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Cochlear Implants in Children: Ethics, Informed Consent, and Parental Decision Making

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The purpose of this article is to examine the process of informed consent surrounding the complex issues of ethics, advocacy, and audiology that arise as a consequence of state-mandated universal newborn hearing screening (UNHS)[1] and the technological progress that encourages increasingly earlier cochlear implantation (CI). Earlier identification of deafness[2] in infants compresses the decision-making process for parents and professionals. Most states have an "opt-out," not an "opt-in," UNHS policy: although parents have the final say, states may structure the decision to encourage screening by requiring parents to sign a waiver of liability should they choose not to have their child screened. In this atmosphere, parents may feel an urgency to act. Thus, the process of informed consent and the content that it includes become even more important in sound decision making and make such sound decisions even more difficult to achieve. Who presents the information; what is told, how, when, and where it is presented, after the parents have been told the screening results, all affect the parents' decision.[2]

The process of informed consent can provide a realistic and objective framework to make an informed decision about surgical intervention for a D/deaf child.[3] That process acknowledges the bias of a medical setting as well as prevailing social policy, that is, a bias toward oralism.[4] Within this process of informed consent, the personal and cultural values of the parent(s) are privileged,[5] and the values and beliefs of medical professionals, while clearly affirmed, are weighed as one of many factors influencing the parents' decision. Informed consent thus becomes a dynamic and evolving process — a means of addressing all of the relevant (medical, educational, psychological, social, economic, and cultural) issues and resolving them in the best interest of that particular family.[6]

UNHS AND PARENTAL DECISION MAKING

With the advent of UNHS, data on the prevalence of newborn deafness is now more accurately collected. Early reporting estimates based on data collected at the state level indicate that the prevalence of newborn deafness is approximately two to three per 1,000 live births in the newborn nursery and two to five per 100 infants in the neonatal intensive care unit (NICU).[7] It is estimated that each year approximately 5,000 infants born in the United States have permanent moderate-to-profound deafness and possibly an additional 7,000 infants are born with mild permanent deafness.[8]

UNHS has changed the trajectory of how parents learn of their child's deafness. Before UNHS, parents were often the first to suspect that their child was D/deaf. For some parents, being the first to suspect their child might be D/deaf helped them to feel they had some control, and, however stressful this was, it could be empowering. This knowledge of their child was important and useful — and this parental knowledge was validated by medical tests. This was not to negate the anger that existed when professionals had not been listening, but to emphasize the importance of the parent-child bond.

With UNHS, medical professionals are now the first to suspect deafness immediately after birth, which medicalizes the condition of a newborn and places expertise about the child in the hands of professionals.[9] The disclosure of screening results occurs at a time when new parents are particularly vulnerable, and the disclosure takes place in a medical setting that quickly sets in motion a number of medically related activities: to confirm and evaluate the child's deafness and to begin educational therapy with early intervention (EI) programs. This activity compresses the events of birth, the creation of a new family, and then the diagnosis — generally unexpected — and may create pressure to take action. This is not an environment that fosters deliberate and informed decision making. Realistically, a decision concerning CI need not be hurried at all. If the process of fully informing parents begins at birth, and parents are advised that they have much to learn but plenty of time to be educated, they can begin to sort out their priorities and values before weighing the benefits and burdens of CI.

If UNHS indicates a need for further assessment, parents are set on a course that can be completed within four to six months, but may take longer.[10] The process of informed consent must begin and be ongoing during this assessment period and continue past diagnosis and prognosis.

The benefits of UNHS are clear. Before UNHS, the greatest burden was the time interval between parents' suspicion of the deafness and a diagnosis. In that interval, parents could have been learning more about deafness and communication options. Now children who are at risk of any degree of deafness are identified very early, and habilitation through amplification and EI programs is initiated at younger and younger ages, which results in better speech, language, and literacy outcomes.[11] Early intervention programs are of great value, in part because they encourage active, involved parenting from the outset. Amplification through hearing aids, assistive listening devices, or CI makes the auditory signal more accessible, and EI educates parents on how to adapt their play, trust their parental instincts, and emphasize their child's typical development in every other respect.

COCHLEAR IMPLANTS: RISKS, BURDENS, AND BENEFITS

CIs are surgically implanted devices that electrically stimulate auditory nerve fibers located in the cochlea, simulating hearing. They are recommended for use when a child or adult has profound hearing loss or deafness and cannot benefit from conventional amplification (that is, hearing aids). The National Institute on Deafness and other Communication Disorders (NIDCD) reports that, as of the year 2002, nearly 10,000 children have been implanted.[12] As the use of CI has become more widespread, the criteria for use have broadened, including the extent to which the person with deafness can benefit from the use of hearing aids and still be a candidate for surgical implantation. Thus the use of CI in children is increasing.

The Food and Drug Administration (FDA) approved CI devices for children two years of age or older in 1990. In 1998, the FDA approved a CI device for children as young as 18 months. While the FDA has strict

requirements for CI used in young children,[13] changes can be expected as experience increases and technology advances. Recently, children as young as 12 months have been considered candidates, and some centers are testing protocols for infants as young as six months.[14] As well, children with significant residual hearing are now receiving CIs.[15]

CIs are not without surgical and medical risk. An incision is made behind the ear and a mastoidectomy is performed. To thread the electrode array through the cochlea requires drilling into the temporal bone, located in the skull. The internally embedded electrodes are connected to an external speech processor, which converts the auditory signal into an electrical impulse and allows the brain to decode this impulse into the perception of speech.

Surgical complications include infection at the site of the wound and damage to the facial nerve. Damage is more likely to occur when anatomic abnormalities exist. Improper insertion of the electrode array, although rare, requires removal and replacement of the device and another surgical procedure. For children less than 12 months, risk for respiratory failure and bradycardia is increased[16] as are the risks of anesthesia. Increased risk must be carefully weighed and balanced with the additional benefits that earlier implantation may provide.[17]

In addition to these surgical risks, young children are prone to otitis media (OM), which, on occasion, will compromise the integrity of the CI device.[18] Aggressive treatment of OM is now the standard of care for children with CI. The risk of OM in young children is that it can lead to meningitis, a life-threatening disease. As a result of reported cases of meningitis[19] by the three CI manufacturers, the Centers for Disease Control and Prevention (CDC), the FDA, and the health departments of 36 states and three cities conducted a comprehensive study of 4,264 children implanted at under age six between 1997 and 2002. The study found that the incidence of meningitis in children who had a CI was "more than 30 times the incidence in a cohort of the same age in the general United States population."[20] While the incidence was highest among children who were implanted with models using a positioner no longer in use, children without that particular positioner were still at a significantly increased risk. Other findings are cause for concern: the incidence of meningitis increased over the six-year period studied, and younger children were at higher risk.[21]

CI technology, as is now applied, causes a permanent physiological change — destruction of any residual hearing — possibly precluding the application of future technologies. As professionals are well aware, the child becomes dependent on a prosthetic and its associated services, requiring both technological and extensive audiological follow up. Likewise, parents must understand that services to repair or correct complications of the device must be readily available to assure ongoing benefit to the child.

The benefits of implantation for children, despite these medical and technological risks and burdens, are considerable — some would argue overwhelming. Recent studies have shown that implantation before the age of five years has improved long-term speech perception, speech production, language, and literacy development, although the exact age for optimal efficacy in these areas is still being tested.[22] For *oral* speech and language development, current research reports that CI by age two years is even more effective than by age five.[23]

Efficacy, however, is variable, as the outcome is also dependent on factors such as IQ, socioeconomic status (SES), gender, family size, and educational program (that is, auditory-oral, auditory-verbal, total communication, or cued speech).[24] While auditory input, which CIs provide, is felt to be optimal as a precursor to oral language development, some researchers suggest that nonverbal communication, shared experiences, attention, and mutual understanding are equally, if not more, important to the development of speech and language.[25] Research indicates that children with all degrees of deafness who experienced high levels of family involvement and early enrollment in EI score most like their hearing peers on a variety of tests.[26]

This evidence of benefit becomes even more compelling for hearing parents whose children are born with medically diagnosed deafness: 95 percent of D/deaf children are born to hearing parents.[27] For these hearing parents, the diagnosis of infant deafness often is coupled with the desire to "fix" what they see as a physiological defect that prevents their child from fully participating in their hearing family and culture. CI then is seen as the appropriate medical "fix." Indeed, it may even be the parents themselves who introduce CI as a remedy.

To hearing parents the desire to "fix" the deafness of their infant may also lead to unrealistic expectations. Parents often interpret the benefits of a CI as "restoring" hearing or "curing" deafness, thus making their child "normal."[28] The CI does not "cure" deafness, although it allows previously inaudible signals to be audible and increases speech production capabilities. While this may be an expected outcome for most D/deaf children, parents still need to make this decision based on a clear understanding of the multiple factors involved in successful implantation. The pairing of a medical problem with a medical solution (that is, hearing can be repaired through surgery), however, can confound informed parental decision making.[29] Even when balanced information is offered, parents are often still grieving and may not "hear" the burdens of the intervention, only the benefits. In addition (and understandably), otolaryngologists, audiologists, and speech-language pathologists are immersed in the medical diagnosis, amelioration, and habilitation of deafness and advocate for CI — a bias that should be clearly stated, and is an added impetus for making certain that parents have contact with resources that are more neutral and represent other points of view.

CI AND DEAF CULTURE

Deafness is not only an inability to hear, but also considered a culture. The relationship between D/deaf children and D/deaf culture is an issue even for those not born into a D/deaf family. Many individuals who are D/deaf do not view deafness as a defect or disability, but as a difference.[30] They see themselves as belonging to a culture that has its own identity and its own language, American Sign Language (ASL). To this group, an inability to hear is of less significance than this shared culture and language.[31] Much as hearing parents want their D/deaf child to belong to the hearing culture, some D/deaf parents are fearful that CI will exclude their D/deaf child from the D/deaf culture, and, if they never achieve "good speech," will indeed make them feel marginalized and disabled in both the hearing and D/deaf worlds.[32] Irrespective of which culture the child is born into, an understanding of both cultures is essential.

Embracing both cultures, however, requires overcoming a history of antagonism between the two, and a more recent history of conflict concerning CI, a technology that threatens ASL, a foundation of D/deaf culture. The initial hostility to CI felt by some in the D/deaf community is perhaps best illustrated by the ASL sign for CI, which is the sign for a vampire (forefinger and middle finger) thrust at the back of the neck. To those parents and families concerned about maintaining and using the language and culture of the D/deaf, the current practice of foreclosing the option of ASL for the implanted child echoes historical bias and rekindles their anger toward oralism, which stems from the latter half of the nineteenth century, when Victorian culture saw silence as being "prey to the devil" and deafness as a sign of sickness that needed to be cured.[33] The forced oralism of Alexander Graham Bell and the oralist educators left a legacy of suspicion and distrust. Not to be minimized is the perception on the part of the D/deaf culture that oralism was inherently paternalistic: a decision made by the hearing and imposed on the D/deaf. This distrust extends to perceived pressure, this time using CI, to once again move D/deaf children from D/deaf culture into the oral hearing world.

The dilemma of the young implanted child who does not belong to the culture of either the D/deaf or of the hearing, who uses a device that does not "cure" deafness, is not as contentious as it once was. The National Association for the Deaf (NAD), probably the most influential advocacy group for the D/deaf, significantly moderated its vehemently anti-CI position, stated in 1991, in 2000. NAD now acknowledges the heterogeneity of the D/deaf and recognizes CI as an option.[34] Since 2000, Gallaudet University, a university for the D/deaf and hard of hearing as well as the hearing, and a learning environment with a commitment to sign communication, has had a CI Education Center that would have previously been unthinkable.

The perception, however, of deafness as purely a disability persists and needs to be addressed. Critics of D/deaf culture point to the seeming contradiction of accepting as an entitlement the disability benefit provided by Supplemental Security Income (SSI). These critics argue that if the D/deaf consider themselves a cultural group, they should not claim disability benefits.[35] But this challenge is difficult to sustain. While superficially it may appear that the D/deaf community's continued claim to benefits may be paradoxical, this is hardly the first such instance. As with any other culture in this nation of racial, ethnic, and religious

diversity, it is often necessary to provide additional means educationally or financially to enable a culture to work or to be otherwise productive in mainstream society. If the word "disability" were changed to "assistance" to achieve parity in the educational and/or job market, perceptions might change. Or perhaps this would be termed "affirmative action" for the D/deaf, a present-day "boost" to balance the inequities of the past, such as forced oralism in segregated residential schools for D/deaf children.

U.S. society often accepts such paradoxes, indeed it sometimes insists on them, choosing to provide assistance to certain groups who have been vulnerable, dependent, or historically were discriminated against, even when not all members of the group are of equal need or status. Consider that when U.S. citizens turn 65, they are eligible to receive Social Security payments, whether or not they continue to work. Victim assistance and compensation are often available to those who suffer from a particular crime or event, irrespective of their personal assets. These examples abound in American society, where we have learned to take advantage of whatever benefit is available. Finally, these are not issues that should in any way influence an individual decision on whether or not to consider a CI. A CI, in and of itself, does not indicate how an individual child or family identifies itself, which makes these contentions irrelevant. Changing perceptions of deafness as other than a disability remains a challenge, and there are those, including those who are D/deaf, who have argued that society should not support individuals who make decisions, such as rejecting CI for a child, that will impose an economic burden on others.[36]

The role of ASL as a basis of not only communication among the D/deaf but also of D/deaf culture has been the focus of disagreement between the organized D/deaf community, and non-D/deaf medical and therapeutic professionals. Specifically, the practice of recommending that children who have been implanted prelingually (under the age of three) be exposed only to oral English contradicts the evidence that children can learn more than one language, as well as denying the language-learning value of ASL. If there is a strong language base in a home language, children will be able to gain fluency and literacy in a second language, whether it is introduced simultaneously or postlingually when the child enters school or preschool.[37] As Oliver Sacks maintains, "it is *language,* rather than any particular language, that kindles linguistic competence and, with this, intellectual competence too."[38]

What is not known is whether the language skills that are developed through ASL — which is a visual, not a spoken language — as a first language provides the same benefits as oral language. Hearing children of D/deaf parents, for example, are ordinarily fluent in both languages, even though they learn ASL before oral English. It should be noted, however, that these are *hearing* children. Evidence strongly supports the conclusion that D/deaf children in programs that expose them to more auditory stimuli have better speech perception/production abilities than children enrolled in programs that do not have this emphasis.[39] Thus, children exposed to ASL at home would need to be enrolled in auditory programs to gain greater access and fluency in oral language and hearing culture. Early implantation and learning ASL need not be mutually exclusive. Thus it would appear that inclusion of ASL in the decision to implant a young child, and the denial of ASL for D/deaf families who choose to implant a child, is a "red herring" that raises a "red flag."

With the evidence of increasing benefits of CI, parents still must make decisions based on their own evaluation of the best interest of their child. For hearing parents of D/deaf children, decisions about whether to expose their child to D/deaf culture and ASL are more difficult than for D/deaf parents, for this decision imposes an additional burden — learning ASL as another language.

INFORMED CONSENT IN THE BEST INTEREST OF THE CHILD

The decision to implant or not, and, if so, when, is complex. Successful CI requires not only expert medical and audiological services, but also intensive early intervention, appropriate educational placement, and a high level of family involvement. The age of implantation is important, but so are variables beyond the parents' control: SES, IQ, the number of children in the family, and gender.[40]

The ultimate effect of CI on a child as she or he reaches majority and seeks her or his own personal and cultural identity should also not be minimized. The first group of children to receive CI prelingually is now

entering adolescence, a time of emerging autonomy and self-identity.[41] Early evidence suggests that some of these children are turning off their CI, exploring and identifying with D/deaf culture, which is consistent with other adolescent searches for identity.[42] Even past adolescence, D/deaf children with implants may find the need or the desire to use ASL in different circumstances, with D/deaf peers or when auditory signals are not clear.[43]

Advocacy groups as well as individuals often contend that neither a careprovider nor a parent can ethically make a decision about implantation: they do not live with the condition of deafness, and thus cannot make a truly informed decision.[44] The child is the one who will be permanently tethered to a mechanism that requires repair, maintenance, replacement, and upgrading.[45] Reliance on reconstructive and reparative technologies can complicate a child's life, creating a permanent dependence and anxiety that persists throughout life. This dependency is even greater if access to fluency in a signing language is denied. In other words, the benefits and burdens can only be evaluated by the person who bears them.

In the case of CI, parents are urged to make irrevocable decisions when the child has no capacity to weigh-in on the decision. EI in the form of reconstruction can preclude later determination of identity by the individual. For example, intersex advocates argue that early surgical intervention that decides gender assignment are often at odds with the gender identification of the adult based on "the belief that the person with an intersex condition has the right to self-determination where his or her body is concerned. Doing 'normalizing' surgeries early without the individual's consent interferes with that right."[46] Similarly, many D/deaf culture advocates argue that early CI denies D/deaf children full appreciation of the richness of D/deaf language and culture.[47]

The difficult question that this raises is whether a case can be made that the benefits of respecting future emerging autonomy regarding CI outweigh any harm or damage resulting from delayed intervention. Delay in implantation has the disadvantage of significantly impairing the acquisition of good oral language skills. Poor oral language skills then become a handicapping or marginalizing condition, an important negative factor to be considered in whether to delay the decision until the child is able to make the best decision for herself or himself when she or he achieves full autonomy and decision-making capacity. On the other hand, early "reparative" interventions may preclude later technological advances that may prove preferable.[48]

AN INFORMED-CONSENT MODEL FOR CI IN YOUNG CHILDREN

Informed consent involves both content (what is delivered) and process (how, when, where, and who delivers information). On the content side, while parents feel the medical aspects of CI are well presented, the cultural/social aspects of deafness are rarely if ever offered.[49] Second, the medical information that is given should include the current state of research, particularly the uncertainties of practice outcomes and possible future developments. For example, there is little research about whether ASL hinders oral language development. Another example noted by Hyde and Power is that little is known about whether children who have state-of-the-art hearing aids who are given the same intensity of support as children who have been implanted, do as well in oral language skills.[50] Parents are capable of understanding, weighing, and accepting uncertainties when these are presented in a clear and unbiased fashion.

The content of informed consent is also influenced by the process — in short, the how, when, where, and who. Information that is delivered in a medical setting by medical professionals is different than that delivered in a nonmedical environment. Parents who first learn about CI through the medical profession tend to use only medical information as their primary source.[51] In contrast, parents who go to other parents with implanted children tend to use a wider range of both medical and nonmedical sources for information, thus receiving a more balanced perspective.[52] At the same time that EI is explained and initiated, typically within the hospital setting, parents must be urged to step outside the medical model and begin learning about deafness from other sources. This expansion of information and options allows for a more considered and nuanced decision.

Different models have been proposed for how parents should access the information. The typical model used in American practice is that professionals within the medical setting are responsible for linking parents to resources such as organizations for the D/deaf, D/deaf and hearing parents of D/deaf children, parent support groups, and literature that examines the social, economic, and cultural implications of deafness and CIs. An alternative model, and one recommended in Australia by Hyde and Power, proposes "that informed consent be conducted in a non-directional independent counselling context; that is, one that involves removing the service provider from the counselling/advice context."[53] A third "compromise" model that may be more realistic for use in the U.S. is that of a patient advocate/educator who is a part of the medical team who can guide families to outside sources and resources and is available to ask and to answer questions.

The process necessarily includes timing. With screening and early diagnoses, medical professionals may feel the need for immediate action, but parents may not be ready to make such decisions. If decisions are forced, more harm than good can occur.[54] Rather, medical professionals, in collaboration with nonmedical professionals, can help parents start to think about decisions, actions, and their ramifications. Specifically, asking parents early in the diagnostic process what types of information would be most helpful demonstrates respect for their feelings, and a belief that parents are capable of making sound decisions based on their unique family.[55] Parents may request different types of information at different times and in different sequences. Thus, information or access to information can be delivered when a family is most likely to process it best.

As pediatric CI centers move toward earlier implantation, bilateral implantation, and implantation when residual hearing exists, decision making will become even more complicated. The decision may not be whether or not to implant, but rather when to implant, and how to encourage participation in D/deaf culture. For hearing parents with D/deaf children, introducing their child to D/deaf culture is an undertaking similar to parents who have adopted children of a different race, religion, or culture who actively pursue participation in that child's race, religion, or culture.

CONCLUSION

The purpose of this discussion is not to discourage the use of CI, but rather to open and broaden the discourse so that parents, professionals, and the public perceive deafness in a more textured context (see table 1). A rational, well-considered, and truly informed decision is complex: an ongoing process that begins at birth and explores all of the options with their concomitant benefits and burdens. It takes into account such diverse factors as home and community environments, cultural beliefs, EI options, parents' ability to support and manage the technology, medical/audiological data, the additional attention required, and respect for the child's future autonomy and individual choice.

The considerations of the hearing parent may differ decidedly from that of the D/deaf parent. What

Table 1
Components of consent to CI

Parents who are asked to give consent for CI for their child should receive the following information:

- The medical/surgical procedure of CI, its risks and future implications for the child, including loss of residual hearing, possible complications of surgery, and need for access to technological maintenance.
- The benefits and burdens of each of the options; that is: to consent to surgery, delay surgery or reject surgery, including the role of the parent as decision maker.
- A description of the range of outcome possibilities, including the possibility of unsatisfactory result.
- Evidence-based data on language and literacy skill development with or without CI, including data on variables that account for more effective language acquisition, and, in particular, the need for a high level of family involvement.
- Communication options; that is: ASL, oralism, cued speech, or total communication, including options for "bilingualism" or "multilingualism."
- Cultural (D/deaf) identity sensitivity and a familiarity with the D/deaf community.
- Child/adolescent identity development, including considerations of how the emerging autonomy of adolescents can raise questions about agency and the appropriateness of parents as decision makers.

must be kept in mind is the course of action that will allow the child to most closely fit into her or his family unit, community, and, down the line, place in the larger society.[56] These concerns can only be addressed when professionals ask the right questions and listen intently to the responses they get. While a child is being assessed, the concerns of parents and quite possibly the child can and probably will change, and new questions and concerns will emerge. Thus, a recommendation of CI, with its risks and benefits, should be tempered by the values and needs of each family. While the ultimate decision may not be unique, the questions and how they are answered may be. The dynamic nature of the process of informed consent optimally allows the final decision to be made entirely by the parents.

NOTES

1. Currently 38 states and the District of Columbia mandate newborn hearing screening allowing for early identification and habilitation of infants with mild to profound deafness. American Speech-Language-Hearing Association, "Incidence and Prevalence of Hearing Loss and Hearing Aid Use in the United States — 2002 edition, *http://professional.asha.org/resources/factsheets/hearing.cfm,* accessed 25 June 2004.

2. Joint Committee on Infant Hearing (JCIH), American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, Directors Speech and Hearing Programs in State Health and Welfare Agencies, "Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs," *Pediatrics* 106 (2000): 798-817; M. Cunningham, E.O. Cox, and the Committee on Practice and Ambulatory Medicine, the Section on Otolaryngology and Bronchoesophagology, "Hearing Assessment in Infants and Children: Recommendations Beyond Neonatal Screening," *Pediatrics* 111, no. 2 (2003): 436-40; T.N. Kluwin and D.A. Stewart, "Cochlear Implants for Younger Children: A Preliminary Description of the Parental Decision Process and Outcomes," *American Annals of the Deaf* 145, no. 1 (2000): 26-32.

3. *D/deaf* is used as a means to include both those who identify with the D/deaf culture as well as those who do not. The term *deafness* is used to describe any degree of permanent limitation of hearing; modifiers such as "mild," "moderate," "severe," and "profound" are used where appropriate. *Hearing impairment* can be understood to be negative, suggesting an individual's deficit rather than a limited ability to hear. *Hearing loss* is used to mean exactly what the two words say, that is, hearing was lost, for whatever reason. *Prelingual* is used to refer to the convention of considering children under three years old to be "prelingual." It does not mean that children under three do not have language skills.

4. Oralism as used in this article refers to a philosophy in D/deaf education. This philosophy asserts that D/deaf children should be taught oral speech and language through techniques that primarily or exclusively utilize spoken language and speechreading. Oralism does not recognize the value or validity of a visually based or Sign language.

5. For purposes of this discussion, it is assumed that parents have the right to make decisions for their children. As Kopelman points out, "to override parental authority, the state must establish, often by clear and convincing proof, that the child has been harmed or is in danger of suffering serious harm." See L.M. Kopelman, "The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22 (1997): 271-89, p. 272.

6. M. Hyde and D. Power, "Informed Parental Consent for Cochlear Implantation of Young Deaf Children: Social and Other Considerations in the Use of the 'Bionic Ear'," *Australian Journal of Social Issues* 35, no. 2 (2000): 117-27, *http://search.epnet.com,* accessed 7 April 2005.

7. L. Dalzell et al., "New York State Universal Newborn Hearing Screening Demonstration Project: Ages of Hearing Loss Identification, Hearing Aid Fitting, and Enrollment in Early Intervention," *Ear and Hearing* 21, no. 2 (2000): 118-30; National Center on Hearing Assessment and Management, *http://www.infanthearing.org,* accessed 25 June 2004; J.L. Northern and D. Hayes, "Universal Screening for Infant Hearing Impairment: Necessary, Beneficial, and Justifiable," *Audiology Today* 6 (1994): 10-13.

8. National Center on Hearing Assessment and Management, see note 7 above.

9. See note 6 above; G. Valentine and T. Skelton, "Living on the Edge: The Marginalisation and 'Resistance' of D/deaf Youth," *Environment and Plan-*

ning A 35 (2003): 301-21.

10. M. Harrison, J. Roush, and J. Wallace, "Trends in Age of Identification and Intervention in Infants with Hearing Loss," *Ear and Hearing* 24, no. 1 (2003): 89-95.

11. Dalzell et al, see note 7 above; ibid.; T.P. Nikolopoulos et al., "Development of Spoken Language Grammar Following Cochlear Implantation in Prelingually Deaf Children," *Archives of Otolaryngology/ Head and Neck Surgery* 130, no. 5 (2004): 629-33; A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," *Archives of Otolaryngology/ Head and Neck Surgery* 130, no. 5 (2004): 634-8; A. Geers, J.G. Nicholas, and A.L. Sedey, "Language Skills of Children with Early Cochlear Implantation," *Ear and Hearing* 24, no. 1 (2003): 46S-58S; E.A. Tobey et al., "Factors Associated with Development of Speech Production Skills in Children Implanted By Age 5," *Ear and Hearing* 24, no. 1 (2003): 36S-45S; D.M. Houston et al., "Speech Perception Skills of Deaf Infants Following Cochlear Implantation," *A First Report: 2001-2002* (2002): 25.

12. National Institute on Deafness and other Communication Disorders, "Cochlear Implants," *http://www.nidcd.nih.gov/health/hearing/coch.asp,* accessed 25 June 2004.

13. At present all of the following criteria for children between 12 and 24 months of age must be met for a CI to be approved: bilateral profound deafness, minimal benefit from amplification, enrollment in EI or a program for children with deafness, and no medical contraindications.

14. Houston et al., see note 11 above.

15. R.C. Dowell, R. Hollow, and E. Winton, "Outcomes for Cochlear Implant Users with Significant Residual Hearing: Implications for Selection Criteria in Children," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 575-81; S.J. Dettman et al., "Cochlear Implants for Children with Significant Residual Hearing," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 612-8.

16. R.L. Keenan et al., "Bradycardia during Anesthesia in Infants: An Epidemiologic Study," *Anesthesiology,* 80 (1994): 976-82; N.M. Young, "Infant Cochlear Implantation and Anesthesia Risk," *Annals of Otolaryngology and Rhinology* 111 (2002): 49-51.

17. Young, see note 16 above.

18. C.M. Discolo and K. Hirose, "Pediatric Cochlear Implants," *American Journal of Audiology* 11, no. 2 (2002): 114-8.

19. As of May 2003, there were 118 cases of meningitis due to CI reported worldwide; 55 in the U.S., with five fatalities. The majority of cases occurred in children five years of age or less. Symptoms of CI-implicated meningitis appeared as early as 24 hours and as late as six years post-surgery; 50 percent of the cases, however, were within one year of surgery. Children who are candidates for a CI should receive the *Haemophilous Influenzae Type B* and *Pneumococcal* vaccinations to offset and decrease their risk of meningitis. J. Reefhuis, M.A. Honein, and C.G. Whitney, "Risk of Bacterial Meningitis in Children with Cochlear Implants," *New England Journal of Medicine* 349, no. 5 (2003): 435-45.

20. Ibid.

21. Ibid., 435.

22. Nikolopoulos et al., see note 11 above; A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," see note 11 above; A.M. Robbins et al., "Effect of Age at Cochlear Implantation on Auditory Skill Development in Infants and Toddlers," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 570-4.

23. A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," see note 11 above; Robbins et al., see note 22 above.

24. J.S. Moog and A.E. Geers, "Epilogue: Major Findings, Conclusions and Implications for Deaf Education," *Ear and Hearing* 24, no. 1 (2003): 121S-125S.

25. D.C. Thompson et al., "Universal Newborn Hearing Screening: Summary of Evidence," *Journal of the American Medical Association* 286, no. 16 (2001): 2000-10.

26. R. Calderon and S. Naidu, "Further Support of the Benefits of Early Identification and Intervention with Children with Hearing Loss," *Volta Review* 100 (2000): 53-84; M.P. Moeller, "Early Intervention and

Language Development in Children Who Are Deaf and Hard of Hearing," *Pediatrics* 106, no. 3 (2000).

27. See note 6 above.

28. Kluwin and Stewart, see note 3 above.

29. Ibid.

30. See note 6 above.

31. J.L. Cherney, "Deaf Culture and the Cochlear Implant Debate: Cyborg Politics and the Identity of People with Disabilities," *Arguments in Advocacy* 36, no. 1 (1999): 22-34; H. Lane and B. Bahan, "Ethics of Cochlear Implantation in Young Children: A Review and Reply from Deaf-World Perspective," *Otolaryngology/Head and Neck Surgery* 119, no. 4 (1998): 297-312.

32. See note 6 above.

33. O. Sacks, *Seeing Voices: A Journey into the Land of the Deaf* (New York: Vintage Books, 1989).

34. NAD Cochlear Implant Committee, NAD Position Statement on Cochlear Implants, *http://www.nad.org/infocenter/newsroom/positions/CochlearImplants.html,* accessed 2 October 2004.

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

36. Ibid.

37. K. Hakuta, *Mirror of Language: The Debate on Bilingualism* (New York: Basic Books, Inc., 1986); V. Gutierrez-Clellen, "Language Choice in Intervention with Bilingual Children," *American Journal of Speech Language Pathology* 8, no. 3 (1999): 291-302.

38. See note 33 above, p. 94.

39. See note 24 above.

40. Ibid.

41. J.B. Christiansen and I.W. Leigh, *Cochlear Implants in Children: Ethics and Choices* (Washington, D.C.: Gallaudet University Press, 2002), 314; J.B. Christiansen and I.W. Leigh, "Children with Cochlear Implants," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 673-7.

42. Christiansen and Leigh, *Cochlear Implants in Children: Ethics and Choices,* see note 41 above, pp. 290-314.

43. See note 6 above.

44. American Academy of Pediatrics Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," *Pediatrics* 95, no. 2 (1995): 314-7; National Institutes of Health 1995 Consensus Development Conference Statement, "Cochlear Implants in Adults and Children," *http://medhelp.org/lib/100coc.htm,* accessed 13 December 2004. Parental decisions concerning CI are typically made now when the child's assent is moot. Where the child has the capacity, however, to make a decision in her or his own interest, she or he should be allowed to at least weigh in on, if not make that decision. The argument made by Ross that a child's questionable ability to implement and/or adhere to decisions that she or he has made do not apply in this particular context. An adolescent with deafness is in a better position to determine what she or he would be most comfortable with. Moreover, whether or not she or he has CI surgery now or delays it is no longer time sensitive; whether or not she or he turns off the CI causes no serious harm. See L.F. Ross, "Pediatric Bioethics: Reintroducing the Parents," *The Responsive Community* 9, no. 3 (1999): 40-7.

45. Cherney, see note 31 above.

46. A. Dreger, "Shifting the Paradigm of Intersex Treatment," *http://www.isna.org/library/dreger-compare.html,* accessed 2 October 2004, p. 1.

47. See note 6 above.

48. A.E. Brusky, "Making Decisions for Deaf Children Regarding Cochlear Implants: The Legal Ramifications of Recognizing Deafness as a Culture Rather than a Disability," *Wisconsin Law Review* 195, no. 235 (1995); E.J. Sher, "Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State," *New York University Law Review* 58, no. 157 (1983); R.G. Hartman, "Coming of Age: Devising Legislation for Adolescent Medical Decision-Making," *American Journal of Law and Medicine* 28, no. 4

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49. See note 6 above; Christiansen and Leigh, *Cochlear Implants in Children: Ethics and Choices,* see note 41 above, pp. 290-316; Christiansen and Leigh, "Children with Cochlear Implants," see note 41 above.

50. See note 6 above.

51. Ibid.; Kluwin and Stewart, see note 3 above.

52. Kluwin and Stewart, see note 2 above.

53. See note 6 above, p. 6.

54. K. English, R. Kooper, and G. Bratt, "Informing Parents of Their Child's Hearing Loss," *Audiology Today* 16, no. 2 (March/April 2004): 10-2.

55. Ibid.

56. Valentine and Skelton, see note 9 above.