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## **Cochlear implants in children: Development in interaction with the social context**

Wiefferink, C.H.

### **Citation**

Wiefferink, C. H. (2012, September 13). *Cochlear implants in children: Development in interaction with the social context*. Retrieved from <https://hdl.handle.net/1887/19779>

Version: Not Applicable (or Unknown)

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**Note:** To cite this publication please use the final published version (if applicable).

Cover Page



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**Author:** Wiefferink, Karin

**Title:** Cochlear implants in children : development in interaction with the social context

**Date:** 2012-09-13

# **Chapter 1**

## **Introduction**

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Approximately one newborn in a thousand has hearing loss at birth; in the Netherlands about 150 children yearly (Korver, Konings, Dekker, Beers, Wever & Frijns, 2010). Besides a serious impact on children's daily functioning, developmental opportunities and social interactions, deafness also seriously affects the position of these children in their direct social environment – not only in their family, but also in a wider societal context, such as school (Spencer & Marschark, 2010).

Due to impressive technical developments regarding cochlear implants (CI), the prospects for deaf children have changed since the 1990s. Nowadays, almost all children eligible for CI in the Western world receive such an implant, usually before the age of two (De Raeve, 2010), and for most children around their first birthday. A CI is a device that electrically stimulates the auditory nerve, bypassing the damaged part of the ear. A microphone transmits sounds to a speech processor, which converts them to electrical pulses that are then transmitted to the auditory nerve through electrodes on an array implanted in the cochlea. Ultimately, signals from the auditory nerve are perceived as sounds by the brain. However, whereas a normally functioning ear has close to 30,000 nerve endings that process sounds, a CI has only a limited number of electrodes that can stimulate the auditory nerve – currently a maximum of 22 (Wilson & Dorman, 2008).

In other words, a CI gives children access to sound, but not to an extent that makes them equal to children born with normal hearing, because the quality of the sound is not nearly as good as in hearing people. Despite this, studies on the effects of CIs in children show a positive influence on speech recognition, speech intelligibility and other aspects of spoken language development and also on reading comprehension compared to deaf children without a CI (Schauwers, Gillis, Daemers, De Beukelaer, De Ceulaer, Yperman & Govaerts, 2004; Svirsky, Chute, Green, Bollard & Miyamoto, 2002; Thoutenhoofd, Archbold, Gregory, Lutman, Nikolopoulos & Sach, 2005; Vermeulen, Van Bon, Schreuder, Knoors & Snik, 2007; Niparko, Tobey, Thal, Wang, Quittner & Fink, 2010; Boons, Brokx, Dhooge, Frijns, Peeraer, Vermeulen, Wouters & Van Wieringen, in press). However, individual outcomes have been shown to vary widely at

implant centers around the world (Peterson, Pisoni & Miyamoto, 2010). While certain factors are known to have a positive influence on language development – such as a young age at implantation, the absence of other disabling handicaps, and involvement of the parents – it is uncertain how other factors, such as cultural and social factors, affect the daily functioning and development of children with a CI. Moreover, little research has been conducted on other aspects of development, such as emotional and social functioning in daily life.

In this context, there is still little literature on the effect of children's deafness and their CI on their development. If the best possible support is to be provided to these children (and their parents), and if they are to be offered an environment in which they can develop adaptively, with the best possible opportunities to deploy their capacities, the effects of a CI on their daily functioning should be understood in the greatest possible detail. This requires close examination of the different layers in their daily environment. Through fuller insight into the influence of child characteristics and environmental factors on CI children's daily functioning and development, it will be possible to provide more specific information on how their rehabilitation and counseling – and that of their parents – can be improved.

This thesis thus examines how a CI affects young children's daily functioning. The age of the children was between 1–5 years. All CI children were born to hearing parents, had profound prelingual hearing loss with no other disabling conditions, and all had had their implant before the age of 43 months, with one exception, who had received it at 57 months (range = 6–57 months). Within the framework of Bronfenbrenner's social-ecological model (1979), it explores the effect of a CI on young children, and various factors whereby this effect might be determined. While the framework describes influences on a child's development from different circles of its social context, this thesis focuses specifically on three topics that are all equally important to understanding and enhancing the daily functioning and development of children with CI:

1. The influence of parents on these children's daily functioning,
2. The influence of language mode on their language development,
3. The influence of a CI on their social-emotional functioning.

## Social-ecological model

While child characteristics such as intelligence, temperament, and physical health are very important factors in children's daily functioning and development, this is only one side of the coin: the environment in which they live and grow can be equally important. The environment includes not only the immediate settings of the developing child, but also the wider social contexts in which these settings are embedded (Bronfenbrenner, 1979).

Bronfenbrenner's social-ecological model describes human development from an interactive contextual perspective, proposing that a child is at the center of a series of concentric circles, each representing a setting that influences him or her bi-directionally (figure 1). While the rings further away from the child represent societal values and culture, those that are closer represent settings on a smaller scale, such as family, neighborhood, and school. The inner circle represents the child's development: language development, social-emotional development, cognitive development and physical development.

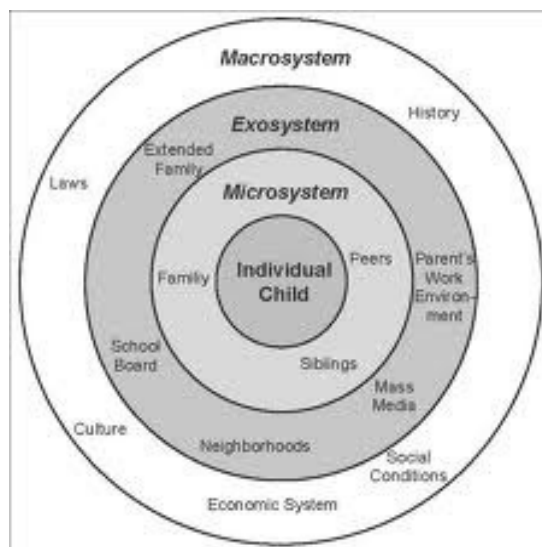


Figure 1. Bronfenbrenner's social-ecological model

A child's development is influenced by factors at all levels of the model, the most direct influences lying in the quality and quantity of the child's interpersonal interactions with family, peers, teachers, and others. Indirect

influences come from the interrelationships between the settings in which the child is an active participant – such as home, day-care centre, and hospital – and the broad ideological, political and cultural patterns of the society in which he or she participates.

The environment of deaf children with a CI is very different from that of hearing children, even to that of their hearing siblings. In the immediate social context, they experience problems in communicating with others, for until they receive their CI they lack any access to spoken language. In the wider social context, too, their environment differs from that of hearing children. For example, rather than going to a mainstream school with their siblings, some may go to special schools for deaf children, where they learn sign language and may eventually become part of deaf culture. They also have to go through a very intensive rehabilitation, such as fine-tuning the sound levels for the speech processor, aural rehabilitation to help children interpret sound in their environment, and speech therapy for facilitating listening skills and speech skills.

It is therefore beyond question that these children's development is influenced by the context in which they are raised.

### **Parental influence on CI children's daily functioning and development**

Parents' influence on the development of their deaf child should not be underestimated. In general, all parents are faced with decisions they have to make on their child's behalf: young children cannot decide on the daycare center they will attend or the clothes they wear. Most parents who discover that their child is deaf have to deal with a condition with which they are barely or entirely unfamiliar. Consequently, even though they know little or nothing about deafness and its consequences on children's daily functioning, they have to make decisions that will have a great impact on the child's future.

Shortly after the diagnosis, when their child is around three months, parents are already faced with the question of whether their child should receive a CI, and at what age. Due partly to the complexity of determining what they believe to be in the child's best interest – a process that is itself influenced by

their values and beliefs – this is a difficult decision (Li, Bain & Steinberg, 2004). But it will be only the first step of many. There will be many other crucial decisions to make – whether they will communicate with their child in sign language or spoken language, for example, or whether he or she will go to a mainstream school or a special school for the deaf.

In short, parents have to make many decisions that will greatly influence their child's development and future. Some of these have to be made in the first year of the child's life, when most hearing parents of deaf children – i.e., 90-95% of prelingually deaf children – experience the feelings of loss and sadness that accompany the discovery that their child is deaf. As with the decisions they have to make, these feelings may cause them considerable stress (Hintermair, 2006). This may in turn influence the way they cope with the child's deafness, which may itself influence the child's development. Moreover, as stated above, parents are affected by factors from the wider social context that indirectly influence the development of the child (Bronfenbrenner, 1979).

According to the social-ecological model, the development of children is directly influenced by parent-child interaction. Research on the quality and quantity of the interaction between parents and their deaf child without a CI shows that parents of deaf children generally have difficulties interacting with their child: mothers interact with them less positively and less flexibly, and are less sensitive to their needs (Meadow-Orlans & Steinberg, 1993). Similarly, deaf children with hearing parents usually spend less time communicating with their parents, and cannot overhear conversations in which they are not directly involved (Gray, Hosie, Russell, Scott, & Hunter, 2007). Parents – who are used to interacting with others by means of spoken language – may have problems finding other ways to interact with a deaf child. Due to communication problems, they are therefore likely to have difficulties connecting with their child.

In short, the quantity and quality of interactions between parents and deaf children are insufficient, and in turn, negatively affect various aspects of children's development even in young children with a CI (DesJardin & Eisenberg 2007). While many children with a CI later have access to spoken language, they are deprived of it before they receive their CI, usually in the first one or two years of their life. In other words, the development of children, who



have access to spoken language after receiving their CI is likely to be delayed, not only with regard to speech and language development, but also to other facets of development.

The qualities of the interrelationships in settings in which children participate indirectly influence the children's development. For those with a CI, most research on this topic has covered the influence of parental involvement in rehabilitation programs on the children's language development (Sarant, Holt, Dowell & Rickards, 2009; Moeller, 2000; DesJardin & Eisenberg, 2007). These studies showed that parent's involvement in rehabilitation programs is related to language development, greater parental involvement in these programs positively influencing the development of their child's spoken language development. It was also shown that parents from higher socio-economic background are usually more involved in the rehabilitation of their child than those from a low one (Niparko, Tobey, Thal, Wang, Quittner & Fink, 2010). However, less is known about the specific reasons why some parents' participation is low, especially in parents of minority groups.

Parents' values and beliefs – and, indirectly, their child's development – are influenced by their wider social context, such as ideological, political and cultural patterns in society. Within any society, these patterns differ per socioeconomic, ethnic, religious and sub-cultural group, each of which reflects contrasting belief systems and lifestyles. Because most studies on the development of children with a CI focus on a general population, little is known about that of such children in ethnic minority groups and about the influence of their parents' values and beliefs on this development.

Two studies from the USA found that such children benefit less from a CI, either because their parents have less access to healthcare facilities (Stern, Yueh, Lewis, Norton & Sie, 2005), or because they find it difficult to decide on the care of their deaf child (Steinberg, Delgado, Bain, Li & Ruperto, 2003). Such problems may be rooted in cultural differences: healthcare systems are usually tailored to the needs of the native population, which may differ from those of minorities. In the Netherlands, access to health care facilities is equal for all documented inhabitants, but immigrants from non-Western countries often experience problems in health care due to cultural differences and language problems (Yumusak & Hoogsteder, 1999) . In the Netherlands, over ten percent

of the population consists of immigrants from non-Western countries. Research showed that the spoken language development of deaf children of Turkish origin is delayed compared to that of native deaf children (Wiefferink, Vermeij, Van der Stege, Spaai & Uilenburg, 2008). Because very little is known about the interrelationship between the dominant cultural values in Dutch society and the ways in which parents in ethnic minorities cope with a deaf child, how they make decisions on its rehabilitation, and how their coping and decision-making are influenced by cultural factors, an exploratory study was conducted in order to comprehend the nature of the delay in spoken language development.

### **Influence of language mode on the language development of children with a CI**

Children's development depends largely on their interactions with their parents, siblings, teachers, peers, and with the other people they meet on a daily basis. Sufficient access to language is a prerequisite for interaction with others. Before the era of CI, sign language was considered to be the natural language for prelingually deaf people (Thoutenhoofd, Archbold, Gregory, Lutman, Nikolopoulos & Sach, 2005). During the 1980s and 1990s, many countries acknowledged that it was the only language deaf children could acquire in a natural way. Some of these countries – especially the USA and Scandinavian countries – thus implemented education in sign language, which in Sweden, for example, was declared an official language in 1981 (Preisler & Ahlström, 1997).

To date, sign language is still not legally recognized in the Netherlands, although its value is certainly acknowledged: in 1998, all major schools for the deaf established “bilingual” programs, i.e., programs for both oral and sign language (Knoors, 2006). In the 1970s, the Dutch Foundation for the Deaf and Hard of Hearing Child had already introduced a bilingual program for infants and their parents. The philosophy was that parents communicate better with their children if they learn the natural language for prelingually deaf children, and that communicating in children's natural language will contribute positively to these children's development. The use of sign language in deaf children and the implementation of bilingual education in pre-schools and schools thus grew out

of the wider social context. As a result, these children's immediate social context is at least partly bilingual, which directly influences their development.

In daily practice, however, there are still various imperfections. Deaf children with hearing parents are much less skilled in sign language than deaf children with deaf parents (Mayer & Leigh, 2010). The reason is assumed to lie in the fact that neither parents nor teachers are native signers, whose mastery of sign language is often insufficient to communicate in a more mature way. This particularly affects their ability to talk about the past and future, but also about abstract concepts such as emotions or thoughts.

Since an important goal of cochlear implantation is to understand speech in everyday listening environments and, as a result, the ability to acquire spoken language, the question raises to what extent children with an implant will benefit from sign language. In this respect, a CI can be valuable for children: remarkable results have been reported with respect to speech and language outcomes, especially in children who received the implant at an early age (Niparko, et.al., 2010; Colletti, Mandalà, Zocante, Shannon & Colletti, 2011). Recent studies show that many implanted children are in fact able to attend mainstream schools (De Raeve & Lichtert, 2011).

As a result, there is a debate between advocates of raising children with a CI bilingually and advocates of the oral method only. Advocates of the bilingual approach state that sign language does not negatively influence the acquisition of spoken language – an idea that has been supported by several studies (Connor, Hieber, Arts & Zwolan, 2000; Preisler, Tvingstedt & Ahlström, 2005; Percy-Smith, Cayé-Thomasen, Breinegaard & Hedegaard Jensen, 2010). Members of the deaf community themselves advocate a bilingual approach (Gale, 2011), which is not surprising, since the deaf community usually considers deafness to be a cultural phenomenon rather than a disability. In their opinion, the use of sign language is central to deaf culture. People in the deaf community fear that if sign language disappears, it might also bring the end of deaf culture. In contrast, advocates of the oral method only approach showed that a bilingual approach might limit the effectiveness of spoken language development in someone with a CI (Geers, Nicholas & Sedey, 2003; Miyamoto, Kirk, Svirsky & Sehgal, 1999; Wie, Falkenberg, Tveté & Tomblin, 2007).

Taken together, in the wider social context of children with a CI, there is no consensus on their mode of communication. As parents and other people in the child's immediate environment depend on the availability of the services provided there, this may affect the child's development. If, for example, parents decide that their child should learn spoken language only, but social services and schools use a bilingual approach, it will be very difficult for parents to maintain their preference for spoken language only. Although children with a CI in the Netherlands are usually raised and educated in a bilingual environment, the effect on their language development of the specific characteristics of the Dutch bilingual environment is unknown. Therefore, a study was conducted at the effect of linguistic environment on spoken language development, in which language development of Flemish children with a CI and Dutch children with a CI were compared. In the Netherlands, children with a CI are educated in a bilingual setting: schools offer bilingual programmes, with both sign language and spoken language. Contrarily, in the Dutch speaking part of Belgium (Flanders), most children with a CI are raised in a dominantly monolingual educational setting where spoken language is used, supported by signs and visual communication strategies.

### **Influence of CI on children's social-emotional development**

One aspect of functioning that depends strongly on language and communication is children's social-emotional functioning (Hosie, Russell, Gray, Scott, Hunter & Banks, 2000; Bosacki & Moore, 2004; Barker, Quittner, Fink, Eisenberg, Tobey & Niparko, 2009). In deaf children without a CI, this seems to be impaired: they have more problems maintaining social contacts and friendships than hearing children do, and also report loneliness more (Keilmann, Limberger & Mann, 2007). Not only are these children less popular and less accepted in their peer group than their normally hearing peers (Wolters, Knoors, Cillesen & Verhoeven, 2011), they also have a higher risk for behavioral problems (Van Eldik, Treffers, Veerman & Verhulst, 2004; Stevenson, McCann, Watkin, Worsfold & Kennedy, 2010).

In normal-hearing children, social functioning is strongly related to emotional functioning (Denham, 2003). In fact, two aspects of emotional functioning are crucial for adaptive social functioning: the ability to regulate and communicate one's own emotions, and the ability to understand and anticipate others people's. The question is whether these aspects are equally important in the social functioning of deaf children.

In normally hearing children, a first requisite for adaptive social functioning is the ability to regulate their emotions and thus to express or communicate them in ways that do not harm their relationships with others, but strengthen them instead (Eisenberg, Fabes, Guthrie, & Reiser, 2000; Trentacosta & Shaw, 2009). The regulation and communication of emotion takes place within the context of social interactions and relationships, which they are intended to affect – by strengthening the bond with the other person, for example (in an expression of love), or by solving a conflict and restoring a former balance (in an expression of anger) (Frijda, 1986).

But in deaf children without a CI, the regulation and communication of emotion seem to be impaired: as Rieffe has shown (2006; 2011), their emotion regulation is less effective than hearing children's. For example, avoidant strategies are more effective than approaching strategies in situations that are beyond one's control, because distracting one's thoughts can diminish the negative impact of the situation, whereas focusing on the event might lead to worrying or rumination. However, eleven-year-old deaf children reported using more approaching and fewer avoidant strategies in negative uncontrollable situations than their hearing children peers (Rieffe, 2011). Not surprisingly, they also reported that the intensity of their negative emotions lasted longer.

Eleven-year-old deaf children were also less skilled in communicating their feelings adaptively in anger-evoking situations in which a peer inflicted harm on them (Rieffe & Meerum Terwogt, 2006). The study in question showed that deaf children explained their displeasure less than hearing children. As a result, they were also more pessimistic about receiving an empathic response from the aggressor than hearing children were. In other words, as well as having a less efficient style of emotion regulation in these kinds of scenarios than their hearing peers, many deaf children had a less effective communication style. As the study by Rieffe and Meerum Terwogt demonstrated (2006), this might cause

peer conflicts to persist rather than be solved, or might harm deaf children's social contacts in other ways.

A second important aspect of emotional functioning that is directly related to children's social functioning is their ability to understand, predict or explain emotions in others. For instance, social competence and peer-rated popularity in children are strongly related to the ability to recognize the facial expression of emotions in other people, and to understand their causes (Denham, McKinley, Couchoud & Holt, 1990). Deaf children without a CI are known for their impairments in this respect. Most deaf children aged ten to twelve years are familiar with the four basic emotions: happiness, anger, sadness, and fear (Rieffe, 2011). They recognize these emotions, can predict them in others, and can attribute them to prototypical situations. However, these children do not understand more complex emotions, such as pride and jealousy. Moreover, they show little attention to emotions of others, often fail to understand them, and have difficulties recognizing the effect of emotion expressions on others (Hosie, et. al., 2000; Meerum Terwogt & Rieffe, 2004; Rieffe &, Meerum Terwogt, 2000; 2006).

These poor social-emotional skills in deaf children can be explained partly by poorer language skills (Barker, et. al., 2009; Wolters, et.al., 2011; Stevenson, et.al., 2010). Children with poor language skills have problems understanding the information in their social environment: this delays their emotional development, which leads in turn to problems in social functioning. When they are about two years old, normally hearing children start using emotion words to express their own feelings and to identify the emotions of others (Way, Yelsma, Van Meter & Black-Pond, 2007). Later, they start to talk about the reasons for emotional states, and also about their consequences. Problems in expressing emotions can lead to inadequate emotion regulation strategies and result in internalizing and externalizing behavior. The way children understand and express emotions influences their social relations with others and how they solve problems with others.

While language is crucial to children's social-emotional development, there is a second important factor: the immediate context in which children learn. For social-emotional development is possible only within a social context (Saarni, 1999). Early social-emotional development occurs within the family

context, an important role being played by parents' ability to recognize, understand, and regulate their own emotions and those of others (Morris, Silk, Steinberg, Myers, & Robinson, 2007). According to Morris and colleagues (2007), emotion socialization involves three processes. The first mechanism through which this immediate environment influences emotional development is children's observation of their parents' emotional displays and interactions. Through this, children learn that certain situations provoke emotions; they also learn how they should react appropriately in similar situations. For example, if parents often display great pleasure when they receive a present, children learn that this is an appropriate reaction. Conversely, if parents often display disappointment when they receive a present, children are less likely to learn socially appropriate emotional reactions when they themselves receive one.

The second mechanism of emotion socialization is emotion-related parenting practices, i.e., parental behaviors that help a child understand his own and other people's emotions (Morris, et. al., 2007). Successful parental behavior consists of seeing opportunities to help children label their emotions, to discuss emotions with their child, and to help it react appropriately to emotions. Emotion-related parenting also involves parents' reactions to their children's negative and positive emotions. In general, negative reactions by parents to children's emotion are associated with poor emotion regulation.

Thirdly, emotional development is affected by the emotional climate in the family, which is reflected in relationship qualities. According to Morris et.al. (2007), a negative, coercive or unpredictable emotional climate puts children at risk for developing inappropriate emotion regulation skills, due either to frequent and unexpected emotional displays, or to emotional manipulation. In contrast, a responsive environment in which children feel emotionally secure and free to express their emotions enables children to develop appropriate emotion-regulation skills.

The social-emotional development of deaf children without a CI differs from that of hearing children because they have less exposure to and modeling by parents, and because of problems in interactions between parents and their deaf child (Rieffe & Meerum Terwogt, 2006; Hosie, Gray, Russell, Scott & Hunter, 1998). The parenting styles of parents of a deaf child also differ from those of parents with normally hearing children. For example, parents with a

deaf child are more likely to use physical discipline in response to perceived child transgression (Knutson, Johnson, & Sullivan, 2004); this models the child with other social rules – probably ones that are less appropriate.

Finally, parental stress, which often occurs in parents of children with a CI (Hintermair, 2006), may result in less supportive (e.g. emotion-focused, expressive encouragement) and more non-supportive (such as those that express distress or are punitive) responses to teach their CI child about emotions (Nelson, O'Brien, Nayena Blankson, Calkins & Keane, 2009). As non-supportive parental responses to negative emotions show a child that the display of these emotions is not acceptable, this can in turn impair social-emotional development. In contrast, supportive parental responses to negative emotions have been found to be related to better emotion understanding and social competence (McElwain, Halberstadt & Volling, 2007).

To date, however, it is unclear to what extent children with a CI also have these social-emotional problems. Even if their language development is similar to that of normal hearing children, they may still have problems and impairments in their social-emotional development. Although such children have gained access to (more) sound, their level of hearing is still far from that of NH children; in most cases, their speech perception in a noisy environment is still poor (Kühn-Inacker, Shehata-Dieler, Müller, & Helms, 2004; Galvin, Mok, Dowell & Briggs, 2007). A study of peer relationships between children with a CI showed that five- to six-year-old children had no difficulty socializing with hearing peers in one-to-one situations, but socialized less easily when faced with an already established dyad (Martin, Bat-Chava, Lalwani, & Waltzman, 2011). However, there are also many instances or situations in which these children cannot or do not want to use their CI – such as at the swimming pool – and are thus isolated from their peers.

In conclusion, it is not clear how emotion understanding, emotion regulation and social functioning in children with a CI develop, and how this development is related to language development and interaction with parents and other people. To fill this gap, children with a CI were compared with normal hearing children on aspects of emotion understanding, emotion regulation and social functioning.



## **Outline of this thesis**

As argued above, children's development is determined not only by their characteristics, but also by the environment in which they live and grow: their immediate and wider social contexts. A deaf child's environment differs from that of normal-hearing children. Although greater understanding has been gained over recent years of their language and social-emotional development, and of the influence on these of their environment, less is known about the development of deaf children with a CI and of how their development is influenced by their social contexts. This thesis aims to provide insight into some aspects of language and social-emotional development, and into the influence of certain factors in their social context that affect it.

In Chapter 2, the focus is on parents of children with a CI from Turkish origin and their family counselors. Their desires, expectations, experiences, and problems regarding rehabilitation and counselling were studied to provide insight into the quality of the interrelationship between the settings in which children with a CI participate. We also sought insight into how parents of Turkish origin are influenced by dominant cultural values in Dutch society, and how these values indirectly influence the development of these children.

In Chapter 3, the effects of the linguistic environment of infants (i.e. a monolingual setting versus a bilingual setting) on their language development is examined. The language development of Flemish children with a CI and Dutch children with a CI were compared. In the Netherlands, such children are raised in a bilingual educational setting: schools offer bilingual programs, with both sign language and spoken language. However, in Flanders – the Dutch-speaking part of Belgium – most children with a CI are raised in a dominantly monolingual educational setting where spoken language is used, supported by signs and visual communication strategies.

In chapter 4 we studied the relation between social functioning of young deaf children with a CI and emotion regulation. Social functioning involves the ways in which children initiate and maintain relationships with meaningful others around them; emotion regulation is an individual's ability to transform an emotion or to devise coping mechanisms to manage emotions. It is assumed that,

in a normal population, proper emotion regulation is associated with good social functioning, such as high social competence and few behavioral problems (Eisenberg, Spinrad & Eggum, 2010).

Chapter 5 explores two aspects of the ability to understand emotions in young deaf children with a CI: emotion recognition in facial expressions, and emotion attribution in a situational context. This ability was assessed for the four basic emotions: happiness, anger, sadness and fear, as these are the first emotions with which children are familiar.

Discussing the results in within the perspective of Bronfenbrenner's social-ecological model, Chapter 6 presents practical implications, and also implications for future research.

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