

Cochlear Implants and Identity Politics: A Parent's Perspective

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ABSTRACT

Most deaf children (90%) are born to hearing parents and yet hearing parents are largely missing from the literature on both sides of the cochlear implant debate. The scientific papers and books are written by professionals for other professionals, or by professionals to share expert advice and opinions on how to parent a deaf child with parents of deaf children. The arguments presented by the Deaf community and disability theorists are open to a wider audience but again tend to focus on explaining a particular position in which the hearing parent is 'othered' as a potential threat to the Deaf community. There are some studies which explore the ways in which parents make decisions about cochlear implantation for their children but these tend to address practical issues rather than the theoretical arguments for and against implantation. This paper seeks to redress the balance and provide a critique of the cochlear implant debate from the viewpoint of hearing parents of a deaf child.

INTRODUCTION

The vast majority (90%) of deaf children are born to hearing parents (Balknay et al. 1996). They are not born into, brought up in, or surrounded by, the Deaf community. Deaf children of hearing parents may 'join' the Deaf community if they attend deaf schools or youth clubs but there is no automatic 'right of passage' for these children. Joining the Deaf community may actually be quite difficult for deaf children of hearing parents as it relies on the actions of their hearing parents. Parents need to act as a conduit and seek out the Deaf community, which, itself, raises practical and emotional issues for the parents. Practically there is a need to seek out the community and the ways in which it can be interacted with, there are language issues for parents with little or no knowledge of British sign language, and there is the emotional challenge of seeking out a community for your child that may both separate them from the community in which you live and into which they were born and is a community into which you, as a parent, cannot easily fit. These are some of the issues which directly affect hearing parents of a deaf child and they are issues which will be addressed in this paper in relation to the cochlear implant debate.

There are plenty of papers exploring the cochlear implantation of deaf children and adults. Scientific papers focus on technological developments in implants, both in relation to the hardware and the software for these devices (Cooper and Craddock 2006), surgical techniques and processes (Graham 2006), and the audiological and neurological impact of these devices on the ability to process and make sense of sound (Nittrouer & Chapman 2009; Geers, 2004; Nittrouer, 2009). Psychological work looks at the impact of implantation on social interaction and family dynamics (Weisel et al. 2006; Zaidman-Zait 2007; Huttunen and Valimaa 2010). There are also papers on teaching children with cochlear implants and a

whole range of booklets and leaflets aimed at supporting the parents of children with cochlear implants, both through the assessment process and beyond (see the National Deaf Children's Society or Ear Foundation websites for examples). More recently a study has emerged which focuses on deaf teenagers reactions to their own implants (Wheeler et al. 2007). Concomitant with the scientific, medical, therapeutic and parent support literatures is a body of work stemming from the Deaf community and disability literature. This work largely focuses on the problems associated with medicalising deafness and the ethical implications of implanting young children, either per se, or prior to their ability to make an informed decision themselves. Some of the recent work has suggested that cochlear implants threaten the Deaf community through the creation of oral deaf people (Levy 2002), that cochlear implants are about cultural assimilation and that this is morally corrupt (Lane and Bahan 1998) and that all work on cochlear implant technology should cease to prevent the further erosion of the Deaf community (Sparrow 2010).

Hearing parents are largely missing from the literature on both sides of the cochlear implant debate. The scientific papers and books are written by professionals for other professionals, or by professionals to share expert advice and opinions on how to parent a deaf child with parents of deaf children. The arguments presented by the Deaf community and disability theorists are open to a wider audience but again tend to focus on explaining a particular position. There are some studies which explore the ways in which parents make decisions about cochlear implantation for their children (Hyde et al. 2010; Weisel et al. 2007; Archbold et al 2006), but these tend to address practical issues rather than the theoretical arguments for and against implantation. This paper seeks to redress the balance and provide a critique of the cochlear implant debate from the viewpoint of hearing parents of a deaf child. As convention dictates, throughout this paper, the term 'deaf' is used to indicate people with audiological hearing loss, whilst 'Deaf' signifies people who self-identify as members of the Deaf community. The paper starts with a brief overview of the authors' credentials as the hearing parents of a deaf child with sequential contralateral cochlear implants. The main arguments within the cochlear implant debate are then reviewed before a parent's perspective is offered. The paper concludes with some thoughts about the future for cochlear implanted children and the Deaf community.

BACKGROUND

Hearing loss is a very small part of our son and we do not want to give the impression in any way that we see him through his hearing loss. For this reason, this section of the paper is split into two parts. The first part presents a brief hearing history incorporating the process of cochlear implantation and the second part reflects our perspective on the process of cochlear implantation, the decisions that we made as the parents of a deaf child and the reasons behind those decisions.

Our Story

Our son was born three weeks after the introduction of the newborn hearing test locally. We had some concerns in the early months as he seemed to respond to some sounds some of the time but his responses were not consistent. He appeared to pass his distraction hearing test at eight months, largely through natural curiosity, and it was not until he was 15 months old that we requested a further hearing test through our health visitor. Having failed two tests locally and we were then referred to the main paediatric audiology department. When he was 22 months old, three weeks after the birth of our second son, we were told our son had a moderate to severe hearing loss and would need hearing aids. We got our first hearing aids two weeks later and he adapted to them fantastically. They made a difference but he

still had no access to some of the higher frequency sounds. Subsequent audiology assessments reclassified him in the severe to profound range and we were provided with state of the art Naida hearing aids. Again these made a big difference and gave him access to sounds that he had not previously heard but we were warned that it was unlikely that he would be able to access the high frequency speech sounds even with these aids. Around the time of his third birthday we requested a referral for a cochlear implant assessment. Several months and a whole series of assessments, meetings and discussions later our son was accepted for cochlear implants. He was offered two (bilateral implantation) but at that time we all felt that binaural hearing (uni-lateral implantation with a hearing aid in the non-implanted ear) would offer him the best access to the widest range of sound. Funding was requested and agreed and we awaited the operation date with trepidation and hope.

When he was three and a half my son had his first cochlear implant operation. We were admitted to the ward on the Thursday evening and the operation was scheduled first thing on Friday morning. It is difficult to describe the emotions of the journey to the operating theatre and the agonising five hour wait to be told that he was in recovery and we could go and collect him. Suffice to say we were glad we would not have to go through it again. We arrived in recovery to hear him calling for us, awake, upright and already remarkably alert. We were taken back up to the ward and within an hour he had devoured two ham sandwiches and some ice cream and was ready to play. Our biggest problem over the next two days was keeping him still. He was discharged on the Monday and we spent the next two weeks in quarantine, avoiding crowded places and large groups of people. A week later we arrived at the implant centre for the switch on. It went really well and we had a series of visits over the next weeks and months to tune and fine tune the device to give him the best possible chance of gaining useful sound. As with his hearing aids, he adapted to the cochlear implants brilliantly and wore them constantly. His listening skills continued to develop, his vocabulary widened, his speech got clearer and he was able to talk to, and be understood by, his friends at nursery. Again we worked hard to make the cochlear implant a positive part of our lives and were so successful that we had to explain to his younger brother why he could not have one too. Trips to the implant centre always involve a cake stop in the local café and the processor was personalised with a range of stickers chosen by our son on a daily basis. He decorated it, owned it, and was proud of it.

Three months after his fourth birthday we began to feel concerned as our son did not seem as responsive as he had been to sound in his aided ear. He told us that his hearing aid was not working and asked for a second cochlear implant. We requested a hearing test and on the 27th January 2010 we were told that he had lost almost all of the remaining hearing in his non-implanted ear. The shock was huge but this time the decision was far easier, the first implant was a huge success, he had asked for a second implant and he had virtually no residual hearing left to lose. We phoned our key contact at the implant centre the next day and asked how to start the assessment process for a second implant. Our MRI and CT scans were very recent and did not need repeating and the ear had been cleared for implantation less than a year earlier so we only needed to complete some questionnaires, have two repeat hearing tests to confirm the loss and attend a parent information session. The PCT took less than 24 hours to agree the funding for the operation and two months to the day after we received the diagnosis (a year to the day after his first implant operation), our son received his second implant. Again we were in hospital for four days but this time in a ward with three other children also receiving cochlear implants, one being one of our son's closest friends also receiving her second implant. The support and companionship made the stay easier for all of us.

The same process of quarantine and post-operative checks were carried out and 6 weeks

later we arrived at the implant centre for the switch on of the second implant. It was set very low and switched on. Our son continued playing and wore the processor happily. We were given three programmes, each louder than the last with instructions to gradually increase the volume to give access to sound. On the way out of the centre he turned to his father, grinned and said “now I can hear”. By the time we reached the car he had decided the first map was too quiet and asked to have it turned up. The tuning process proceeded very smoothly. He loved his new implant and refused to take the processor off, even at night, falling asleep with the processor on for the first two months post switch on. His listening skills improved, his vocabulary started to grow again and his speech got clearer. He started mainstream school (with a statement of special educational needs, a soundfield system, a radio aid, fantastic support from all of the professionals involved in his care and new Buzz Lightyear and Woody stickers for his processors) five months after receiving his second implant. There is a lot more that could be said about the time invested helping our son to develop his speech, the support that we have received, the vast number of people who have cared, supported and worked with us on the journey so far, but at the heart of it is a determined, confident, happy little boy who wants to communicate, talks continuously and, in his own words, loves his cochlear implants.

Reviewing the Arguments

There are two main streams to the arguments against the cochlear implantation of deaf children. The first focuses on Cultural assimilation, hinging on the parallel drawn between the deaf community and other minority linguistic communities and viewing cochlear implants and oralism more widely as a form of ‘ethnocide’. The second, focuses on the idea of the ‘normalisation’ of abnormal, imperfect, or tragic deaf children and adults to allow them to be productive members of the majority hearing world.

Cultural Assimilation

Sparrow (2010) uses the threat of linguistic annihilation to explain some of the more outspoken attacks on cochlear implantation from within the Deaf community. “Imagine that you are a member of a minority linguistic community ... in the not too distant past members of your community have been imprisoned and tortured for daring to use their own language. Perhaps in response to the persecution they have faced in the past, members of your group tend to be fiercely proud of their cultural community.” (Sparrow, 2010: p456). Cochlear implants are simply the latest in a line of ‘historical genealogies of Deaf subjugation’ (Cambell 2009:93) whereby the majority hearing population seeks to dominate and impose their values on the minority Deaf community. In the words of Ladd (cited in Blume 1997) cochlear implants are “Oralisms Final Solution”. The argument then follows that children implanted in childhood are forcibly removed from Deaf culture and assimilated into the majority hearing culture without their consent. Crouch (1997) views deaf children with cochlear implants as outsiders who no longer fit within the Deaf or hearing communities, sentiments echoed by Campbell who suggests that cochlear implants create “hybrids destined to live in the twilight zone” (2009:95).

It is worth noting, however, that this argument of cultural assimilation can only be used in relation to deaf children of Deaf parents. It could feasibly be argued that pressure to communicate orally forces these children to assimilate to a culture other than that of their parents. The same can not be said, however, of the deaf children of hearing parents (90% of all deaf children (Balknay et al. 1996)). Far from forced assimilation to an alien or ‘other’ culture, in this case, the development of oral communication as the primary means of communication in these children allows them access to their own culture. As Hyde et al. (2010) found: “...parents placed great importance on their children sharing their own social,

cultural and linguistic traditions” (2010: 175). Following this argument, one could go so far as to argue that refusing to allow deaf children to receive cochlear implants itself forces deaf children of hearing parents into cultural assimilation with an alien culture. This said, research by Li et al. (2004) suggests that the beliefs, values and attitudes of parents, particularly in relation to the desire for their children to be oral and participate in mainstream society affects the likelihood of parents making a pro-cochlear implant decision. Thus the parents strength of attachment to their own culture can be seen to affect the degree to which they fight to ensure their children’s inclusion within that culture (Archbold et al. 2006).

Further to this, in an exploration of the history of the American Deaf community, Rosen (2008) suggests that Membership of the Deaf community is more about attitude than audiological status. Drawing on the work of linguists such as Padden and Markowicz (1975) and Baker and Padden (1978), Rosen argues that it is attitude that explains “why some hard of hearing people see themselves as deaf, why some profoundly deaf people see themselves as hearing and why some hearing children of deaf parents refuse to speak but instead prefer to sign.” (2008:136).

Cochlear Implants as Normalisation

Discrimination and oppression leading to inequalities in educational achievement, employment opportunities and life chances are highlighted by Sparrow (2010). He suggests that the limitations on opportunities available to deaf children are due to ‘organic dysfunction’ and not just minority linguistic status. Thus he argues that the inequalities experienced are not simply due to a language issue. Following this argument, cochlear implantation stems from, and results in, normalisation, rather than cultural assimilation. This goes to the heart of the argument as to whether deafness is a disability or a difference. Some members of the Deaf community go so far as to suggest that deafness is not simply a difference but a positive state to be sought (Lane et al. 1996). This ties in with work by Tucker (1998) in the US and Middleton et al (2001) in the UK who found that many Deaf families actively want deaf rather than hearing babies. An information leaflet published by ASL-info (2003) suggests that deaf behaviour, knowledge and values, alongside fluency in signed language, are assets in the Deaf community. They go on to state that “Deafness is not a disability but rather a different way of being”. It is not difficult, when viewing the cochlear implant debate from this standpoint to see why some members of the Deaf community are so against cochlear implantation. If deafness is an integral part of Deafness and Deafness is a positive state, then cochlear implants are simply unnecessary and risk making it more difficult for deaf children to become Deaf.

In her work charting the emergence of the cochlear implant industry in Australia, Campbell (2009) suggests that cochlear implants can only be heralded as a technological miracle if deafness is seen as a disability and therefore as intrinsically negative. Such a consensus was required to make the cochlear implant agenda work as it hinges on the idea that deafness needs to be cured. Thus the presence or creation of ‘sound’ takes on a moral status and cochlear implantation becomes ethically valid. Campbell traces this back to the sound good/sign bad debate which was epitomised by the banning of Australian sign language (Auslan) in deaf schools in the 1880s. In his earlier work, Crouch (1997) further suggested that many among the hearing majority see deafness as a tragedy and it is therefore unsurprising that hearing parents of deaf children seek medical assistance to ‘cure’ their children. This raises the question as to whether hearing parents of deaf children view their children as ‘abnormal’ and wish to ‘normalise’ them or whether, as research involving parents (Hyde et al. 2010, Huttunen and Valimaa 2010) tends to suggest, the majority want to maximise the opportunities available to their children. Nonetheless the perception remains

that cochlear implants normalise deaf people and make them 'aesthetically valid' (Hughes 2000; Lane and Grodin). Taking this argument to the next level, Campbell (2009) argues that not only do cochlear implants stem from a desire to normalise deaf people, she uses the work of Foucault (1997) to illustrate how the burden of responsibility for the perceived success of cochlear implantation is shifted to the recipients, or, in the case of children, to their families. "Acceptance into the programme requires the candidate (and their families) to be motivated, productive and compliant with the therapeutic regime installed as [art of the implantation package]." (Campbell 2009:91). Here the argument against normalisation ties in to the argument against cultural assimilation and comes full circle. "Deafness is not a disability. Instead, many deaf people now proclaim, they are a subculture like any other. They are simply a linguistic minority ['speaking' sign language] and are no more in need of a cure than Haitians or Hispanics". (Dolnick 1993:302). The counterarguments to the cultural assimilation would then apply.

A PARENT'S PERSPECTIVE

From Our Perspective

This is a subjective view but represents a reflexive account of our experiences of cochlear implantation with our son. When we were first told that our son had a hearing impairment we went through all of the usual stages of shock and grief. How had this happened, what had caused it and was it our fault? We both had friends at school who were well adjusted, successful and deaf, however, so we were less negative about the diagnosis than we may otherwise have been. It was not until we began the process of audiological assessments, hearing aid assessments and speech therapy and made contact with our teacher for the deaf and community paediatrician that we began to realise the enormity of the potential impact of hearing loss. Our son is an affectionate, happy, bright and sociable little boy who desperately wants to communicate. The idea that this may be harder for him than for other children, not just in the short term but throughout his life, was heartbreaking for us as parents. He adapted to his hearing aids well though, and we adjusted to seeing him with them and worked hard to make sure they were a positive part of his life. He had pictures in his ear moulds and trips to the hospital always came with a chocolate iced bun. Our first encounter with a cochlear implant was when we joined a pre-school for hearing impaired children and met children with implants. Great children who remain friends, but we were so glad that at least our son would not need an implant.

Deciding to seek a cochlear implant for our son was the hardest decision we have ever had to make as parents. We would be giving our son the best possible chance to hear all of the sounds of speech and access high frequency speech sounds that he would never access in any other way. And yet there is no guarantee that an implant will work or that it will result in clear, intelligible speech. Not only was there no guarantee of success, the operation would most likely take away all of the remaining hearing in his implanted ear and so, if unsuccessful we would actually leave him in a worse position than prior to the operation. And then there was the surgery itself. We would be subjecting our child to a long operation with all of the associated risks and with no guarantee of success. Even if the operation was a success he would have a weak spot on his skull, there would be certain sports and activities that he would not be able to participate in and we would be making him stand out, an object of curiosity. In addition we were aware of the debates around cochlear implantation and sign language and the controversy surrounding the whole process, and we read widely prior to making our decision, but this was of little relevance to our decision. We were not choosing an implant through hatred of deafness or a desire to eradicate the Deaf

community. We chose an implant to give our son what we felt was his best opportunity to develop the ability to communicate independently with as many people as possible. The second implant was a far easier decision for us, made with the knowledge that the first implant was a huge success, that our son wanted a second implant, and that he no longer had useful residual hearing to lose.

CONCLUSIONS

Hintermair and Albertini (2005) argue that it is the either/or philosophy (Enterstvedt 1999) that causes the problem when looking at the cochlear implant debate and the impact of cochlear implantation on the Deaf community. They argue that a cautionary approach is needed when approaching the issue and that parents should be provided with objective information on the pros and cons of cochlear implants along with the time and space to make a reasoned decision. This type of inclusive both/and method was deemed more effective. Having experienced the intensive cochlear implant assessment process twice, as both the parent of a potential unilateral candidate and for a second (sequential contralateral) implant, there is little doubt that a cautionary approach is taken in relation to the potential benefits of cochlear implantation. The variable response of children to implantation and the lack of the ability to predict the likelihood of 'success' is emphasised repeatedly throughout the process. The term 'success' is also problematised from a gold standard ability to converse with strangers on the telephone to access to environmental sound. This information is provided alongside the catalogue of potential side-effects and risks of surgery and long term restrictions on certain types of activities (scuba diving, rugby, contact sports etc.). This said, we were not given information specifically about or from the Deaf community about the impact that our decision would have on our son's ability to be a member of the Deaf community and the impact of cochlear implantation and potential oral language development on that membership. There is some evidence that parents who have contact with the Deaf community during the decision making process are more aware of the need to position themselves within a well established and fiercely fought debate (Hyde et al. 2010)

Had we made those contacts and been given that information would it have made any difference? Our son is profoundly deaf. He has two cochlear implants, is developing age appropriate oral/aural language skills and attends a mainstream primary school with a statement of special educational needs. Despite his cochlear implants and spoken language he remains deaf and always will be. We, as a family, are in the process of learning British Sign Language to use alongside spoken English both for when he is not wearing his implants or is unable to hear sufficiently (ie. in background noise) and because we believe it is important that he has access to British Sign Language as a deaf person. We have adopted the approach advocated by Perier (cited in Vermeulen, 2007) who suggested that deaf children be given access to both oral/aural and signed language to enable them to make their own choice when old enough to do so. This seems an entirely reasonable stance maximising the opportunities available. To suggest, however, that we are depriving the Deaf community of a future member by giving our son the chance to develop oral/aural language and that we should put the need to secure the future of the Deaf community before the need to maximise the opportunities available to our son seems less reasonable. Our position is not one held in ignorance. We are well aware that cochlear implants do not give our son normal hearing. We are also aware that he works considerably harder than his hearing peers to access sound and communicate using oral/aural language. Whether he chooses to continue with oral/aural language, to use BSL and or to use a combination of the two, at least we have tried to give him the best foundations from which to make that decision.

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