Ethics Rounds: Should all deaf children learn <u>a</u>sign language?

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# **Contributor's Statement:**

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# ABSTRACT

Every year, 10,000 babies are born in the United States with sensorineural deafness. Deaf children of hearing (and non-signing) parents are unique among all children in the world in that they cannot easily or naturally learn the language that their parents speak. These parents face tough choices. Should they seek a cochlear implant? If so, should they also learn to sign? As pediatricians, we need to help parents understand the risks and benefits of different approaches to parent-child communication when the child is deaf. The benefits of learning <u>a</u> sign language clearly outweigh the risks. For parents and families who are willing and able, this approach seems to be clearly preferable to an approach that focuses solely on oral communication.

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# Introduction

Every year, 10,000 babies are born in the United States with sensorineural deafness. The incidence of sensorineural deafness is similar in most high-income countries and is higher in some low income countries.<sup>i</sup> Many more become deaf before the age of two. In such situations, parents face tough choices. Should they seek a cochlear implant? If so, should they also learn to sign and teach their child to do so? What about speech reading? And there is no time to wait. Experts agree that a child must be exposed to an accessible language on a regular and frequent basis before the age of five in order to develop full language competence.

Prosthetic approaches to hearing restoration have been applied to younger children at increasing rates, with estimates indicating that more than half of US children with early-onset deafness have received a cochlear implant (CI).<sup>ii,iii</sup> Children with CI require intensive rehabilitation throughout childhood in order to learn to communicate orally. Even with this training, some children become better oral communicators than others. Some experts suggest that all deaf children, with or without a CI, should be taught a sign language. Others worry that learning to sign will interfere with the extensive and intensive rehabilitation that is necessary to get the most out of a CI, or that asking parents to learn a new language in order to communicate with their child is too onerous.

To address these dilemmas, we've asked experts in otolaryngology and language development to discuss the pros and cons of teaching <u>a</u> sign language in addition to teaching <u>an</u> oral language.

Our experts include Nancy K, Mellon, Founder and Head of School at The River School in Washington, DC, John K. Niparko, MD, Chair of the Department of Otolaryngology at USC, Sascha Scambler PhD, Senior Lecturer in Sociology, King's College London, Christian Rathmann, PhD, Professor of Sign Languages and Sign Interpretation at the University of Hamburg, Gaurav Mathur, Associate Professor of Linguistics at Gallaudet University, Tom Humphries, PhD, Associate Professor in the Department of Education Studies at the University of California at San Diego, Donna Jo Napoli, PhD, Professor of Linguistics, and Theresa Handley, both of Swarthmore College. None of our experts is presently a child or adolescent, but the views of fifteen CI recipients are found in the reference in note 3, where views of young people are offered. Three of our experts are deaf professionals. Three of them are parents of profoundly deaf children, two of whom have bilateral cochlear implants. As a group, these experts consulted by electronic communication;<sub>5</sub> however, several have ongoing professional relationships and discussed these matters in person, as well.

# The Case:

A newborn is identified as having sensorineural deafness. The parents have normal hearing and no knowledge of sign language. A hearing aid is not medically indicated. They have a few months to decide whether to opt for a cochlear implant. In the meantime, should they learn a sign language and begin to communicate with their child using that sign language. If they eventually opt for a CI, should they continue to sign?

Nancy K. Mellon, MS, and John K. Niparko, MD, comment:

Parents often view the diagnosis of a child's deafness through a prism determined by their own hearing status. Parents who are Deaf may view the diagnosis through a cultural lens, welcoming a child who can easily share their language and culture. However, more than 95% of deaf children are born to hearing parents.<sup>iv</sup> Hearing parents typically think of deafness as a disability.<sup>v</sup> Their views are shaped by their desire to share their own language and culture with their child.

A deaf child born to hearing parents and unable to gain meaningful speech recognition from hearing aids will typically meet criteria for early cochlear implantation. The FDA approved the multichannel CI for children in 1990. Almost 100,000 children have used CIs successfully to develop spoken language. However, a CI can enable strong spoken language only when used with intensive auditory-oral exposure in extended, salient, and child-initiated interactions.<sup>vi</sup> Without a full linguistic and auditory experience, the effects of deafness-associated deprivation can derail the spoken language learning process before it begins.

The timing of intervention is critical. An infant's nervous system is genetically predisposed to accept only a limited range of potential stimuli to drive the developmental learning of language. Experiences that produce language occur in a "biologically expensive" period in which neural circuits are undecided yet amenable to commitment. During this sensitive period, use of neural circuits generates the impulse traffic that differentiates neural development. If a child misses the needed experiences within an optimal timeframe, essential elements in a child's emergent language, either spoken or signed, may be missing.<sup>vii</sup>

Should a parent use sign language with a young child who will receive a CI? As reviewed by Geers and colleagues, case-series reports on sign effects prior to implantation are mixed.<sup>viii</sup> We suggest that early sign language, when used for a short time pre-implant as a bridge to spoken language, cannot hurt and may offer benefit. Early experience with sign language may support a child's participation in the kind of bidirectional parent-child interactions that form the foundation of language learning, for example, by enabling joint attention.<sup>ix</sup> However, an important caveat should be considered. The use of any residual hearing should be maximized. Data from a prospective, national trial in progress indicate that verbal language learning after implantation.<sup>x</sup>

For an implanted child, the timely activation of the device begins a fuller experience with sound. Reliance on sign language over an extended period of time may negatively affect the child's capacity to learn spoken language after cochlear implantation.<sup>xi</sup> Prolonged, inadequate auditory input that fails to support spoken language learning at age-appropriate rates associates with gaps in speech and language after cochlear implantation.<sup>10</sup> Importantly, even extensive (re)habilitative effort will not produce the language sophistication that can be achieved by exposure to spoken language during sensitive periods of development.

A child's ability to successfully acquire spoken language requires a framework of rich, bidirectional communication with language mentors and immersion in an oral language environment. Because the cochlear implant is designed to equip a child with skills to communicate in a hearing world, we strongly advocate for educational programs that allow children to access the pragmatics of spoken language in interactions with their hearing peers. While sign can promote early parent-child communication, the focus of intervention should immediately shift to highlighting the acoustic properties of speech as consistently as possible after cochlear implantation in order to optimize a child's ability to talk and listen.

### Sasha Scambler, PhD, comments:

I write as a hearing parent of a profoundly deaf child. I am also a Medical Sociologist. Until the last few decades, there were few choices to be made by hearing parents of deaf children. Today, with CIs and with the successful roll-out of newborn hearing screening programs, babies are diagnosed within the first few weeks of their lives and they can receive a cochlear implant well before their first birthday. If parents decide a cochlear implant is the way to go, then the first few months of the child's life are then taken up with tests, suitability assessments (for both the parents and children) and medical examinations.

If the child is found to be a suitable recipient, the parents then face the phenomenally difficult decision about whether to have their child implanted in the knowledge that there is no guarantee that the implant will work or that it will result in clear, intelligible speech. Parents are asked to decide whether to subject their child to a long operation with all of the associated risks and with no guarantee of success.

Parents are also often told that it would be best for their child if they, the parents, would learn a completely new, alien language. Sign language is clearly beneficial for deaf children but

families need time and space to adjust and come to terms with everything that is happening to them and to the reality of being the parents of a deaf child.

As the hearing parent of a profoundly deaf son with bilateral cochlear implants, this is an issue that is close to my heart.<sup>xii</sup> My son has had his cochlear implants for 5 years. He has age appropriate oral/aural language skills and attends a mainstream primary school with support from a specialist teacher for the deaf. Despite his cochlear implants and spoken language he remains deaf and always will be. There are times when my son is unable to wear his implants or is unable to hear because of excessive background noise. Cochlear implants have the same limitations as other artificial hearing devices. They work best in close range with little background noise. Given these limitations, it is essential that we have a means of communicating with him, and he with us, when hearing is not an option. Research suggests that speech reading (lip reading plus facial expression) can be a useful additional tool but will only result in 60% accuracy with English language at best.<sup>xiii</sup> So an alternative form of communication is needed.

Sign language is a useful tool for a family of a deaf child whether the child is able to make full use of cochlear implants or not. But learning <u>a</u> sign language as a hearing family is not without problems. Once the child has had their cochlear implants activated the family will be surrounded by professionals giving advice on language development, listening skills, ways to provide a language-rich environment, and ways to maximize the potential of the technology the child has been provided with. Fitting signing in to an already full schedule is hard. And that is before

meeting the needs of other children within the family as well as one's own professional and career obligations.

Another important factor is that the level of signing support available to families depends on the area in which they live. Sign language lessons can be expensive if no subsidies are available. Signing clubs can also be intimidating places for hearing families. Some people in the Deaf community are overtly hostile to cochlear implant users.

We, as a family, are in the process of learning <u>a</u> sign language. We use it alongside spoken English. We chose this because we need it when our son is not wearing his implants or is unable to hear sufficiently because of background noise. We also believe that it is important that he has access to sign language as a deaf person.

We have adopted the approach advocated by Perier 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.<sup>xiv</sup> This seems an entirely reasonable stance, maximising the opportunities available. It would, therefore, seem reasonable to encourage the family of a deaf child to sign with their child. It is essential that they are given the support they need to do so. This includes time and space to psychologically adjust to the new world in which they find themselves as well as practical and/or financial support.

We are well aware that cochlear implants do not give our son normal hearing. We are also aware that he works considerably harder that his hearing peers to access sound and communicate using oral/aural language. Ultimately, he will have to choose whether to continue with oral/aural language, to use sign language, or to use a combination of the two. We have tried to give him the best foundations from which to make that decision.

#### Christian Rathmann, PhD, and Gaurav Mathur, PhD, comment:

There are three strong reasons to learn both signed and written/spoken language. First, a speechonly approach risks linguistic deprivation at a crucial period of development. The risk arises because of the variability in the spoken language development of deaf children with CIs.<sup>xv</sup> In contrast, both sign language and early reading are visually accessible to the deaf child. This bilingual approach virtually guarantees that the child will develop linguistic competence.

Second, bilingualism is beneficial. Bilingual children display better mental flexibility and cognitive control as well as more creative thinking, especially in problem solving.<sup>xvi,xvii</sup> These benefits extend to social and academic settings.

Third, sign language development correlates positively with written<sup>xviii,xix,xx,xxi</sup> and spoken language development.<sup>xxii</sup> No evidence has been found that the use of a visual language affects the outcome of cochlear implantation.<sup>xxiii</sup> In fact, implanted children with early exposure to and, importantly, continued use of a sign language outperform children with only CI on a variety of standardized language measures of English, even when both groups have the same age of implantation and the same years of CI use. It appears that early and continued sign language exposure "may provide a 'framework' for early spoken language development"<sup>xxiv</sup> in deaf children within hearing families as well as within deaf families.<sup>xxv</sup>

# Tom Humphries, PhD comments:

The most important advice anyone can give parents of deaf children is to immediately join an active signing community of both parents and children. This is the vital first step in achieving the type of language, cognitive, and social development that deaf children will need for school.

From birth to 3 years old, a deaf child needs to be part of a language and cognitive ecosystem in which unambiguous linguistic input and rich interaction with print prepare the child for both the acquisition of basic interpersonal communication skills and academic language development. By acquiring <u>a</u> sign language early the child can develop theory of mind<sup>xxvi</sup> and achieve the requisite domestication of vision (eye tracking for reading, for example)<sup>xxvii</sup> to be ready for schooling.

Academic language development is what we expect of children in school, the language that children must both access and demonstrate knowledge in. Being able to communicate in sign with the teacher and with classroom peers affords the child the socially- and intellectuallyengaged interaction that makes up so much of the school day.

This social development is critical to students' ability to learn and to their moral and emotional development. As the deaf child grows, the family is not enough, and a large amount of the child's time is spent away from home. With sign language, the deaf child is able to travel through various social situations and communities without difficulty and not be confined to

communicating only with family and friends, as is often the case for deaf children who have no sign language.

# Donna Jo Napoli, PhD, and Theresa Handley comment:

All deaf children should be taught a sign language as soon as their hearing status is determined, alongside training in spoken language (for as long as they show progress and interest), so that their chances of developing a firm linguistic foundation are maximized.

Simply put, late language learners have a range of problems, particularly with literacy, <sup>xxviii,xxix</sup> while signing deaf children, with or without CI, do better on literacy and on those cognitive skills that require a firm language foundation whether their parents are hearing<sup>17,18,19,20</sup> or deaf.<sup>xxx</sup> They experience overall benefit with no drawbacks if they continue to sign while oral training is still in progress.<sup>xxxi,17</sup> Sign and speech facilitate each other, rather than one hindering the other.<sup>xxxii</sup> The misperception that signing interferes with speech is based on what some call neuro-politics on the part of both the medical profession and the community of parents of children with CIs.<sup>xxxiii,xxxiv</sup> In this common scenario the medical profession puts the burden of success with a CI not on the technology, but on the rehabilitative training the child receives, which amounts to putting that burden primarily on the parents. Parents, in turn, tend to take pride if their children make progress, and blame if they don't; they shame each other and even hide from each other the fact that they sign sometimes with their children. And all this is misguided because there are no reliable predictors of which children (among those who receive training) will succeed and which won't. The fact is, acquiring a firm foundation in a sign language gives the child the base upon which to build skills in reading and, sometimes, speaking,

a second language; but it is impossible to learn to read without a firm foundation in some language to start with.<sup>xxxv</sup>

Raising a deaf child calls for great effort no matter what language choice parents opt for.<sup>xxxvi</sup> Raising a deaf child with a sign language as well as spoken language requires learning a sign language. But raising a deaf child strictly orally requires daily training in vocalization and speech-reading throughout childhood – demanding certainly as much effort as learning to sign – and could still have no positive effects on language development, since it is impossible to predict which children will succeed with a CI.<sup>xxxvii</sup>

Deaf babies need exposure to good signing models – that is, people using a sign language with all of its grammatical richness – not just to good speakers. Various combinations of speech, gestures, and rudimentary signing can help in family communication, and such systems often have some structural similarities to natural language. <sup>xxxviii,xxxix</sup> However, they cannot substitute for bona fide language, nor do they allow the child to communicate with others outside the family.<sup>xl,xli,xlii,xliii</sup> If families bring their deaf children to signing deaf adults who can interact with them, these deaf adults will serve as the resource that allows first language acquisition to develop naturally. Deaf children also need to interact with other signing deaf children. One can find these language and social opportunities through community support groups such as deaf advocacy groups, local deaf and hard-of-hearing community centers, and local and/or state deaf services bureaus. The family can begin sign language classes immediately. Some family members may become fluent signers, while others may always feel awkward at signing; but the quality of the family's signing is far less important than the fact that the family communicates with the child. Deaf children who sign with their hearing mothers show early language expressiveness on a par with hearing children of the same age<sup>xliv</sup> despite variability in the mothers' signing abilities.

Even families who become expert signers need to bring their deaf children to events where they can interact with a signing community because the proper development of language in all its complexity involves its use within a community. Further, there are many things that deaf signing adults tend to do with deaf children that hearing parents are unlikely to do without specific training. Deaf adults often use "child-directed signing,"xlv,xlvi,xlvii where their eye gaze, methods of attention getting, rate and size of signing, and ways of making both signs and objects more visually accessible support the child's language development. Deaf adults often sign on objects, or on the child's body, or move objects into the child's line of vision - all spontaneously and with benefit to the child language learner.<sup>xlviii,xlix,l</sup> This behavior allows the adult and child to interact in a more sophisticated way; deaf children of deaf parents quickly learn to alternate their gaze between a parent and a book or object, enhancing comprehension.<sup>li</sup> All deaf children could benefit from learning this, since sign language skills are essential in successful use of interpreters in school. Further, while there are many ways of being deaf, the deaf person who can gain a positive attitude toward being deaf is on the road to establishing a healthy identity; interacting comfortably with other deaf people via a sign language may be a strong aid here.<sup>lii</sup>

#### John D. Lantos MD comments:

For over a century, doctors, parents, educators, and others have debated how best to raise deaf children. Newborn screening for hearing loss and the development of cochlear implants are the latest technological twists in this debate. But they don't alter the fundamental ethical issue. Children need to learn language. They must learn it from parents, teachers, and community. The more languages that they learn, the better they will be able to communicate. All children would be better off if their parents all spoke five languages and taught all five to their children. Unfortunately, many parents do not speak five languages. Deaf children of hearing (and nonsigning) parents are unique among all children in the world in that they cannot easily or naturally learn the language that their parents speak. Hearing (and non-signing) parents of deaf children are unique in that they are asked to learn, at least in a rudimentary way, a new and foreign language in order to communicate with their children. Some parents eagerly and willingly take on this challenge. Others do not or cannot. As pediatricians, we need to keep up-to-date on the latest research, translate that research into language that parents can understand, and help them make choices that are best for their child, their family, and themselves. There are no risks to learning sign language along with spoken language. There are clear benefits. For parents and families who are willing and able, this approach seems to be clearly preferable to an approach that focuses solely on oral communication.

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