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HEARING THE DEAF: COCHLEAR IMPLANTS, THE DEAF COMMUNITY, AND BIOETHICAL ANALYSIS†

Alicia Ouellette*

I. INTRODUCTION

In 2002, Lee Larson was a single mother to two-year-old Kyron and three-year-old Christian.¹ Like their mother, Kyron and Christian were deaf.² The family's native language and primary mode of communication was American Sign Language ("ASL").³ Larson took great pride in the family's deaf identity and participation in Deaf culture.⁴ Deaf culture is a tight knit social structure whose members share ALS as a common, visual language.⁵ Culturally Deaf individuals "characteristically think it is a good thing to be deaf. . . . [E]xpectant deaf parents characteristically hope to have children with whom they can share their language, culture, and unique experiences—that is, deaf children."⁶

The school Kyron and Christian attended did not share Larson's enthusiasm for Deaf culture. Because there was no room for them in the

† This Essay presents material that will also appear in the author's forthcoming book, *BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS* (Cambridge University Press 2011© Alicia Ouellette). The materials have been adopted from a chapter that comprehensively examines the issues of disability in childhood, and have been modified here to focus specifically on the issues raised by cochlear implants.

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¹ Brief for Michigan Protective & Advocacy Services, Inc. as Amicus Curiae Supporting Respondent, *In re Kyron & Christian Robinson*, No. 01-0702-00 NA (Kent Cty. Cir. Ct.-Fam. Div. Oct. 4, 2004) [hereinafter *Amicus Curiae Brief*], available at <http://www.bridges4kids.org/articles/2002/10-02/Amicus10-5-02.html>.

² Cal Montgomery, *The Cochlear Implant Trial*, RAGGED EDGE ONLINE, <http://www.ragged-edge-mag.com/extra/deaftrial1.html> (last visited Feb. 1, 2011).

³ See *Amicus Curiae Brief*, *supra* note 1 (describing the use of ASL as part of deaf culture).

⁴ See Theresa D. McClellan, *Deaf Mom Gets the 'No' She Wants*, GRAND RAPIDS PRESS (Oct. 5, 2002), <http://www.bridges4kids.org/articles/2002/10-02/GRPress10-5-02.html>. As is customary, I have capitalized the word "Deaf" when I refer to the cultural identity group, and used the lowercase "deaf" when referring to hearing impairment.

⁵ The film *Sound and Fury* is an excellent introduction to Deaf culture. (Aronson Film Assoc., Inc., Pub. Pol'y. Prod., Inc., Thirteen/WNET, & Channel 4 (UK) N.Y. 2000). The film traces the stories of two brothers—one deaf and one hearing—as they and their wives struggle to make decisions about cochlear implants for their hearing children.

⁶ Harlan Lane & Michael Grodin, *Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child*, 7 KENNEDY INST. ETHICS J. 231, 234 (1997) (emphasis omitted).

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school district's ASL-affirmative program, Larson's boys were enrolled at Shawnee Park Elementary School, which offered only an oral-aural program for deaf children. Because they were unable to communicate with teachers, staff, or other children at their new school, officials at Shawnee Park Elementary became concerned that the boys were falling behind their peers. They urged Larson to have her sons treated with cochlear implants.⁷

Cochlear implants are a form of technology that allow deaf people to obtain various degrees of hearing.⁸ Cochlear implants function differently from hearing aids, which simply amplify sound. A cochlear implant transforms speech and other sounds into electrical energy that is used to stimulate surviving auditory nerve fibers in the inner ear. The implant is embedded within the skull, near the ear, and has external and internal components. One part of the device is a microphone that resides outside the ear, while another part processes sounds captured by the microphone. A transmitter sends the processed signals to a receiver implanted under the skin. The receiver converts the signals into electrical impulses, which are then delivered to the auditory nerve. The stimulation of the auditory nerve allows the user to experience representations of sound and might help the user develop spoken language ability.

The degree to which cochlear implant recipients develop spoken language ability varies depending on the age at which the recipient is implanted (younger recipients are more likely to develop spoken language ability than older recipients) and the amount of spoken language training provided to the recipient. Indeed, audiologists strongly recommend that recipients be totally immersed in oral/aural communication at home and in school once the implant is activated.⁹ In other words, a deaf child's success with an implant depends on close interaction with parents for constant monitoring, feedback, and

⁷ McClellan, *Deaf Mom Gets the 'No' She Wants*, *supra* note 4.

⁸ AMERICAN MEDICAL ASSOCIATION FAMILY MEDICAL GUIDE 1019 (4th ed. 2004); SURGICAL CONSENT: BIOETHICS AND COCHLEAR IMPLANTATION 54 (Linda Komesaroff, ed. 2007); see Nat'l Inst. on Deafness & Other Comm'n Disorders, *Cochlear Implants*, NAT'L INST. HEALTH, <http://www.nidcd.nih.gov/health/hearing/coch.asp> (last visited Feb. 1, 2011) (providing more information about cochlear implants).

⁹ See, e.g., Howard W. Francis et al., *Trends in Educational Placement and Cost-Benefit Considerations in Children with Cochlear Implants*, 125 ARCH OTOLARYNGOL HEAD NECK SURGERY 499 (1999) ("Cochlear implantation accompanied by aural (re)habilitation increases access to acoustic information of spoken language, leading to higher rates of mainstream placement in schools and lower dependence on special education support services."); *Children's Program*, U. MICH. HEALTH SYS., <http://www.med.umich.edu/oto/ci/childrensprogram.htm> (last visited Jan. 7, 2011) (recommending that implanted children be enrolled in auditory-verbal therapy to achieve maximum benefits).

reinforcement of good oral speech patterns. The strong recommendation is that families who choose cochlear implants make a total commitment to oral-only communication (no ASL) for the best cochlear implant results.¹⁰ In 2000, the Food and Drug Administration (“FDA”) lowered the acceptable age for implantation of one such device to twelve months old.¹¹ According to the FDA, as of April 2009, approximately 188,000 people worldwide had received cochlear implants, and roughly 41,500 adults and 25,500 children in the United States have received them.¹²

Although they are commonly used, cochlear implants are not risk free: they cost thousands of dollars, there are efficacy problems, and they require surgery, which always entails risks.¹³ Reports of complications are not infrequent. They include injury to the facial nerve, meningitis, cerebrospinal fluid leakage, perilymph fluid leak, infection, attacks of dizziness or vertigo, tinnitus, and loss of residual hearing.¹⁴ Furthermore, cochlear implants do not turn a deaf child into a hearing child. The degree to which they facilitate speech and the ability to understand oral speech varies tremendously from person to person. Children of hearing parents who communicate with oral language or a combination of oral and sign language tend to develop far better oral speaking skills than children of deaf parents. Despite these risks and questions about efficacy, audiologists recommend cochlear implants for deaf children who cannot hear with the amplification of hearing aids.¹⁵

In considering the school’s suggestion that the boys be implanted, Larson researched and spoke with people about implants. Ultimately, she decided that the disadvantages of implantation outweighed any possible advantages. Although she concluded that the boys could make the decision to get implanted when they got older, at this time she wanted them “to grow up with a strong self-esteem, not trying to be

¹⁰ See Lane & Grodin, *supra* note 6, at 235-36; see, e.g., Harlan Lane, *Ethnicity, Ethics, and the Deaf-World*, 10 J. DEAF STUD. & DEAF EDUC. 291, 299-300 (2005); Adam B. Zimmerman, *Do You Hear the People Sing? Balancing Parental Authority and a Child’s Right to Thrive: The Cochlear Implant Debate*, 5 J. HEALTH & BIOMEDICAL L. 309, 317-18 (2009).

¹¹ Nat’l Inst. on Deafness & Other Commc’n Disorders, *supra* note 8.

¹² *Id.*

¹³ Lane, *supra* note 10, at 299-300; Zimmerman, *supra* note 10, at 318.

¹⁴ *Benefits and Risks of Cochlear Implants*, FDA, <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/ucm062843.htm> (last visited Jan. 7, 2011).

¹⁵ See, e.g., *Cochlear Implants*, BAYLOR C. MED., <http://www.bcm.edu/oto/index.cfm?pmid=15404> (last visited Jan. 12, 2011); U. Rochester Med. Ctr., *Cochlear Implant*, <http://www.urmc.rochester.edu/audiology/conditions/cochlear.cfm> (last visited Jan. 7, 2011).

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something they are not.”¹⁶ She also wanted them to be “part of the [D]eaf culture,” and continue to communicate in ASL.¹⁷ The boys’ father, from whom Larson was separated, agreed with Larson’s decision against implants, which she communicated to school officials.¹⁸

In 2002, Larson traveled out of town and left the boys in the care of a friend who was also deaf. Unfortunately, the friend apparently abused the boys and school officials accused Larson of neglect for leaving them in her care.¹⁹ The state issued charges and a court found that Larson neglected the children by leaving them with a care provider who physically abused them.²⁰ The court declared the children temporary wards of the state, and with Larson’s consent, placed the boys in foster care while Larson took parenting classes with the aim of regaining custody.²¹ The foster parents who had temporary custody of the boys did not speak ASL and communicated with the boys through oral speech.²²

The court appointed a guardian ad litem for the boys. The guardian, who was in touch with the foster parents and school officials, sought to have cochlear implants surgically placed in the boys.²³ He filed a Motion for Court to Order Cochlear Implants, claiming it was “in the children’s best interests ‘ . . . that they receive cochlear implants in order for them to realize their full potential in life’ and that time is of the essence given ‘ . . . the ‘window of opportunity’ . . . is from birth through age 4.’”²⁴

The guardian’s petition was unusual. Under state law, Larson retained the clear right to make medical decisions for her children, including decisions to refuse elective (non-lifesaving) treatments. The boys’ placement in temporary foster care did not diminish that right, and cochlear implants are not lifesaving. No state agency supported the guardian’s request. In fact, the Michigan Family Independence Agency, which oversees the children’s foster care, explicitly advised the judge its policy is to allow parents to “decide whether or not a child in foster care

¹⁶ Theresa McClellan, *Deaf Mom Fights to Keep Kids from Ear Implants*, GRAND RAPIDS PRESS, Sept. 6, 2002, at A1, available at <http://www.bridges4kids.org/articles/2002/9-02/GRPress9-6-02.html> (last visited Jan. 12, 2011).

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*; Jon Hall, *Michigan Judge Rules Deaf Boys Needn’t Undergo Surgery*, BOS. GLOBE, Oct. 5, 2002, at A3, available at <http://www.bridges4kids.org/articles/2002/10-02/Globe10-5-02.html> (last visited Jan. 7, 2011).

²⁰ Amicus Curiae Brief, *supra* note 1, at 5.

²¹ Hall, *supra* note 19.

²² *Id.*

²³ McClellan, *Deaf Mom Gets the ‘No’ She Wants*, *supra* note 4.

²⁴ Amicus Curiae Brief, *supra* note 1, at 9 (omissions in original).

should have elective surgery.”²⁵ Nonetheless, the state prosecutor joined the guardian to argue that Larson’s decision against cochlear implants was a form of medical neglect, and her refusal to consent to implantation was the cause of a medical emergency. After a preliminary hearing, the judge agreed to consider the guardian’s petition and scheduled a trial. She also ordered the boys to be physically evaluated in preparation for surgery.²⁶

The case caused considerable consternation within the disability and Deaf communities. Activists came out in force to protest against the real possibility that the court would find the mother’s refusal to ameliorate deafness with cochlear implants a form of medical neglect.²⁷ The judge heard testimony for several days in a courtroom packed with Deaf and disability rights activists.²⁸ The prosecutor questioned the guardian who testified that the boys should get implants because they would benefit from the acquisition of oral language and the opportunities for education and employment that would insure the boys could lead a “healthy, happy, normal life.”²⁹ The State’s expert testified that being deaf will prevent the boys from reaching their full potential because without the implants, the language-processing areas of their brains would not reach full development. The guardian argued that time was of the essence because the window in which the boys would receive the most benefit from the implants was rapidly closing. Multiple expert witnesses testified that implants are crucial for a deaf child’s language development.³⁰

Larson and her lawyer countered. Larson testified that she made a thoughtful and careful decision to decline surgery for her boys after she considered the risks, benefits, and alternatives to treatment. The Michigan Deaf Association produced evidence that speech is not the equivalent to language and that it is access to language, not access to sound and speech, which ensures proper development of the brain. The Deaf Association produced further evidence that sign language, a visual language used in the Larson home, is sufficient to allow the brain to fully develop.³¹ For example, deaf studies specialist Robert Hoffmeister of Boston University told the court that there was no guarantee the implants would benefit the Larson boys in their language acquisition, or

²⁵ Hall, *supra* note 19.

²⁶ McClellan, *Deaf Mom Gets the ‘No’ She Wants*, *supra* note 4.

²⁷ Cal Montgomery, *Ripples, A Tide, An Ocean*, RAGGED EDGE ONLINE, Nov. 2002, <http://www.raggededgemagazine.com/1102/1102ft3.html>.

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

³¹ Montgomery, *The Cochlear Implant Trial*, *supra* note 2.

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that they would improve their schoolwork. According to the research, “it’s all a roll of the dice,” and in most cases involving children who are born deaf, the benefits of cochlear implants are minimal.³²

Also supporting Larson was the Michigan Protection and Advocacy Services (“MPAS”), which submitted an amicus brief that framed the case as one about parental rights. MPAS argued that the decision of whether to consent to or refuse implants was Larson’s choice. The brief confirmed that Larson was not alone in her belief that cochlear implants were not in the best interest of her children. That position, MPAS argued, is widely agreed upon within the disability community. It also emphasized the importance of family autonomy:

ALL families are special and unique, but families who have children with disabilities regularly encounter barriers that impact on the family and require them to form a different view of how “normal” is defined within their family, and how they interact with the world around them. Second-guessing by outsiders is a regular part of that life, and contributes to the development of the family’s culture. A decision allowing “outsiders,” including this Court, to invade the family core by second-guessing parental decisions about how and by whom their children’s disabilities will be treated takes a challenging family environment and threatens its very core.³³

The judge ultimately, but grudgingly, ruled in favor of Larson. She stated, “[t]he court has no doubt it would be in their best interest to have implants,” but “the court has paid close attention to [Larson’s] adamant right to decide and not to participate in [the] after-care”³⁴ needed if the implants had been ordered. The judge stated that the law was clear that courts cannot intervene in parental decisions about medical treatment for their children, absent an emergency, and the refusal to consent to implants did not qualify as an emergency.³⁵

The Larson case is troubling. The problem with that case is not that the judge reached the wrong conclusion—the judge correctly decided that the decision about whether to use cochlear implants is a matter of parental discretion.³⁶ The problem with the Larson case is that a petition

³² *Id.*

³³ Amicus Curiae Brief, *supra* note 1, at 4.

³⁴ McClellan, *Deaf Mom Gets the ‘No’ She Wants*, *supra* note 4, at A1.

³⁵ *Id.*

³⁶ *See infra* Part II.

to override parental choice was brought in the first place. The guardian ad litem and state prosecutor found some support for their argument that parental refusal to consent to surgical implantation of cochlear implants constitutes medical neglect in the bioethical literature; however, that argument ignores the evidence generated by disability and Deaf scholars demonstrating that the affirmative use of cochlear implants is ethically fraught and potentially harmful to children. A more careful bioethical analysis of issues raised with respect to cochlear implantation—that is, an analysis conscious of the evidence generated by Deaf and disability scholars—shows that not only should efforts to mandate cochlear implants for eligible deaf children be rejected, but also more attention should be paid to the assumption that cochlear implantation is always in the best interests of deaf children.

Part II of this essay reviews briefly the legal support for the proposition that parents, not courts, are the appropriate parties to decide whether to use cochlear implants for their children. Part III explores the issues raised by the use of cochlear implants from the perspective of Deaf and disability experts. Part IV contrasts the perspectives of Deaf and disability experts on cochlear implantation with that of various bioethicists, including those bioethicists who take positions that support the mandatory use of cochlear implantation for eligible deaf children. Part IV asserts that the bioethical arguments about the use of cochlear implants, which fail to take into account the evidence generated by Deaf and disability scholars, are incomplete. A comprehensive bioethical analysis requires the use of a more thorough informed consent process for parents who choose cochlear implantation for their deaf children.

II. LEGAL BACKGROUND

Like all parents, parents of deaf children are the primary decisionmakers for their children.³⁷ They make decisions about whether, when, and how to treat illness or use technology to correct or improve functionality. They also make decisions about whether, when, and how to manage the particular physical manifestations or social needs resulting from disabilities, if their children happen to have them. As with most medical decisionmaking for children, the process by which parents make medical decisions for children is mostly unremarkable. The parents consult with the child's doctor, weigh the risk and benefits

³⁷ See *Parham v. J.R.*, 442 U.S. 584, 602–03 (1979) (emphasizing parental rights to make medical choices for children, but limiting this power as a matter of law to ensure against erroneous imposition of unnecessary or improper medical treatment to protect the child's best interests).

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of medically reasonable alternatives, and then make the decision that is, in their estimation, in the best interest of their child.

The deference given to parental decisions in the healthcare setting is more than a matter of convenience or custom. A parent's right to make medical decisions for his or her child is protected by the Due Process Clause of the Fourteenth Amendment.³⁸ This right is not absolute, but it is well-established.³⁹ So long as parents are fit, "there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent's children."⁴⁰ The constitutional protection afforded fit parents clothes them with a presumption that they "act in the best interests of their children"⁴¹ in making choices, including medical choices, for their children.⁴² The presumption that parents act in their child's best interests effectively shields most parental decisions about a child's health care from scrutiny or limitation. Although a court may occasionally override a parent's decision to *refuse* treatment if the choice puts the child's health or life at risk,⁴³ courts almost never intervene when a parent chooses a medically approved alternative to treat a child.⁴⁴ Thus, the law generally leaves the tough decisions to parents.

³⁸ *Id.*

³⁹ *See id.* at 602 (finding "a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life's difficult decisions," and that "natural bonds of affection lead parents to act in the best interests of their children," but also that this presumption only exists "absent a finding of neglect or abuse"); *see also* Prince v. Mass., 321 U.S. 158, 166 (1944) ("It is cardinal with us [the Court] that the custody, care and nurture of the child reside first in the parents . . .").

⁴⁰ Troxel v. Granville, 530 U.S. 57, 68-69 (2000); *see also* Parham, 442 U.S. at 602 (stating that "our constitutional system long ago rejected any notion that a child is 'the mere creature of the State'" (quoting Pierce v. Soc'y of Sisters, 268 U.S. 510, 535 (1925))). Where a parent is deemed unfit, or neglectful, the state may intervene more freely. *See, e.g., In re Sampson*, 278 N.E.2d 918, 919 (N.Y. 1972) (ordering that a child undergo facial surgery and receive blood transfusions despite the mother's religious objection).

⁴¹ Parham, 442 U.S. at 602.

⁴² Troxel, 530 U.S. at 68-69.

⁴³ *See, e.g., Jehovah's Witnesses v. King Cnty. Hosp. Unit No. 1* (Harborview), 278 F. Supp. 488, 505 (W.D. Wash. 1967), *aff'd per curiam*, 390 U.S. 598 (1968) (overriding parental refusal to provide blood transfusion where death would result without the transfusion); *Custody of a Minor*, 379 N.E.2d 1053, 1067 (Mass. 1978) (ordering a child to undergo chemotherapy over the parents' objections because the treatment had inconsequential side effects and would save the child from certain death within months).

⁴⁴ *See, e.g., In re Hofbauer*, 393 N.E.2d 1009, 1014 (N.Y. 1979) (holding that the court would not interfere with parents' decision to forgo conventional chemotherapy for their eight-year-old son who suffered from Hodgkin's disease and instead treat him with laetrile and a special diet); *In re Hudson*, 126 P.2d 765, 783 (Wash. 1942) (holding that a mother was free to refuse surgery to remove her child's deformed arm, despite the recommendation by

With respect to cochlear implantation, no court has overridden a parent's refusal to consent to a medical recommendation for implantation. In light of the strong deference given to parental choice over medical decisionmaking for children, it is unlikely that a court will override a parent's refusal anytime soon; if it did, it is unlikely that the decision would be sustained on appeal. That said, the fact of legal intervention in Lee Larson's case, the apparent approval of the use of cochlear implants in children shown by judges in cases involving the custody of children,⁴⁵ and the strong recommendations by medical professionals that eligible children be implanted, suggests the real possibility of future cases or proposals for legislation or regulation mandating the use of cochlear implants for eligible deaf children. Such proposals would meet fierce opposition from the Deaf and disability communities.

III. VIEWS ON THE CASE OF LEE LARSON'S BOYS AND COCHLEAR IMPLANTATION FROM THE DEAF AND DISABILITY COMMUNITIES

Deaf and disability advocates came together in fierce and unanimous support of Lee Larson. The legal petition to require implants threatened to make a reality what the disability and Deaf communities had long feared: that the medical view of disability would take root in law. If the petition had been granted, the court's decision would have created legal precedent deeming a parent's failure to ameliorate traits like deafness to be medical neglect, based on alleged "proof" that individuals with disabilities need medical fixes to participate meaningfully in society.⁴⁶

The notion that deafness is a defect that needs fixing runs directly counter to beliefs and teachings of the Deaf and disability communities.⁴⁷

two physicians that it should be removed for the child's health, because both courses of action entailed risk).

⁴⁵ See *In re K.S.*, 512 N.W.2d 817, 819 (Iowa Ct. App. 1993) (citing the fact that a child was a candidate for cochlear implantation but had not been implanted was relevant in determining the child's best interests in an abuse case); see also *J.J. v. Smith*, 31 So. 3d 1271, 1272 (Miss. Ct. App. 2010) (noting a mother's resistance to cochlear implants for her child, and the foster parents' support for cochlear implants, as a relevant factor favoring retention of custody by the foster parents).

⁴⁶ See, e.g., Amicus Curiae Brief, *supra* note 1, at 13-14 (explaining that cochlear implants represent a nonemergency and elective procedure, such that parents are not neglecting their children if not providing this service); see also Montgomery, *Ripples, A Tide, An Ocean*, *supra* note 27 (explaining that if the petition were granted it would set a precedent that would have a significant impact on parents of children with disabilities in the future).

⁴⁷ For more information on Deaf culture, see Lane, *supra* note 10. See also, e.g., Margaret Usha D'Silva et al., *Deaf is Dandy: Contrasting the Deaf and Hearing Cultures*, 13 INTERCULTURAL COMM. STUD. 111 (2004) (describing the Deaf Culture and the pride of members who feel they are part of a distinct group); Tingting Gao, *A Neglected Culture:*

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Disability scholars and activists reject the notion that the problem of disability is located in the individual whose body deviates from species normal.⁴⁸ The problem, assert the scholars, lies in society's failure to accommodate all its members. The solution to the problem of disability, under this view, is not to modify the person with the physical difference, but to make social, legal, educational, or other accommodations to ensure full participation in society.⁴⁹ Indeed, disability and Deaf scholars often use the example of deafness on Martha's Vineyard, an island off the coast of Massachusetts, to make the point that overcoming social barriers to participation in the life of a community can in fact eliminate the disabling aspects of impairment. Historically, hereditary deafness was so prevalent on Martha's Vineyard that everyone spoke sign language.⁵⁰ As a result, the Deaf were fully integrated and successful in community life. Deaf islanders were not identified as a distinct group by other islanders, and they were equally successful in terms of work and social lives. The one exception was with respect to school, where the Deaf children tended to *outperform* hearing children.⁵¹ The lesson Deaf and disability experts take from the experience of Martha's Vineyard is that deafness is not disabling in a society that appreciates difference and makes a deliberate effort to fully include people of different abilities.

This social model of disability argument is clearly evident in activist Cal Montgomery's response to Lee Larson's case:

How Cochlear Implants Affect Deaf Children's Self-Esteem, 6 *DIALOGUES@RU* 79, 87 (2007), available at http://dialogues.rutgers.edu/vol_06/essays/documents/gao.pdf (discussing the effect of the cochlear implant on the Deaf community); Claire L. Ramsey, *Ethics and Culture in the Deaf Community Response to Cochlear Implants*, 21 *SEMINARS HEARING* 75 (2000) (explaining how the Deaf community believes it is not a defect that needs to be corrected); Claire L. Ramsey, *What Does Culture Have to Do with the Education of Students Who Are Deaf or Hard of Hearing?*, in *LITERACY AND DEAF PEOPLE: CULTURAL AND CONTEXTUAL PERSPECTIVES* 47 (Brenda Jo Brueggemann ed., 2004) (explaining the reaction of the Deaf community to cochlear implants and the effects it will have on implanted children); Robert Sparrow, *Defending Deaf Culture: The Case of Cochlear Implants*, 13 *J. POL. PHIL.* 135 (2005) (discussing the concept of deafness as a culture).

⁴⁸ Gareth Williams, *Theorizing Disability*, in *HANDBOOK OF DISABILITY STUDIES*, at 124 (Gary L. Alberch et al. eds., 2001); *THE DISABILITY STUDIES READER*, *passim*, (Lennard J. Davis ed., 2d ed. 2006).

⁴⁹ Michelle Fine & Adrienne Asch, *Disability Beyond Stigma: Social Interaction, Discrimination, and Activism*, 44 *J. SOC. ISSUES* 3 (1988); Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 *J. HEALTH CARE L. & POL'Y* 352, 352 (2000); Laura L. Rovner, *Disability, Equality, and Identity*, 55 *ALA. L. REV.* 1043, 1043-44 & n.4 (2004) (citing Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 *J. HEALTH CARE L. & POL'Y* 352, 352-53 (2000)); Richard Scotch, *Understanding Disability Policy*, 22 *POL'Y STUD. J.* 170, 172 (1994).

⁵⁰ See generally NORA ELLEN GROCE, *EVERYONE HERE SPOKE SIGN LANGUAGE: HEREDITARY DEAFNESS ON MARTHA'S VINEYARD* (1985).

⁵¹ *Id.* at 78.

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I am certain that if all participants in the case viewed deafness as just another kind of diversity, the situation would never have arisen.

If the boys' present and future disadvantages were attributed to our hearing-dominated society rather than to their own deafness (and their deaf parents' acceptance of their deafness), teaching them pride in who they are and the skills to struggle would make more sense. Many people who do hold the institutions of the hearing majority responsible (including some who regard cochlear implants as a good thing in some cases) are vehemently opposed to [the state expert's] position.

But because the people who brought the case forward blame these disadvantages on the boys' inability to hear rather than on society's insistence on hearing as a prerequisite to full membership, cochlear implants are seen by many people as a solution to disability. Denying the children implants looks like condemning them to a lesser life.⁵²

Another activist explained:

The medical establishment has continually told us that being Deaf is a tragedy. It refuses to admit that American Sign Language is wholly sufficient to allow the development of the language center of a deaf child's brain and to allow the deaf child to develop full linguistic and cognitive competence, given each individual's potential. It refuses to admit that there are viable options other than a cochlear implant.⁵³

Indeed, cochlear implants are particularly controversial within the Deaf community. Although many deaf adults choose implants for themselves and their children, many others, especially Deaf activists and their supporters, vehemently oppose their use in all cases. The arguments against cochlear implants vary. Some argue that there is an intrinsic value in being deaf. They view deafness as a defining feature of

⁵² Montgomery, *The Cochlear Implant Trial*, *supra* note 2 (emphasis omitted).

⁵³ 2002 *Grand Rapids Cochlear Implant Case*, EQUAL ACCESS COMM., INC., (Oct. 4, 2002), <http://www.equalaccesscommunication.com/2002GrandRapidsRally/index.htm>.

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identity and an essential component of personhood. In their view, using implants deprives children of that essential piece of themselves. Under this view, denying children their deafness deprives them of the key to entry into a rich culture, ripe with language, arts, and tradition.⁵⁴ This argument often compares deafness to other characteristics central to identity such as race, gender, or sexual orientation. Consider, for example, this comment, made by a former president of the National Association of the Deaf:

I'm happy with who I am . . . and I don't want to be 'fixed.' Would an Italian-American rather be a WASP? In our society everyone agrees that whites have an easier time than blacks. But do you think a black person would undergo operations to become white?⁵⁵

Other opponents of cochlear implants argue that treating deafness as an illness needing a cure is insulting and demeaning to the Deaf because of its message that the Deaf are of lesser worth than the hearing. Others argue that widespread use of cochlear implants constitutes a form of cultural genocide.⁵⁶ For example, Harlan Lane argues that

[w]hile surgical programs that implant large numbers of Deaf children do not have as their intent the destruction of Deaf-World culture, both the U.N. Declaration [of the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities] and the Convention [on the Prevention and Punishment of the Crime of Genocide] express humankind's interest in preserving and fostering minority languages and cultures and thus, once the minority language and culture of the Deaf-World is recognized, alert us to the conflict of values arising from those surgical programs.⁵⁷

⁵⁴ See, e.g., Lane, *supra* note 10, at 292-94 (describing how the "Deaf-World" has a rich history, which has been reported in books, films, and more); Lane & Grodin, *supra* note 6, at 234-35 (explaining how Deaf parents like to have children who can share their culture and experiences); Sparrow, *supra* note 47, at 136 (asserting that the cochlear implant technology is an attack on Deaf culture).

⁵⁵ Edward Dolnick, *Deafness as Culture*, ATLANTIC MONTHLY, Sept. 1993, at 38, available at http://gallyprotest.org/atlantic_monthly.pdf (quoting Roslyn Rosen, former President of the National Association of the Deaf).

⁵⁶ See, e.g., Sparrow, *supra* note 47, at 135-36 (arguing that finding a "cure" for deafness constitutes genocide of the deaf community).

⁵⁷ Lane & Grodin, *supra* note 6, at 238 (emphasis omitted).

The arguments against cochlear implants have not convinced most parents to forgo implantation for their children. Most deaf children are born to hearing parents,⁵⁸ and most of those parents choose implants for children who are eligible.⁵⁹ Many deaf adults also choose implants for themselves and their deaf children. In fact, the two deaf parents of a deaf child—whose decision against cochlear implants for their daughter Heather was the subject of the award winning documentary *Sound and Fury*—ultimately had a change of heart and got implants not just for their daughter, but also for another deaf child and themselves.⁶⁰

Despite the internal tension about cochlear implantation within the Deaf community—some members of the Deaf and disability communities would argue against cochlear implants in all cases and others elect implants for themselves and their children—there is widespread agreement on one thing: a decision to use cochlear implants is ethically fraught and should be made with great care and caution. Deaf and disability experts urge that anyone considering the use of implants for their children be advised, in no uncertain terms, not only of the known risks of implantation (nerve damage, infection, meningitis, even death) but also the cultural and psychological costs.⁶¹ For example, Clair Ramsey cautions, “[i]f we take the child as a whole person rather than ‘a broken ear with a child attached’ we are obligated to consider the effects of an implant on the child’s psychological development (especially identity formation), educational progress, and social life.”⁶² Thus, parents should have reasonable expectations. Cochlear implants will not make congenitally deaf children into hearing children. Parents “should be made aware that an implant may augment the patient’s ability to detect sound, but that the patient will still have severely impaired hearing” and limited speech proficiency.⁶³ Moreover, and perhaps most importantly, parents must be advised that implanted children “often find themselves in limbo” as they become independent of their families.⁶⁴ “[T]hey are not deaf people because they do not sign.

⁵⁸ *Quick Statistics*, NAT’L INST. ON DEAFNESS & OTHER COMM. DISORDERS, <http://www.nidcd.nih.gov/health/statistics/quick.htm> (last visited Jan. 7, 2011) (“Nine out of every 10 children who are born deaf are born to parents who can hear.”).

⁵⁹ See, e.g., Gao, *supra* note 47, at 84 (noting that most hearing parents of deaf children “invariably choose cochlear implants for their deaf child in order to facilitate his or her assimilation into the hearing world”).

⁶⁰ Karen Putz, ‘Sound and Fury’ Update: *A Family Comes Together Again*, HANDS & VOICES (2005), http://www.handsandvoices.org/articles/misc/V8-4_soundfury.htm (last visited Jan. 7, 2011).

⁶¹ Ramsey, *Ethics and Culture*, *supra* note 47, at 77–78.

⁶² *Id.* at 78 (citation omitted).

⁶³ *Id.* at 79.

⁶⁴ *Id.*

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Yet, . . . they find that they are not hearing people either.”⁶⁵ As one undergraduate with implants reported, “it is emotionally exhausting to pretend to be a regular, hearing person.”⁶⁶ It is only when deaf people who are raised with oral exclusive education learn to sign as adults that they develop strong self-esteem and experience the end of the psychological distress caused by the deprivation of their most natural and comfortable form of communication.⁶⁷ For this reason, Deaf and disability activists urge parents who choose implants for their children to be sure to expose the children to Deaf culture and Deaf people throughout their lives, and to teach the children ASL from an early age.⁶⁸

Given the varied views on cochlear implants within the Deaf community itself, it is not surprising that the community focused on a more unifying issue in its advocacy for Lee Larson: parental rights. The activists and advocates reacted against the attempt to limit Larson’s parental rights. Claudia Lee of the Deaf Community Advocacy Network explained that the case is about “the *rights of parents* and not whether we agree or disagree with cochlear implants or the choices that parents make.”⁶⁹ In an amicus brief, MPAS argued the following:

Michigan and federal constitutional and statutory law and practices honor and embrace the family unit as the centerpiece of the fabric of America. Taking Ms. Larson’s right to make this core medical decision on behalf of her children would rip that fabric, and imperil her ability to reunify her family.⁷⁰

Moreover, MPAS argued “[a] decision allowing ‘outsiders,’ including this Court, to invade the family core by second-guessing parental decisions about how and by whom their children’s disabilities will be

⁶⁵ *Id.*

⁶⁶ Gao, *supra* note 47, at 87.

⁶⁷ See, e.g., *id.* at 87–88 (“Upon meeting other deaf people and learning American Sign Language (ASL), Mark Drolsbough commented, ‘I am no longer ashamed of my deafness, I am proud of it. I am proud of who I am, proud of what I’ve overcome, and proud of my culture.’”); Mary C. Holte & Maria C. Dinis, *Self-Esteem Enhancement in Deaf and Hearing Women: Success Stories*, 146 AM. ANNALS DEAF, Oct. 2001, at 348, 352–53 (reporting on a study which revealed that deaf women were more likely to report as critical components in self-esteem enhancement both language and communication); Andrew Restuccia, *Michael Schwartz: Multiple Communication Methods Assist Deaf Law Professor in and Outside of the Classroom*, DAILY ORANGE, Mar. 7, 2010, <http://www.dailyorange.com/2.8691/michael-schwartz-multiple-communication-methods-assist-deaf-law-professor-in-and-outside-of-the-classroom-1.1237578>.

⁶⁸ Gao, *supra* note 47, at 87.

⁶⁹ Montgomery, *The Cochlear Implant Trial*, *supra* note 2.

⁷⁰ Amicus Curiae Brief, *supra* note 1, at 4.

treated takes a challenging family environment and threatens its very core."⁷¹

The focus of the disability and Deaf advocates involved in Lee Larson's case on the right of parents of kids with disabilities to make medical decisions for their children is consistent with the official position of the National Association for the Deaf ("NAD"),⁷² a position that appears to represent the mainstream consensus within the Deaf and disability communities about cochlear implants. The NAD recognizes the right of parents to make informed decisions on behalf of their children for or against implantation, but the NAD takes a cautious approach to affirmative choices to implant. To ensure decisionmaking is truly informed,

the NAD strongly urges physicians, audiologists, and allied professionals to refer parents to qualified experts in deafness and to other appropriate resources so that parents can make fully informed decisions—that is, decisions that incorporate far more than just the medical-surgical. Such decisions involve language preferences and usage, educational placement and training opportunities, psychological and social development, and the use of technological devices and aids.⁷³

The NAD also recommends that implanted children be taught to use sign language at home, and that research be conducted to better understand the consequences in the long term for implanted and non-implanted children.⁷⁴

IV. VIEWS ON COCHLEAR IMPLANTATION FROM WITHIN BIOETHICS

Although the case of Lee Larson's boys mobilized the disability community, it appears to have gone largely unnoticed within bioethics. That is not to say that bioethicists have not considered the question of cochlear implants—they have—but they have not responded in public commentary or academic writing to the particular case. The available bioethical commentary suggests that had Larson's case received the

⁷¹ *Id.*

⁷² NAD *Position Statement on Cochlear Implants (2000)*, NAT'L ASS'N DEAF, <http://www.nad.org/issues/technology/assistive-listening/cochlear-implants> (last visited Jan. 7, 2011).

⁷³ *Id.*

⁷⁴ *Id.*

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attention of bioethicists, her choice to refuse cochlear implants for her boys would have caused debate. While many bioethics scholars and clinicians would support Larson's choice as a matter of parental autonomy, others would agree with the state's attorney and the guardian ad litem that Larson's choice to refuse to implant her deaf children was so ethically problematic that intervention is or could be warranted.

Within bioethics, as in medicine in general, respect for parental choice runs deep. A bedrock principle of law and bioethics is that medical treatment must only be provided or withheld on the basis of a legally valid consent or refusal.⁷⁵ To be legally valid, a consent or refusal of treatment must be informed and free.⁷⁶ It must also be made by a person with decisionmaking capacity; that is, someone who is capable of understanding the proffered treatment, its goals, consequences, attendant risks, and the alternatives to treatment.⁷⁷ Children lack the capacity to make their own healthcare decisions as a matter of law in most instances, so it is up to parents to decide whether to consent to treatment. Bioethicists recognize that children should have an increasingly important voice in medical decisionmaking as they mature,⁷⁸ but young children, like Lee Larson's boys, cannot participate meaningfully in medical decisionmaking. Therefore, a substitute decisionmaker is necessary, and because they are best able to assess the needs of a particular child, parents are the preferred decisionmakers for young children.⁷⁹

⁷⁵ *Canterbury v. Spence*, 464 F.2d 772, 783 (D.C. Cir. 1972); *Cobbs v. Grant*, 502 P.2d 1, 11 (Cal. 1972) ("[T]he patient's right of self-decision is the measure of the physician's duty to reveal. That right can be effectively exercised only if the patient possesses adequate information to enable an intelligent choice. The scope of the physician's communications to the patient, then, must be measured by the patient's need, and that need is whatever information is material to the decision. Thus the test for determining whether a potential peril must be divulged is its materiality to the patient's decision."); see also TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 99 (6th ed. 2008).

⁷⁶ *Cobbs v. Grant*, 502 P.2d 1, 9 (Cal. 1972); *Bouvia v. Sup. Ct.*, 225 Cal. Rptr. 297, 303 (Cal. Ct. App. 1986); *State v. McAfee*, 385 S.E.2d 651 (Ga. 1989); *McKay v. Bergstedt*, 801 P.2d 617, 621 (Nev. 1990).

⁷⁷ See generally *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

⁷⁸ E.g., Rachel Bulford, *Children Have Rights Too*, 314 *BMJ* 1421, 1421-22 (1997); see generally Wilma C. Rossi et al., *Child Assent and Parental Permission in Pediatric Research*, 24 *THEORETICAL MED. & BIOETHICS* 131 (2003).

⁷⁹ Am. Acad. of Pediatrics Comm. on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 *PEDIATRICS* 314 (Feb. 1995), available at <http://www.cirp.org/library/ethics/AAP/>; Lainie Friedman Ross, *Growth Attenuation by Commission and Omission May Be Ethically Justifiable in Children with Profound Disabilities*, 161 *ARCHIVES PEDIATRICS & ADOLESCENT MED.*, Apr. 2007, at 418; Erik Parens, *Respecting Children with Disabilities – and Their Parents*, 39 *HASTINGS CTR. REP.* 22, 23 (2009).

As decisionmakers for children, parents are expected to weigh all relevant factors such as the risks, benefits, alternatives of treatment, a particular child's pain tolerance, her medical, and social history, and proceed in accordance with whatever course is, all things considered, in the child's best interests. Deciding whether a particular course of treatment or non-treatment is in an individual child's best interests requires an assessment of the relative importance of each factor. Clinicians and ethicists who place primary emphasis on the principle of respect for autonomy tend to conceive the assessment as a subjective one belonging to the parent, who is free to consider religious, familial, or other values in assessing treatment options. In other words, the commitment to autonomy is expressed through value neutrality—an obligation not to interfere with the choice of another—regardless of whether the decisionmaker is the principal or a surrogate. Except in the rare circumstance in which the decision will have devastating consequences for the child,⁸⁰ the commitment to autonomy requires deference to parental choice. Parents, after all, are in the best position to know what is best for a child. Clinicians and ethicists will thus presume their choices to be in the best interests of the child.

The commitment to parental autonomy expressed through value neutrality is evident in many legal cases in which courts have refused to second guess parental choices about a child's medical care despite medical recommendations for a different course of action.⁸¹ Physician ethicist Douglas Diekema explains that the real question in medical cases involving children is not identifying which medical alternatives represent the best interests of the child but rather "identifying a harm threshold below which parental decisions will not be tolerated."⁸² For many, that harm threshold is reached only when the refusal of treatment directly threatens the life of a child, such as in the case of the refusal of a simple blood transfusion. When there are questions about medical efficacy of a particular treatment, or reasonable disagreement about the therapeutic value of an intervention, bioethics teaches that both intervention and avoidance of intervention are permissible alternatives.⁸³

⁸⁰ *E.g.*, *Custody of a Minor*, 379 N.E.2d 1053, 1056 (Mass. 1978) (ordering a child to undergo chemotherapy over the parents' objections because the treatment had inconsequential side effects and would save the child from certain death within months).

⁸¹ See sources cited *supra* note 44 and accompanying text (identifying cases where the court refrained from infringing on parents' rights to make decisions for their children).

⁸² Douglas S. Diekema, *Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention*, 25 THEORETICAL MED. & BIOETHICS 243, 249 (2004).

⁸³ David Benatar, *Non-Therapeutic Pediatric Interventions*, in THE CAMBRIDGE TEXTBOOK OF BIOETHICS 127, 128 (Peter A. Singer & A. M. Viens, eds., 2008).

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Cochlear implants certainly are not lifesaving treatment. Although they are often touted as “miraculous,” the current state of implant technology is such that their use exposes a child to substantial risks, including infection, meningitis, and nerve damage, and their efficacy for prelingually deaf children is questionable at best. For these reasons, the therapeutic value—the ability of the particular intervention to cure or prevent illness or impairment—is questionable. Given the state of cochlear implant technology, their use in children would be deemed a matter of parental choice under this type of standard autonomy-based bioethical inquiry.

Other bioethicists argue against parental choices for deafness. Australian bioethicist Julian Savulescu is most direct. He argues that all deaf children for whom cochlear implants would be medically appropriate should be implanted:

[W]hen a couple deny an existing child a cochlear implant, they deny that child the opportunity to hear speech, sound, music and to participate in the dominant culture, as well as being able to participate in a signing community. They make that child worse off.

This is analogous to a deaf couple with a hearing child who, wanting that child to be like them, deafen that child. That would be child abuse.

[D]enying a child a cochlear imp[lant] can have a similar outcome. It is [as] neglectful as denying a child with an amputation a limb prosthesis, on the grounds that the child can walk well enough on crutches.

In the case of competent adults, we can leave it to them to decide for themselves whether they have a cochlear implant or remain deaf, or even if they choose to become deaf. I have vigorously defended the liberty [of] individuals to make controversial choices. But when it comes to parents making choices for their children, there are two plausible principles. Firstly, the intervention must plausibly be in the child’s interests. In this case, the use of a cochlear implant is likely to make a child’s life go better than remaining deaf.

Secondly, we should protect the child’s right to decide for herself. In this case, being able to hear has one

advantage over deafness. The hearing can easily become deaf, while the deaf cannot easily become hearing later in life. So a child given a cochlear implant could always choose to have it removed later in life, or turned off somehow. A child, unhappy with the hearing culture, can reject it as an adult. She can be made deaf. But a deaf child cannot easily hear later in life.

To my knowledge, no hearing adult has ever freely chosen to become deaf. But it would be easy to achieve. So the cochlear implant affords the deaf child an extra option: to be deaf or hearing later in life.

Both respect for liberty/autonomy and beneficence argue in favour [of] making the provision of cochlear implants a legal requirement.⁸⁴

Savulescu's argument reflects an understanding of the best interest inquiry as an objective one based upon standardized norms and common goals. One of those goals, he argues, is preserving the child's right to decide for herself.

Ethicist Dena Davis shares Savulescu's view that parents have a moral obligation to preserve future options for their children. Adopting Joel Feinberg's conception of a "child's right to an open future," Davis argues against deference to parental autonomy in favor of protecting a child's potential autonomy.⁸⁵ Davis and Feinberg divide rights into four categories. First, there are rights that adults and children have in common, such as a right not to be killed.⁸⁶ Second, there are rights which are generally possessed only by children and "childlike" adults, which derive from the child's dependence on others for such basics as food, shelter, and protection.⁸⁷ Feinberg calls these dependency rights, and they include the child's right to be fed, nourished, and protected. Third, there are rights that can be exercised only by adults such as the

⁸⁴ Julian Savulescu, *Refusing Cochlear Implants: Is It Child Neglect?*, PRACTICAL ETHICS (July 13, 2009, 5:00 PM), <http://www.practicaethicsnews.com/practicaethics/2009/07/refusing-cochlear-implants-is-it-child-neglect.html> (citation omitted).

⁸⁵ Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549, 575 (1997).

⁸⁶ Joel Feinberg, *The Child's Right to an Open Future*, in WILLIAM AIKEN, WHOSE CHILD? CHILDREN'S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER 124, 125 (1980); see Philip Fetzer & Laurence D. Houlgate, *Are Juveniles Still 'Persons' Under the United States Constitution? A New Theory of Children's Constitutional Rights*, 5 INT'L J. CHILD. RTS. 319, 319 (1997) (emphasizing the difference between having a right and enjoying it).

⁸⁷ Feinberg, *supra* note 86, at 125 (emphasis omitted).

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free exercise of religion.⁸⁸ Finally, Feinberg identifies a category of “rights-in-trust,” rights to be “saved for the child until he or she is an adult.”⁸⁹ Rights-in-trust, Feinberg argues, include “anticipatory autonomy rights”⁹⁰ which will eventually belong to the child when she becomes a “fully formed self-determining adult.”⁹¹ To elaborate, Dena Davis provides the following:

An example is the right to choose one’s spouse. Children and teenagers lack the legal and social grounds on which to assert such a right, but clearly the child, when he or she attains adulthood, will have that right. Therefore, the child *now* has the right not to be irrevocably betrothed to someone.⁹²

According to Feinberg, rights-in-trust can be violated before the child is in a position to exercise them:

The violating conduct guarantees *now* that when the child is an autonomous adult, certain key options will already be closed to him. His right while he is still a child is to have these future options kept open until he is a fully formed self-determining adult capable of deciding among them.⁹³

Parents are morally obligated to protect a child’s rights-in-trust now so that the child can exercise them as an adult. When a parent seeks to violate a right held in trust, Feinberg argues, the state should step in: “Children are not legally capable of defending their own future interests against present infringement by their parents, so that task must be performed for them.”⁹⁴

Applying the open futures approach to cases involving the use of genetic screening to ensure the birth of a deaf child, Davis argues that a

⁸⁸ *Id.*

⁸⁹ *Id.* at 125–26. Laurence D. Houlgate makes a similar argument in *Three Concepts of Children’s Constitutional Rights: Reflections on the Enjoyment Theory*, 2 U. PA. J. CONST. L. 77, 80, 86 (1999).

⁹⁰ Feinberg, *supra* note 86, at 126; see also JOEL FEINBERG, HARM TO OTHERS: THE MORAL LIMITS OF THE CRIMINAL LAW 38 (1984) (explaining that a person has an interest in something when he “stands to gain or lose” depending upon the outcome).

⁹¹ Feinberg, *supra* note 86, at 126.

⁹² Dena S. Davis, *The Child’s Right to an Open Future: Yoder and Beyond*, 26 CAP. U. L. REV. 93, 94 (1997).

⁹³ Feinberg, *supra* note 86, at 126.

⁹⁴ *Id.* at 128.

parental choice for deafness causes children moral harm. Whether one views deafness as a disability or as a culture, Davis contends that a choice for deafness violates the child's right to an open future:

If deafness is a disability which substantially narrows a child's career, marriage, and cultural options in the future, then deliberately creating a deaf child counts as a moral harm. If Deafness is a culture, as Deaf activists assert, then deliberately creating a Deaf child who will have only limited options to move outside of that culture also counts as a moral harm.⁹⁵

Under Davis's reasoning, no healthcare provider should acquiesce to a parental choice "that confines [a child] forever to a narrow group of people and a limited choice of careers."⁹⁶

To be clear, Davis has not explicitly argued in favor of cochlear implants for all children. It is quite possible that she would oppose any legal or other rule requiring cochlear implants, especially given the current state of the technology and its attendant physical risks. That said, Davis's argument would support mandates for cochlear implants if they were risk-free and uniformly successful. She also clearly supports parents who choose to consent to implantation.⁹⁷

Indeed, with the exception of papers published by disability and Deaf scholars in bioethics publications, all the academic writing in bioethics suggests strong support for the right of parents to mitigate deafness with technology. Neil Levy, for example, argues that no parent should be deprived the opportunity to use cochlear implants for a deaf child.⁹⁸ Levy considers, but ultimately rejects, what he calls the disability argument, which posits any disadvantage caused by deafness should be addressed by altering society because that disadvantage is caused by society. Although he acknowledges that much of the disadvantage caused by deafness could be addressed through social adjustments, Levy asserts that the Deaf are at least in part "naturally disabled. They are, for example, disadvantaged by the fact that sound is widely relied upon as a means of alerting people to dangers, from car horns to sirens to fire alarms."⁹⁹ No social fix, including flashing lights on alarms, could fully

⁹⁵ Davis, *Genetic Dilemmas*, *supra* note 85, at 575.

⁹⁶ *Id.*

⁹⁷ Dena S. Davis, *Cochlear Implants and the Claims of Culture? A Response to Lane and Grodin*, 7 KENNEDY INST. ETHICS J. 253, 258 (1997).

⁹⁸ See generally Neil Levy, *Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard*, 16 BIOETHICS 134 (2002).

⁹⁹ *Id.* at 140.

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redress this disadvantage. Levy also concedes that Deaf culture is real and valuable, and the cochlear implants threaten its continued existence. Nonetheless, he argues that hearing parents of deaf children have no special obligations to Deaf culture, which require them to commit their children to Deaf culture, something that is not required of deaf adults. Balancing the competing values, he concludes that

whatever internal restrictions on the Deaf themselves might be justified by the need to preserve that culture, Deaf activists and their supporters have no right to impose the burdens of deafness on hearing-impaired children. So long as Deaf culture survives, the costs associated with it will be relatively high, in that the deaf will remain an effectively isolated and underprivileged minority.¹⁰⁰

In sum, there is no consensus about the case of Lee Larson's boys in bioethics. The many ethicists who apply a value-neutral autonomy principle to support parental choice in medical decisionmaking would agree with disability experts that Lee Larson had the right to decide against cochlear implantation for her boys. Others would disagree on the ground that a parent has a moral obligation to ensure an open future for a child. The one issue about which bioethicists appear to have reached a consensus is that a parental choice *to use* cochlear implants is ethically and morally defensible. That conclusion may be ultimately correct, but it does not justify indifference to the potential physical, psychological, and social harms carried with implantation.

V. BRIDGING THE DISCONNECT: A DISABILITY-CONSCIOUS BIOETHICAL APPROACH TO COCHLEAR IMPLANTATION

The foregoing discussion shows that although most disability experts and bioethicists ultimately support parental choice with respect to cochlear implants, their concerns are quite different. As a whole, bioethics supports parental choice *for* cochlear implants but is concerned about decisions that encourage deafness, such as the decision to forgo the use of cochlear implants. Deaf and disability experts view such interventions to ameliorate deafness as ethically fraught but contend (with a few exceptions) that ultimately parents may choose cochlear implantation so long as they are given accurate and complete information about their physical risks and are educated about the

¹⁰⁰ *Id.* at 152.

potential negative social and psychological effects technological “fixes” have in the lives of children. In my view, the position of Deaf and disability experts results from a more thorough bioethical analysis of the issues raised by cochlear implants than that found within mainstream bioethics.

In arguing about cochlear implantation, bioethics experts focus on the reasons why children should not be denied implants. Whether arguing for a right to choose implantation, or arguing for implantation for all, bioethicists worry about “confin[ing a child] forever to a narrow group of people,”¹⁰¹ or dooming a child to a life of disability.¹⁰² These arguments for implantation incorporate the medical understanding of disability and reflect the medical justification for implantation: the benefits of “fixing” the child outweigh the medical risks of intervention.

This focus on ensuring that children have access to cochlear implantation leaves gaps in bioethical analyses. To be sure, there are strong, evidence-based objections within bioethics to the assertion that being deaf limits life options for children.¹⁰³ And there are bioethicists who contest arguments that equate difference with dysfunction¹⁰⁴ or otherwise make erroneous ableist assumptions about life with disability. For example, a British scholar who works at the intersection of disability and bioethics argues that “if bioethicists want to be able to say that the *bad thing* about disability, the experienced disadvantage of it, is sufficient grounds for morally serious medical interventions, then we need evidence that the disadvantage is as great as is claimed.”¹⁰⁵ Nonetheless, the prevailing bioethical view is that cochlear implants are an ethically viable choice for children because they are medically efficacious, that are “likely to be safe and effective in providing benefit to the patient and improving her quality of life.”¹⁰⁶ Having concluded that cochlear implants are safe and effective, bioethicists appear unconcerned or indifferent to parental decisions to use them in their deaf children.

¹⁰¹ Davis, *Genetic Dilemmas*, *supra* note 85, at 575.

¹⁰² *Id.*

¹⁰³ Robert A. Crouch, *Letting the Deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children*, HASTINGS CTR. REP., July-Aug. 1997, at 17 (arguing that the predominant notion “that the deaf are ‘merely and wholly’ disabled—is wrong and that we should quickly disabuse ourselves of this ill-begotten notion”).

¹⁰⁴ See especially, the writings of Adrienne Asch, Anita Silvers, Leslie Francis, and Alice Dreger.

¹⁰⁵ JACKIE LEACH SCULLY, *DISABILITY BIOETHICS: MORAL BODIES, MORAL DIFFERENCE* 154 (2008).

¹⁰⁶ See Douglas S. Diekema & Norman Fost, *Ashley Revisited: A Response to the Critics*, 10 AM. J. BIOETHICS 30, 37 (2010) (defining the test for medically and ethically acceptable interventions on children).

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The fact that cochlear implants can improve functionality should not end the ethical inquiry. Just as there are medical benefits to the use of other technologies, such as respirators, the use of cochlear implants comes at a cost. As demonstrated by Deaf and disability experts, people who have grown up with cochlear implants and oral-only language are likely to experience psychological trauma until they are exposed to sign language and Deaf culture. That potential for isolation and psychological distress should not be overlooked in any conversation about the benefits of cochlear implants.

The internal debate surrounding cochlear implants within the Deaf and disability communities is more nuanced. Disability experts provide strong arguments that decisions to use technology to ameliorate deafness should be made with care and consultation with disability experts who can help parents understand the child's need for visual language as a complement to whatever oral/aural skills the child will develop via the implants. They advocate specific strategies for educating parents about cochlear implants and protecting the wellbeing of implanted and non-implanted children. These strategies seek to ensure truly informed decisionmaking and better outcomes for children whose parents elect implantation.¹⁰⁷ They insist on continuing research and follow up on implanted children to ensure that implants are in fact benefiting children.¹⁰⁸ These proposals are entirely consistent with the principles of informed consent and the practice of evidenced-based medicine, central to bioethical analysis.

Because they contribute critical information and specialized knowledge about life with disability and the psychological and social costs of "cure," Deaf and disability experts must be heard in debates surrounding cochlear implantation. Their work shows that just as there are risks and benefits to raising a non-implanted child to be fluent in sign language and immersed in Deaf culture, there are benefits and risks to implantation. Ultimately, it is the child's parent or guardian who should weigh those benefits and risks and decide what is best for a child. Bioethicists could help that process by promoting more informed consent processes, better education about the disability and Deaf experience in medical schools, and engaging in empirical research in collaboration with other experts to generate more comprehensive data about the psychological and social effects of cochlear implantation. That work will only be possible, however, when Deaf and disability experts are part of the bioethical conversation.

¹⁰⁷ See NAD Position Statement on Cochlear Implants, *supra* note 72.

¹⁰⁸ *Id.*