

Deafness, Cochlear Implants, and the Right to Live as Ethnicity: Negotiations of Deaf Culture and Policy in Children's and General Literature

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Imagine you are a member of a cultural and linguistic minority, for instance, a Native American in the current United States. In the not-too-distant past, your community has faced severe cultural discrimination, and some of this has survived to this day. The use of your language used to be forbidden, and so were some of your cultural practices and traditions. Legislation was suggested that would allow for sterilization of community members to stop them from procreating, and that would illegalize innercommunity marriages. Today, after a long and difficult struggle, you have finally found a strong voice for yourself as a community and have gained the right to use and be schooled in your language, as well as for your community to be acknowledged as a cultural minority. You are proud of your cultural identity and of the strength and endurance that have led your community to where it is now. At the same time, members of your community still fare worse than those of the majority culture: It is harder for them to successfully complete their education, find a good job, or achieve the level of material success that members of the larger community average. Partly, this is down to social discrimination, partly it is a consequence of being a minority surrounded by another culture whose members speak a different language.

Now imagine: A newly invented computer chip—hailed as the harbinger of social equality—which can be implanted into the heads of the children in your community allows them to speak the majority language, and to thus become part of majority culture. What would be the consequences of a widespread implantation practice? Your children may not be subjected to discrimination on the same scale as you are—if the implant works effectively, that is, which it does not always do—and will most likely be able to prosper. For your community, however, the effects are likely to be devastating: Your children may still learn your language but, as adults, will be less likely to use it as a native language, and even less likely to pass it on to their children. Not able to understand your language, they will not be able to fully take part in your cultural traditions anymore. Within two generations, the size of your community is going to dwindle. As the community diminishes, opportunities for

those who remain in it will grow smaller, making it even more likely for future parents to decide for their children to be implanted with the chip.¹

Let's leave this analogy (which I borrowed from Robert Sparrow from the Centre for Human Bioethics, Monash University) and return to real life. As some readers may have guessed, the inspiration for the analogy is drawn from the debate over cochlear implantation of deaf children; the language chip used in the analogy is a substitute for the cochlear implant. Cochlear implants (CIs) are medical devices which can give (some) deaf people a sense of hearing.² CIs tend to be most successful when implanted within up to four years after hearing loss in post-lingual individuals; with pre-lingually deaf children, cochlear implants are recommended to be implanted within the first two years of their lives—in other words: At a time in their lives where the patients themselves cannot give their informed consent. There are varied reports and studies about CIs' effectiveness (mostly, but not exclusively positive) but there is no reliable method of predicting individual success other than statistic correlation. In the context of the Deaf³ community's struggle for recognition as a cultural and/or ethnic minority, and for the right to live as such, CIs take on a pivotal role. The "end" of deafness they promise does not, to the Deaf community, equate the end of a form of disability, but instead, the end of a vibrant, tradition-steeped, and prolific culture: Cochlear implants are regarded as a threat to the right to live as ethnicity.

After introducing the controversies surrounding the use of CIs and their rootedness in the struggle for and over Deaf culture and identity, this paper will discuss how literary characters wearing cochlear implants are used to negotiate Deaf culture in children's literature. I will argue that, while characters with cochlear implants are rare exceptions in general literature (as are, in fact, deaf characters in general), children's literature dealing with deafness more frequently features CI-characters. At the same time, children's authors seem to be well aware of the heatedness of the discussion surrounding cochlear implants within the Deaf

¹ See Robert Sparrow: *Implants and Ethnocide: Learning from the Cochlear Implant Controversy*, in *Disability and Society* 25/4 (2010), pp. 456–458.

² Cochlear implants only work in patients whose deafness is rooted in their inner ear (i.e. not, for instance, for patients with a profound sensorineural hearing loss, which originates in the brainstem).

³ The category "deaf" (with a lower case "d") is used as a generic term for any individual with impaired hearing. In contrast, "Deaf" (with a capital "D") signifies membership to what is considered Deaf culture, i.e. the notion that being deaf does not imply being inferior or lacking in any sense (see e.g. Sharon Pajka-West: *Representations of Deafness and Deaf People in Young Adult Fiction*, in: *M/C Journal* 13 (3), 2010. <http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/261>, last accessed on Dec, 15, 2016, p. 39).

community, and most novels follow a strategy of avoidance, giving equal space to both sides of the argument and staying clear of any ideological positioning themselves.

Cochlear Implants and the Deaf Community

From its beginnings in the 1970s, the cochlear implant has been met with widespread criticism and often outrage from the Deaf community. Implantation practices have been likened to or explicitly called genocide and ethnocide, and the implant's mere existence been thought of as audist, ableist, and highly discriminatory towards the Deaf.⁴ To a hearing audience, this strong opposition may seem puzzling, and to understand it, one needs to understand the Deaf community's self-identification: Many Deaf people do not regard themselves as disabled but consider themselves members of a cultural and linguistic minority. In their eyes, deafness is nothing that needs to be cured or fixed; rather, it is something in whose traditions, sense of community, and homogenizing tolerance one can (and should) be proud of.⁵ The Deaf community has its own language – and sign language, contrary to previous beliefs, is in fact a language in its own rights⁶ –, their own cultural traditions and artistic representations. As the alternatively admired and condemned character Stella in the young adult novel *Whisper* argues: "To be deaf is to be part of a culture. [...] We need to nurture our culture. We need to build our own society and make rules of our own. We can't trust the hearies to make rules for us."⁷ Instead of defining themselves as speech or hearing impaired, Deaf individuals emphasize their bilingualism and biculturalism (an emphasis expressed in many examples of children's books dealing with deafness, too⁸): "Deaf culture represents not a denial but an affirmation".¹⁰

⁴ See Harlan Lane: *Cochlear Implants: Their Cultural and Historical Meaning*, in: *Deaf History Unveiled*, ed. by J. Van Cleve, Washington, 1993, pp. 272–291; and Harlan Lane, *The Cochlear Implant Controversy*, in: *World Federation of the Deaf News* 2/3 (1994), pp. 22–28.

⁵ See Stuart Blume: *The Artificial Ear: Cochlear Implants and the Culture of Deafness*, New Brunswick 2009; and Robert A. Crouch: *Letting the deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children*, in *The Hastings Center Report* 27/4 (1997), pp. 14–21.

⁶ See Clayton Valli/Ceil Lucas: *Linguistics of American Sign Language: An Introduction*, Washington, D.C. 2000 [1992].

⁷ Chrissie Keighery: *Whisper*, Dorking 2011, p. 155.

⁸ See e.g. Julia Jones: *The Salt-stained Book*, Chelmsford 2011, p. 98.

⁹ For more detailed discussions of Deaf culture, the medical and social model of deafness see e.g. Edward Dolnick: *Deafness as Culture*, in *The Atlantic Monthly* 272/3 (1993), pp. 37–53; Paddy Ladd/Harlan Lane: *Deaf Ethnicity, Deafhood, and their Relationship*, in *Sign Language Studies* 13/4 (2013), pp. 565–579; Harlan Lane/Richard C. Pillard/Ulf Hedberg: *The People of the Eye: Deaf Ethnicity and Ancestry*, Oxford 2011; Richard Clark Eckert: *Toward a Theory of Deaf Ethnos: Deafnicity ≈D/deaf (Hómaemon. Homóglsson. Homóthreskon)*, in *Journal of Deaf Studies and Deaf Education* 15/4 (2010), pp. 317–319; Debbie B. Golos/Annie M. Moses: *Representations of Deaf Characters in Children's Picture Books*, in *American Annals of the Deaf* 156/3 (2011), pp. 270–282; The viewpoint of many late-deafened individuals and their appreciation of technological advancements such the cochlear implant, on the other hand, is summed up by Bonnie Poitras Tucker: *Deaf Culture, Cochlear Implants, and Elective Disability*, in *The Hastings Center Report* 28/4 (1998), pp. 6–14.

¹⁰ Dolnick: *Deafness as Culture*, p. 43.

Many Deaf Studies scholars argue the existence of what Valente has called a Deaf epistemology, i.e. a specific way of thinking and of perceiving the world, that is not secondary to a phonocentric epistemology.¹¹ Harlan Lane,¹² Richard C. Pillard and Ulf Hedberg,¹³ Paddy Ladd, and Joseph Murray¹⁴ (as well as, in the German context, Anne Uhlig¹⁵) have pointed out the characteristics that allow for the Deaf community's claim for an ethnic identity, what Richard Clark Eckert has called "Deafnicity":¹⁶ The existence of a common language (ASL), distinct shared cultural traditions and artefacts, shared (adopted) ancestry, and a sense of group identity that "trumps any other aspect of [...] identity."¹⁷

Let's think back to our analogy from the start of this paper, in which I drew up the image of a discriminated cultural minority. If we follow the idea of a Deaf ethnicity (or even of a separate cultural identity of the Deaf community), the main difference between the Deaf and other ethnic communities is that deaf children are not automatically born into deaf families: Only about every tenth deaf child also has deaf parents, which means that nine out of ten deaf children are born into hearing families, most of whom will not have had any previous knowledge of or acquaintance with the Deaf world. It is therefore, I would like to argue, highly understandable that these parents try to do as much as they can to keep their children within their own cultural reach. Often, this results in parents consenting to cochlear implantation.

From the Deaf community's perspective, however, these children are denied their cultural rights: Not only are they subjected to a highly invasive medical procedure with a (more or less) unknown outcome, they are also denied access to Deaf culture.¹⁸ In theory, they can join majority—hearing—culture, but in reality, they will not suddenly become

¹¹ See Joseph Michael Valente: *Cyborgization: Deaf Education for Young Children in the Cochlear Implantation Era*, in *Qualitative Inquiry* 17/7 (2011), p. 644.

¹² Paddy Ladd/Harlan Lane: *Deaf Ethnicity, Deafhood, and their Relationship*, in *Sign Language Studies* 13/4 (2013), pp. 565–579.

¹³ Harlan Lane/Richard C. Pillard/Ulf Hedberg: *The People of the Eye: Deaf Ethnicity and Ancestry*, Oxford 2011.

¹⁴ Joseph J. Murray: *Insights into Deaf History*, in *Sign Language Studies* 14/1 (2013), pp. 125–129.

¹⁵ Anne C. Uhlig: *Ethnographie der Gehörlosen: Kultur – Kommunikation – Gemeinschaft*, Bielefeld 2012.

¹⁶ Richard Clark Eckert: *Toward a Theory of Deaf Ethnos*

¹⁷ Jason Norman, as quoted in Susan Seligson: *Should the Deaf Be Considered an Ethnic Group? Med Prof*, co-authors *bolster case for culturally distinct "Deaf World"*, in *BU Today*, web, last accessed on Dec 14, 2016.

¹⁸ Following studies such as Ann E. Geers, Johanna G. Nicholas, and Allison L. Sedey's *Language Skills of Children with Early Cochlear Implantation* (in *Ear & Hearing* 24/1 (2003), pp. 46–58), parents are often advised against using sign language with their cochlear implant-using child, fearing that immersion into sign language may slow down or even halt the latter's acquisition of spoken language.

hearing:¹⁹ They will be hearing-impaired, trying to navigate a world that is not cut out for their needs, with no or little guidance from and contact with other deaf individuals. At the same time, because many of these children are mainstreamed in public education, schools for the deaf are closing down. This is a particular problem in terms of enculturation of deaf children from hearing families because deaf schools are one of the most important factors in deaf socialization and, in the absence of deaf family members, are a focal point of entry into the deaf world.²⁰ As the numbers of cochlear implant users rise, the size of the Deaf community dwindles and, along with its traditions, its language and cultural output, comes into danger of declining altogether.²¹

Literary Negotiations of the CI-Debate

Excluding life-writing texts, deafness in general and questions over cochlear implantation in particular play a highly marginal role in literary texts.²² Non-biographical novels that do feature characters with a cochlear implant are mostly romance, and their literary quality is questionable.²³ However, there is one area in which deaf characters have been appearing much more frequently in the last few years, and which has seen quite explicit discussions of

¹⁹ Contrary to common belief, cochlear implants do not “cure” deafness: Although they enable users to understand speech and decipher environmental sounds, they only substitute for hearing, creating sound that, as the narrator of *Whisper* puts it, appears “kind of robotic” (Keighery 21). For a demonstration of the quality of sound achievable through cochlear implantation, see the YouTube-video “Cochlear Implant: Simulation on Speech and Music”, <https://www.youtube.com/watch?v=SpKKYBkJ9Hw>. Implantees need to go through extensive speech and auditory therapy and training after they have received the implant, and even after successful implantation and therapy will most likely not be able to achieve full hearing. For an overview of the therapy needed after cochlear implantation, see e.g. Amy McConkey Robbins: “Rehabilitation after Cochlear Implantation”, in: *Cochlear Implants: Principles and Practices* (ed. John K. Niparko), Philadelphia et al. 2009, pp. 269–312; David R. Moore/Robert V. Shannon: *Beyond Cochlear Implants: Awakening the Deafened Brain*. In: *Nature Neuroscience* 12 (2009), pp. 686–691. Mary O’Leary Kane, Shelley Howard-Robinson, Jennifer L. Mertes and Christa Lopez Tamparong discuss the special attention which implanted children should (but do not always) receive in the classroom (*Classroom Strategies for Early Learners with Cochlear Implants*, in *Cochlear Implants: Principles and Practices* (ed. John K. Niparko), Philadelphia et al. 2009, pp. 323–334).

²⁰ A rather striking analogy is sometimes drawn up by deaf literature enthusiasts: To many deaf children, their deaf school serves as a kind of Hogwarts. Just like Harry Potter is born into a Muggle family, always conscious of his being different, and faced with an uncomprehending and intolerant environment, many deaf children born into hearing families first really feel at ease and truly belonging into the Deaf environment in deaf boarding schools.

²¹ To the Deaf community, this development is particularly troubling in the light of their historical discrimination (see e.g. Donna F. Ryan: *Deaf People in Hitler’s Europe: Conducting Oral History Interviews with Deaf Holocaust Survivors*, in *The Public Historian* 27/2 (2005), pp. 43–52; Tom Humphries: *Our Time: The Legacy of the Twentieth Century*, in *Sign Language Studies* 15/1 (2014), pp. 57–73; Joseph J. Murray: *Insights into Deaf History*, in *Sign Language Studies* 14/1 (2013), pp. 125–129; and Susan Burch: *Signs of Resistance: American Deaf Cultural History, 1900 to 1942*, New York, 2002).

²² See Edna Edith Sayer for an overview of deafness in general literature (*Outcasts and Angels: The New Anthology of Deaf Characters in Literature*, Washington, D.C., 2012).

²³ See e.g. Jill Templeton: *Picture Words: A Love Story*, Minneapolis 2013; Neesa Hart: *A Kiss to Dream On*, New York 2013; Teresa J. Reasor: *Whisper in My Ear: No Sound more Beautiful than Love*, Korbin 2015.

cochlear implantation and questions of Deaf ethnicity and identity: literature for children and young adults.

As the inclusion of deaf characters in children's literature has become more frequent, the number of characters with a cochlear implant has been rising, too. Interestingly, however, apart from those books clearly intended to educate young readers about cochlear implantation,²⁴ very few of the novels feature a protagonist actually wearing an implant, and I argue that this is a conscious strategy of avoidance which is very aware of the fact that Deaf readers might object to and reject an implantee as a protagonist. This strategy of avoidance is countered by many novels' clear exemplification of the controversy around the implants: In *Strong Deaf*, for instance, a young adult novel narrated alternately from the point of view of the deaf and the hearing daughter of a Deaf family, the Deaf community's resentment of cochlear implants and its pride in Deaf culture are highlighted in the deaf mother's response: "Why would I want to hear?", she asks when confronted with the possibility of cochlear implantation.²⁵ The community's concerns are also highlighted in her hearing daughter's evaluation of the discussion around the implants: "I'd heard talk about cochlear implants like they were evil mind-controlling devices. The sign for cochlear implant is just like the sign for vampire, only at the back of the head."²⁶

Like *Whisper*, the young adult novel *Five Flavors of Dumb*, set in Seattle and following deaf high school student Piper's attempts at managing a rock band, focuses on interfamilial as well as –societal struggles over deafness: Coming from a family with a history of deafness and herself severely deaf, protagonist Piper can get by in most situations with the help of her hearing aids and the "Olympic precision" of her lip-reading.²⁷ Her baby sister Grace was born profoundly deaf, however, and their parents have decided for her to get a cochlear implant. Piper feels ambiguously about this decision: She already feels jealous of how much time and fuss her parents spend on Grace, and on top of this sibling rivalry, is also partly envious of her sister's chance of leading a "normal" life. More importantly, however, she mourns the loss of the possibility of a closer bond with her sister—one that she thought

²⁴ See e.g. Susanna Dussling: *Sunny and her Cochlear Implants*, Bloomington, 2010; Elizabeth Boschini/Rachel Chaikof (ill.). *Ellie's Ears*, New York, 2008; Maureen Cassidy Riski. *Abby Gets a Cochlear Implant*, New York 2008.

²⁵ Lynn McElfresh: *Strong Deaf*, South Hampton, 2012, p. 64.

²⁶ Ibid. 65.

²⁷ Anthony John: *Five Flavors of Dumb*, New York 2010, p. 17. Deaf characters being champion lipreaders is a common trope in literature featuring deaf characters. As Edna Edith Sayers points out, this quite regularly results in wildly inaccurate depictions of lipreading (e.g. in the dark or in poor lighting, in a foreign language, when the speaker is turning away from the character etc., see *Outcasts and Angels: The New Anthology of Deaf Characters in Literature*. Washington, D.C., 2012).

would be strengthened by their shared experience of deafness—, and fears that Grace might grow up without any significant involvement with Deaf culture.

Importantly, however, the Deaf community's concerns about cochlear implants are most strongly supported (or assumed to be supported) by two absentees: the sisters' dead grandparents, who were both profoundly deaf, and very proud of Deaf culture: "Grace's implant would have been so divisive [...]. I think they would have been ashamed of Mum, and I think she knew it too",²⁸ Piper sums up her expectation of her grandparents' reaction to Grace's implant. By including only the memory of the grandparents and the suspicion of their disapproval rather than featuring an actual confrontation with the Deaf culture they represent, *Five Flavors of Dumb* avoids too deep an involvement in ideological aspects of the controversy: The frontlines of the discussion are set and detailed but the actual confrontation does not get fought within the pages of the novel itself.

Construction of normalcy is a recurring topic in many children's novels, and in a roundabout way, what Valente has called "phonocentric colonialism"²⁹ of deaf people is broached that way: Struggles over who is allowed control and power of definition and attribution over the deaf child.³⁰ In that context, cochlear implants are configured as both a hope for and an obstacle to what might be construed as normalcy: In *Whisper*, a young adult novel about late-deafened teenager Demi's coming to terms with her deafness, the protagonist wonders whether she would "seem less normal rather than more" if she had an implant.³¹ What is evoked here is Lennard J. Davis's and Rosemary Garland Thomson's notion of disability as a specular moment, as an outsider's recognition of another individual as disabled:³² Without a CI, Demi can pass as hearing. Wearing the cochlear implant would mark her as recognizably disabled (even though, in daily life, it would make her feel *less* disabled).

Technical and medical drawbacks are also highlighted in many novels' treatment of cochlear implants: In *Whisper*, Demi does not get a CI partly because of the risk of an

²⁸ Ibid. p. 48.

²⁹ The employment of postcolonial concepts and terminology within Deaf and Disability Studies and in other theoretical contexts has been criticized by scholars such as Shaun Grech, who have pointed out that talking about disabled bodies as colonized (by ableism) equates a careless de-historicization, and have warned against using (post-)colonial concepts as metaphors of Eurocentric discourses (see *Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate*, in: *Social Identities* 21 (1), 2015: pp. 6–19).

³⁰ See Joseph Michael Valente: *Cyborgization*, p. 642.

³¹ Chris Keighery: *Whisper*. Dorking 2011, p. 244.

³² Lennard J. Davis: *Enforcing Normalcy: Disability, Deafness, and the Body*, New York 1995, p. xvi; Rosemary Garland-Thomson: *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, New York 1997, p. 26.

infection, and in *Ketchup Clouds*, Dot, the protagonist's deaf sister, has had to have her implant removed because of an infection. The continued discrimination and struggle for inclusion after implantation are highlighted in *Whisper*, when a CI-wearer complains:

[T]he PE teacher thinks I disobey her on purpose. That now I have a cochlear implant, I should be able to hear her. [...] It's not true. [...] My hearing's not that much better, even with the cochlear. I haven't had it for very long, so I haven't really learnt how to interpret sounds properly yet. Sometimes it makes it harder to figure out what's going on. But she says I'm just making up excuses.³³

Many Young Adults novels featuring cochlear implants are eager to show both sides of the argument. They are careful not to present a too favorable impression by for instance having the protagonist wear an implant and to thus have to actively deal with possible communication problems, discrimination, medical and technical issues but instead include minor characters with functioning implants and those struggling with theirs. Many novels thus follow a strategy of avoidance: Technical and medical problems as well as the Deaf community's concerns about cochlear implants are thematized; at the same time, the novels are careful not to veer too far towards what could be considered a negative portrayal of the implants by highlighting these issues. The right to live as ethnic minority is being quite actively defended in children's literature. In contrast, excluding life writing texts, deafness has barely arrived in general literature, and the literary negotiation of what might constitute deaf ethnicity is still more or less closed.

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³³ Ibid. p. 209.

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