorders and has personal knowledge of such criticism.
- [15.] M. Arana Ward, "As Technology Advances, A Bitter Debate Divides the Deaf," Washington Post, 11 May 1997.
- [16.] E-mail by Kate T. Kubey of November 1996, submitted to the author by Mildred Oberkotter and Melissa K. Chaikof (in the author's files).
- [17.] Response of Bill Boyle (in the author's files).
- [18.] Response of Melissa K. Chaikof (in the author's files).
- [19.] Response of Mildred Oberkotter (in the author's files).
- [20.] Jean L. Johnson, Gary W. Mauk, Kristine M. Takekawa, Peter R. Simon et al., "Implementing a Statewide System of Services for Infants and Toddlers with Hearing Disabilities," Seminars in Hearing 14 (1993): 105-18, at 117.
- [21.] Thomas Balkany, Annelle V. Hodges, and Kenneth W. Goodman, "Ethics of Cochlear Implantation in Young Children," Journal of Otolaryngology--Head and Neck Surgery 114, no. 6 (1995): 748-55, at 748.
- [22.] Philip Howard, The Death of Common Sense (New York: Random House, 1994).
- [23.] For a discussion of this issue, See Lisa E. Key, "Voluntary Disabilities and the ADA: A Reasonable Interpretation of `Reasonable Accommodations,'" Hastings Law Journal 48 (1996): 75-104.
- [24.] Zimmerman v. Ausland, 513 P. 2d (Or. 1973), 1167, 1169 at 1169.

[25.] Zimmerman, p. 1170; Lucas v. Deville, 385 So. 2d 804, 815 (La. Ct. App. 1979); D. Dobbs, Law of Remedies (St. Paul, Minn.: West Publishing, 1993), pp. 272-73; Key, "Voluntary Disabilities," p. 99.

[26.] Lucas v. Deville, at 815, note 31; Key, "Voluntary Disabilities."

[27.] Some other laws protecting individuals with disabilities from discrimination include the Rehabilitation Act of 1973 the Fair Housing Act Amendments of 1998, the Individuals with Disabilities Education Act, and the Air Carriers Access Act.

[28.] See, for example, Key, "Voluntary Disabilities."

[29.] See, for example, George Will, "Disabilities Act May End Up Granting Special Rights to Jerks," Idaho Statesman, 4 April 1996.

[30.] 1995 c. 50 (United Kingdom), p. 50-8.

[31.] 29 C.ER. app. 1630.2(h). Several courts have followed the EEOC's reasoning. See, for example, Harris v. H & W Contracting Co., 102 F.3d 516, 521 (11th Cir. 1996); Houlihan v. Lucky Stores, Inc., 87 F.3d 362, 366 (9th Cir. 1996); Roth v. Lutheran General Hospital, 57 F.3d 1446, 1454 (7th Cir. 1995); Wilson v. Pennsylvania State Police Department, 6 A.D. Cas. (BNA) 1125 (E.D. Pa. 1997); Sackett v. WPNT, Inc., 4 A.D. Cas. (BNA) 1597, 1600 (W.D. Pa. 1995); Canon v. Clark, 883 E Supp. 718, 721 (S.D. Fla. 1995); Sarsycki v. United Parcel Service, 862 E Supp. 336, 340 (W.D. Okla. 1994).

[32.] Coghlan v. H. J. Deinz Co., 851 E Supp. 808 (N.D. Tex. 1994), p. 813.

[33.] Pangalos v. Prudential Insurance, 5 A.D. Cases (BNA) 1825 (E.D. Pa. October 15, 1996), aff'd, 118 F.3d 1577 (3d Cir. 1997).

[34.] For an article explaining that an insurer's refusal to cover the cost of a cochlear implant and related training will, in many circumstances, violate the Americans with Disabilities Act, see Bonnie P. Tucker, "Insurance and the ADA," DePaul Law Review 46, no. 4 (1997): 915-45.

[35.] Ward, "As Technology Advances."

Bonnie Poitras Tucker, "Deaf Culture, Cochlear Implants, and Elective Disability," Hastings Center Report 28, no. 4 (1998):6-14.

Gale Document Number:A21195461

Disclaimer: This information is not a tool for self-diagnosis or a substitute for professional care.