



## COCHLEAR IMPLANTS IN DEAF CHILDREN

Integration of people with disabilities

# **COCHLEAR IMPLANTS**

## **IN DEAF CHILDREN**

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Integration of people with disabilities

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## **PREAMBLE**

### **Fields of activity of the Council of Europe**

The competence of the Council of Europe is very wide and covers practically all aspects of European affairs, with the exception of defence matters. Where, however, a lesser number of states wish to engage in some action in which not all their European partners desire to join, they can conclude a "partial agreement" which is binding on themselves alone.

### **Partial Agreement in the Social and Public Health Field**

It was on this basis that the Partial Agreement in the Social and Public Health Field was concluded in 1959 by the Council of Europe Committee of Ministers and revised in 1996 by the Committee of Ministers with effect from 1 January 1997. the following States are members of the Partial Agreement; Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland and the United Kingdom of Great Britain and Northern Ireland.

In the sphere of rehabilitation and integration of people with disabilities, co-operation between states is ensured by the "Committee on the Rehabilitation and Integration of People with Disabilities (CD-P-RR)".

Various studies have been carried out and resolutions drawn up. This work has been a continual source of inspiration for member states in connection with their legislative and administrative arrangements.



## **INTRODUCTION**

This report has been written at the request of the Council of Europe, the purpose being to report on relevant research about cochlear implants in deaf children as well as to analyse contributions from member and observer states of the Partial Agreement in the Social and Public Health field as well as from the European Union of the Deaf (EUD).

### **1. BACKGROUND**

The most common question that parents of deaf infants ask their doctor at the time of diagnosis is whether their infant's hearing loss can be surgically replaced. Until recently, the answer was "No". There was no medical or surgical method to cure deafness. But in the seventies, a new technique was developed called cochlear implant (CI). It was first tested on adults and a decade later also on young children. A cochlear implant can briefly be described as a hearing aid surgically placed in the cochlea. The surgeon places a receiver in the bone behind the ear and has a series of electrodes placed within the cochlea. A speech processor is connected to the implant. This speech processor modifies the incoming sounds into signals that are transmitted to the implanted receiver. Added to this is a microphone and transmitter, fitted behind the ear. It remains in place by means of magnets on both the transmitter and the implanted receiver. The microphone receives the sounds and transmits them to the processor.

When cochlear implantation was introduced in the early 1980s the first patients were post-lingually deaf adults. The first operations on children were also made on the post-lingually deaf. In 1990, CI was approved by the United States Food and Drug Administration (FDA) for use on pre-lingually deaf children, after tests on 80 children with profound deafness aged 2-17 years (see e.g. Geers and Moog, 1991; Beiter, et al., 1991; Boothryd, et al., 1991; Allen et al., 1993). By January 1999, more than 25,000 deaf persons around the world had received implants. In 1992, the number of children was approximately 800. By 1993 the number had more than trebled to 2,600. By January 1999, 11,000 children had received an implant.

In most countries, the lower limit of receiving an implant is two years of age. But even younger children have been operated on. The rationale of an early implantation is that early exposure of the child's auditory system is regarded as a means of stimulating his/her speech perception and speech production.

## **1.1 Cochlear implants (CI) in deaf children - different schools of thought**

Countries having performed most implantations and from which results are most frequently reported are the USA, Australia, United Kingdom, Germany and France. Reports from these countries published in international journals and/or presented at international symposia on cochlear implants on children have shown that there are different schools of thought in relation to CI on children. One focus is on the child's ability to produce/imitate speech. Speech training is seen as crucial for a positive result of the implant. Another school maintains a more child-centred perspective, advocating the child's need to be able to communicate with adults and peers in different social contexts. To the author's knowledge Sweden is still the only country maintaining an established sign language communication between the deaf child and his/her family as a prerequisite for being a candidate for a cochlear implant.

## **1.2 Selection of patients**

Selection of patients has been an issue of much concern and discussion in many articles. However, criteria have changed over the years, both with respect to the degree of hearing loss measured in decibels (dB) as a mean for different frequencies, and also with respect to finding out whether conventional hearing aids are an alternative. As younger children are implanted, less emphasis has been put on this latter aspect.

Common to many countries is the emphasis on a careful selection of patients and on rehabilitation. It was stated in the Concensus Development Conference Statement of Health (4 May 1988) that:

"The process of cochlear implantation represents a major change in a person's life. A strong interdisciplinary rehabilitation team provides a prudent support system to aid in this difficult transition. Consulting and counselling the person with an implant and his or her family, coupled with a training program of aural rehabilitation facilitates the maximal use of the implant". (op cit Kileny, et.al.,1991).

Kileny et al. (1991) made the remark: "Nowhere is this statement more relevant than in relation to a children's cochlear implant program" (pp. 144-145).

During the last years emphasis has been more focused than before on psychological consequences of a cochlear implant in children than before. Therefore, not only medical, audiological and educational considerations are taken into account, but also psychological and psychosocial criteria. Motivation, personality and intellectual abilities of the patient as well as support systems are included as important parameters to decide whether to recommend a cochlear implant or not. The idea behind this is, in the first instance, to make a judgement of whether the child can be regarded as being an appropriate candidate for intensive speech and hearing training or not.

## **2. REPORTS FROM COUNCIL OF EUROPE MEMBER STATES**

Delegations from the following countries have sent notes to the Committee on the Rehabilitation and Integration of People with disabilities (CD-P-RR): Belgium, Finland, France, Hungary, the Netherlands, Poland, Slovenia, Spain, Switzerland, and the United Kingdom.

In addition to the reports from these ten member states, a report from a working group of The European Union of the Deaf (EUD) was also submitted - referred to hereafter as the EUD. The EUD had developed a questionnaire that was sent to all centres within the member states of the European Union believed to have established paediatric cochlear implantation programmes. The questionnaire was also sent to the national associations of the deaf and to the associations of parents of deaf children. Responses from teams working in 50 implant centres were received. This was considered a high figure, while the response rate from associations of the deaf and of parents' organisations was low. Teams from ten countries responded to the questionnaire, five of these countries have also written notes to the Council of Europe (Belgium, France, the Netherlands, Spain and the United Kingdom), the other countries were Denmark, Germany, Italy, Portugal and Sweden.

### **2.1 *Analysis***

A content analysis of each report has been made in order to find which issues were mentioned in the reports and with what these issues were concerned with. As the different countries have given very different comments it was not possible to make any sophisticated analysis of the texts, but the analysis still gives an overall impression of what different countries have pointed out as important questions/issues in relation to cochlear implants, particularly in children.

### **2.2 *Results***

#### *Age*

In all ten countries cochlear implants have been made on adults, even if the numbers vary. Operations on deaf children have also been made in all the countries from approximately 2 years of age. In Slovenia the children operated on have been older than 5 years. The age considered appropriate for CI on children is discussed by several delegations. Two to three up to 5 years of age are mentioned by most countries as an appropriate period of the child's life. In the note from the Flemish community in Belgium early implantation in the congenitally and pre-lingually deaf population is seen as an absolute prerequisite to success. Added to this is also the importance of early identification. The note from France states that implantation cannot be carried out before the age of 2-2½ due to technical problems. In the ten-year survey of deaf children in France, the children received their implants by the age of seven years at the latest. The Finnish note states that there is a risk of too early an operation as the children then may lack a first language.

### *Clinics*

Operations have been concentrated at a few centres in each country, and the common opinion is that it is also important in the future to allocate all relevant knowledge and services to a few university hospitals. The EUD reports that four centres accounted for over 50% of all operations reported up to mid-1995.

### *Costs*

Some countries have specified in detail the costs of an implant, others have also discussed the question of reimbursements. Funding differs between the various countries - from the Social Security Department (Spain) to the health authorities (United Kingdom) or no system at all (Poland).

### *Rationales for recommending cochlear implants*

Most countries look upon CI as a *treatment* of deafness, i.e. deafness is regarded as a medical problem that can be solved by a certain treatment. The aim of an implant is to make it easier for the patient to take part in *oral* communication by giving the deaf and profoundly hard of hearing access to the hearing world. Integration and inclusion are important concepts in this context. In order to obtain this goal, speech and auditory training is either regarded as a prerequisite, recommended or implicitly assumed. Two countries, Finland and France, state the importance of sign language for deaf children, even for deaf children with cochlear implants, with the aim of giving the children opportunities to develop bilingualism.

For the ten-year survey of pre-lingually deaf children with cochlear implants carried out in France, a Scientific Committee had been set up to ensure that the subject was approached with the necessary objectivity and that the methods used were relevant. The members of the committee represent a wide range of know-how, among them persons with knowledge of French sign language.

### *Selection of patients*

Criteria for selection of patients and contraindications are mentioned by many countries. Most of them express a similar opinion on the selection criteria:

- Deafness should be total or profound, bilateral, of cochlear origin and unsuitable for correction with a conventional auditory prosthesis.
- Strong motivation and tolerance; realistic expectations as well as an educational and social setting where the child is integrated among people with normal hearing.

In the Belgian note it is explicitly stated that before an implant is made, it must first be approved by a Board of Medical Officers on the basis of a medical report.

Poland has divided the criteria into absolute and relative criteria. Among the relative criteria are the evaluation of the patient's chances for achieving the assumed results, lip-reading ability as well as knowledge of written language. These criteria have not been used by any other country.

#### *Contraindications*

Criteria for exclusion are of an anatomical nature but also mental retardation or low intellectual level, emotional and/or social problems, learning defects with regard to speech, behavioural problems, inadequate motivation, anticipated problems with regard to the parents' participation during rehabilitation may be taken into account. No other additional disability or handicap must be present, which might impair rehabilitation and integration. In Spain, the age of less than two years is regarded as a contraindication.

#### *Ethics*

Two countries explicitly discuss ethical questions, Finland and France, the subject also being mentioned by the Netherlands and the United Kingdom. The note from Finland is written by the Finnish Federation of the Hard of Hearing and the Finnish Association of Parents of the Deaf. The comments from the Finnish Federation of the Hard of Hearing are that there is convincing evidence that the cochlear implant benefits persons who have become deaf. The Federation has a positive attitude to starting cochlear implantations in Finland for children who are congenitally deaf. The Finnish Association of Parents of the Deaf maintains that for persons who had become deaf in adult life, the implant had clearly proved to be useful. But the Association takes a negative position concerning implants on congenitally deaf children or children who have become deaf at an early age. No cochlear implant should be carried out on these children under the age of 15.

One of the three notes submitted by France is a memorandum on ethical aspects of cochlear implants on pre-lingually deaf children. The National Advisory Committee on Ethics (CCNE) has received a request for an opinion from parents of deaf children and representatives of associations working with deaf people. The CCNE is of the opinion that as long as there are uncertainties about the effectiveness of the implants, every effort must be made to avoid jeopardising the children's cognitive development. It recommends that the psychological and social development of children with cochlear implants be secured by combining the learning of sign language, whose effectiveness in this area is said to be proven, with oral French.

### *Multidisciplinary teams*

A further common view expressed in the notes from the countries is that operations must be carried out by specialists, otological surgeons, within a multidisciplinary team (including audiologists, technicians, speech/hearing pathologists, psychologists/psychiatrists and hearing aid specialists, teachers of the deaf etc. The titles differ somewhat between the different countries but the functions are the same). The same results are reported by the EUD in their study.

The EUD states that in the 50 teams throughout ten countries in Europe, no deaf individual is reported to be a member of the CI team. A minority of the centres reported that they had had systematic contact with the deaf community or with deaf adults. From the ten member states, none writes about the possibility of having a deaf member in the teams.

### *Habilitation, rehabilitation and education of children with CI*

In most of the notes, not only multidisciplinary team work is important, but also auditory training, lip-reading and specific techniques for speech acquisition and conversation skills are considered necessary for a positive result. The implementation of these strategies is seen as being of key importance for every deaf child after implantation. In order to facilitate access to oral skills, a rigorous and structured format in terms of a specific speech therapy programme must be provided (France). France also discusses social aspects, like "the importance of the child being accepted by everyone with whom he/she comes in contact, including peers. It is finally stated that it is solely the child who, by dint of his/her new-found sense of potential and progress, is able to steer the project as planned towards change. An implant is, *per se*, not seen as an opening door to integration. However, an implant is thought to promote speech and language skills, which is an important factor to social integration".

The Spanish delegation states that the (re)habilitation phase should relate to "the person as a whole; it shall include teaching how to handle the device, bringing hopes into line with patients' actual capabilities, support to patients and families, encouraging family, friends etc. where oral communication is concerned".

The result from the questionnaires sent out by the EUD was that the implantation teams take different approaches on this issue. Approximately half of the centres wrote that they "required" that a child with a CI should attend an oral/aural school, while a similar number wrote that total communication (TC) or bilingual schools were acceptable. One centre maintained that a TC or a bilingual school was unacceptable.

### *Current and future research*

Common to the content of the notes of almost all of the ten responding member states was a need for more research about the long-term effects of a cochlear implant in children. In some of the notes research was presented - Belgium and the Netherlands - while Poland and

Switzerland reported on subjective evaluations performed by the therapist, taking into account test results, the changes in quality of the patient's life and the potential advantages of the applied device.

France has recently initiated a long-term survey to assess the development of 50 pre-lingually deaf children with cochlear implants with respect to the development of the children's oral communication, psycho-social situation, family integration, parents' satisfaction, rehabilitation and teaching provision as well as the educational and social integration of the children concerned. Four teaching hospitals in France are involved in the study.

To be included in the survey, the children must have been deaf before the age of two, been implanted at the latest by the age of seven, and they must not have any associated disorders.

A control sample of 40 pre-lingually deaf children who have not been implanted is currently being established. A protocol is being used by the teams of the teaching hospitals in order to assess e.g. speech perception and production. They also keep contact with the educational teams in order to assess educational results. Outside psychologists conduct and record interviews with the families. An original protocol has now been adapted to children without implants and refined for the purpose of evaluating the visual/gestural modes of communication.

A common theme in several of the notes is that, however promising a cochlear implant may be, there are still few reliable results on the effects of cochlear implants in children, particularly in pre-lingually deaf children. The Netherlands' note discusses the research being done in the Netherlands as well as international studies. It is said that the conclusions drawn were very susceptible to bias and that the research could say little about the effects with regard to spontaneous linguistic development and the socio-emotional development on a long-term basis.

The Finnish Association of the Deaf is of the same opinion and has found no reliable and objective information available about the effects of cochlear implants on the linguistic, psychological or physical development of the child. It concludes that it had not been proved that the implant would considerably improve the quality of life of the child.

### **3. RESEARCH ON THE EFFECTS OF COCHLEAR IMPLANTS IN CHILDREN**

A review of the research on the consequences of cochlear implants in children up to late 1999 has been carried out in order to analyse the theoretical background to the research, the methods being used, the researchers' own professional status as well as the results obtained.

A summary of the results shows that with few exceptions (e.g. Ruben, 1992; Strojny, 1994), the authors of the research reports maintain that deaf children's language development was dependent on an oral education. The deaf group was looked upon as having a handicap of communication (Mecklenburg, 1988) and that audition was necessary for a normal development of communication in children (Busby, et al., 1989). Very few researchers discuss the effects of sign language for the development of communication and language in deaf children. Total communication or the simultaneous use of speech and signs are discussed in some articles, but have not been systematically studied in relation to cochlear implants.

In the articles, collected through two large data bases on medical as well as psychological studies, Med-Line and Psych-Litt., the main authors are otologists, speech pathologists, technicians, as well as teachers of the deaf and the hard of hearing. Few of them are psychologists. Far from all of the authors have a PhD degree or a comparative exam. Thus, they are not always scientifically trained, but rather representing practitioners working within the CI teams. Therefore, in fact, many of them are evaluating their own work. This fact has also been discussed in an overview of studies of cochlear implants in children by Vernon and Alles (1994). They write: "One major requirement for ensuring validity of evaluation of any intervention procedure - whether medical, psychological or educational - is that the evaluation be independent of the procedure" (p. 486). But most audiological, speech, language, educational and overall findings have been obtained and reported by professionals working within a CI team or they have been funded by implant grants. This is a complication when evaluating the effects of cochlear implant in children as well as in adults.

#### **3.1 *Ideas about child development***

When analysing the content of the articles, it was found that knowledge of child development in general, and of deaf children in particular, was limited. There was a general trend that the researchers looked upon the child as a passive recipient of information given by an active, teaching adult. This was also the opinion of learning and educational psychologists up to the late 1960s, but has since been discarded for a changed view on the child. We now talk about the competent child and even the competent infant. This is the result of micro-analytic studies of mother-infant interaction from the first minutes of the infant's life. These studies show that the infant is very social, very active from birth, and

seeks meaningful, coherent and joyful interactions with his/her caregiver. This new view of the child has had important theoretical implications on research paradigms in developmental psychology. The development of a child is seen from a dyadic perspective. Not only is the child observed but also the way adults engage with and respond emotionally to the infant, how they communicate and interact. Parental styles have been shown to influence the way the child learns and acts upon the world. Several studies have now found that the more didactic and intrusive and the less flexible and approving the parents are in relation to their child, the less favourable is the emotional, social, communicative and cognitive development of the child.

The importance of conducting psychological assessments of the children before an implant operation is pointed out in several articles. However, the purpose of these are primarily to investigate whether the child will be able to stand the psychological pressure to which he/she will be exposed, not only shortly after the implantation, but even several years afterwards. The psycho-social consequences for the child's emotional, social and communicative development are seldom studied or even discussed.

### **3.2 *How results of an implant are measured***

The results of an implant are primarily measured in terms of the child's perception and production of speech (see e.g. Moog and Geers, 1991; Geers and Moog, 1991; Staller et al., 1991; Tobey, et al., 1991; Osberger et al., 1991; Meyer, et al., 1998). But these tests do not necessarily mean that the child will have a more comprehensible speech production after an implantation than before, or that the children will be able to perceive normal speech from the surrounding world, as most of the tests are made in laboratory conditions. The children are exposed to a set of words or sentences and they are supposed to give different answers to the questions asked. Studies in artificial contexts such as a laboratory cannot be compared to the natural life of young children in their families or in their pre-school/school setting with many different adults and peers.

### **3.3 *Selection of children to be implanted***

The criteria for being a presumptive patient are in most countries that the child must be cognitively and emotionally stable and able to endure intensive hearing training after implantation. Mental retardation or other cognitive or psychiatric disorders are seen as contra-indicative for an implant. The motivation of parents as well as of children is seen as important in the post-implant habilitation. It is therefore a selected sample of deaf children who have received an implant that must be taken into account when evaluating results.

### **3.4 Results**

Studies on the socio-emotional effects of a CI on children are still few. Comparisons between deaf children with an implant are made with other deaf children wearing other types of hearing aid or in some cases tactile aids. Research results have shown that a cochlear implant can be more effective than ordinary hearing aids on the development of children's perception and production of speech. A gain in auditory perception/production does not necessarily mean a corresponding gain in taking part in spoken conversations. Studies of even mildly hard of hearing children show that they have difficulties in taking part in natural conversations with more than one partner at a time (Tvingstedt, 1993; 1995).

Studies of deaf children with cochlear implants show that they have mainly been engaged in different oral programmes and the aim has been to integrate them into preschools and schools for the hearing. Most of the studies comprise children older than two or three years of age. They show that the children can perceive sounds in their surroundings, that they can perceive single spoken words and even sentences and also produce a limited set of words and sentences in laboratory conditions or in well-known contexts with one partner (Osberger, et al., 1993; Miyamoto, et al., 1993; Ganz, et al., 1994; Walzman, et a., 1994; Waltzman, et al., 1995).

### **3.5 Theories of language development**

The major theoretical rationale for an early implant in pre-lingually deaf children is based on an assumption of a "critical stage" theory of language development (Lenneberg, 1967). This theory states that there is a specific period from a few months of age up to the age of approximately five years during which the human organism is neurologically and biologically programmed to master its primary spoken language. The primary evidence on which Lenneberg based his theory was that adults have severe difficulties in learning a second language, in spite of the fact that the adult is far superior in a cognitive sense than the infant. But young pre-lingually deaf children would not be learning English (or any other spoken language) as a second language. Lenneberg's stage theory has never been proven to be true in reality. In spite of this, it has been accepted by professionals as axiomatic (Vernon and Alles, 1994). The critical stage or critical period theory is also often discussed with reference to the visual information system, based primarily on experiments with cats. But the visual and the auditory senses differ in many respects, and so do cats and infants. Today, sensitive periods are discussed - it is obviously easier to learn a language when young rather than old, but there is no critical period after which this becomes impossible. Other factors such as motivation, cognitive, emotional and social development, play a more important role in this respect.

One important research finding with special relevance to the development of children with sensory functional disabilities is the notion of amodal perception, which means that infants appear to experience a world of unity and that they can take information received in one

sensory modality and translate or encode it into another sensory modality (Stern, 1985). Severe hearing impairment is seldom detected before the age of 6-12 months, severe visual impairment seldom before the age of 2-3 months of age, as parent-infant interaction is so similar to that of a normal parent-infant interaction. The infants behave as if they could hear and see, even if they actually cannot hear or see at all. This early inter-sensory coordination declines at the age of 4-5 months. The child perceives the world as a whole, with the whole brain, not with particular areas of the brain.

A large part of the discussion about language development in deaf children with cochlear implants has been about speech perception and speech production. But speech is not synonymous with language. Perceiving or recognising spoken words and producing or imitating spoken words or sentences do not amount to commanding a language or understanding the symbolic meaning of a particular word or phrase. Language is not an object or a skill which exists outside the child. It is rather a mode of action into which the child grows because the mode is implicit in the human developmental system (Studdert-Kennedy, 1991). Language learning or language acquisition is about understanding a world of symbols; that something can be represented by something else, that a word or a gesture can represent an object, an event or an idea. Thus, language is a representation of representations (Piaget, 1951).

### **3.6 *The roots of language***

Which then are the developmental growth paths that lead to language? The most common approach to answering this question has, for a long time, been to search for the roots of spoken language in the development of the auditory and vocal modalities and the roots of sign language in the development of the visual-gestural modality. But the most significant things that the infant needs to learn about language from a developmental point of view are written on the face, body, voice and gesture of those who talk (Locke, 1995). The primary contribution of the face to communication is that it reveals the emotional state of the speaker as well as the attitude of the speaker towards the listener. Infants are already from birth attracted to the face, particularly the eyes of the caregiver (Bower, 1977). This is adaptive as the eyes are vital components in the human signalling system implying emotions and social intentions.

Shared gaze between infants and mothers contributes to the establishment of object reference (Bruner, 1975). Infants look at their mothers' eye movement and head orientation as if they were attempting to find out what she might be thinking about (Locke, 1995). Infants tend to follow an adult's line of regard as early as two to four months, but more consistently so at eight to ten months of age. This enables the infants to appreciate an

important concept: the object of the mother's attention. This might be one of the more important conceptual precursors to lexical acquisition. Mothers also spend a great deal of time looking at the things to which their infants attend. The activities of the face, particularly the movements of the eyes, also convey some indexical information (Locke, 1995).

Pre-verbal abilities in children like the use of conventional gestures, such as pointing and showing, symbolic and combinatorial play, imitation and the use of tools are important predictors of language development (Bates et al, 1979). The sharing of meaning in joyful interactions and early mutual play with turn-taking qualities are crucial prerequisites for language development (Trevvarthen, 1988). The interdependence of the spoken language and visual cues can be shown in studies of blind children. One problem for these children is to acquire spoken language. The early language development in blind children is often delayed; some do not speak for several years, in spite of perfect hearing ability (Preisler, 1995). This is probably due to the fact that blind children do not use conventional gestures. It is not possible for them to follow the parent's direction of gaze, or perceive visually emotional cues from the face of their caregiver, and they do not engage in pretend-play until a much later age than a sighted child.

The significance of early close relationships for children's social and emotional development has long been recognised (Bowlby, 1982). Relationships are viewed as the context in which socialisation takes place and basic competences emerge (Hartup, 1985) in which communicational skills are acquired (Preisler, 1983), and in which the regulation of emotions develops (Stern, 1985). But studies in child development have also shown how children acquire important developmental skills as a result of peer interactions (File, 1994). Delays in expressive language abilities affect the development of social skills, which in turn can hinder children from becoming involved in more complex forms of peer interaction (Guralnick, 1986). The ability to use language as a medium for sharing experiences and feelings, for referring to abstract concepts, and for relating to future and past experiences, enables a child to become involved in fantasy and role-play. If preschool children are to be able to take part in fantasy play, it is important that they are also given the opportunity to develop close friendships with other children. Warren and Kaiser (1986) stress the importance of providing children with specific difficulties with the possibility of acquiring language. Failure to do so not only has consequences for their language development *per se*, but also for their emotional, social and cognitive development.

### **3.7 Sign language for deaf children**

The idea still sometimes held that one sign system hinders the development of another, is by no means valid. Studies from the last two decades in particular, have clearly shown the positive effects of sign language learning in deaf children, not only for the communicative, social and emotional development but also for language learning in general as well as for their cognitive development (Nordén et al, 1981; Heiling, 1995). The current debate in

Sweden concerns the choice of language to be used with the moderately to severely hard of hearing children. It has not been self-evident to parents and teachers to use sign language with a child who, equipped with a hearing aid, can perceive auditory information and develop spoken language. However, the communicative difficulties these children encounter in interaction with peers, and in larger groups are well recognised by the hard of hearing and by their parents and teachers. As a consequence, many parents now choose to let their hard of hearing child attend preschool and primary school education together with deaf children (Preisler and Ahlström, 1997).

### **3.8 *Early development of communication in deaf infants***

During the first year of life, when vision plays a most important role in communication, deaf infants are able to share in the communication with their hearing contemporaries much to the same extent as the hearing child. The deaf infants also take part in body games, give-and-take, as well as peek-a-boo games with their parents. They explore toys, they imitate their mothers' actions and they start to take part in early pretend-play. They show their intentions and wishes and they take active part in proto-conversations. The hearing impairment seldom becomes a serious obstacle to communication until the age when hearing children normally begin to talk. If habilitation of the deaf child is focused on the use of communicative signals that are suited to auditory perception and extremely difficult to interpret visually, mutual understanding is often impeded, and breakdowns in communication become the rule rather than the exception, causing language development to stall. Several studies of toddlers or preschoolers have shown that hearing parents following an oral/aural approach to communication using more directives and different control techniques in interactions with their deaf child (Schlesinger & Meadow, 1972; Meadow-Orlans, 1987). The deaf children in these studies were more passive, less attentive and tended more to withdraw from social interaction than hearing children.

## **4. A PSYCHO-SOCIAL STUDY OF CHILDREN WITH COCHLEAR IMPLANTS IN SWEDEN**

In 1981, sign language was declared the official language of the deaf in Sweden. It was declared that schools for the deaf must ensure children develop towards bilingualism in Swedish Sign Language and Swedish, mainly in its written form. Today there is an official consensus that, for a child to be considered a CI-candidate, the family must have an established sign language communication with their child. The child is regarded as a deaf child before implantation as well as after. In Sweden, as in most countries, there is a debate about the ethical aspects of implantation, as well as about how to support the families and how to give the children appropriate language stimulation. As the situation is quite different

from that of most other countries with regard to the official attitude to the use of sign language, it was found that most research from other countries was of little value. Therefore, the Swedish National Board of Health and Welfare supported a psycho-social follow-up study of CI children using sign language in Sweden, which started in 1995 (Preisler, et al., 1996; 1997; 1999).

#### **4.1 *The objective of the study***

One of the objectives of this psycho-social study was to describe patterns of communication between children with CI and their parents, teachers and peers in different natural interactional settings. The questions asked were: How children with cochlear implants communicate with their parents, teachers and peers, in their homes as well as in their preschool settings? Are there factors in the environment that seem to facilitate the child's communicative and social development and are there factors that seem to hinder the child's development, and if so which are these? Are there children who take advantage of cochlear implant, and if so, in what way and in which circumstances? The opposite question was also asked, whether there are children who do not seem to take advantage of wearing an implant and if so, in what way and in which circumstances? The opposite question was also asked, whether there are children who do not seem to take advantage of wearing an implant and if so, in what way and in which circumstances?

#### **4.2 *Method***

The study was longitudinal, descriptive and qualitative. The children were observed every third month by means of video recordings in natural interactional settings with their parents and siblings, and in their preschool settings with teachers and peers. Direct observations and interviews with parents and teachers about the communicative aspects of the development of the children were also made. In these interviews, the parents and the teachers were also asked questions about their feelings, hopes and worries about the implant and how they had experienced the pre-, peri-, and post-implantation treatment. In addition to this, all members of the two multidisciplinary teams conducting the cochlear implantations on deaf children were interviewed about their values, ideas, hopes and worries about cochlear implants in children, their knowledge of child development in general and about the development of deaf children in particular as well as their experiences of the deaf culture and language.

### 4.3 *Subjects*

The study comprised all the children born between 1990 and 1994 who had received implants before the summer of 1996. Twenty-two children participated. The families represented all socio-economic groups and they lived in the cities as well as in urban and rural areas in all parts of Sweden. For an overview of the children participating in the study, see tables 1-5, below. The children belonged to a total population of 27 children. Of the 5 children not taking part in the study, one was not using the implant and therefore the parents did not think it was worthwhile taking part in the study, in one case the parents considered that too many people were involved in habilitation of their child. Two families did not want the researchers to contact them. The families were informed about the research project by the two CI teams and, if they declared that they were willing to participate in the study, they were contacted by the researchers. The five families who did not participate in the study were all informed by the same team.

**Table 1. The sex and the year of birth of the children participating in the study**

Age/ Sex	1990	1991	1992	1993	1994	Total
Girls	3	5	-	2	1	11
Boys	3	3	1	3	1	11
Total	6	8	1	5	2	22

**Table 2. Age in years and months when operated and age when diagnosed as deaf**

Age when implanted/ Age when diagnosed	1:11-2:11	3:0-3:11	4:0-4:11	Total
< 2 years	7	4	5	16
2-4 years	-	4	2	6
Total	7	8	7	22

**Table 3. Age of deafness and time in years and months with implant when last visited**

Time with CI Deafness	1:0-1:5	1:6-1:11	2:0-2:5	2:6-2:11	3:0-3:5	Total
< 2 years	3	5	3	4	1	16
2-4 years	1	-	-	2	3	6
Total	4	5	3	6	4	22

**Table 4. Etiology**

	Number of children
Meningitis, post-lingually	2
Meningitis, pre-lingually	4
Unknown etiology. Pre-lingually deaf	12
Progressive hearing loss	4
Total	22

**Table 5. Preschool and school placement of the children at the start of the study**

The child was attending:	Number of children
Special preschool for the deaf	8
Preschool with group- integrated hard of hearing children	10
Mainstreamed with hearing children acc. by a personal assistant	3
Mainstreamed with hearing children without a personal assistant	1
Total	22

The children used a Nucleus 22 Channel mini 22/20+2 implant. All of the children's parents were hearing. The parents of the 22 children were interviewed at the beginning as well as at the end of the study. Twenty-eight teachers working at the children's preschools were also interviewed as well as 22 members of the two teams. One person in one of the teams did not want to participate. Seventy-two video recordings were taken in the twenty-two children's homes and 57 in the preschool setting.

#### 4.4 *Results*

In the interviews the parents expressed satisfaction with regard to the CI operation. They felt that they had done what was within their power to give their child an opportunity to perceive sounds. The majority of the parents were convinced that sign language was of utmost importance for their child's well-being, enabling them to communicate with peers, parents and teachers. But all of them nurtured a hope that some day in the future, their children would be able to communicate with speech, at least to some extent. This would enable their children to take part both in the deaf society and in the world of the hearing.

Almost half of the teachers who were interviewed were negative or sceptical about the initial information they had received from the teams about cochlear implants in deaf children. Many of them had worked for more than twenty years as pre-school teachers of deaf children and had experience of oral/aural education which they had dismissed in favour of sign language communication with the children. They were also critical to the lack of co-operation between team members and themselves both pre- and post-implantation and the lack of knowledge about deaf children and language development among most members of the team. Of twenty-two members of the two teams, two persons were good signers and had experience with deaf children; the others had no or very little experience of deafness, deaf children and/or sign language. Thus, those with most experience of development in deaf children were informed and educated by those with less knowledge and experience in the field.

Soon after implantation all children in the study were observed by parents and teachers to react to environmental sounds, such as church bells, aeroplanes, telephone and door bells as well as to other children shouting or calling from the room next door. Most of them were observed to react when adults were calling for them from a distance. Parents and teachers reported that all children vocalised more since they started to use their implants. Children having used their implants between 2½ and 3½ years of age could utter and use several single words in communication, primarily for objects and persons, but also as exclamations or to attract their parents' or peers' attention. Certain words and sentences were well-articulated, others were more difficult for an outside observer to understand. Some children could utter three- to- five- word sentences, others even longer sentences. According to the parents, the children could understand more words and sentences than they could produce and this was also observed from the video recordings. Many parents considered that different daily activities had been facilitated since the child had received an implant, and that it had made communication and interaction in the family more easy-going.

The children received speech and hearing training by a special teacher for hearing-impaired persons or a speech therapist twice a week for half an hour was the most common model. This special training was aimed at making the children attentive to sounds and to discriminate between different environmental sounds as well as speech sounds. In these adult-centred, speech-oriented and often very well-structured communicative contexts,

most of the children in the study made efforts to utter spoken words or word-like sounds. The words were mainly the names of persons or of objects, like "Mummy" and "Apple". However, it was observed in these training sessions that some of the teachers tended to overestimate the children's ability to perceive sounds, in particular speech sounds, but also environmental sounds played from an audio recorder. In these cases, the children often showed difficulties in understanding the teacher's intentions, the meaning of the interaction and even the meaningfulness of the situation. On the other hand, there was a tendency to underestimate the children's cognitive development. The content of the interaction in these training sessions was often considerably below the children's intellectual level.

Through detailed observations and registrations from the video-recorded interactions, the patterns of communication between the children and their parents, teachers, siblings and peers were analysed. From these analyses and from the interviews with parents, teachers and members of the CI teams different factors emerged that seem to have a more positive influence on the child's communicative, social and emotional development than others. These were that:

- the parents were satisfied with the decision of having their child operated
- parents and teachers, habilitation staff and others could co-operate
- a well-functioning communication between the child and the parents had already been established before the implantation was carried out
- parents and teachers used a child-centred communicative style in interaction with the child rather than an adult-centred communicative style
- the child did not experience demands from the environment to achieve, particularly with respect to production and perception of speech
- the adults put reasonable demands on the child with respect to the child's capacities
- focus was put on the content in the dialogues, not the linguistic form
- there was a possibility for the children to discuss their experiences about the here and now, present, future and past events with their parents and teachers in order to create a "narrative"
- there was a joyful and meaningful communication between child and adult
- the child could take part in age-adequate pretend- and role-play.

All, or almost all, of these attitudes and circumstances applied to eight children in the study. These children could communicate in sign language with parents, teachers and peers. In this group were also those children who could produce, perceive and understand more speech compared to the rest of the children in the study. They were observed to produce 3-5 word sentences, in some cases longer sentences, in well-known contexts. Their use of the

implant was never an issue of conflict. The group consisted of three boys and five girls. Five of the children were pre-lingually and 3 post-lingually deaf. The children were between 2½ years and 5 years when implanted, with an average age of 4 years and 4 months. They had worn their implants between 1 year and 9 months and 3 years and 6 months with an average time of 2 years and 10 months.

For a second group of children, six boys and four girls, only a few of the circumstances that were considered to promote the child's development were present. Some of the children exhibited advanced sign language development when first observed, others less so. As time passed, the pattern of communication in these families became more based on an oral/aural and directive communicative style from the adults. In these instances the visual rules in social interaction, i.e. to ensure established eye-to-eye contact before talking, did not seem to work any longer. The consequence was that many children had difficulties in perceiving as well as observing what the adults uttered, even if they used single signs simultaneously. Some of these children's parents and teachers put great demands on the children's oral/aural skills. There were also instances when the adults' demands on the children's general behaviour were too low. Several of the children in this group used their implants daily without any complaint, but there were also those who did not use the implants as regularly as the others. This became a source of conflict between the child and the parent. Pretend or role-plays were seldom observed for the children in the group. Instead of giving these children a rich linguistic environment that could be nourishing both for their sign language development and their development of a spoken language, many of them were living in a linguistically poor environment. There were often protests when demands were put that they should produce speech. Seven of the children in this group were pre-lingually and three were post-lingually deaf. The time for operation and fitting of the processor varied between 2 and 5 years with an average age of 3 years and 10 months. The children had been using their implants between 1 year and 1 month and 3 years and 5 months with an average time of 2 years and 3 months.

There was a third group of children consisting of two boys and two girls who were exposed to rich linguistic sign language stimulation in their preschool settings. They could communicate with their teachers and with their peers. In some of these families well-functioning sign language communication had started to develop, while in others the communication was based on non-verbal utterances in combination with single signed or spoken words. Also in this group there were children who did not use their implants on a daily basis, which was a cause of conflict in the families. Most of the circumstantial factors considered as promoting the child's development were not present or only partially present in these children's lives.

The children's speech production as well as their speech perception in natural interactional settings were scored as more or less non-existent. These children were considered by the researchers as well as the teachers as just as deaf after as before the operation. They were

all pre-lingually deaf children, having used their implants between 20 and 36 months. One child was 3 years and 10 months the others were between 4 years and 5 months and 4 years and 9 months old at the time of the operation.

#### **4.5 Discussion**

Comparing the results of the children with CI using sign language with results of international studies of orally raised deaf children with CI, we find some common traits: all children perceive environmental sounds, and most of them perceive and produce a limited set of spoken words/sentences in well-defined contexts.

The situation for the children with CI in preschools where speech is the main language, gave cause for apprehension. Their opportunities to take part in dialogues with peers were limited, they interacted mostly with signing adults, and adults often took the role of interpreter for both other adults and children. The importance of play and relations with peers has been emphasised by many researchers. What are the consequences for a child who has an adult functioning as a mediator? It does not promote friendship, as normal peer relations become impossible. The dialogue with other persons is of great importance for the child's development. In these encounters, the child forms inner models for future encounters and relations. What inner model for encounters and relations will these children form?

The view held today is that the child acquires language in natural interactional settings. In a number of studies Hart and Risley (1968, 1974, 1975, 1980) have shown the advantages of using incidental teaching in comparison to traditional language training methods. Other studies have shown that children often react negatively to questions asked by adults which they perceive as inquiries (Hedenqvist, 1987). But questions asked by adults with a clear intention of getting to know the children's opinions, ideas or views, elicit many more responses from the children (Pramling, 1986). The possibilities for the child to engage in meaningful interaction depends to a great extent on the ability of an adult to adapt to a child and to give space for the child to take an active part in the interaction - to follow rather than direct the child. If we regard the children as passive receivers of information, they might successively develop a sense of self as passive, or even incompetent and disabled. This will have severe consequences for the child's social, emotional, communicative and cognitive development.

Many of the children in this longitudinal study are now schoolchildren and part of another longitudinal study in this new environment. Video-recordings are made twice to three times per year in the children's classrooms in order to study their modes of communication with peers and teachers as well as their reading and writing skills. Interviews are being made with parents, teachers and the children themselves (Preisler, Tvingstedt and Ahlström, under preparation).

## 5. GENERAL DISCUSSION

An analysis of the notes from the Council of Europe member states participating in this study indicates that there is a positive attitude towards cochlear implants in deaf adults, particularly those who have become deaf in adult life. The analysis further shows that among the countries participating in this study, there is a positive attitude also towards cochlear implants in deaf children, but with some restrictions: not before the age of 2-2,5 years and not in children with other disabilities as well as deafness.

Intensive habilitation - often expressed as rehabilitation - is regarded as necessary for a positive outcome of the implant. It is worth noting that habilitation comes from the Latin word *habilitare*, and means to make suitable, to qualify. It is often used in the meaning of facilitating, to make life easier for a person with functional disabilities. Re-habilitation means to enable a person to become as he or she was earlier, i.e. to become "normal". In the case of young children born deaf, the word re-habilitation rather indicates an attitude: to make the deaf child "normal" i.e. hearing. And this is the idea among many surgeons, to make the deaf child a normal hearing child. But the results of the studies reported so far about the effects of cochlear implants on communication and language development, show that a cochlear implant does not convert a deaf child into a normal hearing child. What is achieved is that the majority of the deaf children with a cochlear implant can perceive sounds from the environment including most speech sounds. They also gradually show improvements in speech production compared to pre-implant conditions. But this does not mean that they can take part in spoken dialogues with other persons, particularly not in groups of more than two persons. To hear sounds does not necessarily mean to understand what is heard. To hear speech sounds does not mean to understand a spoken language. The CI children are deaf children. Without the implant they are as deaf as before the operation. Even if they will be able to perceive speech and to express themselves orally when using the implant, they will still be socially deaf in much the same way as is reported among even moderately hard-of-hearing children (Tvingstedt, 1993; 1995; Preisler and Ahlström, 1997).

A conclusion drawn from the analysis of the latest research on cochlear implants in children is that being a member of a society where deafness is seen as a condition to be cured from, where normalisation and integration are crucial concepts, a cochlear implant will, for many deaf children, be a positive alternative to conventional hearing aids.

In societies where deaf children have acquired language spontaneously, the way hearing children do, in communication with parents and/or teachers using signs, and have become bilingual by means of signed as well as written language, the situation is somewhat different. To introduce speech and hearing training at the cost of sign language stimulation among these children can result in a regression in their development.

If we can enable the children with cochlear implants to become multilingual - in sign language as well as in reading and writing - and to gradually also be able to use speech, then the implant can become something positive, an extra asset for them. But if we solely rely on their ability to take part in social interaction by means of auditory perception through the implant, their future emotional, social and also cognitive development will be at risk.

### ***Implications for the future***

Studies on cochlear implants in deaf children indicate that it is not possible to reduce the question of effects of the implant on development in general and development of hearing and speech in particular, to single predictors, like age at the time of implantation, etiology, age when becoming deaf or time with the implant. Rather, it is a question of a complex set of relations between children's biological (capabilities) and their possibilities of interacting and forming relationships with parents, siblings, peers, teachers and other important persons in their environment as well as the way the social environment interacts with them.

Thus, there must be a broad psycho-social developmental starting point when deciding upon a cochlear implant in deaf children in combination with medical and ethical considerations. Multidisciplinary teams including social workers, teachers and psychologists as well as medical and technical experts, specially trained on deafness and the development of deaf children, on development of language and communication, and on emotional and social aspects of development are therefore important to establish, in order to ensure that the child's total situation is considered before the decision on an operation is made.

Continuous scientific follow-up studies should be conducted in order to evaluate the effects of the implant on the children's emotional, social, communicative and cognitive development as well as on language, speech and hearing development. Control groups of children without implants, all other circumstances being equal, should also be included in these studies. As the group of deaf children in each country is fairly small, cross-cultural European studies on the consequences of cochlear implants on deaf children are recommended. This information could give us a deeper understanding of the situation of and for the children and therefore give valuable directions for the future.

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## APPENDIX

### *Summaries of the country reports*

#### **Belgium (French and German-speaking community)**

Cochlear implants are discussed in terms of fitting costs. Four main conditions are formulated for an operation: 1) It must be approved by a Board of Medical Officers on the basis of a medical report indicating the patient's total, bilateral loss of hearing; 2) the results of specific audiometric tests exclude the use of an external hearing aid; 3) the results of a trial electrical stimulation of the auditory nerve; 4) the outcome of a multidisciplinary assessment including logopaedic and psychological reports. The operations must be carried out by specialists, with a multidisciplinary team (including a logopaedics specialist, a psychologist and a hearing aid specialist from a speech re-education department.) The device must have certain characteristics and be approved by a Technical Council. Reimbursements are granted only every five years.

#### ***Summary***

An economic - medical - technical approach. An oral/aural approach.

#### **Belgium (Flemish community)**

The report starts with the question of reimbursements. The same conditions as in the French/German community report; one exception: electric stimulation tests are not required for children. It is possible to use neonatal otoacoustic emissions. Early assessment is mandatory, because of the window of opportunity in the developing auditory system. Implantation recommended before the age of 5.

A survey of the situation in Flanders is made, the focus being on criteria used for recommending implant. The medical criteria concern different aspects of assessment of deafness. The minimum age recommended is 2 years. Other criteria are: parents situation - strong motivation and tolerance, realistic expectations, - educational and social setting in view of integration into the hearing world. No additional disability, since it might impair rehabilitation and integration (questioned). Rehabilitation and special education are performed in close co-operation with the CI team.

Twenty-three children younger than 10 years had been operated on in Flanders when the report was written (1996?). The youngest was 2½. A report on the state of the art in Antwerp, written by Professor F. Erwin Offeciers, of the Department of Otolaryngology, Medical Institute Sint Augustinus, University of Antwerp was appended. Implantation of deaf children started in 1995. The prognosis is: 20-25 children per year in Flanders. Early implantation in the congenitally and pre-lingually deaf population is an absolute

prerequisite to success, defined as "the rehabilitation of the auditory function to such a degree that the child can develop its linguistic and communicative faculties to their normal level". Six prerequisites are stated in order to achieve a successful result: early identification, early oral/aural rehabilitation, early implantation, correct fitting, intensive long-term rehabilitation and parental guidance and integration in mainstream education.

***Summary:***

An economic-medical-technical perspective is taken to cochlear implants in deaf children. An oral/aural approach is also recommended, including early identification, early implantation and intensive training programmes.

**Finland**

The report starts with ethical aspects of cochlear implantations for congenitally deaf raised at the 19th meeting of the Council of Europe Committee on the Rehabilitation and Integration of People with Disabilities, June 1996. The Finnish Ministry of Social Affairs and Health had asked for comments from the Finnish Federation of the Hard of Hearing (FFHH) and the Finnish Association of Parents of the Deaf (FAPD). Comments from FFHH: convincing evidence exists that cochlear implants benefit persons who have become deaf. They show a positive attitude towards CI for congenitally deaf children and emphasize that each case should be carefully considered. Activities are concentrated on few university hospitals. It is necessary that continued rehabilitation services be provided. New information about the significance of the time of operation is expected and should be taken into account when deciding about implantations. The age of 2-3 years is considered to be optimal. Sign language is mentioned: it is recommended to be used as support for speech; before an operation and long afterwards. Society's support for sign language services is to be secured even after an operation. Parents need reliable information about CI, in order to decide upon a CI. Financing should be arranged; no specifications are given as to how.

The Finnish Association of Parents of the Deaf states that the implant has clearly proved to be useful for persons who have become deaf in adult life. But they express reservations on implants on congenitally deaf children or children who have become deaf at an early age. No cochlear implant should be carried out on these children under the age of 15; no reliable and objective information about effects of cochlear implants on linguistic, psychological or physical development of the child is available. It has not been proved that the implant considerably improves the quality of life of the child. FAPD focuses on communication and the deaf child's right to communicate. Families should be given time to learn sign language to give the child a good first language. No study has yet shown that a congenitally deaf child learns spoken language by means of the implant so that he/she can cope with normal

communication outside the laboratory. Sign language is considered important for the development of identity. The Association finally wants a discussion on values amongst physicians and other rehabilitation staff, parents and the organisations of people with hearing impairments.

In the conclusions, the Finnish delegation recalls a clause in the amendment of the Finnish Constitution, securing the rights of those who use sign language and need interpretation or translation services. Even after cochlear implantation persons should be treated as bilingual and have the right to choose in which language they want social, health and other services to be provided.

### ***Summary***

The Finnish note is based on the opinions of the Federation of the Hard of Hearing and the Association of Parents of the Deaf. It states ethical aspects, the risk of too early operations as the children might lack a first language, the need for sign language also after an implantation, reliable and objective information to parents in order to be able to make a decision, attitudes of those who conduct the operations should be made clear, the need for more psychological and social research in order to evaluate the results of an implant is recommended.

### **France**

Takes primarily an oral/aural approach to the issue of implantation. The aim of an implant is to make it easier to take part in oral communication. But it is possible to use other means of communication. The cochlear implant is presented in terms of the external and internal parts and the difference between different devices is made clear. It is further stated that patient selection criteria are of prime importance in adults but particularly in children. If the child is post-lingually deaf the situation is considered to be identical to that in adults, but if deafness has developed pre- or peri-lingually, implantation should be made in order to enable language (meaning speech) acquisition under optimal conditions. It is said that due to technical problems, the operation cannot be carried out before the age of 2-2,5.

The fact that the family must be highly motivated is considered absolutely essential. Contra-indications are described. These are anatomical, auditory nerve palsy, low intellectual level and inadequate motivation. Teamwork is stressed, as well as auditory training, lip-reading and auxiliary methods (without specification) and specific techniques for speech acquisition and conversation skills. The implementation of these strategies is seen to be of key importance for every deaf child post implantation. In order to facilitate access to oral skills, a rigorous and structured format in terms of a specific speech therapy programmes must be provided. Social aspects are discussed, such as the importance of the child being accepted by everyone with whom he/she comes in contact, including peers. It is finally stated that it is solely the child who, by dint of his or her new-found sense of

potential and progress, is able to steer the project as planned towards change. An implant is not seen *per se* as an opening door to integration. However, an implant is thought to promote speech and language skills, which is an important factor in social integration.

A memorandum was enclosed, about ethical aspects of cochlear implants for pre-lingually deaf children. The National Advisory Committee on Ethics (CCNE) received a request for an opinion from parents of deaf children and representatives of associations working with deaf people. The CCNE is of the opinion that as long as there are uncertainties about the effectiveness of the implants, every effort must be made to avoid jeopardising the children's cognitive development. It recommends that the psychological and social development of children with cochlear implants, be secured by combining the learning of sign language, whose effectiveness in this area is proven, with oral French. Information to parents about possible complications and expected benefits are to be distributed as well. The parents must also be warned that no objective data are yet available on the development of spoken language or on the psychological and emotional equilibrium and social integration of children with implants among people with normal hearing.

### **Summary**

Paper 1. An oral/aural approach, with an opening towards the use of alternative means of communication. Bilingualism is mentioned, but the term sign language is not used. The recommended earliest age of implantation is 2-2,5 years. The importance of the motivation of the parents and the children themselves is stressed. As much as the importance of the child being accepted. Whether there will be a successful result or not depends to a large extent on the child him/herself.

Paper 2. In this memorandum the benefit of sign language to learning oral French is maintained and therefore the learning of sign language is recommended. Information of parents on restrictions and benefits is considered important.

### **Hungary**

The note from Hungary states that there is one centre for cochlear implants in Hungary and that 61 patients have been operated. They have been financed by the National Sick Fund. The results of the adults have been positive, the results of children less favourable. More detailed and systematic follow-up will be provided at a later stage.

### **The Netherlands**

A report by the Sickness Funds Council to the Minister of Health, Welfare and Sports was submitted in December 1996. It is concluded that a number of results indicate that CI in children have positive consequences. Long-term results are not fully known. Plans for

rehabilitation and education need much attention. A final decision on a number of points, e.g. the socio-emotional development, is still regarded as premature because of a restricted follow-up period and limited data. Only a selection of children should be recommended to undergo a CI.

In the report a study of 20 deaf children between the ages of 3-12 years is presented. The children were selected and implanted over a period of 2 years. Inclusion criterion was that there was no speech comprehension through conventional amplification. Psycho-social criteria for exclusion from the operation were e.g. mental retardation, emotional and/or social problems, learning defects with regard to speech, anticipated problems with regard to the parents' participation during rehabilitation. Various tests were carried out 6, 12 and 29 months after the operation.

The results after implantation were: auditive development had improved and sound detection had improved considerably. No difference had been noticed during the first year as to the development of voice and speech compared to deaf peers wearing hearing aids. The subjective audibility had improved significantly during the first 24 months after implantation. Verbal linguistic skills were measured with structured linguistic tests. Children with acquired deafness reduced their average language deficiency compared to hearing children. For children born deaf, the results were less pronounced, but the results were better during the second year. The researchers believe that the children with CI will catch up. Spontaneous speech - deaf children with verbal communication expressed themselves more with words than children with full communication means.

Socio-emotional development improved favourably. The children with an implant appeared to have a slightly better overall quality of life than children without an implant.

The costs are defined for each phase of the procedure. The NWO OG committee assessed the final report and a critical analysis of the results was made. As no control group was used, the conclusions drawn from the research are susceptible to bias. The conclusions drawn from the results are illness-specific and the changes to these specific parameters have not been sufficiently clarified. In the note international research is also mentioned.

A convention was held in the Netherlands where deaf adults, parents, social workers, policy-makers and doctors discussed medical, social and ethical aspects of CI in children. It was stated that both Dutch and foreign research could say little about the effects with regard to spontaneous linguistic development and the socio-emotional long-term development. Attention was given to ethical aspects as well as questions concerning identity. The final report indicates that children with cochlear implants will never recover full hearing.

The recommendation states: "The deaf community has largely come to the conclusion that one is not adverse to the application of CI in children, but that one considers it as experimental until more long-term results are available."

A letter from a deaf organisation states that they agree with this statement. They recommend further studies into the long-term effects of CI in deaf children. They want to postpone a definite decision concerning the character of this provision until more information is available about the long-term effects of this experimental technique.

### ***Summary***

The Dutch note consists of several parts: research results from a study of 20 children with CI, a critical analysis of the results and a statement of the organisation of the deaf. It is recommended that CI be applied to a selected number of children only. Treatment ought to be concentrated in one central location. A better understanding of CI in children on e.g. their socio-emotional development is thought to be obtained through research. A scientific approach is thus taken. Economic factors are discussed.

### **Poland**

The report provides a detailed picture of how the patients at the two operating centres in Poland, in Warsaw and in Poznan, are treated before and after implantation. Until October 2000, more than 300 patients had received an implant in Poland. The minimum age of implantation was 1 year and 9 months. One third of these patients were between 2 years and 10 months when implanted. An estimated number of 500 children were at that time waiting for an operation in Warsaw. The problem of financing is one of the first issues discussed in the Polish note. That problem has now been solved. Cochlear implantation has become a highly specialised procedure supported financially by the Ministry of Health. The diagnostic procedures and patients' selection for treatment are described. The criteria used for selection of surgical treatment are almost the same as those used in other countries. The difference is that Poland has divided these into absolute and relative criteria. Among the relative criteria are chances of achieving the assumed results, lip-reading ability and knowledge of written language. These criteria have not been formulated by any other country. Evaluations of the implantations were made by means of objective and subjective evaluations performed by the therapist, taking into account test results, the changes in quality of the patient's life and the potential advantages of the applied device. 60 % of the results were scored as excellent or good. 12,5 % were judged as unsatisfactory while 8 % were non-users. The rest had satisfactory results. In some patients the effect could not be evaluated due to a short period of training (less than 3 months after implantation). In an appendix pre-, peri-, and post- operational protocols are enclosed with detailed descriptions of all the different measures, such as medical, psychological, pedagogical etc., that were taken for each patient and by which member of the team.

### ***Summary***

The Polish note consists of research results from patients, (adults and children) with CI. A scientific approach was taken. Economic factors are also discussed. Although there are no strong recommendations for using an oral/aural approach with the children, this is implicit in some of the relative criteria - lip-reading and knowledge of written language.

### **Slovenia**

The note was prepared by a counsellor to the government and states that four operations, of which two were on children over five, had been conducted by the central medical institution in the country. A specially qualified team makes up the audiologic rehabilitation programme - otorhinolaryngologists, speech therapists, linguists, teachers of the deaf and psychologists. Auditory training is carried out after a cochlear implantation. 300-400 patients meet the selection criteria for a CI. It is considered a routine operation in other countries which justifies its professional use also in Slovenia. Extensive diagnostic evaluations are considered a requirement for a proper selection of a candidate. Prolonged rehabilitation in the patient's mother tongue. Costs are discussed. Five operations per year can be funded by governmental means. The Slovenian National Association of the Deaf has reservations, particularly concerning implants on children. They state that an operation involves great expenses yet the outcome is considered as uncertain.

### ***Summary***

Still few operations. A specialist team has been set up. Selection of candidates and the importance of rehabilitation is stated. Costs are discussed. The association of the deaf has certain reservations.

### **Spain**

Financing is the first point. Costs have been met by the department of National Health. 320 operations had been carried out by 1995. Ninety-two children are estimated as candidates for an operation per year. Criteria for selection are presented, based on the patients' bilateral auditory thresholds. The following absolute contraindications are stated: age less than two, congenital malformations, absence of functionality of the auditory canal, severe psychiatric illness, illness during surgery, lack of motivation, failure to meet audiological criteria, and existence of an additional speech or language pathology.

Psycho-pathological, psychological and psychiatric disorders are very thoroughly described. It is further stated that the implantation of CI requires a programme to be organised in order to guarantee that the right patients are selected, the surgery is carried out efficiently, rehabilitation is appropriate and sufficient. The rehabilitation phase relates to the person as a whole; teaching how to handle the device, bringing hopes into line with the patient's actual capabilities, support to patients and families, encouraging family, friends etc. where oral communication is concerned.

The CI technique for children is applied by a multidisciplinary team - technicians, speech psychiatrists etc. Assessment of children concerns ear, nose and throat, audiological audioprosthetic, phoniatic and speech therapy, as well as psychological and psychiatric assessments.

Research results indicate that for children and adults who have acquired speech, the results are favourable from the first six months after implantation. Stable levels were attained two years after implantation. For children who have not yet acquired speech, definite information is still lacking. Checks five years after implantation give satisfactory results. Surgical complications were also discussed.

### ***Summary***

First questions of financing are discussed, then criteria for implantation and contraindications. The use of multidisciplinary teams is emphasised. Rehabilitation needs to see the person as a whole.

A scientific approach is taken, favourable results are reported, but information on pre-lingual children is still lacking.

### **Switzerland**

The report describes how the criteria for operation and reimbursement have developed from 1988 to 1994. CI is now a treatment for deafness in children suffering from peri- or post-lingual deafness and adults, who became deaf later in life, then extended also to persons who were born deaf. The treatment is to be performed by any one of five ear-nose-and-throat centres. The centres are required to keep an assessment register. Auditory training is an essential part of the therapy. There was initially an age-limit of 5 for insured minors for reimbursement, which has now been abolished. Subjective evaluations of treatment success have been made showing that approximately 75% of the patients scored excellent results and significant benefit. The register, a documentation of quality and success, must be constructed as objectively as possible and strive to be complete. It contains medical data on the patient, communication status, rehabilitation results, audiological status etc. and is completed regularly. By the end of March 1996, 170 patients had been implanted, since 1977 when the first operations were made.

### ***Summary***

First, questions of financing are discussed, then criteria for selection. Detailed documentation forms an important part. Auditory training is mentioned.

### **United Kingdom**

One note and one memorandum were submitted by the United Kingdom. The note is a press release about a report, commissioned by the Department of Health, where it is said that there is clear evidence that the new procedure of CI is safe and effective for the vast majority of patients and that most patients who become profoundly deaf after learning to speak benefit from cochlear implantation. The report also concludes, the release says, that children benefit from cochlear implants. The best results were among those implanted before the age of 5. It further says that this is evidence that purchasers need to ensure that they are using their resources wisely in funding cochlear implant operations. The report marks the end of a period of central funding of CIs by the Department of Health. Since then each health authority has been responsible for commissioning CI for suitable candidates. CI is relatively expensive and therefore has to compete with other priorities in the health service. There were at the time, 19 cochlear implant centres in the United Kingdom, 13 of which in England, 3 in Wales, 2 in Scotland and 1 in Northern Ireland.

Research issues are discussed, e.g. that there needs to be research on the relation between volume of activity and quality of outcome. More detailed research is needed to evaluate the effectiveness of CI in children. Some children have had "miraculous" results, for other the improvements have been less dramatic. Issues of geographical factors are discussed – "readily available" means close to their homes. An area of controversy is discussed: some members of the deaf community, primarily those born deaf and sign language users, find CI a threat to their community and culture. The British Deaf Association object to implantation on very young children who cannot give their consent to an operation. "Are hearing parents giving their children the choice where they want to belong?" is one of the questions asked. It is finally questioned whether there are serious attempts to present positive deaf role models to hearing parents of deaf babies and children, while they are considering a cochlear implant.

### ***Summary***

CI is considered a safe treatment, giving good results both on adults and children. A scientific approach is used. The position of the Deaf Association is reported, who objects to implantations on very young children. The situation of hearing parents of deaf children is discussed.

### **General summary of all member states' reports**

The following issues were raised by at least half of the countries reporting to the Council of Europe:

- criteria for selection including contraindications,
- rehabilitation,
- the need for multidisciplinary teams including medical people,
- financial issues like reimbursements,
- the need for more research about the effects and consequences of cochlear implants in above all pre-lingually deaf children.