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Cochlear implants – ethics and choices*

KEYWORDS

cochlear implants, sign language, spoken language, deaf culture, identity, bimodal bilingual

ABSTRACT

This study discusses the ethical issue of the development of hearing technology in the form of cochlear implants that are used by an ever-growing number of deaf and hard of hearing people. The development of this kind of technology has progressed so quickly all over the world, including Poland, that the deafness paradigms have drastically changed. This may affect, to a greater or lesser degree, not only the implementation of early support programmes, but also the image of the Deaf communities using their respective sign languages on a daily basis. It is therefore necessary to create an eclectic model of education for deaf and hard of hearing people which would allow for the ethical option to integrate the conflicting approaches on the proper procedure for deciding on the language (spoken or signed) and the culture (the hearing or the Deaf one) for the development of deaf and hard of hearing students with cochlear implants or hearing aids.

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(...) a fascination with new technologies should not replace sound educational or psychological principles, ethical practice, or socially agreeable and peaceful human interaction.

Hintermair, Albertini (2005: 190)

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Deafness – a dichotomy between pathology and culture

In Poland – especially in professional literature – there are few discussions on the practical problems of ethical conduct when deciding on the choice of a given language for the development of young deaf children¹ with cochlear implants (CI)² or with the latest generation of hearing aids (HA) brought up in a variety of environmental conditions. Therefore, this paper will discuss the ethical aspects of the impact of two models of change on the education system of deaf students³. The first one refers to the achievements of medicine and hearing aids technology, which are mainly CI⁴. The second concerns the process of reconstructing and recognising deafness as a socio-cultural category.

In the first model, the chances of deaf children are narrowed, as they deal with only one method of communication, which stems from the medical approach dominant in many countries (including Poland), namely diagnosing deafness as a stigma of disability, defect (Hintermair, Albertini, 2005; Komesaroff, 2007; Homffeister, 2007; Lane, 2009; Humphries, Kushalnagar, Mathur et al., 2012a,b). The medical perspective of deafness defines the educational needs of deaf people in the context of hearing dysfunction, reducing early development support activities to hearing care (e.g. CI) and education in spoken language. The aim is to reduce the differences between the deaf and the hearing, where the indicator of social success – understood from the perspective of society as a whole – is to maximise the similarities between the deaf and the hearing. Wanting to popularise this vision, Polish and world mainstream media present cochlear implantation in the form of films, articles or accounts from the first time the child recorded a sound stimulus (cf. Komesaroff, 2007; Potrzebka, Moroń, Tomaszewski et al. 2015). Of course, it should be stressed that technology and medicine offer more and more perfect devices, allowing not so much for better education of the deaf as for their education together with the hearing in the form of integrative education (Tomaszewski, Sak,

¹ The terms “deaf child/deaf children”, “deaf person/deaf persons”, “deaf students”, “the deaf” will be used throughout the entire work – not only to define those who are typically deaf, but also those who are hard of hearing.

² Depending on the type of hearing loss, different hearing implants are used: cochlear, stem, middle ear, bone conduction and other implants (cf. Skarżyński, 2009). The acronym CI (cochlear implant) is used to refer not only to one implant, but also to other kinds of implants.

³ In this paper the author adopts an emistic perspective – taking into account such variables as: internal research, contact with the data source, understanding of the behaviour of a given social group, its language, the perspective of the participant in its culture.

⁴ There is still the question of progress in genetic engineering, which is one of many indicators of medical achievement, but this issue has not been discussed in this paper.

2014). However, there are issues related to the risk of an increase in cases of linguistic alienation with all the resulting consequences, which will be discussed in this study.

As for the second model – the linguistic and sign model – long-term global studies have shown that national sign languages (including the Polish sign language – PJM) constitute complete language systems, having both the features of natural language and social functioning patterns; they are also a cultural distinguishing marker of the linguistic minority of the Deaf who use sign language on a daily basis (Brentari, 2010; Pfau, Steinbach, Woll; 2012; Tomaszewski, 2010; Rutkowski, Łozińska, 2014; Baker, Bogaerde, Pfau et al., 2016)⁵. This has given rise to a paradigm shift in the education of the deaf, which emphasises the need for a type of education that, as underlined by the *Convention on the Rights of Persons with Disabilities*, would provide them with education “in the most appropriate languages (...), as well as in an environment that maximises educational and social development”⁶. Moreover, as Hintermair and Albertini (2005: 189) observe: “taking a cultural view of deafness into account, acknowledging the role that sign languages and community organisations play in the lives of many deaf people may serve as an ‘antidotes’ to ill-considered use of technology”.

“Presenting our point of view” – disputes and controversies around CI

The medical model of disability still dominates in many countries – one-sided efforts are being made to develop modern standardization technologies without the complex socio-cultural conditions of adaptation (Obasi, 2005; Power, 2005; Tomaszewski, Bargiel-Matusiewicz, Pisula. 2015). In the case of d/Deaf people, “the most important factor determining change is the rapid progress of medical science in screening, early diagnosis, otolaryngology, oto-surgery and the associated revolution in technology expressed in the design of new ‘intelligent’ hearing aids of a new generation and increasingly advanced cochlear implants” (Adamiec, 2011: 1). Hence, an important aspect is the influence of surgical technology in the form of CI implantation to “normalize” deafness. Nowadays, CI are becoming more and more popular, both in the United States, Australia and

⁵ The term “deaf” in lowercase refers to all deaf and hard of hearing people, regardless of the degree of hearing loss, whereas “Deaf” is a term referring to a social group using sign language and sharing similar experiences, beliefs and cultural qualities.

⁶ Journal of Laws 2012, item 1169, Art. 24, section 3c

Europe, including Poland. Children are implanted with CI shortly after birth, whereas 20 years ago it was normal to use hearing aids. Since 2006, 80% of deaf babies in northern Europe have received CI (Boyes Braem, Rathmann, 2010: 24), and since December 2010 about 40% worldwide (Humphries, Kushalnagar, Mathur et al. 2015: 1). It is possible that in the near future all deaf children will have implants. However, unlike hearing aids, CI are a stronger – and permanent – interference in the body of a deaf person, so their impact on the general discussion about the education of the deaf or on the entire culture of the Deaf seems to be extremely important, as CI changes the image of deafness and the d/Deaf community.

CI is an electric winding surgically implanted into the inner ear, specifically the cochlea, which is designed to stimulate the auditory nerve and act as a hearing prosthesis – as it does not restore normal hearing ability. The use of CI was approved in the USA in 1990 by the Food and Drug Administration (FDA) at the request of the Cochlear Corporation, which wanted to implant CI in children over 2 years of age (Christiansen, Leigh, 2002: 39). Surgery is performed under general anaesthesia, often resulting in the removal of residual hearing, if any, in the child. The use of CI has been made possible because of their alleged effectiveness in minimizing the effects of deafness. This is the most radical form of combating deafness so far, which is supported by education focused mainly on learning phonics – while minimizing the importance of sign language. Adamiec (2011: 3) describes it as “a huge media propaganda pressure, which often leaves very little room for doubts and hesitation on the part of the parents” of deaf children, which results in the myth that “a small, almost new-born child, after receiving (...) cochlear implants has been cured and his/her hearing restored”. As a curiosity it is worth mentioning that Gerald E. Loeb, who sees himself as the co-founder of CI, predicted in 1993 the “extinction of the alternative culture of the Deaf, probably within a decade”, which shows that the supporters of CI “saw no harm in eliminating sign language and Deaf culture” (Bauman, Murray, 2014: XVI). As Humphries and his colleagues write, when presenting the ethical side of cochlear implantation in young children:

Cochlear implants (CIs) in small children who do not yet have a firm footing in first language acquisition are an on-going experiment with human subjects, in the sense that the risks involved have not been properly identified, much less assessed, due to the failure to focus on the biology of language and its role in first language acquisition. Too often, the developmental cognitive milestones of the deaf child and the right to language are not considered, and we risk contributing to cases of linguistic deprivation with all the ensuing consequences. We propose an immediate remedy: to teach deaf children a sign language,

along with training in speech and speech-reading. For many families, such as those that live far from a Deaf community, as in a rural situation, this presents practical problems, which we address. (Humphries et al, 2012b: 193)

The data indicate that in many European and Scandinavian countries, children with CI are subject to impact aimed at shaping their spoken language with limited or no sign language learning opportunities (Bergman, Engberg-Pedersen, 2010; Boyes Braem, Rathmann, 2010; Quer, Mazzoni, Sapountzaki, 2010). For example, the President of the Danish Association of the Deaf announced that almost 99% of babies and children with CI are raised without a chance to learn sign language because they are not enrolled in schools for the deaf (Bergman, 2008; for: Bauman, Murray, 2010: 214). A similar situation has been observed in Ontario, Canada, where the number of children with CI learning the basics of sign language is decreasing year by year (Cripps, Small, 2004; Snoddon, 2008). Before the introduction of CI, these practices were gradually abandoned due to their low effectiveness and the fact that so much time was devoted to learning speech and lip reading that other school subjects suffered, whereas they could be successfully implemented using sign language. However, CI is recommended to parents by audiologists, otolaryngologists, speech therapists and manufacturers, and the child is under constant medical and pedagogical control. These children do not cease to be children with impaired hearing, as clearly stated at the Conference of National Institutes of Health (Humphries et al., 2014). In addition, CI is a long-term and global interference in the child's life and certainly affects the child's self-image – an electronic device is permanently attached to the child's head. Moreover, the cost of such a procedure and subsequent therapies and consultations is estimated at USD 40,000-50,000 in the first year after CI implantation⁷.

What are the risks of CI implantation? For example complications related to general anaesthesia and surgery in small children. These include pain, infections, siphoning, facial nerve damage, necrosis, skin flap decomposition, postoperative complications, e.g. dizziness, cerebrospinal fluid leakage, epithelial leakage, noise or buzzing in the ear, damage to hair follicles, incorrect electrode location or meningitis – which can be up to 30 times more likely to occur than in the case of children who had not undergone surgery (Biernath, Refhuis, Whitney et al., 2006, Cohen, Roland, 2006; McJunkin, Jeyakumar, 2010; Rubin, Papsin, 2010; Thom, Carlson, Olson et al., 2013). There is also a very high risk – affecting 40-74% of patients – of dizziness, which can last for years (Steenerson, Cronin, Lucinda, 2001;

⁷ The costs are still valid (see: <http://www.asha.org/public/hearing/Cochlear-Implant-Frequently-Asked-Questions/>).

Walker, 2008). Of course, candidates for CI are subjected to multiple tests before they are qualified, and these tests are designed to exclude those at risk of complications or minor consequences of the operation. However, the fact remains that a child with CI is a patient for life – the implant may break down, which will require repeated surgery with all the risks associated with it; structural damage to the inner ear is irreversible. One operation may not suffice and each surgical intervention carries a further risk of complications. However, it must be said that this does not exceed acceptable norms and does not happen that often (Brito, Monteiro, Leal et al., 2012; Brito, Bittencourt, Goffi-Gomez et al., 2013).

Parents of a deaf child – especially those who hear – hope that CI will “cure” their child, that it will be able to communicate normally and function in the hearing society. This of course happens, but before the operation doctors are often not able to predict the potential effects of the surgery (Humphries et al., 2012b). The 22-channel electrode in the implant is to stimulate the auditory nerve (Christiansen, Leigh, 2002). The quality of the sound received is therefore generally so low that deaf adults who have a CI often complain about it and consider it ineffective (Paludnevičienė, Harris, 2011). Studies show that children with two CIs developed normal language skills for their age (Tenenbaum, 2011), but other observations have shown that although CI helps deaf children to recognise words and sentences in spoken language, their recognition is not equivalent to their understanding of the meaning of words and sentences (Peterson, 2004; Preisler, Tvingstedt and Ahlström, 2002). Other studies have shown that compared to hearing children, deaf children with CI had more linguistic difficulties, problems with attention and behaviour (Barker Quittner, Fink et al., 2009). CI can improve children’s hearing and, with intensive care after surgery, improve their hearing and speech skills, but the consequences for overall linguistic development of a deaf child are not yet clear (Marschark, Sarchet, Rhoten and Zupan, 2010; Moores, 2010; Spencer, Marschark, 2011). Thus, a CI itself does not teach the language, nor does it allow for the same understanding, speaking or development of language as in the case of children with normal hearing (see Adamiec, 2011). When reviewing research on the linguistic development of children with CI, some researchers stress that the scale of the impact of the use of CI on the acquisition of spoken language is difficult to estimate, because various studies focus on different variables and use different methodologies, and because the technology used in implantation is constantly evolving and is differentiated among people with CI (Humphries et al., 2014). In short, although there are scientific reports of progress, early detection of a defect and early intervention, the implantation has not been proven to be a panacea (Preisler, 2007). Based on reports from different studies, there are two main reasons for

which CI may in some cases lead to linguistic deprivation. First of all, CI technology does not automatically give full access to spoken language. Secondly, teams of specialists do not recommend or even advise against teaching small deaf children sign language, which is crucial for their linguistic development in the first years of life. “This happens even if the delay in the development of spoken language is very long and impossible to make up for effectively” (Adamiec, 2011: 7). All this can result in a series of misunderstandings, a sense of confusion or disinformation, and even severe stress on the part of the parents.

If the child is deaf from birth, then any kind of benefits from CI implantation may depend on a number of factors, such as: the length of time from the moment of implantation (the longer, the better), the age at which the implantation takes place (the earlier, the better), the number of CIs (it is better to have two CIs than one), the degree of hearing loss (both in the implanted ear and the other ear), the age of hearing loss (the older the child, the better), the degree of mastery of language skills when hearing loss occurs (the higher, the better), cognitive abilities of the child, frequency and type of rehabilitation therapy after implantation (Marchark, Hauser, 2012). Therefore, if the child became deaf at the age of 5, after he or she had a chance to learn a spoken language, the results may be much better. It is also worth mentioning, that the hearing organ shows the highest plasticity up to about 3.5 years of age, and CI implantation up to this age brings the greatest effects, and the highest risk of complications after the procedure is in the case of children up to 7 years of age (Cohen and Hoffman, 1991).

Implanting a child is often associated with unpredictable effects in terms of speech development and school achievements. Children with CI have different predispositions for speech and sign language understanding, as well as different predispositions for speaking and using sign language. It is not possible to recommend a single pedagogical method that would be appropriate for all children and young people with implants. This is related to a large number of factors influencing the success of speech therapy (cf. Tomaszewski, 2008). It is possible that a child in adolescence will reject the implant and start learning sign language in order to become a member of the d/Deaf community (Lane, Grodin, 1997; Hyde, Power, 2006; Paludnevičienė, Harris, 2011). What is more, he or she may never be as skilled in this language as those who have been speaking it since birth. Watson and Gregory (2005) found that from among 200,000 children implanted since 2000, 47% have not used their implants for reasons such as lack of language satisfaction, severe pain caused by noise and equipment, facial cramps, postoperative scars and stigmatization. Referring to the results of these studies, Humphries et al. (2012b: 197) believe that “the human drive to communicate with others is so strong that

if these children had actually found satisfaction in their linguistic abilities with the implants, we fully expect that most would not have stopped using them". This is confirmed by Wheeler, Archbold, Gregory et al. (2007): they conducted interviews with 29 children with CI aged 13 to 16 years. Those respondents who gained positive benefits from CI in terms of the use of spoken language in contacts with hearing people were satisfied with the CI. If the CI did not work or did not work properly, they experienced significant stress caused by the inability of perceptual reception of the sound environment.

It is worthwhile taking a look at the issue of the development of social and cultural identity in a child with CI. When using CI, the child undergoes tedious speech therapies, does not acquire competence in sign language, and has a visible electronic device permanently attached to its head – all of this may have an impact on the development of his or her identity, and a problem can arise between the two communities, i.e. between the deaf and the hearing. Such a child may not be culturally present in any of the alternative groups, and the treatment is often “experimental” with unclear effects, as CI does not represent the way in which the hearing hear sounds in an accurate manner and does not guarantee full access to the world of the hearing (Ladd, 2007; Leigh, Maxwell-McCaw, 2011; Marschark, Hauser, 2012). However, when immersed in sign language, a deaf child can learn to cope by growing up with the support of the d/Deaf community. It is also exposed to their cultural values (Hauser, O’Hearn, McKee et al., 2010; Holcomb, 2013). Moreover, it is ethically questionable that the FDA, when it gave its consent to the use of implants at the beginning of the 1990s, did not carry out any consultations with organisations associating the d/Deaf, only with the medical community and implants manufacturers – which shows disregard and ignorance for the entire d/Deaf community (Lane, 1996).

American studies show that CI are perceived by the Deaf community as one of the greatest historical threats to their identity (Humphries, Humphries, 2010; Leigh, 2010), as “oppressive technological normalization, aspiring to the standard of a hearing body”. (Zdrodowska, 2014: 40). The main accusation of many Deaf people against the use of CI is a sense of personal insult, and the personal approach makes it impossible to objectively assess this invention. Many members of the Deaf culture see cochlear implantation as an insult to their own feelings: in their opinion, CI is only a medical aid tool, it is treated as a medicine, whereas the deaf do not consider themselves sick (Blume, 2010; Lane, Hoffmeister, Bahan, 1996). Undoubtedly, the option of using advanced technologies to improve the hearing of deaf people provides them with many new opportunities, but it also poses a clear threat to their identity, culture and community (Cherney, 1999; Lane et al., 1996; Woodcock, 2001; Hyde, Power, 2006). As Leigh points out:

Negative opinions about the cochlear implant appear to be a reaction to messages that deaf is defective and reflects a “spoiled identity”. For many Deaf community members and their supporters, to get an implant is seen essentially as a representation of the need to get rid of the deaf person’s “spoiled identity” through repairing a so-called defect and gaining some semblance of hearing identity to achieve a more “normalized” stance. This demonstrates how the power of a technology inserted within the person can affect the perceived value and identity of the person. (Leigh, 2010: 203-204)

Another important issue is the implantation of young children, which is decided by their parents and not by themselves because of their young age, which can be seen as particularly acute for the formation of children’s identity as a Deaf person (Padden, Humphries, 2005). Some authors oppose the implantation of small children and believe that only adults, who can make an informed decision about the procedure at their own risk (Lane, Bahan, 1998), can undergo surgery. However, as of today, such an opinion is no longer realistic and “the discussion about the age of the operation is almost non-existent” (Skarżyński, 2009: 103). The main reason for this is that scientific research provides evidence that the earlier a child receives CI, the more effective the hearing (re)habilitation is, so that the child can gradually acquire linguistic skills in the context of speech use, although this is not yet comparable with hearing children (cf. Niparko, Tobey, Thal et al., 2010). In addition, early implantation of a child is primarily related to the possibility of taking advantage of the sensitive period of development of its central nervous system. The optimal age for surgery ranges from 8 to 12 months (Skarżyński, 2009). No wonder that parents decide on early implantation in order to maximize the chance of developing spoken language in their child. It is worth noting that these children, when they are older, often express gratitude to their carers for making the decision, as demonstrated by research by Wheeler et al. (2007), of course, when they benefit from the use of CI.

The fact that children with CI are discouraged by doctors and their environment to use sign language arouses particular indignation and tension among active members of the Deaf community, as the use of sign language is considered to be the main bond of their culture (Hill, 2013; Holcomb, 2013; Humphries, Humphries, 2010; Leigh, Andrews, Harris, 2016). And the argument against the use of sign language by children with CI is based on the belief that sign language is much easier than spoken language, that by using sign language deaf children will become “lazy”, will prefer to use sign language rather than speak (Marschark, Hauser, 2012), and that the signs of sign language are “prosthetic elements” that replace spoken words (Tomaszewski, 2014). In fact, there is no evidence that the use of sign language is an obstacle to speech development after implantation (Spencer,

Marschark, 2010; Knoors, Marschark, 2014). On the contrary, early sign language acquisition may cognitively and linguistically support the process of acquiring spoken language after cochlear implantation (Knoors, Tang, Marschark, 2014; Marschark, 2007; Marschark, Hauser, 2012; Woll et al., 2010; quoted after: McKee, Hauser, 2012). Many authors believe that due to the fact that the use of CI does not restore hearing completely, and that the restored hearing is not uniform with the hearing of the person who has normal hearing from birth, a person undergoing this procedure may find himself as if suspended between two worlds – not fully belonging to the culture of the Deaf, or to the hearing community (Ladd, 2007; Lane et al., 1996; Woodcock, 2001). This is confirmed by the results of a study by Wheeler et al. (2007), in which most implanted people perceived themselves as internally deaf in the medical sense, meaning that without CI they could not hear, although in the social sense they did not show the cultural identity of the Deaf. As deaf people with CI – especially those with hearing parents – they constitute another generation that, regardless of the norms of the hearing or Deaf people, creates a variant of identity that reflects, as Ohna (2003, 2004) notes, the existence of a new maxim of “being deaf in their own way”. In addition, other studies on the quality of life conducted among 231 young people with mild to profound hearing loss showed that those who mastered only spoken language felt stigmatized because of their hearing loss more often than those who used a combination of speech and sign language (Kushalnagar Topolski, Schick et al., 2011). A similar conclusion was drawn from observations of Australian children and adolescents with CI (Punch, Hyde, 2011).

Although CI are relatively new and many studies show that they are effective, the “effectiveness” itself may have different meanings for parents, teachers, researchers and specialists. Parents take on a great responsibility and often attach more significance to the fact that the child learns to speak, even if only to a narrow extent, than is fluent in sign language. From an ethical point of view, however, children with CI should not be deprived of the right to bilingual teaching, which can be a better safeguard for their future than contact with only one language, especially spoken language, and thus only the world of people with normal hearing (Baker, 2006; Grosjean, 2008; Tomaszewski, 2005). Research has shown the risk of postponing the contact of a child with CI with sign language during the critical period of brain development, which has additional consequences for its cognitive and social competences (cf. Knoors, Marschark, 2014). As a result of these observations, some researchers suggest that before, during, and at the end of therapy, the child with CI could learn sign language and spoken language in parallel, which would provide him/her with the best possible opportunities for linguistic devel-

opment and long-term positive effects for its overall development (Christiansen, Leigh, 2002; Humphries et al., 2014; Preisler, Tvingstedt and Ahlström, 2005; Preisler, 2007), as the use of CI does not solve all the problems that may arise in the child's development (Spencer, Marschark, 2011).

This is, of course, an extremely complicated ethical problem, the detailed discussion of which exceeds the topic of this paper, but to sum it up and reflect on it, it is worth citing an incident that took place during a discussion about CI, when a hearing mother said that she fully respected the d/Deaf community, but she had the right to desire for her child an operation that would make it similar to her community, i.e. the hearing community. She was answered by a lawyer, Gary Malkowski, who said paradoxically: "Then you will probably have nothing against a deaf parent demanding surgery for his or her hearing child in order to make him or her similar to himself or herself" (Lane, 1996: 294). Likewise, when presenting the medical paradigm of deafness, Koch (2001) expresses the opinion that although the Deaf community does not perceive deafness as a defect, the medical perspective sees it as something that should be repaired in the name of human health. In short, in Polish conditions many parents of deaf children often do not know about the alternative offered by the possibility of raising a child based on the socio-cultural model of deafness (Tomaszewski and Sak, 2014). As Hoffmeister (2007: 79) notes, the lack of this knowledge results from the so-called "ethnocentric transmission": from the perspective of the dominant culture of the hearing, many doctors, speech therapists, educators and psychologists, present the parents of deaf children with a medical model of deafness, avoiding its socio-cultural aspects – the reality of life of deaf users of natural sign language as a visual carrier of their culture⁸. McKee and Hauser present a similar view:

Many parents of deaf children are not fully informed by the medical community of the benefits and risks of cochlear implantation, including alternative treatments or doing nothing. Parents often are not aware of the true limits of cochlear implants and may hope that it is a "cure." They might feel that they do not need to learn how to raise a deaf child because the implant will solve everything. (McKee, Hauser, 2012: 55)

Finally, the unique status of the Deaf community as a linguistic minority should also be considered. If the Deaf do not consider themselves to be a "medi-

⁸ Another reason for the domination of the medical paradigm is also the fact that Poland does not yet have numerous teams of specialists dealing with creating a linguistic environment for deaf children and their families on the grounds of not only audio-vocal modality, but also visual and gesture modality: the number of d/Deaf assistants to families of a deaf child is still negligible, there is no methodology for teaching sign language on a mass scale, there are no bimodal bilingual teaching models.

cal problem”, then why does the medical approach to deafness dominate in many countries, including Poland? It seems obvious and natural that we do not try to change children by biological interference to make them belong to the majority and not to a minority – we do not change the colour of the skin of races other than white, even if we believe that due to racial discrimination to which they are exposed they would be better off. As previously agreed, the d/Deaf community contributes to the pluralistic diversity in the world, and it is a mistake to try to avoid it, disregard it and ultimately reduce its size – this is too close to the eugenic approach. Unfortunately, this tendency is quite visible in genetic research, gene testing before implementation and genetic therapies that “heal” genes (Ekberg, 2007; Hanson, 2013; Hubbard, 2006). Consequently, future developments in medicine, including genetic monitoring, may lead to the reduction in the number of deaf children being born, which is likely to affect the slow disappearance of sign language communities (Fenlon, Wilkinson, 2015; Lane, Bahan, 1998; Lane, 2009). These fears are based on Johnston’s observation (2004), who pays significant attention to the situation of Australian sign language (Auslan), which is at risk of extinction. The author warns that there is a decrease in the number of deaf children being born, an increase in the number of CI use and in the number of educational institutions that do not include Auslan in their curricula, the development of further genetic tests that allow parents to prevent the birth of deaf children. In his opinion, the systematic use of genetic knowledge to prevent the birth of deaf children may result in the extinction of the d/Deaf community. On the other hand, Adamiec believes that:

The culture of the Deaf is much richer than the creators of utopian theories would like to admit. The culture of the Deaf is pluralistic. Every deaf person takes their place in it, more or less exposed, occupies more or less space, but the machine of culture moves forward, develops, changes. It will not die because new technologies are increasingly dominant and there are countries where all children with profound hearing loss have an implant, where schools for the deaf are being eliminated. (Adamiec, 2010: 77)

Despite divided opinions, others envisage an option of a much slower impoverishment, but ultimately the survival of d/Deaf communities and national sign languages (Carty, 2006; Hyde, Power and Lloyd, 2006). To sum up, the struggle against d/Deaf communities is taking place on the medical lines and cultural models of deafness, and this occurs in an ideological area of normality, oppression, disability, identity and culture.

On the other hand, recently there have been voices in the d/Deaf community on the need to implant CI; the number of d/Deaf people who choose CI for them-

selves or for their deaf children is increasing (Christiansen, Leigh, 2002; Most, Wiesel, Blitzer, 2007; Leigh, 2010, Gale, 2011; Leigh, Paludnevičienė, 2011; Mitchiner, Sass-Lehrer, 2011; Mitchiner, 2015). The deaf often perceive CI as more of a device that improves the perception of sounds than as a device that compensates for hearing loss and thus increases their communication skills (Tomaszewski, 2016). It is also worth noting the growing number of young d/Deaf people, e.g. in England, who prefer audio communication (O’Neill, Arendt, Marschark, 2014). In the work *Introduction to American Deaf Culture* Holcomb expresses his opinion on this issue:

Further compounding the complications of this discussion is the growth of the number of Deaf adults who have chosen to undergo implant surgery. Although it can be argued that these individuals are perpetuating the perception that there is something wrong with being deaf, they are also reinforcing the concept that there are many different ways of being Deaf. For example, just like the hard-of-hearing members of the Deaf community, most Deaf adults who have cochlear implants have no desire to disassociate themselves from the Deaf community. Although they don’t consider themselves superior to those who have less hearing or believe that all deaf people should be implanted, they have chosen this path to be implanted for different reasons, such as being able to enjoy music more, have an easier time communicating with hearing people, or being more attuned to environmental sounds. At the same time, they continue to enjoy the benefits of Deaf culture, such as full and unrestricted access to communication and information, healthy identity formation, and so on. Perhaps these cochlear implantees, as well as the hard-of-hearing members of the Deaf community, have much to teach those families who are contemplating surgery for their deaf babies and the professionals involved with the implants regarding their realistic perspectives of what it means to be Deaf. (Holcomb, 2013: 78-79).

Potrzebka et al. suggests, however, that an alternative reason for the decision on implantation is that some of the d/Deaf, especially those in Poland:

(...) may have a completely different motivation than the desire to draw from the benefits of both cultures – the world of silence and the world of sounds. The deaf in Poland point to the need to “equalise social opportunities” for deaf children. It seems that in the Polish reality, revalidation of hearing loss through implantation is the “lesser of two evils”. (...) it seems that they are increasingly affected by various means of social oppression on the part of the society, which may lead to their exclusion (...). (Potrzebka et al., 2015: 83)

There are also the results of the Mitchiner study (2015): several deaf parents in the US whose children have a CI have expressed their frustration at the barriers and limitations they face in terms of promotion opportunities in workplaces where English is the dominant language. They agreed that many deaf people still experience discrimination and oppression because of deafness. As the author

writes: “societal forces (...) may be one of the reasons why an increasing number of Deaf parents choose to provide their children with cochlear implants” (Mitchiner, 2015: 61).

To sum up: some members of the Deaf community are beginning to accept CI, although there are still “points of resistance” to children’s implantation, because the visible effect of the deafness treatment system is that the deaf question their own identity, which can lead to self-doubt and reduced self-esteem. The fight conducted by the Deaf to maintain a sense of identity when the majority oppressively imposes labels on them, thus weakening their control over the formation of their identity, continues, which can cause uncertainty as to their own linguistic, cultural and social identity.

Bimodal bilingualism as the golden (?) mean

As we know, cochlear implantation is now the method of treatment of choice in most children with sensorineural deafness, whereas sign language is considered, as Broesterhuizen and Leuven (2008: 106) write: “a symptom of treatment failure”. A sceptical attitude towards sign language is related not only to a common belief that sign language is lacking linguistic status in relation to phonics, but also to the position of some researchers dealing with the issue of neuroimaging in the field of trans-modal plasticity of the brain. They advocate the so-called visual takeover hypothesis, which assumes that visual stimuli “take over” the auditory cortex – especially the higher order – responsible for processing sound signals, thus contributing to functional decoupling between this cortex and the primary cortex, which gathers the sound stimuli coming from the environment (Lee, Giraud, Kang i in., 2007; Kral, Sharma, 2012). Therefore, cortical activity is minimised in the sense that fewer and fewer acoustic signals penetrate into the higher order of the auditory cortex, which begins to process visual stimuli, which can practically reduce the chance for a deaf child to develop spoken language. Therefore, some recommend limiting the access of young deaf children to visual stimuli (sic!) in the form of gestures, sign language, facial expressions or mouth movements while speaking, at least for several months, until they have the CI, so as not to risk the transition of the auditory cortex to sleep.

However, the results of neuroimaging studies, which have shown the presence of trans-modal plasticity of the brain, are not in line with this belief: the brain is flexible in its ability to use the language and easily adapts to its modality, so that this ability can be shaped both by spoken language, as well as by sign language, it

has an impact on one and the other (Petitto, Zatorre, Gauna et al., 2000; Petitto, Katerelos, Levy et al., 2001; Capek, MacSweeney, Woll et al., 2008; Campbell, Capek, Gazarian et al., 2011; Jasinska, Landgdon, Petitto, 2013; Kovelman, Shalinsky, Berens in., 2014; cf. Campbell, MacSweeney, Woll, 2014). This means that while children are waiting for CI implantation, the sign language environment activates their main brain regions responsible for language processing, keeping the brain open to the language and its ability to receive linguistic texts until implantation and training in spoken language. As stressed by Petitto (2016), the brain does not discriminate against modality, but accepts both audio and visual code. This is confirmed by recent international research results on the impact of bimodal bilingualism of a sign-speech type (two-way teaching of two languages: spoken and sign) on the linguistic development of deaf children with CI, having Deaf parents: it was initially shown that these children successively assimilated spoken (audio) language when raised in the environment of natural sign language (Jiménez, Pino, Herruzo, 2009; Hassanzadeh, 2012; Davidson, Lillo-Martin, Pichler, 2013; cf. Morere, 2011). Similar results were obtained from observations of linguistic development of a deaf child with CI of hearing parents in bimodal bilingualism of the sign-speech type (Rinaldi, Caselli, 2014). Although early and continuous bilingual stimulation of children with CI or hearing aids may contribute to their educational and social development and is certainly not an obstacle to the development of spoken language, it is too early to assess the positive results of initial research in detail and in terms of substance, as the long-term consequences of early sign language acquisition for academic development are still in question. It is therefore necessary to carry out further research in this direction.

However, reports from the above observations suggest that bimodal bilingualism of the sign-speech type in children with CI is a remedy that can be applied at an early intervention level to support families in order to provide the best possible long-term developmental outcomes for deaf children in a society dominated by hearing persons. Deaf parents from the Mitchiner study (2015: 60) expressed the opinion that for them and their children with CI English is the “linguistic survival” i.e. the language of survival, and ASL is the “cultural language”. In their opinion, proficiency in English, not only in written, but also in spoken (sic!) form, is necessary for survival and success in a country with a dominant English language, and ASL is necessary for the construction and development of a socio-cultural identity. This solution is also sought by more and more Deaf adults, who are in favour of combining CI with sign language in order to maximize their linguistic skills in both modalities: auditory-vocal and visual-gesture (Padden, Humphries, 2005). To sum up: many researchers believe that teaching children with CI in the spirit

of bimodal bilingualism of a sign-speech type can provide them with maximum opportunities for language development, and thus a chance to achieve cognitive competence and psychosocial well-being (Cormier, Schembri, Vinson et al., 2012; Nussbaum, Scott, Simms, 2012; Humphries et al., 2014; De Quadros, Lillo-Martin, Pichler, 2016; Leigh et al., 2016).

Prospects for resolving the CI dispute

After proving that sign language is a complete linguistic system, and after recognising that sign language should be used as the first language in the upbringing of deaf children, when they were still equipped with hearing aids (HA) and not CI, it was assumed that bilingualism was the best educational programme for these children (cf. Hansen, 2002). It provides for the use of two languages in teaching deaf people: sign language as the first language and spoken language (mainly in written form) as the second. This solution has been implemented in many schools for the deaf in many countries around the world (cf. Marschark, Tang, Knoors, 2014). Although this idea had a strong theoretical basis, there was still not enough data necessary to evaluate the linguistic development of deaf students in sign-written bilingual conditions⁹ (Knoors, Marschark, 2014; Knoors et al., 2014; Mayer, Leigh, 2010; Spencer, Marschark, 2010). However, due to the accelerated development of CI and HA technologies, there is a growing need to revise the policy of bilingual teaching (Knoors, Marschark, 2012), as well as to redefine the model of becoming and being bilingual in the context of education (Mayer, Leigh, 2010) due to an important fact: sign language and spoken language are now being absorbed in any order – regardless of which of these languages is to be implemented first¹⁰, as it depends on the diverse cognitive and linguistic abilities of the deaf children and the environment in which they grow up. Moreover, from the perspective of 2015, many deaf children are beginning to have greater access to spoken language through very early cochlear implantation (Leigh, Marschark, 2016, see also Spencer, 2016), which has initiated an “implant discourse” that has changed the cultural proportions, creating a group of “hard of hearing”, but no longer typically d/

⁹ In the past, there was a majority of deaf children (until most of them were equipped with CI) for whom sign language was the first language, and writing as a form of phonetic language was their next way of communicating – hence bilingualism of the sign-written type.

¹⁰ This is mainly about bimodal bilingualism of the sign-speech type, when we are dealing with a group of deaf children with CI or HA, who can communicate in the phonetic language (not to mention the written form of this language), and not only in the sign language.

Deaf. This was observed in earlier studies on interactions with hearing peers: the communication behaviour of deaf children with CI was similar to that of children with typical hearing impairment in conversations with hearing peers (Antia, Kreimeyer, Metz et al. 2011). It is worth noting that maintaining the imperative position that *all* deaf children should be taught sign language as early and as soon as possible may become ethically incorrect. Homogenization of all cases negates the existence of diversity in the whole population of deaf children. A similar situation occurred in the time of oralism, when deaf children were educated only in spoken language without the use of sign language, which at that time was considered to be a primitive system of gestures, limiting both mental development and human speech development. Therefore, it is necessary to approach children with CI (and also HA) in a flexible way, so that their preferred sensory modality can be recognized in terms of a multidimensional continuum from visual through visual-auditory to auditory, preferred forms of communication, both receptive and expressive, preferred ways of learning, i.e. to comprehensively diagnose the specific trajectories of development of each deaf child. Due to the incomplete permeability of the auditory canal, flexibility in providing two-way linguistic stimulation can – regardless of the socio-economic status of their families or any other factors – guarantee better security for the future than a single-modal teaching of a deaf child in only one language. What is more, the development of a competence such as bimodal, or rather multimodal¹¹, bilingual cognitive adaptation to constant changes in learning conditions can help to overcome the limitations it may encounter using spoken language or sign language. As a result, any of these languages would become a practical tool for the child to bind together all his/her experiences and thus construct an increasingly complex mental representation of the world. It would also reduce the risk of developmental delays.

However, the development of a deaf person's sense of identity, for which bilingual teaching is also important, remains an important issue. According to the *Convention of the Rights of People with Disabilities*, the development of the cultural and linguistic identity of the d/Deaf community should be supported¹². The point is that the deaf person can identify with the d/Deaf community and feel part of the hearing world, drawing positive values from both environments. The Kobosko study (2010) shows that both spoken language and sign language are equally important for many deaf people and they try to find their place in both worlds at the

¹¹ It is a multimodal bilingualism of the sign-speech-written type, where a deaf child learns two languages: sign language on the basis of visual and gestural modality, spoken language on the basis of audio-vocal modality and written, which is connected with another type of modality – visual and graphic.

¹² Journal of Laws 2012, item 1169, Art. 24, section 3b and Art. 30, section 4

same time. However, it should be remembered that the identity of a deaf person who has a dual affiliation develops in a specific way, since multiculturalism in the context of deafness as a phenomenon of socio-cultural integration requires above all the ability to “negotiate tensions between competing and profoundly contradictory beliefs, lives and activities, those that are embedded in the lives of hearing people on one hand and those of Deaf people on the other” (Padden, 1996: 87).

It is not insignificant that the limited access of parents of children with CI or HA to a variety of information on early development support for their children with CI may result in a one-sided choice of education options for children with CI, regardless of their preferences as to the form of communication or ways of learning. Therefore, the basic, and often neglected, issue in bringing up children with CI is to inform their parents about a number of alternatives, one of which concerns the possibility of a bimodal and bilingual learning process. It is necessary to develop programmes to support the development and parallel use of spoken and sign language, both within and outside the family, from the moment deafness is detected in the child. This type of action, as some authors observe, is supposed to be a guarantee of taking care of all aspects of the development of the child with CI, which may have a positive impact on its functioning in the future (Humphries et al., 2014; Hintermair, 2014; Moeller, 2006; Preisler, 2007).

However, it should be remembered that the possibility of a bimodal bilingual upbringing of a deaf child with CI usually takes place in a unique situation, when it has Deaf parents, who are bilingual themselves, thanks to which they constitute a bilingual bimodal environment for their children, if they are deaf and if they have CI. The situation is completely different in the case of deaf children of hearing parents, who, according to Mitchell and Karchmer (2011), account for as much as 95% of the population in relation to deaf children of Deaf parents. As Knoors (2016) points out, when discussing the appropriate choice of communication options for a deaf child, we focus on the child itself, often ignoring the fact that the child is brought up by parents, which clearly means that its development is situated primarily in the context of the family. Therefore, the option of bimodal bilingual upbringing of a deaf child could be, on the one hand, an optimal solution, but on the other hand, this alternative may turn out to be a great challenge, too difficult a task, even impossible for parents who hear. Although this does not mean that a deaf child of hearing parents does not have a chance to be immersed in two languages in the early stages of development, as shown by the preliminary results of the Rinaldi, Caselli studies. (2014). Nevertheless, addressing this issue requires a paradigm shift in early support for the development of a deaf child whose parents have normal hearing. Being aware that the greatest risk for a deaf child is not

sensory deprivation, especially auditory deprivation, but linguistic deprivation in the sense of poor access to full language resources, an objective programme of early intervention or early development support could be developed together with hearing parents, which would include the whole family and take into account its specific situation, providing for the possibility of participation of adults who are deaf and hard of hearing in creating for a deaf child from a hearing family real conditions for early, parallel, continuous and, above all, flexible – if possible – contact with spoken and sign language. This could give him/her an optimal cognitive and linguistic advantage throughout his/her life in relation to the later contact with the second language, regardless of which language it will be.

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