

Choosing for the child with cochlear implants: a note of precaution

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Abstract Recent contributions to discussions on paediatric cochlear implantation in Norway indicate two mutually exclusive doctrines prescribing the best course of post-operative support for a child with cochlear implants; bilingually with sign language and spoken language simultaneously or primarily monolingually with speech only. This conflict constitutes an ethical problem for parents responsible for choosing between one of the two alternatives. This article puts forth the precautionary principle as a possible solution to this problem. Although scientific uncertainty exists in the case of both doctrines, there exists a scenario of possible irreversible harm to some of the children habilitated monolingually. An application of the precautionary principle may hence suggest that it is rational to agree on the bilingual approach, at least for the time-being.

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Introduction

In January 2008 The Journal of the Norwegian Medical Association published an editorial letter titled “The

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cochlear implant and sign language” (Siem et al. 2008) written by three staff members of the paediatric cochlear implantation team at the Rikshospitalet University Hospital. The authors made an interesting announcement: Rikshospitalet University Hospital advises parents of newly implanted children to choose habilitation through “auditive verbal/oral training” (Siem et al. 2008, p. 69) for the child. The editorial letter states that the development of speech is the objective of such habilitation, and sign language is recommended only as a secondary option for those children who fail to develop speech.

Though probably unintended, this clear statement adds a new question to the ongoing bioethical discourse on cochlear implants. Since 1998 the Norwegian Educational Act (Section 2, 6th paragraph) has asserted deaf children’s legal rights to acquire both Norwegian Sign Language as well as spoken Norwegian (Kunnskapsdepartementet 1998) simultaneously. Bilingual education is a form of post-operative support and follow-up offered to implanted children by the Norwegian government and this approach is also recommended by the Norwegian Deaf Association. The parents responsible for choosing post-operative intervention on behalf of their implanted child are thus faced with a choice between two mutually exclusive interventions. Even though few countries besides Norway have established bilingual education for deaf children as a legal right, the question of choosing between these mutually exclusive alternatives must be confronted by parents of implanted children in other countries as well (Niparko 2009).

This text discusses this dilemma as an ethical and decisional problem. Decision theory normally assumes that rational decisions can be made provided that one can assign “probabilities and utilities to the outcomes” (Peterson 2007b, p. 306) of an intervention. This might however prove to be a difficult task in the case of post-operative

follow-up of implanted children. A review of relevant outcome studies suggests that such assignment of probabilities and utilities is infeasible for a number of reasons, the most important being that the variability in outcomes is indeterminable.

A characteristic feature for the bioethical discourse on cochlear implants is the rather clear division between those in favour of implanting a prelingual deaf child, and those who oppose cochlear implantation (see for example Lane and Grodin 1997; Levy 2002; Nunes 2001). In the latter group, activists and academics arguing that Deaf¹ people are primarily a linguistic minority and not disabled people needing (re)habilitation are a prominent voice. In many ways, this author is sympathetic to the Deaf cause. However, an attempt to develop an ethical argument that could guide parental decisions after cochlear surgery means trying to decide what might be in the best interests of the child, not trying to defend the interests of Deaf communities. If a deaf child acquires more hearing with cochlear implants, it may not be reasonable to argue as if the child is still deaf. Hence, questions of what choices should be made on behalf of the deaf child with cochlear implants, after surgery, may not be the same questions that concern people who already consider themselves members of Deaf communities.

The analysis in this text points out that it is difficult to choose between monolingual habilitation with speech and the bilingual approach because there is little scientific evidence supporting either of the alternatives. As a practical and ethically defensible way of coping with this situation, this text explores if, for the time-being, some form of a precautionary principle (Peterson 2007a, b; World Commission on the Ethics of Scientific Knowledge and Technology 2005) might be reasonable to apply. The analysis suggests that such a principle—as a weakly formulated normative epistemological principle guiding beliefs rather than actions—could imply that the bilingual approach should be considered as the preferred alternative until the risks involved in monolingual habilitation as well as the bilingual approach are better understood.

The argument for preferring the bilingual approach combines what we know about historic outcomes of habilitation of deaf children before cochlear implants, with the understanding that some children do not gain very much hearing with their implants. There might be reason to believe that habilitation with speech only is a poor alternative for these children who—despite being implanted—remain seriously hearing-impaired.

¹ I follow the custom of differentiating between the medical condition of being *deaf* (which is written with a lowercase 'd') and being a member of a signing community (which is written *Deaf*, with a capital 'D') (Padden and Humphries 1988).

Describing the alternatives

In the Norwegian context the choice between habilitation with speech only and the bilingual approach represents a choice between mutually exclusive alternatives. A more detailed account of the alternatives is offered here in order to further explain this parental dilemma.

The bilingual approach

Historically, the attempt to teach deaf children spoken Norwegian was the modern doctrine of normalisation which provided the guiding principles for deaf children's education in Norway (as in many other countries) from the end of the 1880s to the middle of the 1980s. The underlying premise for this doctrine—today often referred to as “oralism” among Deaf people, a term with derogatory connotations—was the conviction that sign language was a primitive form of communication unsuited for rational thinking and proper education (Grønlie 2005; Kermit 2006). Deaf children thus had to learn speech in order to be rescued from a life without language. The means for achieving this acquisition of speech was monolingual habilitation, and the children were expected to pick up speech using hearing aids, whatever residual hearing they had as well as compensatory techniques such as lip reading. Signing had no place in the curriculum, not even as a method for promoting speech.

A feature of habilitation with speech, as we know it historically, was its poor results (Grønlie 2005; Kermit 2006). Many deaf children never acquired spoken language. This resulted in severely delayed and/or harmed linguistic development with subsequent consequences for the children's general development. A study from 1983 concluded in this manner:

“Early language deprivation and social isolation often prevent the deaf from learning the rules of the majority culture, which is indeed handicapping” (Kusche et al. 1983, p. 158).

The epistemological presumption underlying the historic attempts to habilitate deaf children with speech was that language meant spoken languages exclusively. The ambition of teaching deaf children speech was thus anchored in the ethically irreproachable notion that all humans need language (Kermit 2006). When the first linguistic publications refuting this understanding of sign language were published at the beginning of the 1960s, the consequences were far-reaching. This research reported the discovery that sign languages—instead of being crude forms of communication—were full-fledged natural languages equal to spoken languages (Armstrong et al. 2002; Stokoe 2005). This paved the way for a theoretically plausible

explanation for why habilitation with speech failed to deliver good results: In the choice between speech and signing, the language with the modality least suitable for children with severe hearing impairments had been chosen. It is in this context bilingualism was suggested as a new and supposedly more theoretically consistent approach to the question of deaf children's education. Parallel to this, the new knowledge of signed languages became an important pillar in what can be described as a project of emancipation among Deaf people (Kermit 2009). Central to the Deaf activist movement was the articulation of the claim that Deaf people should be recognised as a linguistic minority, with sign language as their first language, rather than labelled a group of disabled people (Nakamura 2006).

This terminology of sign language as “first”, and spoken language as “second”, was adopted in the Norwegian Educational Act when bilingual education was established as a right for deaf children in 1998 (Kunnskapsdepartementet). This might leave the impression that deaf children should focus on acquiring Norwegian Sign Language first, and then start learning spoken Norwegian. Such an understanding can not be substantiated, however. The Educational Act defines bilingual education as the simultaneous acquisition of both Norwegian Sign Language and spoken Norwegian. Norwegian Sign Language is recognised as a language in its own right, but the law primarily lays down the idea that access to speech is easier for a deaf child who can contrast knowledge of Norwegian Sign Language with knowledge of spoken Norwegian. Thus, the bilingual approach in Norway does not comply with the Deaf radical notion that knowing only a signed language suffices the deaf child's every need. The law has even been criticised for its emphasis on sign language as merely a means to promote the end of acquiring spoken language (Erlenkamp 2009). Nevertheless, the Educational Act advocates the view that recognising the deaf child as bilingual and making a strong effort to provide the child with both a signed and a spoken language may be a good way to secure the best interests of the child.

Habilitation with speech first

Habilitation with speech alone defines the acquisition of spoken Norwegian as the primary objective for children who receive cochlear implants. For those who, for different reasons, do not achieve this goal, Norwegian Sign Language or some form of sign-based communication is suggested as a secondary option (Siem et al. 2008). In other words, this potentially represents a sequential approach to two different languages, but for those children who acquire speech, Norwegian Sign Language is regarded superfluous.

Cochlear surgery in itself does not define the outcome of implantation. Rather, it is generally assumed that the

subsequent post-operative intervention followed with implanted children is a decisive factor for outcomes: “Children with prelingual deafness must use the auditory information they receive from a CI [cochlear implant] to acquire speech production and spoken language skills” (Kirk and Choi 2009). This necessitates a period of habilitation during which the child learns to interpret the implant's input as auditory information. There are different approaches to the undertaking of this task. In Norway, so called *audio verbal therapy* is among the most frequent approaches (Heian and Hillesøy 2009).

To this author's knowledge, no proponents for this alternative regard the simultaneous acquisition of a spoken and a signed language (the bilingual alternative) as harmful in the sense that learning a sign language hampers the acquisition of speech, and no scientific evidence suggests this possibility (Archbold et al. 2000; Archbold and O'Donoghue 2009). Learning a signed language in addition to a spoken one is rather seen as impractical and unnecessary, provided that the child acquires speech. For those who do not acquire speech, sign language is a secondary option. One frequent argument for this sequential approach is that learning sign language demands extra parental effort in addition to the effort required to secure the child's acquisition of speech:

“Although bilingual education has intuitive appeal, at present it remains a theoretical rather than practical option. Deaf children of hearing parents experience difficulty acquiring a first language in either spoken language or ASL.² The former requires functional hearing; the latter requires appropriate models who can support developmental learning” (Niparko 2009, p. 340).

Nancy K. Mellon also argues that the bilingual approach is a demanding alternative especially for hearing parents of deaf children with no prior experience with sign language. She adds that if parents choose one—and only one—language, having a spoken language potentially opens a wider scope of possibilities than having a signed language (Mellon 2009). The latter argument, however, presupposes that choosing either a spoken or a signed language is an alternative. In the Norwegian context, however, no one advocates choosing only Norwegian Sign Language as a relevant option. Parents who choose the bilingual approach are provided a forty week long course in Norwegian Sign Language in order to obtain basic skills in Norwegian Sign Language. Choosing the bilingual approach does not imply that the child is bound to attend a deaf kindergarten/school. The child might also be placed in a mainstream educational setting and the kindergarten/school is legally obligated to

² American Sign Language, author's remark.

provide staff members who know Norwegian Sign Language. Choosing habilitation with speech in Norway means placement in a mainstream kindergarten/school with possible additional specialist educational support to varying degrees.

The precautionary principle

Decision theory is a discipline influenced both by philosophy and mathematics (especially statistics) which generally deals with the question of how rational decisions are made. In the words of Martin Peterson the “most widely accepted rule in decision theory is the principle of maximizing expected utility” (Peterson 2007b, p. 306). Peterson formulates this principle as follows:

“[R]ational individuals should choose an act so that the sum of the utilities of all the possible outcomes of the act, weighted by the probability of each outcome, is maximized” (Peterson 2007b, p. 306).

This principle is generally intended as a rational principle, and when the decisions made involve matters of ethical significance, the underlying utilitarian impulse suggests that also outcomes with different normative implications can be weighted differently in terms of their utility.

Decision theory is largely a quantitatively orientated discipline. Applying the above principle quantitatively when making practical decisions in situations where certain outcomes are desired and others are unwanted or maybe even harmful, would mean assigning numerical probabilities and utilities to the different possible outcomes and weighing the outcomes against each other in order to calculate the risk involved in making the decision. Such quantitative risk assessment “has become the dominant paradigm in the risk policies of many nation-states. This approach is often regarded as scientific, because it draws on empirical evidence” (World Commission on the Ethics of Scientific Knowledge and Technology 2005, p. 29). The risks of cochlear implantation, when regarded only as a matter of the medical safety of the surgical procedure, could well be calculated according to the above: The probability (in percentages) that the surgery will not have unwanted medical side effects is high. Medical complications related to implantation are continuously researched and reported, and as the frequencies of severe complications like pneumococcal meningitis are low and other complications are either treatable or preventable, the risk involved when opting for surgery is accordingly small provided that the utility of having surgery is assessed as reasonably high (Kim et al. 2008; Wei et al. 2007a, b).

Assigning numerical probability and utility to outcomes is not always regarded as feasible, however, especially

when making decisions that involve “considerable scientific uncertainties about causality, magnitude, probability, and nature of harm” (World Commission on the Ethics of Scientific Knowledge and Technology 2005, p. 13) and where outcomes generally are poorly known. This has resulted in calls for more qualitative approaches to the question of rational decision making and understanding of risk. Qualitative decision theory is recognised as a “fully respectable sub-discipline of decision theory” (Peterson 2007b, p. 306), and it is in this tradition the so-called precautionary principle is suggested as a decision rule. The principle addresses decisions made under uncertainty when there is plausible—but not evident—knowledge of possible harmful outcomes, but little knowledge of the probability or nature of different outcomes. If the possible harmful outcome is regarded as serious, irreversible or otherwise ethically unacceptable (World Commission on the Ethics of Scientific Knowledge and Technology 2005), the precautionary principle implies that the most rational course of action might be to refrain in the first place from making the decision involving the possible harm. Instead, one must make do with preserving the status quo until more knowledge becomes available.

It has been pointed out that the precautionary principle in essence seems to command something that could be labelled a ‘better safe than sorry’ strategy. The principle is, however, highly contested as a rational decision rule. Peterson (2007a, b) points out that one problem with the precautionary principle is the numerous ways in which it is formulated. Attempting to sum up different formulations Peterson suggests that the following is the weakest possible:

“If one act is more likely to give rise to a fatal outcome than another, then the latter should be preferred to the former, given that both fatal outcomes are equally undesirable.” (Peterson 2007a, p. 6)

The precautionary principle is mentioned as a guiding principle, for example, in the Rio Declaration on Environment and Development (The United Nations Conference on Environment 1992). The declaration suggests that the principle should be applied where there is reason to believe that new technology or changes in human activities may cause serious and irreversible harm to the environment. “Reason to believe” is thus considered sufficient cause with reference to probable outcomes, even in cases where there is little actual scientific knowledge of what effects a new intervention may have. This idea of preventing irreversible harm by restraining one’s conduct can be found, among others, in Hans Jonas’ formulation of what he labels the principle of responsibility (Jonas 1985).

However, as the precautionary principle is contested, this text seeks an understanding of the principle that could

make it acceptable for as many as possible. Peterson addresses the application of the principle especially in medical practices and argues convincingly³ that the formulation of the precautionary principle above, when applied as a decision rule intended to guide our actions, is logically inconsistent with other principles for rational decision making. Nevertheless, Peterson holds that the precautionary principle is valid and consistent as an *epistemic* principle which can “influence decisions more indirectly” (Peterson 2007b, p. 307). Put plainly, Peterson argues that it is rational to believe, for example, that a newly developed drug or substance “is dangerous until sound scientific knowledge shows that it is safe” (Peterson 2007b, p. 307), something which should motivate—but not dictate—people involved in, for example, clinical trials to make risk-averse decisions.

Understood in this manner, this text then investigates the use of the precautionary principle as an epistemic principle in the case of choosing a course of post-operative intervention for the child with cochlear implants. It is reasonable to presuppose that whatever choice is made on behalf of the child, those making the choice, as well as those supporting or recommending it, think of it as the choice best suited for ensuring the interests of the child. It may hence be unreasonable to try to argue that one choice is unethical in some fundamental way whilst the other is not. This does not exclude the possibility, however, that one choice might be more well-founded than the alternative.

Outcomes of follow-up of children with cochlear implants

Medicine’s preferred method for comparing the effects of different interventions treating the same condition is usually randomised, single- or double-blinded controlled studies (Sagi et al. 2007). However, this is not a feasible method for comparing the bilingual approach and monolingual (sequential) habilitation, among other reasons because it is problematic to predefine common measurable outcomes. The first alternative considers a bilingual capacity in two languages as the preferred outcome, the second the mastering of a spoken language.

In this paragraph the choice between the bilingual approach and monolingual habilitation is analysed in order

to uncover what the predictable outcomes of the different interventions might be according to existing research and independent of the fact that direct comparison seems to be methodically difficult.

Outcomes of the bilingual approach

Summing up research indicating outcomes of the bilingual approach is not easily done as such research, to this author’s knowledge, hardly exists. In 1994, Ahlgren and Hyltenstam edited a volume of *International Studies on Sign Language and Communication of the Deaf* titled *Bilingualism in Deaf Education* (Ahlgren and Hyltenstam). Many of the contributing authors offer theoretical and political arguments for why bilingualism should be the preferred approach to deaf children’s education, though no empirical studies sustaining these views are reported. Even though bilingualism has been an educational doctrine for deaf children in Norway for more than 10 years, there are no studies reporting how bilingual education is carried out, nor what results have been achieved. In Sweden, where the bilingual approach has been the established doctrine for deaf children’s education even longer than in Norway, Svartholm claimed in 2005 that bilingual education had proved beneficial and that deaf students in Sweden achieved better results than anywhere in the world (Svartholm). Similar claims are made by Rydberg et al. (2009), but neither they, nor Svartholm, present any actual study to sustain this claim.

It may thus be fair to say that the main argument for the bilingual approach remains theoretical and political: In general, bilingual education research considers bilingualism as potentially beneficial to the child’s cognitive and lingual development (Engen and Kulbrandstad 2004; Cummins 1999). This research is based, however, on studies of bilingual children with two spoken languages, and there are a number of factors influencing outcomes, such as the duration of bilingual education and whether both languages are mastered on an age appropriate level. Politically, the main argument for the bilingual approach is based on the historic notion of the poor outcome of habilitation with speech before cochlear implants were available to deaf children. Deaf people’s rejection of the historic “oralist” approach as an educational doctrine that failed to recognise sign language is also significant in this context.

Outcomes of habilitation with speech

Probably because direct comparison of monolingually habilitated and bilingually educated children by means of controlled studies is infeasible, clinical outcome research focusing on monolingual habilitation has mainly resorted

³ Peterson holds that in order for the precautionary principle to be applied as a decisional rule, it must be logically consistent with other established decisional rules. Conducting an investigation of the logical premises for these different rules, he concludes that the precautionary principle can not consistently exist as a decisional rule together with the rule of maximizing expected utility, for example.

to studying different cohorts of implanted children undergoing monolingual habilitation. Many of these studies use tests that generate quantified results (see for example Balkany et al. 2007; Beadle et al. 2005; Geers 2006; Lin and Niparko 2006; Nicholas and Geers 2007; Spencer et al. 2004; Tait et al. 2007; Tobey et al. 2003; Wie et al. 2007); different hearing tests and speech tests at different times after implantation (Kirk and Choi 2009). In general, these studies display statistical evidence indicating that cochlear implants work well for many children in the sense that their hearing is improved and that they can produce and pick up speech. Two things seem documented beyond doubt: No child achieves full normal hearing with cochlear implants, but early implanted children statistically have higher scores than prelingually deaf children implanted later in life. The demarcation between “early” and “late”, however, is not static as age at implantation has dropped steadily. In Norway, many children receive implants before their first birthday.

The emphasis on testing hearing and speech production and speech perception may not tell us about other aspects of what it means to know a language, however. This is something Thoutenhoofd et al. (2005) commented upon in a review on outcome research in 2005:

“Very few studies attempt to assess the child’s ability to perceive and produce spoken language in their day-to-day lives, after implantation, rather than in clinical tests.” (Thoutenhoofd et al. 2005, p. 241)

The ability to interact through language constitutes complex functions and relations. Measuring certain perceptive and productive language skills by testing a child’s ability to pick up and produce speech gives knowledge of some aspects of the child’s language mastery. Such testing, however, hardly captures the totality of what it means to know or develop language in the full sense (Lahey 1988; Vygotskij 1978; Wittgenstein 1967). Nevertheless, several cohort studies argue that implanted children’s measured scores in speech tests can be seen as documentation of the children’s general language development (see for example Nicholas and Geers 2007; Dettman et al. 2007; Richter et al. 2002; Schauwers et al. 2004; Tomblin et al. 2007; Young and Killen 2002).

There are also empirical studies “assessing literacy and other domains of academic achievement among children with cochlear implants” (Marschark et al. 2007, p. 269). Reviewing these studies, Marschark et al. conclude that improved hearing by means of cochlear implants is no doubt beneficial for many children: “Research to date has provided strong evidence that paediatric cochlear implantation can provide many children with significant advantages in reading and other academic domains” (Marschark et al. 2007, p. 280). This is not, however, an argument that

automatically supports habilitation with speech as the underlying factors determining outcomes for a large part remains unknown. Marschark et al. thus stresses the need for more research:

“Rather than assuming that [academic] achievement necessarily will follow enhanced hearing and language skills, it is essential that we determine which factors support development for different children in different academic placements and family settings” (Marschark et al. 2007, p. 280).

To sum up, cochlear implants are clearly a promising technology with the potential of easing many deaf children’s access to spoken language. When it comes to the effects of habilitation with speech, however, no conclusive evidence is yet presented indicating that such habilitation in itself is a vital factor for outcomes.

It thus seems infeasible to attempt reaching a decision between the bilingual approach and habilitation with speech using decision rules—like for example the principle of maximizing expected utility—where different probable outcomes are weighted against each other. However, a plausible scenario of possible harm connected to habilitation with speech might be taken into consideration.

A scenario of possible harm

In March 2009 Hilde Holtsmark and Jørgen Borrebæk, parents of a deaf girl with cochlear implants, published an article in *The Journal of the Norwegian Medical Association* (Holtsmark and Borrebæk 2009). In this text Holtsmark and Borrebæk tell their story about having a deaf child, getting cochlear implants and choosing habilitation. In accordance with the recommendations of the Rikshospitalet University Hospital, the parents opted for habilitation with speech, expecting—as they were told—that their daughter would have “a normal, yet delayed development of speech” (Holtsmark and Borrebæk 2009, p. 662). After 2 years it turned out that the child’s hearing impairment was caused by a condition which the cochlear implant can not correct or improve. Thus the child had been subjected to attempts to be habilitated in what later turned out to be an obviously erroneous manner, and the hospital now recommended signing.

The parents describe this as a “costly experience” (Holtsmark and Borrebæk 2009, p. 663) of delayed lingual development for their daughter, as she could have started to acquire Norwegian Sign Language—as well as spoken Norwegian in a bilingual program—at an earlier stage, had the recommendations from the hospital been different. Peter C. Hauser and Marc Marschark have made a comment on cases like this:

“Instead of educational settings being accountable and monitoring deaf children’s progress so as to be able to alter communication and instructional programming, there is a continuing tendency to seek a “one-size-fits-all” point of view and place blame on the child. This situation is evidenced in the common reference to “implant failures”—children who have received CIs [cochlear implants] but have not developed spoken language—rather than recognizing that the underlying variability in etiologies, prior language experience, and cognitive flexibility makes cochlear implantation an unpredictable business for any child” (Hauser and Marschark 2008, p. 443).

In the context of the decisional problem discussed in this paper, this implies that habilitation with speech may have harmful effects in some cases. This does not imply that habilitation with speech can not be defended. A decision aiming at maximizing utility for most children with implants could still be attempted, provided that there was a clear understanding of the percentages of children gaining little from their implants or, even better, if one could foretell prior to surgery which children should not expect too much from their implants. Unfortunately, these two conditions can not be met at the present time.

Uncertainty and outcomes of cochlear implantation

Even if clinically conducted cohort studies (see for example Wie et al. 2007; Pisoni and Cleary 2003; Sarant et al. 2001; Miyamoto et al. 2008; Geers 2004; Uziel et al. 2007) can be criticised for skewing perspectives on what outcome means, it is in itself important to observe that the statistical presentation of the results of these studies on the whole displays variances that range “from the excellence of some individuals whose auditory performance is near normal, to the unfortunate few who, despite major advances in technology and surgery, remain seriously impaired” (Hawker et al. 2008, p. 467; for a recently updated reference, see also Kirk and Choi 2009). This variance can not be methodologically ignored in the same way one can ignore such observed differences in other controlled studies with randomised patient samples. On the contrary, cohort studies must seek to identify the variables that can explain variance. This has been achieved only to a certain extent in the case of cochlear implanted children:

“Among implanted children in general, approximately 40 to 65% of the existing variance in outcome measures can be accounted for in terms of a small number of traditional demographic variables such as duration of deafness, length of device use, age at implantation, and residual hearing before implantation” (Pisoni and Cleary 2003, p. 107S; see also Pisoni et al. 2008)

Apart from the above, little is evident. Hawker et al. suggest three categories of possible causes for the variance: the implant itself, the child’s aetiology/ear anatomy and cognitive factors (Hawker et al. 2008). However, Hawker et al. observe that two children can be almost equal in terms of “the cochlear implant [...], the ear, and the brain” (Hawker et al. 2008, p. 467) and still their implant outcomes may vary considerably. This has led Hawker et al. (and others, see for example Lian 2008) to suggest that also factors like undiagnosed language difficulties can play a role in determining outcomes. Such a hypothesis is plausible, but still only one of several imaginable ones. This illustrates the complexity at hand: It is not only problematic that there are many questions without answers; it is also problematic to identify which questions should be asked.

Even with the most optimistic reading of the above figures, it would seem that at least 35% of variance in outcome (measured narrowly as speech production and speech perception in a clinically controlled environment) can not be scientifically accounted for. In addition, there is another aspect that adds to the uncertainty at hand; the variance is neither precisely described nor reliably quantified. As different cohort studies have different samples, test batteries and categorisations, there is no way of telling whether it is nine children out of ten or one child out of ten which see less than optimal outcomes from the implants. The only thing we know is that *some* children gain little from their implants. In the opinion of Hawker et al. (2008) and Siem et al. (2008) the number of children in this category is small. By way of comparison, two randomly selected cohort studies (Uziel et al. 2007; Bakhshaei et al. 2007) of children with between 5 and 10 years’ use of implants report that approximately two out of ten children utilise their implants only to a small degree. That this would be a high figure (20%) is not the point. The point here is that we know some children gain little in terms of hearing and development of speech with their implants, but we are unable to quantify the probability for this happening, not to mention predict the outcome for one particular child prior to implantation.

Discussion

Classical quantitative risk assessment would seem infeasible in the decision between monolingual habilitation and the bilingual approach because the probability factor for different outcomes remains largely unknown. The damage factor can be rendered scientifically probable, however, and so the theoretical condition for applying the precautionary principle may be met.

The scenario of possible harm indicated here is as follows: If habilitation with speech is recommended as the primary intervention for *all* implanted deaf children, it is plausible to anticipate that children whose hearing does not improve despite cochlear implantation are put in a situation resembling the habilitation previous generations of deaf children received before the cochlear implant existed. There is scientific evidence suggesting that this form of habilitation caused harm to some deaf children's lingual, cognitive and social development.

It is not at all implied here that habilitation with speech today represents exactly the same as the historic attempts to teach deaf children a spoken language. Nevertheless, as habilitation with speech is again suggested as an option for deaf implanted children, it is vital to ask in what manner today's monolingual habilitation represents something different from the historic model of habilitation. For children with a satisfactory outcome—for example measured clinically as the ability to produce and pick up words or sentences—it may be that monolingual habilitation is quite reasonable. However, it is far from obvious that the same can be said about the children whose outcome from their implant is poor.

Today's monolingual habilitation differs from the historical habilitation model in that no one today denies that sign languages are full-fledged languages. Sign language is also recommended as the secondary approach in case habilitation with speech fails (Siem et al. 2008). The question of whether this represents any practical difference remains, however. To give speech priority, again conveys the signal that speech is more desirable than signing. Those children gaining little from their implants hence risk a double loss: First, they may be unnecessarily delayed in their lingual development due to exposure only to the language with the modality least suitable for them (because they can not hear very well). Secondly, in addition to facing the challenge of having their language development delayed, those children who start learning sign language after having the monolingual attempt terminated, must grow up knowing that they did not achieve what others considered their primary objective.

Implications of the seriousness of the harm

That the potential harm outlined in this scenario is serious, in itself strengthens the argument for why the precautionary principle could be applied. In classical quantitative risk assessment, serious harm will produce a high estimated risk even when the probability factor is low. In this case, we do not know the probability factor, but hypothetically it is plausible to suggest that even low probability still represents a considerable risk. It is thus reasonable to argue that it is ethically unacceptable to expose a child to a

habilitation that could cause this kind of irreversible harm when such harm is not rendered as likely to occur for those choosing the existing alternative. Although there is little research documenting the merits of the bilingual approach, there is nothing indicating that attempting to provide the child with the chance of acquiring more than one language can be harmful and even those advocating habilitation with speech does not consider bilingualism as more than impractical.

This is not necessarily to say that advising parents in the manner Rikshospitalet University Hospital has done is unethical, but rather that the counselling lacks the necessary rational basis according to the argument of decision theory outlined above. The precautionary principle conceived in the manner Peterson (2007a, b) recommends—as a principle guiding our beliefs rather than our actions—implies that Rikshospitalet University Hospital (and other institutions advising parents on these matters) should see it as rational to be risk averse. Even if the belief that children experiencing good results with their implants will benefit more from monolingual habilitation than from the bilingual approach turns out to be correct (something we cannot assert today), it is not rationally defensible to advise all parents to choose the monolingual alternative as long as it is plausible that some children will gain little from their implants.

Conclusion

Initially I have pointed out something which is scientifically well-documented: If we accept that clinically conducted outcome studies assess outcomes when testing monolingually habilitated children's ability to pick up and produce spoken words and sentences with the help of cochlear implants, some children do not experience the intended outcome. However, we can neither predict the chances for "high" outcome, nor assess how many "low" outcome children there are. The main reason for this is insufficient knowledge of what causes some children to experience the outcome sought and others not. This uncertainty as well as uncertainties related to the alternative to monolingual habilitation—the bilingual approach—makes it difficult to compare the alternatives and difficult to apply quantitatively orientated decision theory in order to decide which alternative one should choose.

The second part of my argument outlines a scenario of harm that is also historically documented: Some hearing impaired children, who are subjected to attempts to habilitate them monolingually, might be irreversibly delayed in their lingual, social and cognitive development.

The precautionary principle applies to cases in which decisions are taken under uncertainty, where one can not

assign, for example, numerical probabilities to outcomes, and in which a plausible scenario of harm is one possible result of the choice made. Arguing in line with the precautionary principle, the following conclusion seems to be an ethically defensible one: For the sake of the few or many deaf children who gain little from their implants, it is rational to be risk averse and thus advise the form of post-operative intervention with the least probability to cause harm to any implanted child.⁴

The bilingual approach is the intervention which historically has replaced interventions based on speech only. Bilingualism is not scientifically documented as being the end-all solution, but as this approach recognises spoken and signed languages equally, it has both a scientific as well as ethical basis. If the bilingual approach can be flexibly adapted to match the child and his or her abilities, such a flexible and individually-orientated approach might have at least the theoretical potential to promote the interests of the child independent of implant outcomes.

One benefit of applying the precautionary principle to the discussion of post-operative interventions for children with implants is the possibility of balancing the most extremely opposing positions in the cochlear implant discourse. Applying the principle does not imply that implantation itself must cease, as some radical activists have demanded (Nakamura 2006). Hence, this argument does not propose limitations upon the continued technical development of implants or upon paediatric cochlear surgery. On the other hand, those who are most optimistic about the technology, believing that sign language and signing minorities are about to become history, might curb their enthusiasm slightly. Sign language should not be seen as something deaf people 'have to use', and from which technology should strive to liberate them. Sign languages are as natural to signing people as spoken languages are to speaking people. Utilising the potential of this understanding is hardly at odds with attempts to restore hearing and provide better conditions for the acquisition of spoken language for deaf children.

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⁴ It might be added that this is a rational thing to do also since the children themselves have not consented to treatment involving an unquantifiable chance of being harmed.

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