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## Note

# To Hear or Not to Hear: How “Best Interest” Determinations Can Help in the Cochlear Implant Debate

*Tessa Wright\**

## I. INTRODUCTION

By now, almost everyone has seen one of the viral videos showcasing deaf babies and toddlers hearing for the first time after their cochlear implant surgery. In fact, in 2011, one of these videos reached over twenty-seven million views.<sup>1</sup> Many found these videos of babies smiling as they heard their mother’s voice for the first time to be heartwarming and uplifting; something inspirational to brighten up the day. However, what most people probably failed to notice is that these videos also contain hundreds of angry comments and dislikes. Indeed, beneath the surface of these viral videos lurks a very contentious debate.

Cochlear implants – surgically implanted devices that provide electrical stimulation to the brain and increase auditory input – are a commonly used tool for assisting individuals with hearing loss.<sup>2</sup> According to medical research, children should receive cochlear implants before the age of three in order to receive any measurable benefit to their language and speech development.<sup>3</sup> The opportunity to provide their profoundly deaf

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1. Amelia Cooper, *Hear Me Out*, 116 MO. MED. 469–471 (2019).

2. *Cochlear Implants*, NAT’L INST. ON DEAFNESS & OTHER COMMUN DISORDERS (Mar. 24, 2021), <https://www.nidcd.nih.gov/health/cochlear-implants>.

3. *Cochlear Implants*, BOSTON CHILDREN’S HOSP., <https://www.childrenshospital.org/treatments/cochlear-implants#:~:text=Children%20can%20receive%20a%20cochlear,years%20old%2C%20earlier%20if%20possible> (last visited Mar. 30, 2023).

children with access to sound is often an amazing prospect for parents, as cochlear implants present the opportunity for their children to communicate orally with them. However, there are many in the Deaf community<sup>4</sup> who believe children should not receive cochlear implants until they at least reach the age of consent.<sup>5</sup> Members of the deaf community regard themselves, their identity, and their interpretation of the world as the norm and believe “deafness opens them up to membership in a community with its own rich history, language, and value system” (often referred to as “Deaf culture”), “rather than as a disability that condemns them to a world of silence”.<sup>6</sup> Many deaf parents with deaf children reject the idea of providing their children with cochlear implants.

Traditionally, decisions about the medical care of minors requires parental and state consent, with the focus being on the “best interest” of the child.<sup>7</sup> This means that parents who choose not to implant their children with cochlear implants have the right to do so. However, in certain jurisdictions the state has the right to intervene in a child’s medical treatment despite parental objections in order to solve “a substantial medical problem.”<sup>8</sup> A “best interest” test is used to help courts decide when this intervention is necessary.<sup>9</sup> Exploring what “best interest” means in a legal context and discussing how it impacts the decision of whether to use cochlear implants on children is important for trying to find a solution to this debate and determining if courts can compel parents to get cochlear implants for their children.

This Note reviews the history of the cochlear implant debate between audiologists and those in the Deaf community and how legislation and the courts have handled pediatric cochlear implants. This Note then looks at how courts interpret “best interest” and discusses how “best interest” can be used in the cochlear implant debate. Part II provides a background of

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4. See Glenn Hladek, *Cochlear Implants, The Deaf Culture, and Ethics*, OHIO UNIV. (July 27, 2009), <https://www.ohio.edu/ethics/2001-conferences/cochlear-implants-the-deaf-culture-and-ethics/index.html> (defining and explaining the Deaf community as a group of people with a shared identity in deafness who also identify with Deaf culture).

5. Serena Byrd et al., *The Right Not to Hear: The Ethics of Parental Refusal of Hearing Rehabilitation*, 121 LARYNGOSCOPE 1800–1804 (2011).

6. Hladek, *supra* note 4.

7. *In re D.R.*, 20 P.3d 166,169 (Okla. Civ. App. 2001).

8. *Id.*

9. *In re C.O.*, 856 P.2d 290, 296 (Okla. Civ. App. 1993).

cochlear implants and the Deaf community. Part III situates cochlear implants within the legal definition of “best interest” and evaluates how it can be used in cochlear implant decisions. It then proposes a possible solution for courts that attempt to intervene using the traditional “best interest” factors. Part IV briefly concludes.

## II. BACKGROUND

According to a study conducted between 1999 and 2007, an estimated two out of every one thousand children in the United States are born with some hearing loss in one or both ears.<sup>10</sup> Because of this, almost all states currently have a process in place to screen newborns for hearing loss before they even leave the hospital.<sup>11</sup> If the newborn fails their first hearing test, the family will then be referred to an audiologist who will perform more detailed hearing tests in order to determine the best plan of action.<sup>12</sup> In particular, audiologists want to work closely with families to ensure that the child’s hearing loss does not interfere with their language development and will not impact their ability to learn.<sup>13</sup> This plan will look different for every family, and will depend on the unique circumstances surrounding each child’s hearing loss. However, one of the most common options presented to parents for children with severe hearing loss is cochlear implants.<sup>14</sup>

### A. COCHLEAR IMPLANTS

A cochlear implant is a surgically-placed electronic device that can help a person who is profoundly deaf process sound.<sup>15</sup> The implant consists of two parts: an external portion that sits

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10. *Quick Statistics About Hearing*, NAT’L INST. ON DEAFNESS & OTHER COMMUN DISORDERS (Mar. 25, 2021), <https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing>.

11. *Hearing Loss in Children*, CTRS. DISEASE CONTROL & PREVENTION (CDC), <https://www.cdc.gov/ncbddd/hearingloss/features/baby-hearing-screening.html> (last visited May 2, 2023).

12. *Id.*

13. *Id.*

14. *Hearing Loss Treatment and Intervention Services*, CTRS. DISEASE CONTROL & PREVENTION (CDC), <https://www.cdc.gov/ncbddd/hearingloss/facts.html> (last visited May 2, 2023) [hereinafter *Hearing Loss Treatment*].

15. *What Are Cochlear Implants?*, NAT’L INST. ON DEAFNESS & OTHER COMMUN DISORDERS, <https://www.nidcd.nih.gov/health/cochlear-implants> (last visited May 2, 2023).

behind the ear and an internal portion that is surgically placed under the skin.<sup>16</sup> The external component of the cochlear implant contains a microphone, a speech processor, and a transmitter.<sup>17</sup> The microphone picks up acoustic sounds and sends it to the speech processor.<sup>18</sup> The processor then analyzes and digitizes the signal before sending it to the transmitter, which codes the signals and sends them to the internal portion of the implant.<sup>19</sup> The internal part of the implant includes a receiver and one or more electrode arrays.<sup>20</sup> The receiver is located under the skin on the temporal bone, which allows it to collect the signals from the transmitter and convert them to electrical pulses.<sup>21</sup> It then sends the pulses to the electrodes, implanted in the inner ear, which stimulate the auditory nerve throughout the cochlea and allow the brain to interpret these signals as sounds.<sup>22</sup> Essentially, cochlear implants allow sounds to bypass damaged portions of the ear and directly stimulate the auditory nerve.<sup>23</sup>

Inserting cochlear implants requires surgery. Cochlear implant surgery can be done either in a hospital or an outpatient clinic, and normally takes between two to four hours.<sup>24</sup> The surgeon makes a cut behind the ear and then opens the mastoid bone.<sup>25</sup> The surgeon will then make an opening between the facial nerves to create access to the cochlea.<sup>26</sup> The electrodes will be implanted into the cochlea and the receiver will then be placed under the skin behind the ear.<sup>27</sup> Then, the surgeon will close the incision and allow time for recovery. Most patients will be released within a few hours of the procedure. Recovery lasts about four to six weeks and then the external parts of the

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16. *Id.*

17. Joy Victory, *Cochlear Implants*, HEALTHY HEARING, <https://www.healthypearing.com/help/hearing-aids/cochlear-implants> (last visited May 2, 2023).

18. *Id.*

19. *Id.*

20. *Id.*

21. *Id.*

22. *Id.*

23. Hearing Loss Treatment, *supra* note 14.

24. Stephen Bowditch, *Cochlear Implant Surgery*, JOHNS HOPKINS MED., <https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/cochlear-implant-surgery> (last visited May 2, 2023).

25. *Id.*

26. *Id.*

27. *Id.*

cochlear implant can be added.<sup>28</sup> Once the external parts are activated and programmed, the internal device is stimulated and the cochlear nerve will begin responding to sounds.<sup>29</sup>

Just like any surgery, there are risks that come with inserting a cochlear implant. Primarily, inserting a cochlear implant destroys any residual hearing in the ear, so the surgery cannot be reversed.<sup>30</sup> Additionally, there is a chance of bleeding, infection, device malfunction, facial nerve weakness, ringing in the ear, and dizziness.<sup>31</sup> Although rare, one long-term risk is meningitis.<sup>32</sup> There have only been ninety-one cases out of 60,000 patients—however, seventeen of the patients with meningitis died.<sup>33</sup> Furthermore, the FDA maintains a relatively extensive list of other risks associated with cochlear implants, including: people with cochlear implants may have their implant fail, may not be able to have some medical examinations (such as MRIs or ionic radiation therapy), will have to use the implant for the rest of their lives (even if the cochlear implant manufacturer goes out of business), may have to make lifestyle changes (including not playing contact sports or having difficulty with cellular phones), and may have many other unknown or uncertain effects.<sup>34</sup>

Cochlear implants can be very expensive, and cost far more than hearing aids.<sup>35</sup> The average cost of cochlear implants can range from \$30,000 to \$50,000 without insurance, however, most major insurance agencies and federal insurance programs do provide coverage for cochlear implants.<sup>36</sup> In fact, all state Medicaid agencies are required to cover cochlear implant costs

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28. *Id.*

29. *Id.*

30. *What to Expect from a Cochlear Implant*, STAN. MED., <https://stanfordhealthcare.org/medical-treatments/c/cochlear-implants/what-to-expect.html#:~:text=The%20standard%20surgical%20risks%20of,the%20fluid%20around%20the%20brain> (last visited May 2, 2023).

31. *Id.*

32. *Id.*

33. *Id.*

34. *Benefits and Risks of Cochlear Implants*, FOOD & DRUG ADMIN. (FDA), <https://www.fda.gov/medical-devices/cochlear-implants/benefits-and-risks-cochlear-implants> (last visited May 2, 2023).

35. *Cochlear Implant Cost*, BOYS TOWN NAT'L RSCH. HOSP., <https://www.babyhearing.org/devices/cochlear-implant-cost> (last visited May 2, 2023).

36. *Id.*

for children under twenty-one.<sup>37</sup> Additionally, some organizations, such as the Disabled Children's Relief Fund, will assist families with limited financial resources and insurance in order to ensure that families who want cochlear implants for their children can access them.<sup>38</sup>

While it is important to remember that cochlear implants are not a cure for deafness, nor can they restore normal hearing, they are a useful communication tool and can provide users with more access to speech information than they would have received with a hearing aid.<sup>39</sup> Due to their beneficial effect on speech development, medical professionals view implantation as early as possible as a critical factor in the success of cochlear implant surgery.<sup>40</sup> In fact, families with a congenitally deaf child hoping to receive cochlear implants should have the implantation surgery before the child is three-years-old in order for them to maximize the benefits of cochlear implants.<sup>41</sup>

#### B. THE COCHLEAR IMPLANT DEBATE

More than ninety percent of children who are born deaf or hard of hearing are born to parents with little to no hearing loss.<sup>42</sup> Finding out that their child is deaf or hard of hearing can be very overwhelming for these parents who have had little to no exposure to deafness. When faced with concerning statistics about their child's future for language development, employment outcome, and other quality of life statistics, cochlear implants can present a solution for these parents.<sup>43</sup>

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37. *Id.*

38. *Id.*

39. *Frequently Asked Questions*, UNIV. CAL. SAN FRANCISCO, <https://ohns.ucsf.edu/otology-neurotology/cochlear-impant-center/faq> (last visited Apr. 8, 2023).

40. 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 & BIOMED. L. 309, 309–10 (2009).

41. See Byrd, *supra* note 5, at 5 (discussing the fact that language and speech development will be significantly delayed if a child with hearing loss does not receive appropriate intervention while their brains are still in a specific stage of development).

42. Cooper, *supra* note 1.

43. See Carrie Lou Gerberoglio et al., *Deaf People and Employment in the United States: 2019*, NAT'L DEAF CTR. (2019), [https://nationaldeafcenter.org/wp-content/uploads/2019/10/Deaf-People-and-Employment-in-the-United-States\\_-2019-7.26.19ENGLISHWEB.pdf](https://nationaldeafcenter.org/wp-content/uploads/2019/10/Deaf-People-and-Employment-in-the-United-States_-2019-7.26.19ENGLISHWEB.pdf) (noting that employment rates for those diagnosed as deaf or hard of hearing was 53.3% in 2019); see also Tom

However, a major subset of the Deaf Community strongly opposes cochlear implants.

### 1. The History of the Deaf Community

Prior to the 1800s, the Deaf community (written with a capital “D” when referring to the culture and community of Deaf people)<sup>44</sup> did not exist in America.<sup>45</sup> Deaf people were widely seen as people with an insurmountable disability and were usually physically and socially isolated from the rest of society.<sup>46</sup> It wasn’t until the first American deaf school was founded in 1817 that deaf people were able to come together in large groups and form a sense of community.<sup>47</sup> It was in these schools that deaf children first began to communicate using hand signs, and sign language began to develop.<sup>48</sup> Today, the Deaf community encompasses about 700,000 Americans,<sup>49</sup> and each year roughly another 1,200 deaf children are born to deaf parents.<sup>50</sup> “Deaf people as a linguistic minority have a common experience of life, and this manifests itself in Deaf culture,” which “includes beliefs, attitudes, history, norms, values, literary traditions, and art shared by Deaf people.”<sup>51</sup>

### 2. The Deaf Culture Movement

The Deaf culture movement is the label given to those within the Deaf community who “rejects the label of deafness as a disability and instead views deafness as a unique cultural

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Humphries et al., *Language Acquisition for Deaf Children: Reducing the Harms of Zero Tolerance to the Use of Alternative Approaches*, 9:16 HARM REDUCTION J. (2012), <https://harmreductionjournal.biomedcentral.com/articles/10.1186/1477-7517-9-16> (noting that the majority of children born with hearing loss will struggle with language acquisition).

44. *Deaf*, DIVERSITY STYLE GUIDE, <https://www.diversitystyleguide.com/glossary/deaf-deaf/> (last visited May 2, 2023).

45. Tia Kilgore, *Exploring the Cochlear Implant Controversy: The Role of and Experience with Deaf Culture for Parents of Pediatric Cochlear Implant Users*, 5(2) URSIDAE J. 27, 30 (2019).

46. *Id.*

47. *Id.*

48. *Id.*

49. Hladek, *supra* note 4.

50. Zimmerman, *supra* note 40, at 316.

51. *Understanding the Deaf Culture and the Deaf World*, THE OUTREACH CTR. FOR DEAFNESS & BLINDNESS, <https://deafandblindoutreach.org/understanding-the-deaf-culture-and-the-deaf-world> (last visited Apr. 16, 2023).



subset.”<sup>52</sup> Members of the movement believe that any disadvantages of being deaf are actually due to social constructs.<sup>53</sup> Indeed, the key talking point of the Deaf culture movement is a view called “Deaf Gain”.<sup>54</sup> Deaf Gain is the concept of “reframing deafness, not as a lack, but as a form of human diversity capable of making vital contributions to the greater good of society.”<sup>55</sup> Moreover, Deaf culturalists frequently compare “their minority status to that of a racial or ethnic group.”<sup>56</sup> It is unclear how many people consider themselves to be a part of the Deaf culture movement, however, it is certain that they comprise a large portion of the Deaf community.<sup>57</sup>

Another significant aspect of the Deaf culture movement is a widely held disdain for cochlear implants, especially when they are used for children.<sup>58</sup> There are several reasons for this belief. Primarily, part of the opposition to childhood cochlear implants is due to concern that many clinicians prioritize the acquisition of hearing above all else, even if it has negative consequences for the child.<sup>59</sup> This bias against deaf or hard-of-hearing individuals is known as medical audism, and many Deaf individuals believe that it is quite prominent in the medical community.<sup>60</sup> Cochlear implants are far from a cure for hearing loss.<sup>61</sup> After surgery, recovery can be extremely challenging and children must undergo extensive therapy to train the brain to interpret the sounds that it has begun to hear.<sup>62</sup> Moreover, a 2020 study of children in the United States who had received cochlear implants reported that ‘half had difficulty expressing ‘many to most’ concepts in spoken English, and 13% didn’t speak English

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52. Zimmerman, *supra* note 40, at 314.

53. *Id.* at 314.

54. Eve G. Pollack, *Comparative Analysis of Deafness and the Deaf Cultural Experience in the U.S. and in Israel*, SENIOR THESES TRINITY COLL. (2020).

55. *Id.* (citing ANNELIES KUSTERS, DEAF GAIN AND SHARED SIGNING COMMUNITIES 285 (H.D. Bauman & J. Murray eds., 2014)).

56. *Id.* at 29.

57. Hladek, *supra* note 4.

58. Chloe Kent, *Audism and the Ethics of Childhood Cochlear Implantation*, MED. DEVICE NETWORK (June 9, 2021), <https://www.medicaldevice-network.com/analysis/audism-cochlear-implants/>.

59. *Id.*

60. *Id.*

61. Kilgore, *supra* note 45.

62. Kent, *supra* note 58.

at all.”<sup>63</sup> Many in the Deaf community compare this to evidence that deaf children who are exposed to sign language as their first language have better spoken language skills, and that children who learn sign language only after being implanted with cochlear implants and failing to acquire spoken language never learn the use of complex grammatical structures.<sup>64</sup> Some in the Deaf community point out that based on this evidence, continuing to encourage the use of cochlear implants is harmful for these children’s ability to develop spoken language.<sup>65</sup>

Additionally, there is fear in the Deaf community that an increased use of cochlear implants will lead to a weakening, and a potential elimination, of Deaf culture.<sup>66</sup> This is because Deaf culture views deafness as birthright, and they perceive cochlear implants as actively depriving congenitally deaf children of that privilege.<sup>67</sup> Some have gone so far as to refer to the increased use of cochlear implants as genocide.<sup>68</sup> This widespread disdain of cochlear implants can even be seen in the ASL sign for cochlear implants, which is a “two-fingered stab to the back of the neck, indicating a ‘vampire’ in the cochlea.”<sup>69</sup> However, today, most members of the Deaf community do not share such extreme views.<sup>70</sup> Despite the continued distrust and disdain for cochlear implants, opposition to pediatric implants has “gradually [given] way to a more nuanced view,” with new emphasis on bilingualism and biculturalism.<sup>71</sup>

### C. PEDIATRIC COCHLEAR IMPLANTS AND THE LAW

The first cochlear implant was implanted in 1961.<sup>72</sup> Despite the many advances and evolutions the implant technology has gone through since then, the law has remained sparse surrounding their use. Legally and ethically, parents have the

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63. *Id.*

64. *Id.*

65. *Id.*

66. Hladek, *supra* note 4.

67. *Id.*

68. Cooper, *supra* note 1, at 470.

69. Bonnie Poitras Tucker, *Deaf Culture, Cochlear Implants, and Elective Disability*, 28 HASTINGS CTR. REP. 6, 9 (1998).

70. Lydia Denworth, *Science Gave My Son the Gift of Sound*, TIME (Apr. 25, 2014), <https://time.com/76154/deaf-culture-cochlear-implants/>.

71. *Id.*

72. Albert Mudry & Mara Mills, *The Early History of the Cochlear Implant: A Retrospective*, 139 JAMA OTOLARYNGOL HEAD NECK SURG. 5 (2013).

right to raise their children according to their own values, and have the right to make whatever medical decisions they think are best for their own children.<sup>73</sup> Any non-emergent medical procedures for minors simply require the consent of a parent or legal guardian, and it is expected that they will have the child's "best interest" in mind.<sup>74</sup> It is typically only when there is a child suspected of being neglected or maltreated that Child Protective Services and other state-funded organizations decide to intervene with parents' medical decisions.<sup>75</sup>

In particular, the few cases involving cochlear implants that courts often see involve medical neglect. Medical neglect is perceived as "the failure to seek, obtain, or follow through with medical care for the child, with the failure resulting in or presenting risk of death, disfigurement, or bodily harm, or with the failure resulting in an observable and material impairment to the growth, development, or functioning of the child."<sup>76</sup> For example, in *Kelly C. v. State of Alaska*, a mother appealed the termination of her parental rights to her daughter who had been removed from her custody for several reasons, including medical neglect.<sup>77</sup> One of the reasons for the Office of Children Services' concern was the child's hearing loss.<sup>78</sup> However, in this case, the court noted that "getting cochlear implants 'is always a difficult decision and [Kelly] had valid criticisms and concerns'" about getting cochlear implants for her daughter.<sup>79</sup> Though the mother lost her parental rights for other reasons, in this case she would have had the right to determine the "best interest" of her child when deciding whether or not to get cochlear implants.<sup>80</sup>

The majority of available caselaw dealing with the cochlear implant debate follows a similar format.<sup>81</sup> These cases were all brought to the court when dealing with situations of medical neglect or child custody, and each case ultimately left the

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73. Byrd et al., *supra* note 5.

74. *Id.*

75. *Id.*

76. *Id.* at 4.

77. *Kelly C. v. State Dep't of Health & Soc. Servs., Off. of Children's Servs.*, No. S-16356, 2017 WL 3122391, at \*8 (Alaska July 19, 2017).

78. *Id.*

79. *Id.*

80. *Id.*

81. See *In Int. of K.S.*, 512 N.W.2d 817, 819–820 (Iowa Ct. App. 1993); *Clupper v. Clupper*, 869 N.Y.S.2d 253, 254 (N.Y. App. Div. 2008); *Moses v. Rosol*, 2019 WL 2145709, at \*5 (Iowa Ct. App. 2019).

cochlear implant decision to the parents.<sup>82</sup> It is clear that, as of today, there is no official stance in any court as to whether or not cochlear implants are legally in the best interest of children, however, there is a definite bias towards giving children cochlear implants.<sup>83</sup>

#### D. WHERE DOES THIS LEAVE US?

The cochlear implant debate has been going on for decades. It has become increasingly more acceptable for those in the Deaf community to choose to get cochlear implants for their children. However, for better or for worse, there is still much controversy in the community surrounding this debate, and there are no clear legal guidelines to help determine whether or not cochlear implants are in the best interest of children. The concept of “best interest” could be helpful in discussing this debate.<sup>84</sup>

### III. ANALYSIS

This Note will evaluate who has the right to decide whether or not a child receives a cochlear implant. Infants and young children do not have the competency to provide informed consent for themselves, so it is necessary for children to have a competent adult to make these medical decisions for them.<sup>85</sup> Typically, this person is the parent or the legal guardian of the child.<sup>86</sup> Therefore, it is generally up to the parent or legal guardian to decide whether or not cochlear implants are in the best interest of the child.<sup>87</sup> However, there is much debate in the Deaf community about whether or not hearing parents can truly make a “best interest” decision about cochlear implants, when

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82. See *K.S.*, 512 N.W.2d at 819–820; *Clupper*, 869 N.Y.S.2d at 254; *Moses*, 2019 WL 2145709, at \*5.

83. See *K.S.*, 512 N.W.2d at 820.

84. See CHILD WELFARE INFORMATION GATEWAY, DETERMINING THE BEST INTERESTS OF THE CHILD 2 (2020), [https://www.childwelfare.gov/pubPDFs/best\\_interest.pdf](https://www.childwelfare.gov/pubPDFs/best_interest.pdf) [[https://web.archive.org/web/20230327015300/https://www.childwelfare.gov/pubPDFs/best\\_interest.pdf](https://web.archive.org/web/20230327015300/https://www.childwelfare.gov/pubPDFs/best_interest.pdf)] (“Although there is no standard definition of ‘best interest of the child,’ the term generally refers to the deliberation that courts undertake when deciding what type of services, actions, and orders will best serve a child as well as who is best suited to take care of the child.”).

85. Hladek, *supra* note 4.

86. *Id.*

87. *Id.*

they have little knowledge about Deaf culture.<sup>88</sup> Moreover, there are also concerns about whether or not a court might be able to compel parents to choose cochlear implants for their children if the court deems it is in the child's "best interest."<sup>89</sup> This section will evaluate how a "best interest" decision is made, and try to address these various concerns by discussing how "best interest" tests can be modified to be used in cochlear implant decisions.

#### A. THE LEGAL DEFINITION OF "BEST INTEREST"

Familial privacy is a fundamental right that is protected by the constitution, as stated by the Supreme Court in *Pierce v. Society of Sisters*.<sup>90</sup> Therefore, it is parents who have the right to make decisions about the care and control of their children.<sup>91</sup> In fact, unless the court determines that the parents have acted with negligence or abuse, they generally have the freedom to make decisions relating to child rearing, education, and health care for their children.<sup>92</sup>

Most jurisdictions do, however, permit state intervention into children's medical decisions when the court deems it is in the child's best interest.<sup>93</sup> Jurisdictions use different frameworks to determine whether the state has subject matter jurisdiction – some jurisdictions only authorize state intervention and order treatment for cases involving emergency or impending death<sup>94</sup> while other jurisdictions expand state authority by ordering medical treatment over parental objections to solve "a substantial medical problem."<sup>95</sup> Cochlear implants clearly fall into the latter category – hearing loss and deafness are often categorized as a substantial medical problem, but hearing loss is not an emergency condition and it does not indicate impending death.

#### 1. State Intervention to Solve a Substantial Medical Problem

Even when a child's life is not at risk, some jurisdictions will permit state intervention to address a substantial medical

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88. Zimmerman, *supra* note 40, at 311.

89. *D.R.*, 20 P.3d at 169.

90. *Pierce v. Soc'y of Sisters*, 45 S.Ct. 571 (1925).

91. *Id.*

92. *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

93. *In re Green*, 292 A.2d 387, 389–90 (Pa. 1972).

94. *Id.*

95. *D.R.*, 20 P.3d at 169.

problem, particularly if the medical issue could result in future harm.<sup>96</sup> For example, *In re Jensen*, an Oregon state appellate decision, considered whether the court had authority to intervene in treating a substantial medical condition that was non-life-threatening, but had the potential to lead to serious medical repercussions.<sup>97</sup> This case involved a 15-month-old child who was suffering from hydrocephalus.<sup>98</sup> The physician recommended a series of operations to relieve the pressure on the child's brain and asserted that this could reduce the chance of medical retardation.<sup>99</sup> Due to their religious convictions, the parents refused the doctor's recommendation.<sup>100</sup> The court held the child was at risk of severe and irreparable brain damage without surgery, and stated that the court may assess not only whether the child's life is endangered, but also whether the child's quality of life is endangered.<sup>101</sup>

Once the court has determined it has the authority to intervene, it will consider whether requiring treatment would be in the child's best interest.<sup>102</sup> There are many different ways for a court to decide what best interest is. Indeed, different jurisdictions adopt a variety of formulas and weigh these factors differently when determining whether mandated treatment would fall within the child's best interest.<sup>103</sup> Some courts determine the child's best interest by considering (1) the severity of the illness and (2) the benefits of treatment against risks and burdens.<sup>104</sup> Some also address (3) the threshold for survival and likelihood treatment will be effective.<sup>105</sup> Finally, some courts adopt a comprehensive approach that includes psychosocial considerations.<sup>106</sup> All jurisdictions and states (including the District of Columbia, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands) have

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96. *Id.*

97. *In re Jensen*, 633 P.2d 1302, 1303–04 (Or. Ct. App. 1981).

98. *Id.* at 1303.

99. *Id.*

100. *Id.*

101. *Id.*

102. Katherine Drabiak, *Resolving Physician-Parent Disputes Involving Pediatric Patients*, 20 HOUS. J. HEALTH L. & POL'Y 353, 357 (2021).

103. *Id.*

104. *Id.*

105. *Id.*

106. *Id.* (defining psychosocial considerations as the child's social and emotional well-being).

statutes describing the factors that must be considered to ensure that decisions regarding a child's custody, or regarding who can make medical decisions for a child, serve that child's best interest.<sup>107</sup>

## 2. STATE INTERVENTION REGARDING COCHLEAR IMPLANTS

Thus far, the courts have said very little on the topic of cochlear implants in children. There are a few cases (mostly family cases and civil suits) that touch on parents' right to choose whether or not to implant their children with cochlear implants. For example: *Kelly C. v. State, Dep't. of Health & Soc. Servs., Off. Of Children's Servs.*,<sup>108</sup> *In Int. of K.S.*,<sup>109</sup> *Clupper v. Clupper*,<sup>110</sup> *Upon the Petition of Lindsay Ann Moses v. Zachary Ray Rosol*.<sup>111</sup> Most of these cases do not even touch on "best interest" regarding cochlear implants, but the few that do mention it do not go into depth about the actual factors that are being considered.<sup>112</sup>

The one case that provides the most analysis of a "best interest" consideration is *Kelly C. v. State, Dep't. of Health & Soc. Servs*<sup>113</sup>. This case notes that in Alaska, a "best interest" analysis may consider "any fact relating to the best interests of the child," and lists several vague examples of considerations such as "the harm caused to the child" or "the history of conduct by or conditions created by the parent."<sup>114</sup> However, this case, as discussed earlier in this Note, addresses a custody determination for a parent who has shown many potential signs of neglect.<sup>115</sup> There is no specific discussion in this case regarding how exactly cochlear implants fit into the "best interest" factors.<sup>116</sup> If there had been, it is questionable whether

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107. U.S. DEPT. OF HEALTH AND HUMAN SERVS., DETERMINING THE BEST INTERESTS OF THE CHILD 1 (2020).

108. *Kelly C.*, 2017 WL 3122391.

109. *K.S.*, 512 N.W.2d 817.

110. *Clupper v. Clupper*, 56 A.D.3d 1064 (N.Y. App. Div. 2008).

111. *Rosol*, 2018 WL 11367203.

112. See *Kelly C.*, 2017 WL 3122391; *K.S.*, 512 N.W.2d 817; *Clupper*, 56 A.D.3d 1064; *Rosol*, 2018 WL 11367203.

113. *Kelly C.*, 2017 WL 3122391, at \*7-\*8.

114. *Id.*.

115. See *supra* Part II.C.

116. *Kelly C.*, 2017 WL 3122391.

the typical “best interest” factors would have applied to cochlear implant cases.

The first factor to consider is the severity of the illness. However, it is important to note that it is uncertain if deafness can be considered an illness.<sup>117</sup> There are many who consider it to be a culture and a community, and some consider it to be a handicap.<sup>118</sup> But an illness is not the typical classification.<sup>119</sup> However, severity of deafness generally could certainly be a consideration – the more severe the hearing loss, the more beneficial a cochlear implant could be for the child. Moreover, if the child already has profound hearing loss, there is no real cause for concern about the child losing their residual hearing.<sup>120</sup> The second consideration is a cost-benefit analysis of the treatment itself.<sup>121</sup> This is a more difficult discussion for courts to have, however based on the discussion in Part I, there are a large number of benefits to cochlear implants, and a large number of risks. However, if this were to be a consideration in discussing “best interest” for cochlear implants, it is likely that the discussion would need to look individually at the child being considered, and a court would likely need to consult with medical experts. Finally, the third consideration that courts often make is an evaluation of the threshold for survival and the likelihood that the treatment will be effective.<sup>122</sup> This discussion could be changed slightly for cochlear implants, given that they do not typically deal with a risk of fatality.<sup>123</sup> Additionally, modern cochlear implants are fairly effective, and it is rare that they

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117. Zimmerman, *supra* note 40, at 314-17

118. *Id.*

119. Christina Kim, *Deafness: More than a Medical Condition*, YALE SCI. (Mar. 3, 2016), <https://www.yalescientific.org/2016/03/deafness-more-than-a-medicalcondition/#:~:text=The%20state%20of%20being%20%E2%80%9Cdeaf,a%20capital%20%E2%80%9CD%E2%80%9D>.

120. *See generally* Bowditch, *supra* note 24 (listing the risks of cochlear implant surgeries, which does not include residual hearing); *see also* Amit Walia, et al., *Is Characteristic Frequency Limiting Real-Time Electrocochleography During Cochlear Implantation*, 16 FRONTIERS NEUROSCIENCE 2022 (discussing the difficulties patients with residual hearing may face with cochlear implant surgery, but not the difficulties those without residual hearing would have).

121. *See generally* Drabiak, *supra* note 102 (noting that some courts determine the child’s best interest by considering the benefits of treatment against risks and burdens).

122. *Id.*

123. *See generally* Bowditch, *supra* note 24 (listing common risks of cochlear implant surgeries, which do not include fatality).



have any defects.<sup>124</sup> However, there are some situations where they do not function properly or are not effective in improving the patients' hearing, and these would be relevant considerations in making a decision about cochlear implants.<sup>125</sup>

These factors then, could probably be used in a case considering state intervention for a family considering cochlear implants for their child. However, it seems that they might warrant a more nuanced consideration before moving forward.

## B. APPLYING THE BEST INTEREST FACTORS TO COCHLEAR IMPLANTS

The “best interest” test does seem to be applicable to the cochlear implant discussion, however, if it is going to be successfully used for non-fatal medical concerns, it will likely need some adjustments. There are four factors that I propose should be applied to “best interest” cases that deal with state intervention for substantial medical problems that are not life-threatening, particularly when dealing with cochlear implants. These factors are (1) the severity of the medical condition; (2) the likelihood that the treatment will be effective; (3) the benefits of the medical procedure against risks and burdens; and (4) a cost-benefit analysis of the quality-of-life factors.

### 1. The First Factor

The first factor – the severity of the medical condition – is essentially the same factor that is already used in standard “best interest” considerations.<sup>126</sup> However, this analysis uses the term “medical condition” instead of “illness.”<sup>127</sup> When dealing with situations like deafness, it is difficult, and sometimes seen as offensive, to classify the condition as an illness.<sup>128</sup> Making this change in terminology opens the door to other “best interest”

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124. See Jamie Berke, *How Likely Is Cochlear Implant Failure?*, VERYWELLHEALTH (Jan. 21, 2022), <https://www.verywellhealth.com/cochlear-implant-failure-reimplantation-1046199#:~:text=A%2010%2Dyear%20retrospective%20analysis,cochlear%20implant%20are%20pretty%20high> (noting that just seven percent of CIs in the last 10-years have experienced a malfunction).

125. See Bowditch, *supra* note 24 (listing the risks that may arise with cochlear implant surgery).

126. See Drabiak, *supra* note 102 (noting that “best interest” tests often consider the severity of the illness).

127. *Id.*

128. Zimmerman, *supra* note 40, at 314-17.

considerations for medical conditions that many people would not classify as an illness, but that medical professionals believe could benefit from medical intervention. For example, Autism is a medical condition that is not considered to be an illness, however, most children diagnosed with Autism benefit from certain medical interventions.<sup>129</sup> While this language doesn't make much of a difference in terms of the court's considerations, it does help extend the legal definition of what medical conditions can be considered for state intervention, which would be beneficial when incorporating cochlear implants into the discussion.

## 2. The Second Factor

The second factor – the likelihood that the treatment will be effective – is part of one of the original “best interest” factors.<sup>130</sup> It is important that a medical procedure only be performed if it will actually be effective for a child, because any medical procedure comes with risks. While it is not always possible to predict whether medical treatments will be successful, there are different factors and statistics that medical professionals can use to predict the effectiveness of a treatment.<sup>131</sup> If there is a large statistical probability that the treatment will be effective, then the court should definitely take that into consideration.

## 3. The Third Factor

The third factor – the benefits of the medical procedure against the risks – is also the same as one of the original “best interest” factors.<sup>132</sup> No matter what type of medical condition is being considered, it is important to understand both the risks and the benefits of the medical treatment. No sound decision can be made unless both of these considerations are carefully weighed against each other.

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129. *What is Autism?*, NAT'L HEALTH SERV., <https://www.nhs.uk/conditions/autism/what-is-autism/#:~:text=Autism%20is%20not%20an%20illness,not%20until%20you're%20older> (last visited Apr. 23, 2023).

130. Zimmerman, *supra* note 40.

131. UNIV. CAL. SAN FRANCISCO, *supra* note 39.

132. Zimmerman, *supra* note 40.

#### 4. The Fourth Factor

Finally, the fourth factor – a cost-benefit analysis of the quality-of-life factors – should be added to any consideration for whether a state should intervene in a family’s decision for medical treatment. This is a new consideration, but it is an essential one when dealing with serious medical conditions that are non-life-threatening. In situations that are life-or-death, the court has a very specific decision to make. They are trying to decide whether they intervene to save a life, or leave the situation alone in respect of the personal beliefs of the child and family. While it is a difficult decision, it is not the same as the decisions being made in a case that deals with non-life-threatening conditions. In a situation such as a cochlear implant case, courts are deciding what quality of life a child will have with cochlear implants as opposed to without them.

“Quality-of-life” is defined by the World Health Organization as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.”<sup>133</sup> Traditional factors include wealth, employment, the environment, physical and mental health, education, recreation, and leisure time, social belonging, religious beliefs, safety, security, and freedom.<sup>134</sup> Therefore, there are many components that can go into a quality-of-life discussion – the child’s ability to learn, their future job prospects and earning potential, their ability to function in society, their ability to communicate, their ability to care for themselves, their family’s cultural values and belief systems, etc.<sup>135</sup> This myriad of factors can be considered by a court when deciding what quality-of-life the child might have with or without cochlear implants.

Having a quality-of-life discussion is an important addition to the “best interest” evaluation, because it can show extreme variations depending on the family being considered, and can make the ultimate determination as to whether a family should be compelled to choose a certain medical treatment for their child. What may be a very careful cultural decision for one family

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133. *The World Health Organization Quality of Life (WHOQOL)*, WORLD HEALTH ORG. (Mar. 1, 2012) <https://www.who.int/publications/i/item/WHO-HIS-HSI-Rev.2012.03>.

134. *Id.*

135. *Id.*

may actually be medical neglect for another family, and it is up to the court to make that distinction. Therefore, courts should carefully consider all factors that can contribute to the child's quality of life when deciding whether or not the child should be compelled to undergo a particular medical treatment.

### C. APPLYING THIS TEST TO THE COCHLEAR IMPLANT DEBATE

To see this new test in action, this Note will apply the test to the facts of *Kelly C. v. State of Alaska*. In this case, a mother was appealing the termination of her parental rights to her daughter who had been removed from her custody for several reasons, including medical neglect.<sup>136</sup> One of the reasons for their concern was the child's hearing loss.<sup>137</sup> However, in this case, the court noted that "getting cochlear implants is always a difficult decision and [Kelly] had valid criticisms and concerns" about getting cochlear implants for her daughter.<sup>138</sup>

If the court were to apply this Note's modified best interest test to this case, then they would first need to look at the severity of the daughter's hearing loss. The facts of this case do not specify the degree of the child's hearing loss, but it is labeled as severe and physicians have recommended cochlear implants to improve the hearing.<sup>139</sup> Therefore, her hearing loss would qualify for cochlear implants, and there would be little concern about a loss of residual hearing.

The next consideration would be the likelihood of the cochlear implants being effective for the child. It is unclear from this case whether the doctors believe cochlear implants will be entirely effective, as there are no doctors notes included in the case. However, it is relevant to note that the child suffers from many other medical issues and while the child may gain hearing from the cochlear implants, it does not seem clear that it would aid in her language development. However, it is clear that doctors have recommended cochlear implants, so it is likely that they believe the child will derive some benefit from the implants.<sup>140</sup>

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136. *Kelly C.*, 2017 WL 3122391, at \*2.

137. *Id.*

138. *Id.* at \*8 (internal quotations omitted).

139. *Id.* at \*1–\*2.

140. *Id.* at \*2.

Next, a court would need to weigh the risks of the medical procedure against the benefits of the procedure. As discussed earlier in this Note, there are risks with cochlear implant surgeries.<sup>141</sup> Not only will inserting a cochlear implant destroy any residual hearing, the surgery also comes with the risk of bleeding, infection, device malfunction, facial nerve weakness, ringing in the ear, and dizziness.<sup>142</sup> Though the benefits of the cochlear implants would include improved hearing, and increased access to speech and language, this child in particular has quite a few medical conditions that may already impede her ability to communicate. While better hearing might help the child communicate better, the court would likely need to defer to a doctor to determine how much benefit hearing would provide to the child, and to determine if the child's additional medical conditions would have any impact on the risks of a cochlear implant surgery.

Finally, a court would need to conduct a cost-benefit analysis of the quality-of-life factors for the child. It is important to note that in this case, the mother had made the choice to have her child learn sign language and be a part of Deaf Culture.<sup>143</sup> She stated that she thoroughly researched the choice and decided that not using cochlear implants was the right choice for her child.<sup>144</sup> In this case, the court would need to see proof that the mother, and other family members, were making an effort to incorporate this decision into the child's life. Additionally, the child in this case has been removed from her family for many reasons, so it would be important to consider where she would ultimately be placed and which decision would fit best with the ultimate placement. Ultimately, the Court's final decision would need a lot more information, however, these considerations would help the court make a decision that is truly best for the child.

Indeed, when applied to the cochlear implant debate, the "best interest" test highlights the fact that neither side holds the right answer. Each family's situation is unique, and while one deaf child might benefit from cochlear implants, another might do even better without them. The essential issue with the debate

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141. STAN. MED., *supra* note 30.

142. *Id.*

143. *Kelly C.*, 2017 WL 3122391, at \*1

144. *Id.* at \*8.

is that both sides tend to take an all-or-nothing approach to the question. When using a modified version of the “best interest” test to structure a discussion, it is easy to see that both sides of the debate lose ground, and there is no one right solution. If this modified test becomes a part of the conversation, with the courts acting as a safeguard, when necessary, this Note is hopeful that the cochlear implant debate will slowly be laid to rest as each family is able to make whatever decision is right for them.

#### IV. CONCLUSION

Ultimately, a “best interest” test can be used to help courts decide when intervention is necessary in a family’s decision regarding cochlear implants.<sup>145</sup> In jurisdictions where the state has the right to intervene in a child’s medical treatment despite parental objections to solve “a substantial medical problem,”<sup>146</sup> the modified “best interest” test can help courts evaluate the substantial medical problem in a way that doesn’t consider life-or-death concerns. It can instead focus on quality-of-life and the risks and benefits of the treatment itself, which are essential considerations for non-fatal medical treatments. In custody cases where parents do not wish for their children to have cochlear implants, but the state feels otherwise, the courts can use this test to determine how beneficial cochlear implants would really be for the child.

Second, this modified test can help structure conversations surrounding the cochlear implant debate and remind both sides that this is not an all-or-nothing conversation. Each family is unique, and while cochlear implants might work in one situation, they might not in another. It is not a debate that will ever be decided with one overarching decision, but hopefully, with time it will become a less contentious conversation.

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145. *D.R.*, 20 P.3d at 169.

146. *Id.*

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