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# **LIFE CIRCUMSTANCES OF CHILDREN AND ADOLESCENTS AFTER COCHLEAR IMPLANTATION**

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## ABSTRACT

**Introduction:** In Sweden, about 300 children every year are born with hearing impairment (HI), and about 50 of them with severe HI. Today, these children are treated with either hearing aid (HA) or cochlear implant (CI). The goal of the CI is for the child to develop hearing and spoken language, facilitating communication with the hearing majority society and thus increasing the child's wellbeing and participation in society. Where the child is not using his or her CI, the intended spoken language development does not occur. Cochlear implantation was introduced as a treatment in the 1990s, so intensive research and development has taken place in the field. However, few studies have focused on the children's physical, emotional, and social situation or on the functioning of the CI, especially from children's own perspective.

**Aim:** The overall aim of the thesis is to provide increased knowledge about life circumstances and condition of children and adolescents after surgery with CI.

**Methods:** This thesis comprises four studies on children with a CI, focusing: children's own experience of using CI compared to the experience of children with HA (Study I); the children's self-reports of their mental health compared to their parents' and teachers' perspectives (Study II); the children's personal and social resources (Study III); and the parents' perspective of having a child with CI (Study IV). Both quantitative (studies I–III) and qualitative (Study IV) methodology has been used. Studies I–III are cross-sectional, based on questionnaires completed by four participant groups: children with CI, children with HA, parents, and teachers, whose data has been used in different ways in the three studies. Children with CI included in studies I–III were obtained from the same sample (36 children with CI). Study IV is a retrospective, qualitative study using meaning categorization to analyze individual interviews with twelve parents of children with CI.

**Results:** In Study I, children with CI were able to function well in everyday life situations, also in comparison to children with HA. In Study II, they expressed greater concern about their mental health compared to their parents and teachers. However, they did not show more difficulties or mental ill health compared to children in general. Children with CI who had a high sense of coherence (SOC) also had good mental health. Closeness of the social network, especially in school, was seen as important for good mental health (Study III). Parents of children who use the CI full-time were determined and used clear parenting strategies whereas parents of children with limited use of the CI paid more attention to attitudes in their environment (Study IV).

**Conclusion:** Children who were implanted with CI during the period 1994 - 2005 had good functioning in everyday life; better than children with HA in outdoor and group activities. They showed good personal and social resources. This, however, does not mean that difficulties do not exist. The child's own perspective on e.g. mental health problems needs to be attended to. Good parenting strategies are facilitating the child's use of the CI, why it is important to enhance parent's knowledge about disability, and it's challenges, foster positive coping strategies, and give individualized rehabilitation both to the parents and the child.

## LIST OF PUBLICATIONS

This thesis is based on the following studies which are referred to in the text by their Roman numerals:

I. Anmyr L, Olsson M, Larsson K, Freijd A. Children with hearing impairment – Living with cochlear implants or hearing aids. *International Journal of Pediatric Otorhinolaryngology* 2011; 75 844-849.

II. Anmyr L, Larsson K, Olsson M, Freijd A. Strengths and difficulties in children with cochlear implants – Comparing self-reports with reports from parents and teachers. *International Journal of Pediatric Otorhinolaryngology* 2012; 76 1107-1112.

III. Anmyr L, Olsson M, Freijd A, Larsson K. Sense of coherence, social networks and mental health among children with a cochlear implant. *Manuscript*

IV. Anmyr L, Larsson K, Olsson M. Children's use of cochlear implant – the parental perspective. *Manuscript*

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## LIST OF ABBREVIATIONS

ANOVA	analysis of variance
AVT	auditory verbal therapy
CI	cochlear implant
CSOC	children's sense of coherence
db	decibel
dBHL	decibels hearing level
HA	hearing aids
HI	hearing impairment
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for children and youth
IQ	intelligence quotient
OAE	otoacoustic emissions
PTA	pure tone average
SDQ	Strengths and Difficulties Questionnaire
SDQ-SWE	Strengths and Difficulties Questionnaire, Swedish version
SOC	sense of coherence
UN	United Nations
VAS	visual analog scale
WHO	World Health Organization





# 1 INTRODUCTION

The present thesis deals with the life circumstances of children and adolescents (in the following presented as part of the children) after cochlear implantation. The origin of this thesis was a number of clinical questions about children with a cochlear implant (CI). A survey from 2002, targeting parents of children with CI and asking about their frequency of CI use, revealed that 15% of children who had undergone surgery during the 1990s were not using their CI (unpublished data). This intrigued me and I decided to find out more about the subject. As well as wanting to find out what factors are relevant to use or non-use of a CI, I also had musings and questions about how children with CI perceive their own life situation. The starting point for this research has therefore been my practice-based questions, asked to increase my understanding of the life circumstances of children with CI.

The introduction starts with an overview of hearing impairments, followed by a description of what living with a CI means, and ends with different perspectives of circumstances of the children with cochlear implants.

## 1.1 HEARING IMPAIRMENT

It is estimated that over 360 million people across the world have an HI, 32 million of whom are children [1]. Annually, about 300 children in Sweden are born with HI, and about 50 of these have a severe to profound hearing loss [2]. Hearing impairment can affect one ear or both ears, and be symmetrical or asymmetrical, sudden or progressive, and stable or fluctuating in level. The most common type of HI is sensorineural, where the injury is located either in the cochlea, along the auditory nerve or along the central auditory pathways. Depending on severity, HI leads to difficulty in hearing conversational speech and a reduction in the ability to communicate with others, and this can have an impact on the individual's quality of life [1]. Today, children with HI are treated mainly with traditional hearing aids (HA) or with CI, depending on the degree of hearing loss.

### 1.1.1 Degree of hearing impairment

There are several ways of classifying the severity of HI [3, 4]. One generally used classification has been proposed by an EU expert group [3, 5]. In their classification system, HI is categorized according to the degree of hearing loss on the average hearing at 500, 1000, 2000 and 4000 kHz in the best hearing ear [3]. Impairment may be mild (20-40 decibels hearing level (dBHL)), moderate (41-69 dBHL), severe (70-94 dBHL) or profound (>95 dBHL). Hearing impairment in children refers to hearing loss greater than 30 dB in the ear with the better hearing[1].

### 1.1.2 Neonatal hearing screening and early hearing aid fitting

Screening for HI, with otoacoustic emissions (OAE), in newborns was introduced in Sweden in 1995 [6]. Since 2006, hearing screening has been offered to all newborns in Sweden. This means that it is possible to identify children with HI when they are only a few weeks old. The average age at which HI is confirmed has dropped from 24–30 months to 2–3 months [7-9]. Early-identified children with appropriate early intervention and fitted with HA before 6 months of age can better maintain language development and social-emotional development, compared to children fitted after 6 months of age [9, 10].

## 1.2 COCHLEAR IMPLANTS

A CI is a technical device which enables persons with severe or profound sensorineural hearing loss to perceive sound and speech. The use of CI does not restore hearing to a normal level, but provides an opportunity for the child to develop spoken language, including facilitating communication with the hearing majority society in order to increase the children's participation and well-being [11].

### 1.2.1 The cochlear implant device

A CI has an external and an internal component. The external part, the processor, has a microphone that picks up sounds and converts them into digital signals. The processor transmits the signals to a surgically implanted receiver, the internal part. The receiver sends electrical signals to electrodes placed in the cochlea, where it stimulates auditory nerve fibers. The signal is sent, as in normal hearing, via the auditory nerve to the brain, where it is recognized as sound [11]



Figure 1. External and internal parts of CI.

### 1.2.2 Criteria for cochlear implantation

The criteria for receiving an implant have changed over the years. At first, only adults who had no benefit from conventional HA were candidates for CI. Later on, children with postlingual, profound bilateral hearing loss were included. Today, the prerequisite for CI surgery is generally severe to profound HI in both ears. A CI may be considered

if aided soundfield thresholds are >50 dBHL for the frequencies 2 and 4 kHz. A four frequency (250 Hz, 500 Hz, 1000 Hz, and 2000 Hz) pure tone average (PTA), without an HA, of >70–80 dBHL is an alternative benchmark. The thresholds are only a decision support among others. Since 2004, almost all Swedish children have received bilateral implants if HI is profound in both ears.

### **1.2.3 Cochlear implants in a historical perspective**

The first CI with multiple electrode channels was surgically inserted in an adult in Vienna, Austria, in 1977 [12, 13]. In Sweden, the first CI operation in adults was performed in 1984 and in children with acquired deafness in 1990. Since the mid-1990s, children with congenital deafness have been able to receive a CI. During the first years, only a few operations were performed, but these have over time become extensive.

Today, most children born deaf are implanted and the minimum age for surgery has successively been lowered over recent years. From the beginning, children underwent implantation surgery between the ages of approximately 2 and 5 years, but today it's possible to perform CI surgery in infants at 5 months of age. An upper age limit is not applied to children with acquired deafness. However, children operated at an early age, <1 year, have a chance to acquire spoken language much more easily compared to children who undergo the CI intervention at a later age. Therefore, for children with severe congenital hearing loss/deafness, age is of significance due to increasing difficulty with age to develop hearing and speech understanding.

Technically, CI have developed from one channeled analog to multi-channeled digital devices which enable more detailed sonic information to be transferred to the auditory nerve. The implant processors have increased their performance while getting increasingly smaller. Today, they can be carried like a hearing device behind the ear (Figure 1) rather than be body worn. Together with the technical and habilitation progresses, expectations for results from CI have grown. Today, normal speech and language development is expected if a child without additional disabilities is operated within his or her first year [14, 15]. Auditory Verbal Therapy (AVT) [16] was introduced as a new habilitation option in Sweden in 2005 and is used across Sweden today. The change in focus and the increasingly younger age at implantation together give affected children the opportunity to acquire spoken language.

## **1.3 LIVING WITH A COCHLEAR IMPLANT**

Living with a hearing impairment means living with a disability; disability is a reduction in the physical, mental, and/or intellectual function capabilities and entails limitations for a person in relation to his or her environment [17]. In research, different perspectives have been taken on the relation between impairment and disability. These have included individual, social, and bio-psycho-social perspectives [18]. Hearing impairment may also be described from different perspectives, e.g. from a purely medical perspective, or from audiometric, psycho-social, communicative, educational, and cultural perspectives [19, 20].

### 1.3.1 The International Classification of Functioning, Disability and Health – a bio-psycho-social framework

The International Classification of Functioning, Disability, and Health for children and youth (ICF-CY) [21] is derived from the International Classification of Functioning, Disability, and Health (ICF) [22-24]. It has been developed to cover the developmental aspects of childhood, and to synthesize biological, personal, and social perspectives into a coherent view of health. The purpose of the ICF-CY is to describe a condition and its severity in terms of limitations in the child's functioning and to identify environmental factors that affect the child's functioning (Figure 2). It is a framework that attempts to describe the effects of context on a child's functioning and includes several environmental factors to examine the impact of facilitators for, and barriers to, features in the child's physical, social, and attitudinal world.

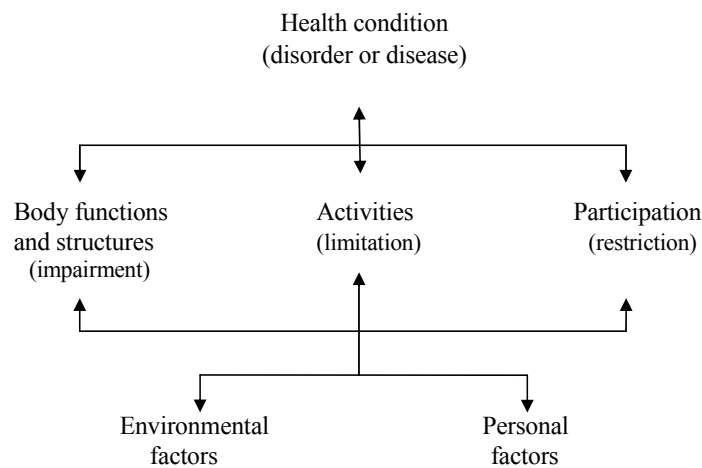


Figure 2. Theoretical model of the interactions between a health condition and the components of the International Classification of Functioning, Disability and Health (ICF) [23]. (Disability and its limitations have been given in brackets)

The ICF-CY consists of two parts: (1) functioning and disability, including body functions and structures, activities, and participation; and (2) contextual factors, which include environmental factors and personal factors. Functioning indicates non-problematic or neutral aspects of health and health-related states related to body functions and structures, activity, and participation. Disability indicates problems that influence health, or health-related status, which are related to functional impairment in body functions and structures, activity limitations, and restrictions to participation. Environmental factors include the physical, social, and attitudinal environment in which people live and conduct their lives (family, school, culture, etc). The basic construct of environmental factors is to facilitate or hinder their impact on features of the physical, social, and attitudinal world. Personal factors are the background of an

individual's life and living, and consist of personal characteristics unrelated to a health condition, e.g., age, gender, coping style and lifestyle, that might influence functioning and disability.

Children with CI represent a very heterogeneous group. Body functions and structures vary, e.g., the children differ in etiology of HI, in the functioning auditory pathways, and in brain plasticity. Children's age at CI surgery (in relation to the hearing level) varies as well, and so do presence of additional disabilities, communication mode, and parental resources. These factors can have an impact on the outcome of the child's speech/language development. Furthermore, other important factors may be the parent and child interaction, attitudes in the school setting, the self-esteem and wellbeing of the child with the CI, and the parents' educational level [25, 26]. We wanted to examine these aspects further and in Study I selected the ICF-CY as the frame of reference, in order to describe health in, and functioning of, children and adolescents with HI. Aspects discussed below are explored throughout the thesis.

### **1.3.2 School-settings for children with cochlear implant**

Today, there are four educational settings for children with CI in Sweden. They can either be individually integrated into a mainstream setting or they can attend classes for children with HI integrated in mainstream school. With these alternatives, the communication mode is oral. Alternatively, children can attend a special school for children with HI, with signing for communication support. Finally, they can attend school for the deaf and hard of hearing where different options such as sign language and oral language with supportive sign are available (the situation and interlocutor determine which language is most suitable) [18]. School placement of children with CI is dependent on factors such as social resources and personal resources, as discussed below.

### **1.3.3 Social resources**

Social resources – relations and networks - are important for human health [27]. A large part of socialization takes place within social networks. In this socialization process, people adopt the values, norms, and rules for fellowship of their communities [28]. Children's social networks include the relationships surrounding the child in everyday life and therefore plays a fundamental role in the child's life [29]. Based on the child's perspective, the network consequently comprises parents, family, other relatives, friends, and neighbors, but also formal contacts through various social institutions, such as school staff and other professionals. A network that is able to meet the child's basic needs often has clear boundaries, good communication, and a high level of sustainable and reciprocal relationships. Relationships are seen as the context where both the social emotional and cognitive development takes place. In relation to others, the child acquires basic skills, develop language and communication and establish capacity for empathy and regulation of emotions [30]. As such, it provides an opportunity for the child to develop [29, 31, 32]. Social networks are also important for reducing the negative effects produced by stressful situations on the child's mental

wellbeing [33], and have been shown to be an important factor in many areas of mental health development [34].

In this thesis, social networks are defined as the interpersonal environments constituted by individuals and their social relationships. This differs from social support, which is the material, instrumental, and socioemotional resources transferred within these interpersonal environments [35].

Network characteristics have been found to be related to psychological adjustment in direct and indirect ways. For instance, social ties may have negative as well as positive effects on mental health. Negative social interaction, as in conflicts, with lack of security, continuity, and stability, may decrease perceived support and lead to an increase in psychological distress in the child's development [28, 32, 36].

### **1.3.4 Personal resources**

#### *1.3.4.1 Mental health*

Mental health has been defined by the World Health Organization (WHO) as a state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, and can work productively and contribute to society [37]. The positive dimension of mental health is the foundation for individual wellbeing and, by extension, the effective functioning of a community [37]. Mental health is an integral part of health and is determined by socioeconomic, biological, and environmental factors. Poor mental health can occur in situations such as rapid social change, stressful working conditions, social exclusion, and physical ill health.

Children with profound hearing loss or deafness are more vulnerable to compromised psychological wellbeing compared to hearing peers from the general population in terms of mental health and psychological problems [38-42]. Children with HI and low communicative competence are found to have low self-esteem and poor social-emotional adjustment; also, the levels of family stress may be high [20, 43-45]. Hearing impairment has been found to have a significant impact on everyday life, causing feelings of loneliness, isolation, and frustration in a child [1, 19]. The hearing loss and poor auditory performance is not the only reason for these feelings; factors such as additional disabilities, intelligence quotient (IQ), parental resources, and educational circumstances are also relevant as explanatory variables [41, 46, 47]. As for children with CI, some studies, however, indicate that the mental health status and self-esteem of children with profound hearing loss or deafness can be comparable to that of normal hearing peers [43, 48].

In this thesis, the mental health of children using a CI is examined from their own, as well as their parents' and teachers', perspectives through the Strengths and Difficulties Questionnaire (SDQ) [49] to assess behavior and emotional strengths and problems as well as prosocial behavior in children with CI.

#### *1.3.4.2 Sense of coherence*

The concept of sense of coherence (SOC) has received attention in social and medical science during the last decades in line with the changing conception of health from a pathogenic view to one of relative well-being, or salutogenesis. [50]. This is also applied in studies of children with HI and their parents [50]. Antonovsky's salutogenic model is a global orientation reflecting the extent to which an individual is able to use his or her general resources in handling stressful situations. In order to resolve, or deal with, various demands and conflicts, the individual uses several components of the SOC construct: (1) comprehensibility (the feeling of understanding the own environment); (2) manageability (feelings of control and confidence that positive rewards are available); and (3) meaningfulness (motivation and interest in investing effort in different tasks) [51]. These components make the individual confident in life and in his or her own abilities, with a sense of being able to master even unexpected events in life [52].

Sense of coherence is a personal resource that has been shown to hold unique importance for understanding individuals' coping with stressors and an indicator of resilience and personal strength [53, 54]. When there are many internal and external resources available during childhood and adolescence, such as physical factors, social support, economic opportunities, and cultural stability, a strong SOC will probably develop [50]. Children with a low SOC are more likely to perceive stressful situations as threatening and less likely to appraise them as manageable [55].

Among adults SOC is strongly related to health, especially mental health, but can also be associated with other factors, such as age, social support, and education. The relation between SOC and health is the same for children and adolescents as for the adult population [56].

When planning this thesis, the children's SOC (CSOC) was seen and chosen as an important individual resource.

### **1.4 PERSPECTIVES ON CIRCUMSTANCES OF CHILDREN WITH COCHLEAR IMPLANTS**

In recent decades, a new paradigm has emerged within childhood research. In focus are children's own activities and perspectives – their perceptions of time and space, and their ways of viewing their life conditions [57]. The United Nations Convention on the Rights of the Child strengthens the child's role within both the family and the society, which requires an active child perspective [58]. The term “child perspective” is ambiguous. It is used variously in common debate and within research as either an ideological or a methodical term [57, 59].

It is important to take note of the difference between the terms “a child perspective” and “the child's perspective.” A child perspective is the perspective of adults on children's experiences, conditions, perceptions, and actions. This is an outside perspective, albeit with the individual child and his or her best interests in mind.

A child's perspective, by contrast, is characterized by the child's insider perspectives on his or her own experiences, conditions, perceptions, and actions, based on what he or she perceives as important [60].

A child's perspective is not the same for all children, since children are individuals as much as grownups are. In the UN Convention on the Rights of the Child, it is stated that a child has the right to be heard and to have his or her opinions respected [61]. A prerequisite for a child's perspective to be understood correctly is for the adults to listen to the child and capture and learn the ways a child experiences and understands a situation from his or her own perspective [62].

In this thesis, we mainly refer to the child's perspective, but occasionally we also refer to a child perspective to examine how parents' and teachers' perspectives of a child relate to that child's own perspective.

#### **1.4.1 Parental perspective**

It is well known that having a child with special needs causes a lot of strain on the parents [63, 64]. The specific strain parents of children with HI undergo has been reported to be psychological distress [44, 65-69]. The ability of the family to function well depends on its resources and on its ability to change its structure. An acceptance of the diagnosis, understanding and knowledge of HI and its effects, and confidence in the rehabilitation process are essential to provide security in this parenting situation [70].

How individuals react to, and deal with, various stressful situations can be studied using coping theory [71]. In the theory of stress and coping developed by Lazarus and Folkman [72], coping has been defined as cognitive and behavioral efforts to handle external or internal demands that are appraised as taxing or as exceeding the resources of a person. As a basis for how a situation is handled, it is essential to understand how an individual assesses and evaluates stressors [71]. Coping processes comprise two types of coping strategies: problem-focused and emotion focused. Problem-focused coping means that the person tries to influence a particular situation or set of circumstances. Emotional-focused coping is used when the individual feels that the situation cannot be influenced or is difficult to change. Emotional coping consists of mental efforts, which means that the individual is trying to find the positive in situations that can be perceived as negative [73, 74]. With regard to deafness, a parent's coping strategies may be influenced by past experience of disability, access to parent support groups, and familiarity with legal and educational processes [69]. In summary, coping consists of appraising the stressor and the available resources and choosing behaviors to regulate emotions or solve problems.



## **1.5 RATIONALE**

Intensive medical, technological, pedagogical, and linguistic research and development have taken place in the area of HI and treatment through cochlear implantation during the last two decades. Few studies have investigated children with CI when it comes to their health-related quality of life, physically, socially, and emotionally, especially from the child's perspective. Also, few studies have been devoted to the understanding of frequency of use of the CI.

## **2 AIMS**

The overall aim of the thesis is to provide increased knowledge about life circumstances and condition of children and adolescents after surgery with CI. Specific aims were to:

1. Study the daily living of children with CI or HA, and their thoughts regarding their own hearing and others' attitudes to it (Study I).
2. Study how children with CI, their parents, and their teachers perceive the children's mental health in terms of emotional and behavioral strengths and difficulties (Study II).
3. Explore the personal and social resources of children with CI (Study III).
4. Explore parents' experience of having a child with CI, and identify facilitators of, and barriers to, children's use of CI (Study IV).

### 3 METHODS

This thesis is based on findings from four studies using data from questionnaires (studies I–III) and interviews (Study IV) to describe life circumstances for children with CI (Table 1).

**Table 1.** Overview of studies I–IV.

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b>Study population</b>	Children with CI and children with HI	Children with a CI, and their parents and teachers	Children with CI	Parents of children with CI
<b>Data collection period</b>	2005–2008	2005–2007	2005–2007	2005–2006
<b>Sample</b>	36 children with CI and 38 children with HA	22 children, 22 parents and 17 teachers	32 children	12 parents
<b>Design</b>	Cross-sectional quantitative	Cross-sectional quantitative	Cross-sectional quantitative	Qualitative
<b>Method of data collection</b>	Questionnaires	Questionnaires	Questionnaires	Individual interviews with semi structured questions
<b>Analysis</b>	Descriptive and analytical statistics	Analytical statistics	Analytical statistics	Meaning categorization

#### 3.1 DESIGN

To fulfill the aim of this thesis, both quantitative (studies I–III) and qualitative (Study IV) design was used. Studies I–III had a cross-sectional design with four different participant groups: children with CI, children with HA, parents, and teachers, whose data has been used in different ways in the three studies. Study IV had a retrospective, qualitative design using meaning categorization [75] (Table 1).

#### 3.2 PARTICIPANTS

The characteristics and number of subjects included in studies I–IV are presented in Table 2. Children with CI included in studies I–III were from the same sample, whereas the children with CI in Study IV were another group.

**Table 2.** Characteristics and number of participants in studies I–IV.

	Study I		Study II			Study III	Study IV
	CI	HA	CI	P	T	CI	P
<b>Subjects<sup>1</sup></b>							
<b>Number of subjects</b>	36	38	22	22	17	32	12
<b>Gender</b>							
Female	22	23	15			20	9
Male	14	15	7			12	4
<b>Age, yrs<sup>2</sup></b>							
6	13	13				13	
9	14	13	12			13	
12	6	10	7			6	
15	3	2	3				
<b>Grading of HI<sup>3</sup></b>							
Mild		13					
Moderate		19	1			1	
Severe	3	6	3			2	
Profound	33		18			29	

<sup>1</sup> CI= children with cochlear implants, HA= children with hearing aids, P= parent/parents, T= teacher

<sup>2</sup> For Study II, a more specific age classification was performed

<sup>3</sup> Grading of hearing impairment (HI) in Study I was as follow: mild 20–40 dB, moderate 41–60 dB, severe 61–94 dB, profound >95 dB (pure tone average (PTA): 500, 1000, 2000, 4000 Hz), compared with studies II–III: mild 20–40 dB, moderate 41–69 dB, severe 70–94 dB, profound >95 dB (PTA: 500, 1000, 2000, and 4000 Hz)

### 3.2.1 Studies I–III

In total, 80 children with CI in the age groups 6, 9, 12, and 15 years old met the inclusion criteria for studies I–III. All children in these age groups treated at the Cochlear Implant Clinic at Karolinska University Hospital in Stockholm, Sweden, from 2005 to 2007 were included (Table 2). Children with multiple impairments, and children from non-Swedish speaking families (n=16) were excluded, leaving 64 children for inclusion. Of the 39 families who agreed to participate, three dropped out due to difficulty scheduling a meeting. This left a study group of 36 children with CI (Figure 3), giving a response rate of 56%.

In Study I, 36 children with CI, aged 6, 9, 12, or 15 years, participated together with a sample of children with HA (n = 38). Children with HA were selected to match the number of children with CI in each age group. The same exclusion criteria were used in both groups, namely, multiple impairments (CI: n = 11; HA: n = 28), and living in non-Swedish speaking families (CI: n = 5; HA: n = 9).

In Study II, participants were 22 children with CI, 9, 12, and 15 years old and 22 parents as well as 17 teachers.

Participants in Study III were 32 children with CI, aged 6, 9, and 12 years. Depending on the measures used, all these 32 children or a subgroup of 9- and 12-year-olds (n = 19) were included in the analyses.

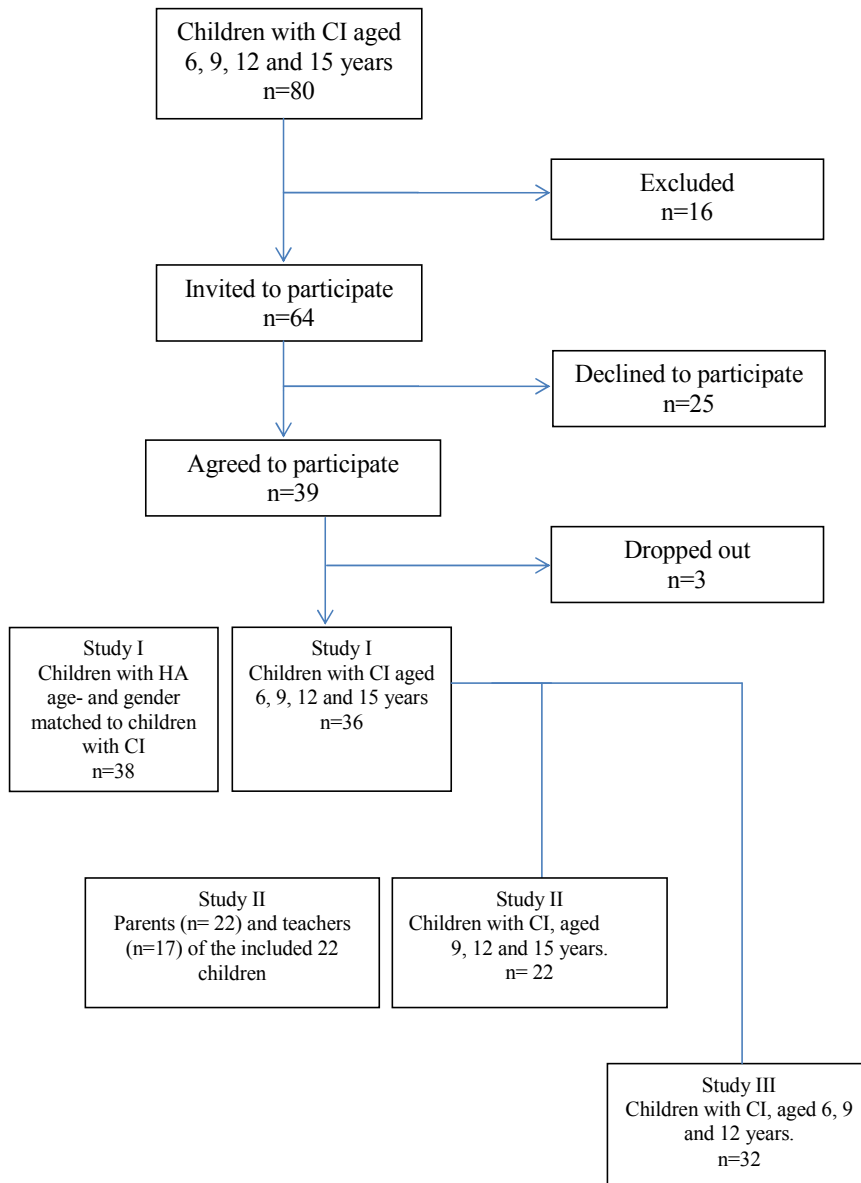


Figure 3. Flowchart of inclusion of studies I–III.

### 3.2.2 Study IV

Study IV was based on parents whose children were implanted with a CI during the period 1995 to 2000 at the Karolinska University Hospital in Stockholm, Sweden. The sampling frame consisted of 54 parental pairs. Two groups were formed, based on a previous questionnaire on the frequency of use of their CI among children (unpublished data). Ten parental pairs were randomly selected from each group: parents of children who were “full-time users,” and parents of children who were “limited users.” Out of this sample, four parental pairs of limited users declined participation and one parental pair of limited users dropped out due to difficulties in scheduling a meeting. Three of the interview recordings with parents of full-time users were lost due to technical failures. Lastly, one full-time user had by the time of the interview become a limited user and this parent was interviewed as a limited user. Hence, the final sample consisted of eleven parents and one parental pairs, six in each group.

### 3.3 DATA COLLECTION

The data in the present thesis was collected by questionnaire and individual interviews using semi-structured questions. An overview of the data collection methods used is given in Table 3.

**Table 3.** Data collection methods in studies I–IV.

	I	II	III	IV
<i>Questionnaires</i>				
Study-specific questionnaires	X			
SDQ		X	X	
CSOC			X	
Network map			X	
<i>Individual interviews about parents’ perspectives on the CI</i>				
				X

CI = cochlear implants; SDQ = Strengths and Difficulties Questionnaire, CSOC = children’s sense of coherence

#### 3.3.1 Studies I–III

##### 3.3.1.1 Study-specific questionnaires

A study-specific questionnaire was developed and used in two versions, one for children with CI and one for children with HA, to assess the children’s quality of life. The questionnaire was pilot tested by three children with HA, to test the comprehensibility of the questions. The two versions of the questionnaire comprised 24 questions each and were identical, except for the name of the aid (i.e., CI vs. HA). The question areas were: (1) use of the CI/HA by age and related factors; (2) hearing in different everyday situations; (3) thoughts about the children’s own hearing and about others’ attitudes to it; and (4) choice of language. Attitude questions were answered on a visual analog scale (VAS) ranging from “no problems at all” to “many problems.”

A study-specific questionnaire for parents was also developed and used in two versions, one for parents of children with CI and one for parents of children with HA, to gather information on gender, parental age, parental education, family status, presence of siblings, and the child's type of school. The information has been used in studies I–III as sociodemographic data.

### *3.3.1.2 Strengths and difficulties*

The SDQ has been developed for screening mental health in children and adolescents [76]. The questionnaire has been developed in nearly identical versions for parents and teachers of children aged 4–16, and for self-assessment of 11–16-year-olds [76, 77]. The SDQ consists of 25 items forming five subscales, containing five items each. The subscales are: emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behavior. Ten items reflect strengths, 14 reflect difficulties, and one is neutral but is scored as a difficulty item on the peer problems subscale. The items are responded to on a 3-point scale, where 0 = not true, 1 = somewhat true, and 2 = certainly true [49, 76]. Each subscale score ranges from 0 to 10. Higher scores on the prosocial behavior subscale reflect strengths, whereas higher scores on the other four subscales reflect difficulties [76]. The total difficulty score is calculated by adding the sum of scores on the emotional, conduct, hyperactivity, and peer problems subscales, with a possible range of 0–40 [49]. The construction of cutoff values is based on normative SDQ scoring, as proposed by Goodman [76]. Ten percent of a norm sample with the highest scores was classified as abnormal, the next 10% as borderline, and the remaining 80% as normal. The self-assessment version SDQ self-report has mostly been used for children aged 12 years and older, but a few studies have also used it for younger children (7–10 years old) [78–80].

The instrument has been translated into Swedish and has been established as a valid and useful instrument with satisfactory reliability [81, 82]. In studies II and III, we used the Swedish version of the SDQ (SDQ-SWE). Internal consistency (Cronbach's alpha) for the Swedish parental questionnaire has been reported as 0.76 and test-retest as 0.96 [82]. In our study II, Cronbach's alpha was 0.79 in self-reports, 0.76 in parental reports, and 0.55 in teachers' reports. In Study III, Cronbach's alpha was 0.80 in self-reports.

### *3.3.1.3 Children's sense of coherence*

Sense of coherence is a measure of a global tendency to view life situations as comprehensible, manageable, and meaningful [51]. The first self-report measure comprised the adaptation, for children, of the SOC scale: the CSOC scale [83]. This form consists of 16 items measuring how the child perceives his or her environment, expressed through three subscales: the (1) sense of comprehensibility (the feeling of understanding the own environment); (2) sense of manageability (feelings of control and confidence that positive rewards are available); and (3) sense of meaningfulness (motivation and interest in investing effort in different tasks) subscales. Children respond on a 4-point Likert scale ranging from 1 (= never) to 4 (= always).

The items are summed to a total score ranging from 16 to 64. The subscale score ranges are: comprehensibility 5–20, manageability 7–28, and meaningfulness 4–16. Higher scores indicate a greater SOC.

In Study III, we used the children's version of the SOC scale, translated into Swedish for children aged 12 and under [84]. The internal consistency (Cronbach's alpha) was 0.80.

#### *3.3.1.4 Network map*

In Study III, a six field network map was used to investigate the children's social networks [85]. This map consists of five concentric circles which are divided into six sectors, one each for family, relatives, formal contacts, school, associations (e.g., sports clubs), and friends/neighbors. The center represents the child itself. The child was instructed to draw symbols (men – filled triangles, women – filled circles, boys – unfilled triangles, and girls – unfilled circles) for those persons who were important to her or him in the different sectors. The child started with the family and continued clockwise. The most important persons were placed in the inner circle, and the least important persons in the fourth circle. In the outer (fifth) circle, the child placed people who were important but in a negative way. These persons would occupy the child's thoughts, but negatively, i.e., they were persons whom the child felt he or she was on bad terms with.

Map variables were calculated based on the number of children, the number of adults, and the total number of persons in each sector as well as the total number of persons on the map [33]. Samuelsson et al's (1996) measure of the closeness factor was used. This factor was obtained by multiplying the number of people in the nearest circle segment by 8, the number in the next circle segment by 4, and those in the next two segments by 2 and 1, respectively, thus differentiating the degree of importance that the child holds for the persons in the map. Closeness was calculated for each sector, and a total closeness score was also calculated.

### **3.3.2 Study IV**

#### *3.3.2.1 Parental perspectives on cochlear implants*

In Study IV, interviews with parents were performed using an interview guide with semi-structured questions. The interview guide was divided into six areas of experience: "to have a deaf child," "presurgery experiences," "surgery experiences," "postsurgery experiences," "reactions/attitudes to the CI," and "the future with the CI," in order to cover the process the families went through from having a deaf child to having a CI-implanted child. The interviewer made sure that the focus was on the parent's/parents' experiences of having a child with a CI. This was ascertained by follow-up and elucidating questions.



### **3.4 PROCEDURES**

#### **3.4.1 Studies I–III**

Written information and an invitation were sent to all families who had a child aged 6, 9, 12, or 15 years who had been treated at the Cochlear Implant Clinic, Karolinska University Hospital, Stockholm, Sweden. Attached to the letter was an acceptance form, to be signed by the parents and also by children aged 15 years, and a pre-paid reply envelope. Once the parents and children with CI had agreed to take part in the study, the teachers were also asked to participate (Study II).

Written information and an invitation were also sent from the Pediatric and Adolescent Habilitation Unit at Karolinska University Hospital to families who had a child with HA in the age groups above (Study I). Children with HA were first sampled within a small geographic area. These areas were later enlarged to cover the greater Stockholm area in order to recruit a group of children matching the CI age groups. Information and an invitation to participate in the study were given during their ordinary visit to the Habilitation Unit.

Children with CI answered the questionnaire while visiting the CI unit in Stockholm (between November 2005 and June 2007). Children with HA completed the questionnaire while visiting the Habilitation Unit (between November 2005 and December 2008). Each child answered the questionnaire in the presence of an experienced medical social worker. The children's parents answered a study-specific questionnaire giving sociodemographic data.

#### **3.4.2 Study IV**

Written information about the study, with an invitation to participate, was sent to 20 randomly selected families. An acceptance form and a prepaid reply envelope were attached to the invitation. Parents were contacted by telephone after they agreed to take part in the study. A time for the interview was arranged. Interviews took place in 2005–2006 and lasted approximately 90 minutes. All interviews were audio-recorded.

### **3.5 DATA ANALYSIS**

#### **3.5.1 Analysis of quantitative data (studies I–III)**

Descriptive statistics (means and percentages) were used and are presented to describe the distribution of patients and characteristics in each study. In studies II and III, both parametric and non-parametric statistics were applied as the study population was small and the data was on an ordinal level. Cronbach's alpha coefficient was used in studies II–III for the instruments SDQ and CSOC.

Table 4. Overview of statistical methods used in studies I-III

	Study I	Study II	Study III
Pearson chi-square test	X	X	
ANOVA		X	X
Kruskal-Wallis test		X	X
Independent <i>t</i> -test			X
Mann-Whitney test	X		X
Pearson's <i>r</i>			X
Spearman's <i>rs</i> tests			X
Cronbach's alpha		X	X

ANOVA = analysis of variance, Pearson's *r* = Pearson's correlation, Spearman's *rs* tests = Spearman's rank correlation coefficient

Pearson chi-square test was used for comparisons of the groups of children with CI and children with HA and to identify any correlation between background variables and study outcome (studies I–II). Analysis of variance (ANOVA) (one-way repeated measures) and Kruskal-Wallis test (non-parametric equivalent) were used to explore differences in estimation between groups: children with CI, parents, and teachers, in Study II and between age groups of children with CI in Study III. Independent *t*-test and Mann-Whitney test were used to study differences in scores between boys and girls (Study III). Pearson's correlation (*r*) and Spearman's rank correlation coefficient (*rs*) tests were performed to examine correlations among the CSOC, social network closeness, and SDQ scores (Study III).

The data in studies I–III was analyzed using the statistical software program SPSS, versions 15, 17, 18, and 21 (SPSS Inc., Chicago, IL, USA). The significance level was set at  $p < 0.05$ . The statistical methods used in studies I–III are presented in Table 4.

### 3.5.2 Analysis of qualitative data (Study IV)

An inductive, exploratory approach was adopted and the data from interviews with parents was analyzed inductively by means of meaning categorization, according to Kvale (2009). The process started with naively listening to and extensively reading all interview texts in full. All expressions relating to the aim of the study were identified and the meaning units were marked with open codes to capture the ideas of the material. The codes were grouped according to related content and sorted into categories and themes. The themes and categories were examined and scrutinized for their content as well as their relevance to the context. This resulted in further reducing and condensing the categories. The interview texts from the two groups were kept separate during the analysis to facilitate detection of any differences. The analysis was conducted by the first author, while the last author critically reviewed the process and the coding and categorization. The analyses were performed using NVivo 8 (QSR International, Doncaster, Victoria, Australia).

### **3.6 ETHICAL CONSIDERATIONS**

Parents and adolescents (15-year-olds) signed a consent form to participate in the study after they had received both written and verbal information about the study. They also received information that they could withdraw their participation at any time without any consequences.

The studies were approved by the Regional Ethics Review Board in Stockholm, Sweden, (Dnr 05/720-31 1-4 and Dnr 388/02).

## **4 RESULTS**

### **4.1 MAIN FINDINGS**

Children with CI and children with HA in some respects have equally good functioning in everyday life situations. However, some differences in functioning, regarding symptoms from the neck and shoulders, use of aids, use of sign language, and hearing problems when participating in outdoor activities and team sports, were found (Study I). Children with CI expressed greater concern about their mental health compared to their parents and teachers (Study II). However, they did not show more difficulties or mental ill health compared to children in general (studies II–III). Children with CI and a high SOC also had good mental health. Closeness of the social network, especially in school, was important for good mental health (Study III). Parents of children who used the CI full-time differed from parents of children with limited CI use regarding how they handled stressors (Study IV).

#### **4.1.1 Study I – children’s everyday life with hearing impairment**

This study focused the daily lives of children with CI compared to children with HA, and their thoughts regarding their own hearing and others’ attitudes to it.

Children with CI and children with HA functioned equally well in daily life. Both groups considered their hearing to be well functioning in a number of different circumstances and surroundings. However, 50% of the children with CI and 41% of the children with HA had difficulties hearing in large groups. There were also situations when the children (52% of children with CI and 65% of children with HA) wished for better hearing, e.g., during conversations with family members. However, most of the children in both groups did not perceive their own hearing as a problem, nor did they think that others found their hearing to be a problem.

There were some differences between the groups. One difference was that children with HA used their aids less often compared to children with CI. Children with HA had significantly more symptoms from the neck and shoulders compared to children with CI. More children with HA than children with CI had hearing problems when participating in outdoor activities and team sports. These differences were not dependent on level and type of HI, gender, or age.

More children with CI compared to children with HA attended a special school (using sign language). Children with one CI were overrepresented in the group that attended special school. Altogether, 41% of the children with CI and 50% of the children with HA attended mainstream school. Children with CI had more friends with HI compared to children with HA.

#### 4.1.2 Study II – strengths and difficulties among children with cochlear implant

This study focused on the mental health of children with CI, according to self-reports by the children themselves, and reports by their parents and teachers, in terms of emotional and behavioral strengths and difficulties.

##### 4.1.2.1 Children’s own perspectives

New situations and fears caused emotional difficulties for many children. Some of the children had problems with anger and loss of temper (conduct problems). Almost half of the children reported difficulties concentrating and staying still for a long time (hyperactivity–inattention). The children stated that they got on better with adults than with children of their own age (peer problems). A comparison between the age groups showed that the younger children (9-year-olds) had significantly more emotional symptoms compared to the older children (12- and 15-year-olds).

##### 4.1.2.2 Children’s mental health assessed by children, parents, and teachers

The assessments by children, parents, and teachers are shown in Figure 4.

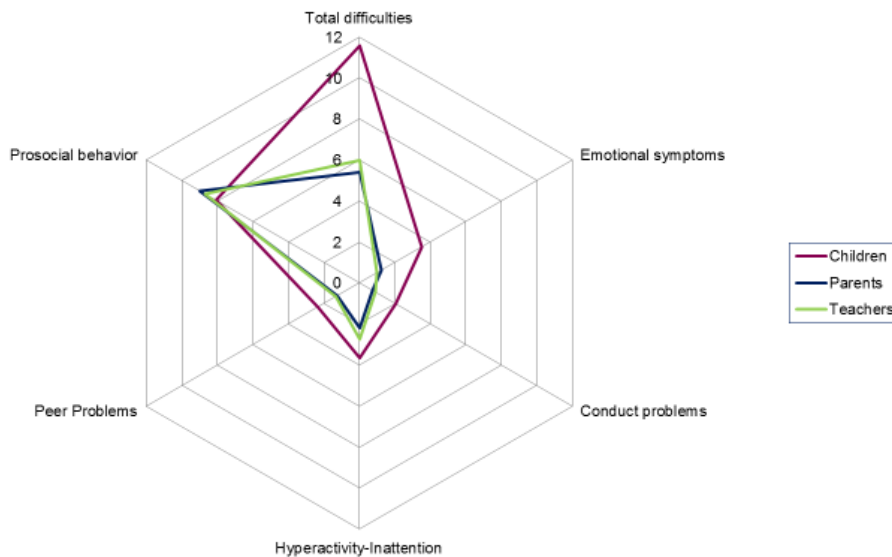


Figure 4. Children’s mental health (strengths and difficulties), according to the children themselves (n = 22), and their parents (n = 22) and teachers (n = 17). Strengths and Difficulties Questionnaire (SDQ) scores are given in total difficulties and mean subscale scores. The possible range of the total score is 0–40 and of each subscale 0–10. Higher scores on the prosocial behavior subscale reflect strengths; higher scores on the other four subscales reflect difficulties.

Children with CI scored significantly higher compared to parents and teachers on emotional symptoms, conduct problems, and total difficulties. Five of the children rated

themselves in a way that indicated ill health on total difficulties. One parents and one teacher indicated mental ill health for one child, but not the same child. Sociodemographic characteristics, hearing-related data, and speech language development showed no significant correlations with SDQ outcome.

#### **4.1.3 Study III – personal and social resources of children with cochlear implants**

This study explored the personal and social resources of children with CI in terms of how the children rated their own SOC and strengths and difficulties, and how they drew their social network. Furthermore, the relationship between children's SOC, and their social networks and mental health (SDQ) was studied.

##### *4.1.3.1 Sense of coherence and social network*

Children's SOC appeared to increase with age; however, the differences between either age groups or gender were not significant. In the social network, all children except six had a close relationship with both their parents. Two of the six children had a close relationship with one parent; the other four children had a relationship with their parents, but not a close one.

All children except five reported having one close friend or more. The children had more peer relationships in school than outside. Four of the children had no close peer relationships either in or outside of school. Many children reported having a relation with a number of adults at school, such as teachers and remedial teachers, with at least one teacher being close to them. Nearly half of the children had at least one conflict with siblings or friends in or outside school. There were no significant differences in social network closeness scores between boys and girls.

##### *4.1.3.2 Associations between sense of coherence, social network, and mental health*

The correlations between children's SOC, their social network, and SDQ scores indicate that children with CI who have a high SOC also have good mental health. Close relationships were seen as important for mental health. Children with close relationships in school reported higher SOC scores and better mental health compared to children with lower closeness scores.

#### **4.1.4 Study IV – facilitators of, and barriers to, children's use of a cochlear implant**

This study explored parents' experiences of having a child with a CI and aimed to identify facilitators of, and barriers to, the children's use of the CI.

Parents' experiences were categorized into four themes: (1) experiences of children's deafness and treatment; (2) experiences of the implant system; (3) parenting aspects; and (4) dealing with other people's attitudes.

#### *4.1.4.1 Experiences of children's deafness and treatment*

The first theme contained three subcategories: reaction to the diagnosis, decision about surgery, and expectations of the child's functioning with CI.

Parents from both groups had suspected early on that there was something wrong with their child's hearing. At first, they had received no response to their concerns from health care. By the time the child was finally diagnosed with severe hearing loss, it was more like a confirmation of their suspicions. The two groups of parents differed as follows: parents of limited users had stronger reactions to the diagnosis, needed more time to decide on surgery, and had lower expectations of the CI compared to parents of full-time users. The full-time user group saw the diagnosis as a challenge that they could manage. They had fairly high expectations of the child's functioning and speech development with CI.

#### *4.1.4.2 Experiences of the implant system*

The second theme consisted of three subcategories: surgery-related problems; experiences of the technology; and introduction to the CI. Children in the full-time user group had suffered more complications associated with surgery, while many limited users had experienced technical problems with their CI. All had experienced a loud sound from their body-worn CI. The habituation process was quick and easy for full-time users, but for the limited users it took up to 6 months to accept the CI. The technical problems in turn made it difficult for the parents to urge the child to use their CI.

#### *4.1.4.3 Parenting aspects*

The third theme contained two subcategories: strategies for upbringing; and the impact of the CI on the child's life. Strategies for upbringing differed between the groups. Parents of full-time users were determined to abide by their own decisions and had clear strategies to encourage daily use of the CI. Parents of limited users were more eager to please the child and some parents were ambivalent about using the CI. However, both groups saw the benefits of CI use.

#### *4.1.4.4 Dealing with other people's attitudes*

The fourth theme consisted of two subcategories: other people's attitudes towards the CI; and receiving social support. Parents in both groups had met with positive attitudes to the CI from family and friends, but resistance against the CI from professionals in habilitation units as well as personnel at special preschool. What distinguished the groups from each other was that parents of full-time users did not listen to the negative attitudes, while parents of limited users did. Social support was related to the attitudes encountered in the networks. Parents described problems they had experienced to get support from habilitation. Often, they had had to fight against the professionals. Both groups had also experienced objections to the CI from people they did not have a relationship with.

## **5 DISCUSSION**

This thesis was performed to gain increased knowledge about the life conditions for children and adolescents after CI surgery. The primary focus was to highlight the child's own perspective, with emphasis on his or her daily life and mental health. The secondary focus was to examine parents' experiences of having a child with CI and to thereby identify facilitators of, and barriers to, use of the CI.

### **5.1 LIVING AS A CHILD WITH COCHLEAR IMPLANTS**

In previous research, examining the children's with CI daily lives and mental health has often been based on parents' perspectives [43, 86, 87]. In this thesis parents and teachers were included in Study II as a comparison in order to illuminate both the child perspective (adults' perspectives concerning the child) and the child's own perspective on his or her mental health.

#### **5.1.1 Activities and participation**

In this thesis children with CI functioned well in daily life. These results are also supported by previous studies [88], in which children with CI viewed their disability/HI as a non-barrier to occupational performance and participation in various life situations. However, in our study some difficulties hearing in situations involving many people were reported. Many children experienced situations where they would like to have better hearing, e.g., in the classroom and in conversation with family members. This is consistent with other studies, both in self-reported [88-90] accounts and in parent reports [86, 91].

Many of the children in this study could sign and used sign language both in school, and at home during leisure time. The majority of the children preferred to use total communication (spoken language supported by signs), regardless of the environment, although a preference for oral language was associated with children provided with two CIs rather than only one CI.

Today, a clear shift in communication mode is apparent. Children implanted with CI, without additional disabilities, are able to communicate using mainly spoken language [26, 92]. In recent studies, it has been shown that children who get their CI before 1 year of age will obtain the same spoken language level that their hearing peers do' [14, 26, 92].



### **5.1.2 Social resources**

In our study, children with CI attended a range of different schools or school types. More than half of the children with CI attended a special school using sign language, a rate which is consistent with Wheeler et al [88]. According to our clinical experience today, children with CI, without additional disabilities, more often, go to mainstream school and sometimes, but not always, have a resource person.

Making use of the network map as a complement to other instruments gave an opportunity for broader access to children's social relationships with family, friends, and other people in their network. This also gave an opportunity to gain insight into the children's sense of closeness in these relationships. Knowledge about the quality of social relationships is important to better understand the social and emotional wellbeing of children with HI [34]. The quality of social support has been shown to be more important than quantity in the social network [33] although in general people with larger networks are better able to cope with social stressors [93].

Furthermore, the social network of children in this thesis comprised close relationship with family members, friends, and teachers. Most of the children had both friends with and friends without HI. However, our findings were somewhat contradictory; even if the children had a close relationship with friends, many of them tended to get on better with adults, according to their answers in the SDQ. This might indicate a difficulty in relating to others of the same age. One reason could be that children want to be seen as socially acceptable individuals and therefore overestimate the closeness in the relationship with peers. It may then be difficult to acknowledge social difficulties in contact with other children [89] and the network maps might be more a map of desired relationship. Using social network map in conjunction with a qualitative interview could give a broader perspective [34].

### **5.1.3 Personal resources**

We could not find that children with CI in our studies were more vulnerable to compromised wellbeing compared to hearing peers of the general population in terms of mental health and psychological problems. The children in our studies had good mental health and a strong SOC both compared to other children from norm populations [49, 76] and to children with hard of hearing [94, 95] as well as to community samples in Sweden [84]. The mental health of Swedish children with CI seems to be comparable to that of a community sample in Nordic countries [96-98] as well as a community sample in Europe [46, 76, 80]. The studied children's SOC also was comparable to that reported for school children in Israel with and without difficulties [99].

In this thesis, SOC had a strong association with mental health, which is in line with previous research [56, 100, 101].

## **5.2 DIFFERENT PERSPECTIVES**

### **5.2.1 Child perspectives in relation to the child's own perspective**

It is important to illuminate the child's own perspective, as his or her experience of a certain situation does not always match the picture the adults around the child have. In Study II, it can be seen that the mental health the child is him or herself describing is different from that described by both his or her parents and teachers. If we were to rely solely on the adult perspective, the information about the child's own experience would be lost and we would draw a different conclusion. To use both a child perspective and the child's perspective may contribute to a deeper understanding, especially if the child and the parents and/or teachers have different opinions. There are studies that show that parents rate children's quality of life lower than the child does her or himself [102].

In our Study II, however, the parents rated the children's mental health higher than the children themselves did. The reason for this can only be speculated. One reason might be that the parents, in the context of being questioned, felt the need to defend their decision to implant their child. Alternatively, they may have invested so much hope in a better future for the child after the implantation, that they subconsciously overestimated their child's mental health in order to gain legitimation, retrospectively, for the difficult decision to let him or her undergo a non-vital operation.

Furthermore, the parents of children with CI in this study reported more strengths compared to Swedish parents of hard of hearing children [94] and English parents of children with normal hearing [46, 49]. The results of our study also disagree with a similar study by Huber and Kipman [48]. Parents and teachers in that study reported more mental ill health in their children compared to the parents and teachers in the present study. Factors behind these differences might be cultural differences, and differences in health care routines and/or treatments.

However in other types of studies it has been shown that children's experiences and opinions can differ markedly from those of adults [103]. In certain situations, the adult view of the child can be flawed or inaccurate. This might lead to poor support of the child. To use a child-centered strategy in research and clinical work means that the adults around the child have competence of a child's development and living condition and knowledge about the specific child in his or her own context [60]. It is therefore important both in research and in clinical work to highlight the child's perspective to gain a better understanding of the child's experiences and needs.

### **5.2.2 Parental stress and strategies**

In recent years there have been a number of studies about family stress related to children with CI [65, 67, 68, 104, 105]. Only a few of these, however, deal with difficulties with the children's use of their CI [68, 106]. In Study IV investigating parental experiences of CI use, we also included parents of children with limited CI use to see if there were differences in the parents' experiences with special reference to facilitators of and barriers to, continued CI use. The findings show that all the parents had experiences of stress throughout the CI process. Previous research reports that

parental stress is much higher in the early stage of the CI process [65, 68, 105]. For many parents in this thesis, the decision to give consent to surgery for their child was stressful, especially as the CI operation is not absolutely vital [68]. To try to force the child to use the CI against his or her expressed will, sometimes in the face of technical problems in the functioning of the CI, tends to further increase the level of stress for parents of children with limited CI use and thus became a barrier, in our study population to more active parental encouragement towards more frequent use of the CI.

One factor that additionally increased the parents' stress probably derived from negative and disrespectful attitudes in the health care system. In our study, a clear difference in educational preferences emerged between the parents and the professional network. Many parents felt betrayed in varying degrees and felt that they had to fight against the professional network to provide their children with the auditory development they believed in. Scarcity in professional resources, lack of flexibility, and/or negative attitudes towards the CI in children meant that parents had to adapt to what was offered, e.g., when the parents preferred more focus on training for hearing and oral speech development but had to comply with a strict focus on sign language. These findings are consistent with Sach and Whynes [68].

In this thesis, there were differences between the two groups of parents, i.e., parents of full-time users and parents of limited users, regarding how they handled stressors. Parents of full-time CI users adopted an active role and used problem-focused coping. Their strategy lay mainly in confronting and changing the situation itself by active information gathering and solution-focused behavior related to various issues regarding different aspects of their child's CI.

By contrast, parents of limited users took a more cautious role and used primarily emotion-focused coping. They listened more to professionals' opinions in their decision making. This strategy was not a successful way, either of making a decision about the implantation, or of finding own parenting strategies. Parents of limited users tried to adapt to the professionals' expectations.

When parents use different coping strategies it is important that they meet flexible professionals who are able to adapt to the specific issues to achieve enhanced coping and participation in habilitation. This requires a close and respectful relationship between the family and professionals in early intervention, but it leads to improved outcomes for the child [107-109].

### **5.2.3 Changing attitudes**

There are several possible explanations as to why the parents in our studies were not entirely happy with the support and information from the health care system. One reason was that the medical development was out of phase with the experiences of the professionals at habilitation. In their eyes, CI was a new method that was presumably meant to make deaf children hearing again. Similar attempts at trying to make deaf children hearing with traditional HA had not been very successful in their experience and consequently the CI also tended to receive a negative stamp. The professionals at

the habilitation units had a more holistic view on the children's HI based on attitudes in Sweden at this point of time. This is consistent with previous studies reporting that attitudes are based on beliefs and values in cultural and religious settings and on the norms of the society in which a child grows up [110, 111].

The Swedish government acknowledged sign language as an official language in its own right in 1981. Since then, sign language has retained a strong position in Sweden [112, 113]. When cochlear implantations were introduced, there was a skeptical attitude, among both the deaf and professionals, towards CI for children [114]. A strong fear remained during the 1990s and into the beginning of 21<sup>st</sup> century, that a focus on spoken language would mean that, if they were not taught sign language, children would come to lack adequate language and effective communication skills [112]. Special schools for deaf and hard of hearing children in Sweden had a bilingual approach, which at this time meant that sign language was the first language and written Swedish was the second language for deaf and hard of hearing pupils. Later also the development of spoken Swedish was been included in the policy of the schools [115]. During this time, most of the children with CI attended preschools and schools where sign language was their main language and teaching medium. The expectations on the children's spoken language development were very low during that time, not only from health care and, habilitation, but also from pre-schools/schools [116].

As increasingly more children in Sweden have undergone CI surgery and support methods and systems for the children and their parents have developed, the attitudes towards CIs have slowly and gradually changed. Although changes have occurred over the years, both within habilitation and in preschool/school, there are still challenges facing the systems that support parents and children in several areas, especially for families whose children do not do as well as expected with the CI [106]. Support is important with individually tailored interventions, based on latest knowledge about disabilities, parental coping strategies and the needs of the children also seen from a child's perspective [107, 108, 117].

### **5.3 METHODOLOGICAL CONSIDERATIONS**

In this thesis, different types of data as well as approaches (quantitative and qualitative) have been used. The data provides an idea of the reality of everyday life and its conditions for children after CI surgery. As the aim of the thesis was primarily to explore the life circumstances of children with CI, cross-sectional designs and interviews were used. The children with CI and the parents who participated in studies I–IV were treated at one single CI center, in Stockholm, Sweden, which has long experience of cochlear implantation. The children and their parents were from central and northern Sweden. This provided us with an opportunity to investigate children's and parents' experiences from different parts of the country, where support and habilitation may differ. However, the study design also has limitations. For example, the cross-sectional design (studies I–III) only represents one measuring point for each participant.

There are several reasons for being cautious when generalizing results from the studies in this thesis. One factor is that children with CI are a very heterogeneous group. They vary with regard to medical, audiological, cognitive, linguistic, and environmental conditions. Furthermore, the study groups in studies I–III were fairly small, which hampers the possibility to identify differences and draw conclusions. Another limitation is that the children were not evenly distributed across the different age groups. This was due to the limited number of children available at the clinic, to the fact that multi-impaired and non-Swedish-speaking children were excluded, and to several children declining participation. We cannot be sure that non-participants would have the same experiences as the participants in studies I–III.

The children's age at implantation with a CI has dropped gradually during the last 10 years, from 2 years to 5–6 months of age, and the development of implant technology has progressed further. This means that the outcome regarding hearing and speech and language development is considerably better for many children receiving a CI today compared to most of the children who were implanted during the 1990s and in the first decade of the 21<sup>st</sup> century [26]. We do not know how this opportunity for earlier speech and language development, compared to the opportunities of children receiving implants at an older age, affects children's social and emotional development. The life circumstances of children who undergo CI surgery today may present a different picture when they become schoolchildren or adolescents, compared to this study group who were implanted 10–20 years ago.

Studies II–III used validated instruments, of which the SDQ and the CSOC scale have been used in previous studies of this group of children. Reliability (Cronbach's alpha) in this study is sufficient and comparable to previous studies [81, 82, 84]. So far, the children's own experiences of daily life and the personal and social resources of children with CI are sparsely studied in Sweden. Therefore, results need to be related to results from other countries. Most of these studies are based on individuals with CI growing up in culturally different settings, which can limit the ability to compare results. Further, a possible threat to the validity is that we used the SDQ for children aged 9–12 years, which has not often been done previously [78–80]. The reliability test and the researcher's experience, however, indicate that the results are valid also for the younger children. Moreover, some of the children in different age groups had limited speech and language skills. This was, however, addressed, as far as possible, by the assistance of research staff.

In Study IV, an inductive, exploratory approach was adopted and data was analyzed inductively using meaning categorization, according to Kvale [75]. The study is retrospective and relies on descriptions by parents of their experience of having a child with CI and of the facilitators for, and barriers to, the children's CI use. A strength of the qualitative study is the fact that it is one of a few qualitative studies capturing parental perspectives on "limited use" of CI. The trustworthiness of the findings is strengthened by the analysis, which was conducted by the study's first author (L.A.) and critically reviewed by the last author (M.O.). Discrepancies in the coding process were resolved through discussion and a joint review of the original transcripts [75]. The parents' views of their own parenthood and parenting strategies may change over the years and it may be difficult to draw conclusions about the actual process. Still, their

own recollection of the process is important in our search for factors facilitating or complicating a child's use of CI.

A further limitation is that the dropout rate was 50% among parents of limited CI users. The high dropout rate may be due to difficulties to admit, and talk about, negative experiences. The child's limited use of the CI may be seen as a failure, which is difficult to reveal, especially to an interviewer representing the Cochlear Implant Clinic. However, the identified themes all exist according to the parents' experiences, and are important to address as potential barriers to the children's use of the CI.

Furthermore, the study sample comprised only hearing, Swedish-speaking parents. However, no other options were available at the time of the study.

## **6 CONCLUSIONS**

This thesis has provided new knowledge about cochlear implantation and life circumstances with CI from the child's perspective. The included children, implanted with CI during the period 1994-2005 had good functioning in everyday life. Their functioning was better than that of children using HA e.g. regarding hearing when participating in outdoor activities and team sports and regarding pain in neck and shoulders.

Children with CI had mainly good personal and social resources. This, however, does not mean that difficulties do not exist. Parents and teachers tended to oversee difficulties mentioned by children, why the child's perspective must be taken into account.

Parents in this thesis who used clear strategies and successfully used problem-focused coping helped their child to use the CI. Parents who had a more cautious approach had a harder time getting their child to use his or her CI.

Based on the findings in this thesis, it is important for parents of children with CI to be acknowledged as valuable and competent. It is also important that contact with professionals should give parents hope for the child's future. If parents do not get the right response there is a risk that the relationship with the professionals instead becomes a struggle for the support parents believe their child needs.

## **7 CLINICAL IMPLICATIONS**

Although the majority of the children in this study showed good personal and social resources, it still is of vital importance to identify the children with difficulties. This can be done by using screening tools in the daily work at the CI center or the habilitation unit. In this and other studies the SDQ [49] and CSOC scales [51, 83] have been shown to be appropriate for this purpose. An implication is that psychosocial support needs to be developed from the child's perspective as well as the child perspective, and addressed by individually tailored interventions.

It is equally important that health care resources promote parental coping and participation when it comes to providing care for children with special needs, such as children with CI. This should be done by individualized support to help parent's address the known stressors in the CI-process but also by encouraging the parents to engage in parental supports groups that could well be organized in the habilitation unit.

Although children with CI in this thesis did not reveal any major problems with physical complaints, it is still important that health care professionals should ask questions about their physical wellbeing, as children with HA in Study I and children with HI in other studies have reported health problems, e.g., headaches, and neck and shoulder pain [19, 118].



## **8 FURTHER RESEARCH**

There is a need for further studies aimed at investigating a larger population of children with CI. A prospective design would have been preferable, allowing observation of the children's psychological and physiological development through their school years. In a future study, a control group of children with normal hearing should also be included for comparison of the variables studied in the children with CI.

It is important to identify factors related to risk as part of developing effective intervention programs. This may prevent future problems and help children with specific individual or environmental difficulties enhance their health and wellbeing. It is also important that health care professionals increase their knowledge of how to respond to, communicate with, and support children of different ages with CI from both a child perspective and a child's perspective. Today, children can be implanted with CI from 5 months of age and the knowledge about how this opportunity for earlier speech and language development affects the children's social and emotional development is still limited.

## 9 SAMMANFATTNING

**Bakgrund:** Ca 300 barn föds i Sverige varje år med hörselnedsättning, varav ca 50 har en grav hörselnedsättning. Idag behandlas dessa barn, beroende på grad av hörselnedsättning, med antingen traditionell hörapparat (HA) eller cochleaimplantat (CI). Målsättningen med CI är att barnet ska kunna utveckla hörsel och talat språk bl.a. för att underlätta kommunikation med det hörande majoritetssamhället. Målsättningen är också att öka barnets delaktighet och välbefinnande. Om barnet inte använder sitt CI är den avsedda talspråkutvecklingen utesluten.

Det finns en mängd litteratur från mitten av 1960-talet fram till slutet av 1980-talet som beskriver svårigheter med självkänsla och anpassningsförmåga hos barn med grav hörselnedsättning. I litteraturen lyfts också fram att funktionshindret medför påfrestningar för barnets familj. Efter att CI introducerades som behandlingsform på 1990-talet har en intensiv forskning och utveckling ägt rum inom området, men få studier har inriktas på barns fysiska, känslomässiga och sociala situation och funktion av hjälpmedel. Det finns än färre studier där barnets eget perspektiv framkommer.

**Syfte:** Det övergripande syftet med avhandlingen är att ge ökad kunskap om livssituationen och dess villkor för barn och ungdomar efter operation med CI.

**Metod:** Avhandlingen innehåller fyra delstudier. Studier I- III är tvärsnittsstudier med kvantitativ design. I studien ingår två urval, varav båda (barn med CI och barn med HA) används i studie I medan ett urval (barn med CI och deras föräldrar, n=22 och lärare, n=17) används i studie II-III. Barn i åldrarna 6, 9, 12 och 15 år som antingen har blivit opererade med CI eller använder HA och som har kontakt med CI-teamet eller hörselhabiliteringen vid Karolinska Universitetssjukhuset inkluderades. Barn med CI som ingår i studierna I-III erhöles från samma urval (n=36), men skiljer sig i antal och åldersgrupper mellan studierna. I studierna I-III används studiespecifikt frågeformulär, självskattningsformulär (Styrkor och svårigheter, SDQ och barnKASAM, CSOC) samt nätverkskarta. Data analyserades med statistiska beräkningar. Studie IV är en retrospektiv, kvalitativ studie med meningskategorisering av data från enskilda intervjuer med 12 föräldrar till barn som antingen använder sina CI på heltid, deltid eller inte alls.

**Resultat:** Resultaten från studie I visade att barn med CI och barn med HA upplevde en väl fungerande funktion med sina hjälpmedel i vardagslivet förutom i följande avseenden: Barn med HA hade oftare besvär med nacke och skuldra, använde sina hjälpmedel mer sällan och upplevde sämre hörselfunktion i lagsporter och friluftsliv, jämfört med barn med CI. Barn med CI använde teckenspråk i större utsträckning än barn med HA. De två grupperna skilde sig inte åt beträffande tankar om sin egen hörsel och ansåg inte hörselnedsättningen vara ett problem. De upplevde inte heller att omgivningen hade en negativ attityd till deras hörselnedsättning.

I studie II analyserades barns mentala hälsa utifrån deras egen, föräldrarnas och lärarnas perspektiv. Barn med CI uttryckte större oro för sin psykiska hälsa än vad föräldrar och lärare gjorde. Nästan en fjärdedel av barnen rankade sig själva på ett sätt som indikerar

psykisk ohälsa. Däremot uppvisade barnen inte fler svårigheter eller psykisk ohälsa jämfört med barn i allmänhet (II-III).

Resultaten från studie III visade att barn med CI med hög känsla av sammanhang hade god psykisk hälsa. Barnen med nära relationer rapporterade bättre mental hälsa jämfört med de barn som inte uppgav att de hade nära relationer. Förekomst av nära sociala relationer i skolan var också viktigt för en god psykisk hälsa och känsla av sammanhang.

Resultaten från studie IV visade att föräldrar till barn som använder sina CI heltid skiljer sig från föräldrar vars barn använder sina CI på deltid gällande hantering av stressorer. Föräldrar till heltidsanvändare var bestämda och hade tydliga strategier för att stödja sitt barns användning av CI. Föräldrar till deltidsanvändare tog mer hänsyn till andra människors åsikter om CI.

**Slutsatser:** Denna avhandling visar att barn med CI har bra funktion i vardagliga situationer. De barn som hade en hög känsla av sammanhang hade också god psykisk hälsa. Närhet till relationer i det sociala nätverket, särskilt i skolan, var viktigt för en god psykisk hälsa. Även om majoriteten av barnen i denna studie visade goda personliga och sociala resurser är det fortfarande mycket viktigt att identifiera barn med svårigheter. Detta kan göras med hjälp av screeningverktyg i det dagliga arbetet inom habilitering och CI-team. Det är lika viktigt att hälso- och sjukvårdsresurser främjar föräldrars coping och delaktighet när det gäller barn med CI. Detta kan uppnås genom att ge individuellt stöd, kunskap om hörselnedsättning och CI samt främja positiva copingstrategier.

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