



# Experiences, networks and uncertainty: parenting a child who uses a cochlear implant

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To parents, children and their  
allies

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## Abstract

The aim of this dissertation project is to describe the ways people experience parenting a deaf child who uses a cochlear implant. Within a framework of social science studies of disability this is done by combining approaches using ethnographic and netnographic methods of participant observation with an interview study. Interpretations are based on the first-person perspective of 19 parents against the background of their related networks of social encounters of everyday life. The netnographic study is presented in composite conversations building on exchanges in 10 social media groups, which investigates the parents' meaning-making in interaction with other parents with similar living conditions. Ideas about language, technology, deafness, disability, and activism are explored. Lived parenting refers to the analysis of accounts of orientation and what 'gets done' in respect to these ideas in situations where people utilize the senses differently. In the results, dilemmas surrounding language, communication and cochlear implantation are identified and explored. The dilemmas extend from if and when to implant, to decisions about communication modes, intervention approaches, and schools. An important finding concerns the parents' orientations within the dilemmas, where most parents come up against antagonistic conflicts. There are also examples found of a development process in parenting based on lived, in-depth experiences of disability and uncertainty which enables parents to transcend the conflictive atmosphere. This process is analyzed in terms of a social literacy of dis/ability.

**Keywords:** *parenting, parents, cochlear implant, first-person perspective, lifeworld, netnographic, everyday life, orientation, deaf, disability, sign language, allyship, social literacy*

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# Chapter 1 Introduction

We were totally shocked when we found out and not surprised, shocked actually. Oh my goodness, how will we manage? Suddenly I was exposed to all this medical language which isn't my background. We were totally unprepared so we had no one on either side of the family to our knowledge who is hard of hearing. Nothing. No benchmark. No one to speak to that we knew either, so we never had actually met anyone a child or an adult. Actually it took quite a few months before it was finally diagnosed because there could be you know, various things when they are born. Water in the ears and it could have been something quite simple. So we kept doing these tests and then finally it was confirmed that he was actually very hard of hearing possibly totally deaf. We sort of just said 'Okay'. In a way maybe this is good it's happened to us because my background is languages and development of language you know. All that so in a way it was kind of 'Wow, you know maybe, this is really interesting. We can help. What can we do? But in the beginning, it all seems hopeless. And you just think, oh my god, you know, he's going to have to learn sign language and English and Swedish and we didn't know at that time so much about the cochlear you know so when you first get it, it's like this massive black cloud. One day it feels wonderful and we can help this child and there are a lot of possibilities and a lot of opportunities and then the other day it all feels too much and dreadful and how are we going to cope with it. So there is not *one day*. It really varies in the reaction but the worst anyone can say is 'Aw, it must be really tough!' And I really understand because I would probably say the same.

*Parent of a child who uses a cochlear implant*

The aim of this dissertation is to explore and describe experiences of parenting a child who uses a cochlear implant (CI). How the parents' lifeworld becomes shared is studied through participatory methods and is used to understand parents' own perspectives through interviews. An interpretation of these experiences is used to illustrate a description of parents' development of social literacy about individuals and groups who may identify based on language, ability and disability in the use of senses and technology. This is done to contribute to knowledge about parenting across the life span of both the child and the parent.

Some stories are easier to understand than others especially the ones which resonate with our own. Parenting is a situation of developing for the other. After you realize that it takes a lifetime to learn language, perspectives about parenting can change. Parents who find themselves in situations where they

must make unexpected choices about how to care for their child who uses a cochlear implant gives us opportunity to think about ‘in case’ thinking: in case it doesn’t work, in case they get sick, in case it breaks, in case they change their minds, in case they don’t want to use it, in case they become someone not like us. I should do this, just in case. In case is existing ‘in the event that’. Possibility is uncertainty combined with hope.

In the summer of 2006, I came into contact with parents who chose to learn sign language to communicate with their children with cochlear implants. The observations for this dissertation project began when I saw how these parents went in and out of ways of communicating with and contemplating their children and others who created and shared these spaces. An example of this is when a parent signed with a child who uses a cochlear implant, and then used spoken language with other family members. Another example involved when a parent would converse using sign with deaf instructors and child-care workers and then speak with the other hearing adults. At times when both deaf and hearing were in the mix, one parent would speak at the same time as they signed for the benefit of a child or a beginner signing parent. How a parent decided to communicate was seldom the use of only one language system, strategy or modality. I connect these occurrences as all taking place in an in-between space, *sensorial differentness*, in order to accentuate the bodily senses and cues being interpreted and interwoven with the influence of technology use, communication strategies and social relations.

Meditations about senses, perception and imagination related to questions of identity sent me down this path to study transformations through the new experiences of parenting and adulthood. Working with adults in non-formal education contexts has provided the foundation for being able to consider adults as always becoming: becoming in groups, becoming informed and knowledgeable, becoming liberated and wise, becoming parents. Multiple becomings are ascribed and adopted through entering new identity categories.

A key element of becoming the parents of a child who uses a cochlear implant consists of individual and social experience to orientate in a new world of sensorial differentness. An important starting point for my study began with an effort to understand what I came to call the parents’ communication orientations and how these orientations influenced their parenting of a child who uses a CI. The concept ‘orientation’ was borrowed from the phenomenological analysis of Sara Ahmed (2006b). Becoming a parent, in and of itself, is disorienting and it is productive to think of the parenting of a child with a CI as an essential reorientation in relation to the anticipated parenthood and in relation to the parent’s foundational

understanding of their life and interaction with other human beings as well as objects. Exploration of parenting as a learning process through the lens of the parents' own experiences leads to where they are intertwined in a web of relations beginning with other people like professionals at the hospitals and CI clinics, other parents in similar situations and the technological devices and practices linked to the implant. Becoming as a process can then be seen as perspective changing through reorientation. This is where sense-making pivots around acknowledging that when you become a parent, you leave a previous way of existing. This brings us to consider how the child, who makes the other into a parent, is the one who shows the path in the way they bodily inhabit the world. This is an example of how deafness, disability, needs of communication and interventions with technology remain in the parent's 'field of vision' so to speak, because of the child's body. The path is constantly being cleared through how the parent and child exist with these circumstances. This notion of the child's body showing the path to the parent extends into 'orientation' as a concept. How do children create paths for their parents?

Whereas this way of orientating about communication deals with new circumstances which have entered society through technological developments, understanding different perspectives relating to hearing and language have to be investigated. Stuart Blume (2009), in his book *The Artificial Ear* states that explanations to understanding the deaf response to CI, involve understanding both the history of medical technology and the history of sign language. Through the CI debate the deaf have become more visible and thus sign language figures more prominently as well which demonstrates how a technological development impacts social and cultural climates. A concern Blume raises is that the development shows how emancipatory and rights thinking underlying the minority status of deaf and disabled people needs to be researched more extensively to determine if the lives of the people concerned benefit or are harmed by new technology. This involves seeing the short term and long term effects of neuroprosthetic devices (Blume, 2013 p. 57). Alternative explanations and paths of development to the biomedical model which inform the hearing field are to be found in communities of deaf and hard of hearing individuals and families. In a medical biotechnological friendly culture, Blume emphasizes that extra effort needs to be put forth. Dilemmas will always be posed by the introduction of new medical technology. The role of social science research is to intervene and mediate different kinds of knowledge, which is compatible with the ideals of a democratic system.

Important themes that have impacted changes in education practices include the effects of science-based technology on sign languages. Priorities in health care spending use cost and benefit analyses and since these sectors increasingly overlap, this type of analysis is also applied to costs of deaf

education. Blume reviews these issues and reveals a type of neo-liberal thinking and policy making that attempts to relate the high cost of deaf education to the economic benefit of mainstreaming deaf children. This is an example of where accessibility and inclusion are proposed based on fiscal arguments and austerity rather than focusing on the betterment of lives of people who are deaf or hard of hearing; a case of “managing disability” (Komesaroff & McLean, 2006). Another result emanating from the changes brought on from the cochlear implant revolution which gained momentum during the 1990s with the approval of operating children is the biosocial grouping of children: deaf, hard of hearing, CI-users, and hearing aid users (Christiansen & Leigh, 2002 pp. 35, 43). This has resulted in the growth of different lobbying forces for changes in schools where certain groups wish for school placement in mainstream education and other groups prioritize bimodal/bilingual environments (Holmström, 2013 p. 77, Study II pp. 31-33).

## Studies including parents of children who use cochlear implants

A vital part of this project began with studying the literature on cochlear implants in children on the Internet available to parents in Sweden and North America. This led to examining works from the major countries which have implemented this technology and the issues parents would discover important leading to matters about which they would want to be informed (Christiansen & Leigh, 2002; Gallaudet Research Institute, 2011; Hassanzadeh, 2012; Meadow-Orlans, Sass-Lehrer, & Mertens, 2003; Pisoni et al., 2008; Preisler, Tvingstedt, & Ahlström, 2002; Solomon, 2012). To further understand the situation for parents, the recent work done in the areas of medical, audiological and habitative science were reviewed to understand how parents figured in studies involving their children (Anmyr, 2014; Asker-Árnason, 2011; Ibertsson, 2009; Karlsson, 2013; Löfkvist, 2014; Magnuson, 2000). An example of what was found was that the research on pediatric cochlear implantation development in Sweden has included studying the attitudes and well-being of parents (Åkerström, Eriksson, & Höglund, 1995) and how the world of the deaf in Sweden changed after the CI revolution but prior to widespread implementation of early pediatric cochlear implantation (Eriksson, 1993). Reading these works together to understand the broad area of pediatric cochlear implantation contributed to discerning the problem of understanding how human behavior and values are overtly or covertly involved in available information and research findings.

Continuing with how conclusions are made regarding outcomes and benefits of cochlear implantation and how parents are involved, there is an interest in beginning with what is known to foster positive development. In the following works this is the primary research interest which motivates a concentration on interpersonal relations. These include Swedish studies in special education and psychology involving parents in investigations of learning in children (Ahlström, 2000; Preisler, Tvingstedt, & Ahlström, 1999; Preisler et al., 2002; Preisler, Tvingstedt, & Ahlström, 2003; Preisler, 2009; Tvingstedt, Preisler, & Ahlström, 2003). Perspectives of parents alongside those of teachers and personal assistants are included in these works. For example in one study, parents and teachers of a group of 22 children were observed and interviewed during the preschool years (Preisler et al., 2002). Half of the children attended specialized schools for deaf and hard of hearing (DHH) children and the other half regular schools. The adults maintained that the children enjoyed their school situation, regardless of school placement because of the meaningful interaction in the relations in the environment. It was found that in order for positive development to take place these children strove to understand symbols and to be able to create symbols that they could share with others, adults as well as peers. These studies contribute to knowledge of how cochlear implant use is seen to facilitate communication in everyday contexts which involves a broader understanding of human language and interaction.

## Parents in society

In a survey of sociological studies in Sweden, Åkerström (2004) examines how parenting in modern society is interwoven with societal authorities, which is magnified when children have disabilities. Åkerström demonstrates the influences of expert knowledge on parenthood by drawing on an accumulation of findings in studies involving parents of children from different categories of disability and illness, encounters with groups who are responsible for medical, social and educational services. She provides descriptions of the disagreements and opposition between parents and experts involved in the everyday parenting of children who are disabled. In the final discussion of this work Åkerström focuses on the roles of institutions and systems of expertise and how their influence has changed. Being a parent today involves relating to experts but in the case of having a child who is disabled they also must relate to expert groups that are collections of parents with similar experiences. These are seen by many parents as 'half' or 'semi' professional sources of knowledge, a part of institutional knowledge because of how they provide referral reports to policy makers making them important groups to practitioners. Åkerström

describes how these parent groups were founded on a supportive need for parents to find other parents and be able to utilize their experiential knowledge. This source of support can also function as an additional force to be reckoned with alongside the treatment and care recommendations. This involves adopting, rejecting or adapting which demands a form of relating to ‘experienced parents’ in the same way. The parents above all wish to be able to access a defined, limited and moderate amount of expertise (Åkerström, 2004 p. 133).

The National Deaf Children’s Society (NDCS) supported by the Department of Health in Great Britain funded a literature review aimed at compiling strategies to meet parenting needs and was presented in the report *Parenting and deaf children: a psycho-social literature based framework* (Young, 2003). The problem at the center of this work materialized and gave concrete examples of parental uncertainty and concerns. A specific focus was put on parenting as opposed to parents as a part of treatment and how this social relationship has been studied. The aim was to identify the major influences on this type of parenting where verbal communication between hearing parents and their children is not possible due to deafness. The review identified a need for knowledge of the parental perspectives in positive frameworks which identify the parents’ pragmatic strategies which they found to be the most successful in their own lives. The authors encourage research focusing on parents’ experiential expertise.

There is much still to be learned about the process of becoming a parent of a deaf child over time, and how each new phase of child development brings new opportunities and challenges for parents and service providers alike (Young, 2003 p. 35).

This overview avoids only summarizing difficulties and places focus on the needs of both parents and service providers. However, generalized observations did include how medical personnel were seen to be the least appreciated group parents come into contact with. This led to the perception that clear and comprehensive information about communication methods were not available and that parents were frequently advised not to sign.

It appears that embracing difficulties cannot or should not be avoided in practice or research due to the magnitude of the impact on deaf and hard of hearing (DHH) individuals. The NDCS overview also reiterated that communication decisions were experienced to be the first decision parents felt that they had to make without feeling informed which is clearly in line with Blume’s understanding of parental decision-making (2009 pp. 111-172). This is connected to how it appeared that many parents expressed that they were generally more concerned with messages in communication than

mode of communication. A questionnaire study of 892 parents carried out within the same NDCS project revealed that most parents felt that they had not been told in an impartial manner about strategies concerning communication for raising their child. The study included many descriptions of experiences where parents realized that they had not known about a full range of options before making the crucial decisions surrounding raising a deaf child which cover areas about language, the child's social development and school choices (Young, Greally & Nugent 2003 p. 29). It was also found that parents find all forms of interaction with other parents, formal, informal and via Internet as positive. This can also be linked to how hearing parents expressed needing emotional support (Young, 2003). Related to this is how the needs of hearing parents will differ for example from that of deaf parents whose main concern was with getting appropriate services. In general it was understood that both hearing and deaf parents consult the deaf community, deaf parents and deaf professionals about their situation. One of the points parents, both hearing and deaf, emphasized was getting a complete, unbiased picture of the options including what the controversy in communication education is about and thoughtful explanations as to why it is so complex. In addition to these conclusions from the NSCS overview, the author summarized which types of messages from parents of older children that new parents appreciated: advice to 'treat the child as a child first' and to do whatever you can to get beyond grief and shock. This final point is likely related to stigmatization and the different views and perspectives of professionals.

Parents appear to have to choose between ways to communicate with their child at an early age, making it an important area to explore and to critique. When embarking on experiences of parenting where a child is assumed to be at risk of receiving too little language input the emphasis should be on answering the common question of what will foster the relationship between the parents and the child in their unique family situation. Orientations in parenting approaches in respect to communication style is linked to what views parents hold about what is effective, acceptable and stimulating. This builds on striving towards a goal of using one spoken language but is shown to be pragmatic depending on the situation. In *Children with cochlear implants: the communication journey* (Watson, Hardie, Archbold, & Wheeler, 2008a) a questionnaire study including 142 replies from families of CI users, the researchers found that modes of communication in families are not fixed, instead they gradually change alongside the increased use of the auditory system and oral communication by the child. At the same time, parents and families also valued signed communication. A qualitative study based on the experiences of 12 of these families before and after cochlear implantation in their child showed that different approaches are adopted depending on the development of the child (Wheeler, Archbold, Hardie, &

Watson, 2009). Family experiences were analyzed and it was found that parents choose the most effective way to communicate before and after cochlear implantation. Their communication goal remained to be development of oral communication skills. The contribution of this study is over time parents utilize different approaches along the stages of the child's development (Watson et al., 2008a).

## Parents, identity and disability

Most parents of deaf children are hearing (95%) which implies that they have limited knowledge of deaf culture when they become parents (Mitchell & Karchmer, 2004; Roos, 2009). The passion surrounding issues of cochlear implants led to a review of research that investigated questions of identity and belonging in groups where a child could participate (Christiansen & Leigh, 2002; I. Leigh, 2009; Preisler et al., 2002; Preisler, 2009; Tvingstedt et al., 2003). Christiansen and Leigh's study addresses how parents grapple with what it means for a child to have a Deaf identity and how CI use impacts children's identification with groups. Hearing parents use terms such as 'creating possibilities' for their child with technology and with communication. The option to enter or engage with the deaf communities is also a possibility which adds to technology use. In addition Christiansen and Leigh say parents are practical regarding the necessity of using signed languages, particularly in pre-implantation stages and 'as needed' after implantation (Christiansen & Leigh, 2002). The researchers also found that parents are open to acceptance of the use of bimodal bilingualism and that the CI does not automatically mean for them that spoken language goals are their only concern. On the contrary the subject of signing stays with most parents as an idea of communicating with relatives, other DHH children and peers and as an area of possible and/or desirable interest (Watson et al., 2008a p. 58).

In summary, a picture of how parenting experiences are intensified when combined with disability and technology begins to take form as differing pieces of discourses and practices are brought together. The way parents make sense of their situation and their role impacts their lives in many respects; however the simplified notion that the choice to implant is a "once and for all" solution is an oversimplified misconception. Research indicates that this parental experience is complex and there is a tendency to overly simplify, misaccount, and ignore the many ways cochlear implant use by a child serves as a significant event over time and as starting point for a new way to exist in a family.

The guiding question of the present research is: What contributes to positive and negative experiences of parenting in disability contexts? Likewise and just as important is the question of what value these experiences have in the lives of individuals. At times it seems that disability is viewed so negatively that investigating experiences parents have is seen as unnecessary since there are such firm conceptions. Words like ‘tragic’ and ‘cure’ are used often to describe these views. These negative assumptions are deeply imbedded in westernized societies which motivates why it is necessary to break up binaries which limit the knowledge that is produced. A compelling problem and a key aspect of this research is to investigate parent experiences when children differ from their parents (Solomon, 2012). Understanding this better can contribute illuminate the complex ways in which disability is constructed. This is done also by not beginning with impairment or using impairment language. Also, the intensity of the familial relationship offers researchers an entrance into seeing how and when expectations of acceptance, tolerance and a situated way of knowing are involved in influencing attitudes about other groups. When *differentness* unexpectedly enters into one’s world, *transformations* occur.

In reference to identity futures for children in *Cochlear implants in children: Ethics and choices*, Christiansen and Leigh conclude that CI children are not stuck between worlds, but rather able to ‘shift identity’ depending on what situations demand (Christiansen & Leigh, 2002). One of these situations will be communication with parents who may or may not sign themselves, but realize the importance signing may have in the life of their CI using child. This is what is referred to as ‘both/and’ rather than ‘either/or’ thinking. This interpretation is based on two large studies of CIs and children, both in North American contexts (Christiansen & Leigh, 2002) (Meadow-Orlans et al., 2003). The Gallaudet Research Institute (GRI) conducted the *Survey of Parents of Pediatric Cochlear Implantees* in 1999 including 439 parents in 15 states. In addition to this 83 parents were interviewed (Christiansen & Leigh, 2002). Parents were found to be aware that a CI is not a guarantee for hearing and mainstreaming. These parents found their child to “still be deaf”. A CI enhances the quality of life for the child and the parent because family communication improves. The least appreciated element involved the sensitivity to factions which engaged in campaigning their philosophy. This created difficulties in being able to “figure others out”. The best “type” of professional was the one who did not push parents in a specific direction which meant they were able to feel at ease. These parents were much more likely to meet CI clinic professionals and staff members than they were to meet deaf individuals. A majority of these parents chose to continue to sign and encourage their children to maintain and use signing at the same time as they focused on audition.

The present study of parenting involves this “sensitivity to factions” and identity politics which makes possible a study of parental experience of disability in a polarized field reinforced by groups insisting on approaches which are in opposition i.e., verbal communication and multimodal communication. This combines social factors of access to health care, technological advancement and investment, with recently entered into force accessibility definitions of discrimination and the unique legal status of the rights to learn and use of Swedish Sign Language. It has become necessary to explore the types of parenting relationships these afford and how societal change is experienced as lived conditions.

## Framing the problem

My initial interest in this topic has been directed by alertness to the complexity of a learning situation in adulthood, the life experience of becoming a parent. Parents of deaf or hard of hearing children, hearing technology using children, children with diagnoses or disabilities were meeting Swedish deaf culture in order to learn how to communicate through the use of signing. At the same time these parents were interacting with each other, with their own children and other parents’ hearing and DHH children. The setting was new for most of the participants in these week long courses for families where the parents were learning sign language in a state funded program (TUFF). This entailed being a participant in a non-formal education context with other parents being taught by deaf and hearing sign language instructors at the same time as their children were with child care workers and youth leaders who were either Swedish Sign Language interpreter students, (adult) children of deaf adults (CODA) or cochlear implant and hearing aid users. I began to envision this study by thinking of *sensorial differentness*. Experience of these situations can be studied as a process of transformation.

In this study of parenting, negotiations of belongings to social categories or social groups begin from whether the parents themselves are hearing or deaf. By becoming a parent of a child with hearing impairment the parent adds a new category to who they are. Very likely the hearing parents encounter becoming a part of a group which is seen to be disabled in communication with one’s child and with others who are deaf or hard of hearing. Studying this process involves using an approach to take into consideration not only the individual person’s hearing status and what facets of identity they adopt and are ascribed by others, but what happens between the parent and child in terms of how the parent conceptualizes sensorial differentness. The child brings the parent with them and places them into new categories. As the

child becomes a patient, a child with hearing impairment, a sign language user, a student of a school for the deaf, a mainstreamed student, a target of discrimination or exclusionary practices, an object of economic support, the parent takes on a “parent of” identity. The parent also contributes to their own understanding of themselves through placing the child into categories through continuous and traversable decision making about technology, schooling and language use in the home and with others.

Studying what gets done in parenting, the doing, is an attempt to bypass prescriptive ideas about what is right and especially when such ideas are expressed through conflicting cultural values and moral dilemmas. As a transdisciplinary researcher, I am interested in examining what is experienced and how it is shared. It is useful to think in the terms of culture when it comes to technology use and practices. Observing and interviewing parents who enter a morally charged field are important to study from social and cultural approaches. Hearing parents become hearing first when they have a deaf child. Hearing parents seldom have experience with interacting with deaf people. Hearing parents of deaf children seldom have had experience with hearing impairment. Making medical decisions for a child is a new experience. This enacts parent culture, disability culture and minority culture as they are interwoven with biotechnological medical science. This combination of conditions can be compared to entering a new country or province where different values become important. Sensorial differentness is a new mode of existence for parents pivoting on the use of senses. There is a gap in studying experiences of modality as a navigator for understanding parenting a deaf child, as well as studying experiences of differentness in families. There are critical studies in whiteness, heteronormativity, privilege, able-bodiedness, but not many which depart from ‘hearingness’ and parenting positions involving intersections with deaf sign language cultures. I argue that there is a step towards understanding sensorial differentness which requires that researchers draw on other sectors of identity. The position of parenting is one way to unify fields of study to be transdisciplinary.

My first thoughts about this group of people were that their parenting entails a concentration on language learning and acquisition and development of communication skills *for another person*. Parents need to learn to communicate because the child does not use hearing in the same way. What gets done in parenting between the parent and the child, between two or more parents or caregivers, and the other children in the family, is the starting point of this study of lived parenting. The next step was to consider how experiences involved in parenting impact the parent’s own way of existing including how they interact with new groups, especially other parents and the groups their child will come to belong to. Parenting in

differentness, like all social inquiry, has the potential to raise critical issues. Approaching a research problem in parenting children who are deaf or hard of hearing leads directly to questions of whose reality is being privileged in any given context. Theories and approaches that include prioritizing social justice, human rights and respect for cultural norms were adopted in order to fulfill aims of ethical research (Mertens, 2010 p. 470).

## Language development

When thinking about the particular viewpoint of the new parent of a cochlear implant user the debate zooms in on the optimal language learning period and chain of treatment in the regime of care utilized in pediatric cochlear implantation practices. This raises the questions of what is carried out in these practices with children at such a young age and who is actually the object of the therapies? A significant part of practices early in the life of a child are really practices focused on the parent. If hearing impairment is detected through universal hearing screening for infants, these educational practices begin in a neonatal ward. Learning how to be flexible in language use, providing a rich language environment in a ‘bath of communication’, interacting intentionally with an infant all have been used as goals of early intervention for children who are hard of hearing or deaf. These intentional practices involving parents overlap the informal processes in day to day parenting in different contexts. A way to study them together is from the viewpoint of the parent. Also, through a child’s deafness, hearing parents are presented with identity politics mechanisms where strong views on a collective struggle against oppression is answered with pride and action directed at scrutinizing norms in society. The experience of social interaction, with others in similar situations and in boundaries with other groups, affects what takes place in parenting practices.

In discussions of language choice and use for children who are deaf or hard of hearing, controversy has swirled around what is best to focus on in the earliest years of life. References to critical periods of time in neurological development for learning language and in particular spoken language have become an area to guard when it comes to therapies to use in early intervention strategies. Only 5-6% of deaf children are born to two deaf parents (Kyle & Woll, 1985). Since linguistic research established sign languages as fully grammatical linguistic systems it has been known that a deaf child’s first language is sign language (Stokoe, 1978). It is also evident that adults learn language differently than children learn language and have difficulty in mastery of languages because of language acquisition patterns (Kennedy, 1988). That there is a critical period for language acquisition and that child and adult language learning differ is the case for signed languages

as well (Newport, 1991 pp. 117-121). This means that a child has a different set of semantic structures and neurological patterning from parents who are hearing (Klima & Bellugi, 1979).

## Cochlear implantation

A cochlear implant is an electronic medical device that replaces the function of damaged parts of the inner ear. The implant is different from conventional hearing aids designed to make sounds louder. Cochlear implants are surgically placed in the inner ear (cochlea) to provide sound signals to the brain. The goal of cochlear implantation is to make the use of sound accessible for people who are deaf in order to make possible oral and aural communication (Eisen, 2009). The candidates for cochlear implantation are patients who are deaf because of the state of hair cells, the sensory receptors in the cochlea. Sound is accessed through electrically stimulating nerves inside the inner ear. These implants usually consist of two main components, an externally worn microphone, sound processor and transmitter system and an implanted receiver and electrode system. The electronic circuits in this system receive signals from the external system and send electrical currents to the inner ear. The cochlear implant device has a magnet that holds the external part next to the implanted internal system behind the ear (FDA, *Cochlear implants*, 2014).

The cochlear implant is an alternative for those people who are severely hearing impaired or deaf and benefit minimally or not at all from normal hearing aids. A comparison of typical hearing and hearing with a cochlear implant can be described as ‘acoustic hearing’ as opposed to ‘electrical hearing’. Normally a person has thousands of hair cells tuned to different frequencies. The cochlear implants often used today have 22 electrodes. Children implanted with a CI then do not have restored hearing, rather electrical hearing.

The development of the cochlear implant escalated during the 1970s and was originally intended for adults who became deaf. During the 1990s cochlear implantation began to focus on children who were deaf (Eisen, 2009). In Sweden today, 90% of children born deaf are implanted (Socialstyrelsen. *Vård vid nedsatt hörsel*, 2009). There are close to 1000 children in Sweden who have been implanted with a CI as of 2014, which is about 1% of all the CI-users in the world (HRF, 2014).

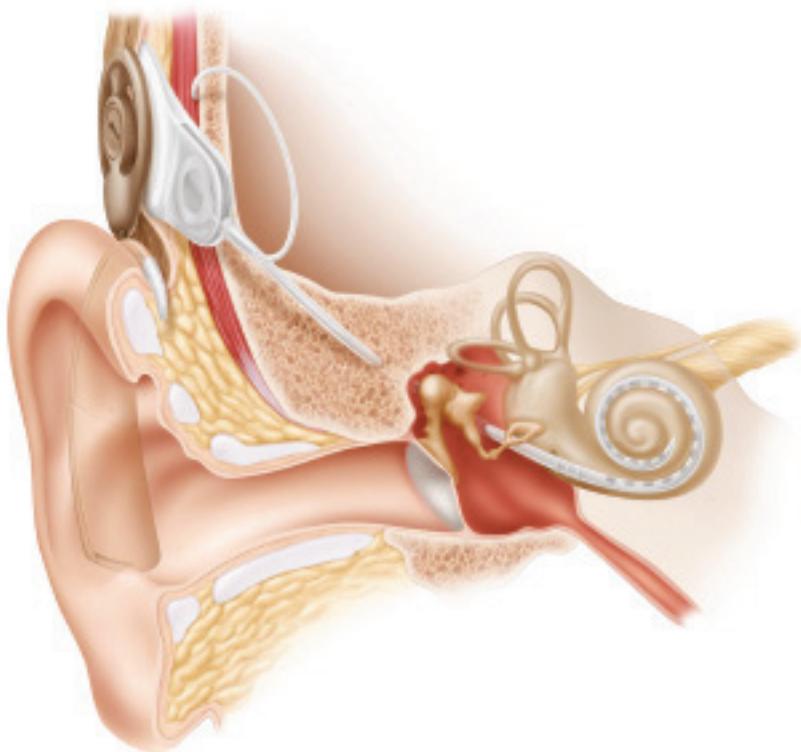


Figure 1: The cochlea after a CI has been implanted. Illustration provided by Staffan Larsson.

## Cost of a CI

According to a report from the Swedish Council on Health Technology Assessment (SBU), a cochlear implant is estimated to cost 220 000 SEK, which is roughly 25 000 USD (*Pediatric bilateral cochlear implantation*. 2006), and which including surgery comes to a total cost of 350 000 SEK or 42 200 USD (Socialstyrelsen. *Vård vid nedsatt hörsel*. 2009). This cost is covered by the universal health care program in Sweden. The total cost for an implant including assessment, surgery, and activation and programming of the speech processor as well as follow-up visits the first year can be approximated to be 350 000 SEK (40 000USD).

## Hearing impairment (HI) definitions

According to the WHO guidelines for measuring hearing impairment and hearing loss, the grades are ‘profound’, ‘severe’, ‘moderate’ and ‘slight/mild’ (WHO, 2015, 2016). Hearing levels in decibels (dB) with modified descriptions are displayed in Table 1.

*Table 1: Grades and descriptions of hearing loss in children (Deafness and hearing loss. 2015; Grades of hearing impairment. 2016)*

<b>Slight/mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Profound</b>
26-40 dB	41-60 dB	61-80 dB	Over 81 dB
Trouble understanding soft speech, speech from a distance and in noisy environments	Difficulties in hearing regular speech in conversations	Able to hear very loud speech and sounds like sirens and slamming doors. Unable to hear speech in conversations	Loud sounds may be perceivable as vibrations in body.

## Stages in pediatric cochlear implantation

Neonatal hearing screening, early hearing aid fitting and use, computerized tomography (CT) and/or magnetic resonance imaging (MRI) are medical tests used in examination to determine if infants have a functioning auditory nerve and to detect possible anatomical malformations. After these tests and requirements for surgery are met, the CI or CI's are implanted. Post-implantation appointments with a CI team are scheduled during which the team performs programming, audiological management and therapy.

Neonatal hearing screening uses automated otoacoustic emissions (AOAE), a method developed in the 1970s (Kemp & Ryan, 1993) which consists of producing sounds or series of clicks and then measures a weak echo sound in the ear canal. These sounds are picked up by the microphone inserted in the external ear canal which detects a normal functioning of the middle ear and the outer hair cells of the inner ear (Magnuson, 2000 p. 28). The Joint Committee on Infant Hearing and Audiological Assessment (American Speech-Language-Hearing Association, 1994) worked to establish the use of this technology in universal programs.

The goal of early hearing detection and intervention (EHDI) is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social-emotional development (1994).

In the United States, more than 95% of all newborns currently receive a hearing screening test shortly after birth. In Sweden, universal hearing screening was implemented in 2007 for all newborns (HRF, 2007).

A cochlear implant can be used unilaterally, i. e., a single implant in one ear, bilaterally where CIs are implanted on both sides, or together with a hearing aid on the non-implanted ear. Implantation can be done simultaneously or sequentially. In clinical practice, a ‘bimodal approach’ or ‘bimodal hearing’ refers to the use of a CI with a hearing aid on the other ear (Löfkvist, 2014 p. 21).

## CI implanted children and their parents in Sweden

Parents are essential to the care of the recipient of a CI, and are focused on in the post implantation period. The year after a child receives an implant involves intense contact and visits to the cochlear implant clinic and rehabilitation centers. The teams there usually consist of the following professional categories: surgeons who are medical audiologist physicians, engineers, speech pathologists, counselors, psychologists and audiology care experts. After the first year, the family is typically scheduled to return to the clinic at half year intervals for the next four years in addition to other therapy appointments and programs at rehabilitation clinics focused on speech therapy and related educational goals. Until the child is approximately 18, yearly visits are made to the CI clinic. At the same time the parent and child may attend appointments at an audiological services center which provides training and education for families.

The history of pediatric cochlear implantation in Sweden starting in 1990 to the present date implies that there is a “new generation” of cochlear implant users, which typically refers to the children who receive implants in connection with universal newborn hearing screening programs. This enables the use of hearing aids very early and implantation as early as six months and before the age of two years. Each case is different and involves continuous monitoring of the nature of the hearing impairment, the use of hearing aids and etiology (Åkerström et al., 1995; Eriksson, 1993; Jacobsson, 2000). The causes of hearing loss and deafness can be divided into congenital causes and acquired causes. Congenital causes may lead to

hearing loss being present at or acquired soon after birth. Hearing loss can be caused by hereditary and non-hereditary genetic factors. Acquired causes such as infectious diseases, may lead to hearing loss at any age.

## Secondary data related to cochlear implantation and post-implantation in Sweden

Three main sources have been used to compile the Swedish data related to the birth of deaf children to hearing parents, the practice of pediatric cochlear implantation and school placements. These are *Barnplantorna's statistics CI children under 18* (Barnplantorna, 2015) and two reports from The Swedish Association of Hard of Hearing People (HRF, 2007; 2014). In Sweden there is no reliable compilation of statistical data about the number of children who are born deaf in Sweden (Roos, 2009). This is due to the fact that different classification systems are used. Often the estimate is roughly 70 children per year. Approximately 200 deaf children are attending preschool. The percentage of how many deaf children in Sweden who have deaf parents is around 5%. After conducting a survey study to collect detailed information in these areas from 2007 and 2008, Roos found that it is more likely that of the approximately 100 000 children born in Sweden per year, 25-30 of these children are born deaf, meaning they have severe hearing loss according to WHO's definition which is 61-80 dB or above (WHO. *Grades of hearing impairment*. 2016). Most sources seem to commonly indicate that the number of deaf children born to deaf parents ranges from 5 to 10 %.

How sign language is regarded in CI clinic practices in Sweden was included in a 2010 thesis on the current circumstances of young CI users in Sweden (Samp, 2010). A general conclusion is that parents are informed about Swedish Sign Language through contact with a teacher of the deaf, a medical audiologist or a speech pathologist where information about TUFF, a program for sign language tuition for parents, is provided at some point. Involvement in clinic environments by organizations including signing alternatives was limited to being informed that courses are available but that signing is generally not recommended. The therapy after implantation is individually designed. There is no standard procedure for post-implantation training implemented in Sweden. Depending on where you live, signing can be encouraged depending on the child's needs and in certain regions a bilingual approach is recommended (Samp, 2010 pp. 75-77).

The Swedish context can be put into perspective with how many cochlear implants have been implanted worldwide. As of December 2012, this number was approximately 324,200. Further, about 2 to 3 out of every 1,000

children in the United States are born with a detectable level of hearing loss in one or both ears and roughly 58,000 devices have been implanted in adults and 38,000 in children (FDA. *Cochlear implants*. 2016). These estimates are based on manufacturers' voluntary reports of registered devices to the U.S. Food and Drug Administration.

Carin Roos found that it is likely that nearly fifty percent of parents of a deaf child wait at least until after the child is above the age of one to have their children implanted with a CI (2009). Deaf parents can be interpreted to be waiting longer than hearing parents or turning down cochlear implantation. The commonly occurring message is that practically all deaf children receive a CI during their first year. The results from Roos's study cannot be used to determine how accurate this is. Reliable information cited does include the number of children who have been operated up to the present, the number of deaf children who receive a CI and at what age, and where deaf children attend school. Practically all deaf children in Sweden are implanted with a cochlear implant. Further, the majority of deaf children are placed in regular preschools with hearing children.

In Sweden, as of January 2014 the Swedish Association of Hard of Hearing People (HRF) approximates that 2700 people in Sweden have cochlear implants, 700 of those are under 18 and 2000 are adults (HRF, 2014). During the past five years the number of adults with a cochlear implant has doubled. Barnplantorna, a Swedish special interest organization for children with cochlear implants and hearing aids, compiles annual statistics on the reports of the number of children under the age of 18 who have a cochlear implant in Sweden. The organization estimated in 2015 that there are 933 children who have undergone cochlear implantation where 433 children have been unilaterally implanted and 500 children have been bilaterally implanted. The total number of children in Sweden who have undergone re-implantation procedures is 61 (Barnplantorna. 2015).

To summarize, the social, political and historical situation in Sweden is interesting for this study for a number of reasons. The first is that the status of sign language is decreed by law as an official language which affords the corresponding group members rights to instruction, translation and accessibility to all official authorities and civic information for Swedish citizens (Ahlgren & Bergman, 2006). In addition, The Swedish Language Act states that the public sector has a responsibility to protect and promote the national sign language, Swedish Sign Language and to provide access to individuals to learn it (Language Act. 2009). The individuals with this right are "persons who are deaf or hard of hearing, and persons who, for other reasons, require sign language" (Section 14 2009:600). A significant factor is that Sweden is a welfare state with universal health care but regional

health care is organized and financially run under the governing of 20 county councils throughout the country. Also, considering the development and practice of pediatric cochlear implantation in Sweden, and the research connected to it, Swedish Sign Language has received more attention and awareness as a result (Blume, 2009 pp.58-84).

## Wonder about parents' lives and the role of communication

Since 2003 I have been in contact with parents of deaf, hard of hearing children and children with speech and language disorders. This began through early intervention programs and groups using supportive signing and continued with Swedish Sign Language courses and related activities for parents and families. This is in large part due to developments in providing services for parents of deaf, hard of hearing, deaf/blind children, and children with language disorders and intellectual disabilities. The parents of children in this diverse group which relies on signing as part of their mode of daily communication is entitled to 250 hours of tuition-free instruction (National grant for sign language instruction 1997). Habilitation for children with deafness includes supporting parents' communicative interaction with their child. This may or may not include instruction in supportive signing or sign language.

Another factor influencing parents' actions is that the use of signing in families where there is a CI user differs from the families not using hearing technology. The main goal of cochlear implantation is to maximize the use of the CI device which encourages concentration solely on therapies and intervention approaches that focus on verbal production and comprehension. Medical and rehabilitative consultations for CI users in Sweden are individualized and focused on solutions for using hearing technology (Karolinska universitetssjukhus, 2016). Some parents choose to use sign language to improve their ability to communicate with their child as well as stimulating their child's ability to communicate which partially bypasses or subverts the medical agenda. Spontaneous exchanges with parents giving insight into their intuitive reasoning of why they do this is what first sparked my curiosity.

Families usually have been introduced to basic signs and gestures to stimulate communication with their infants prior to surgery. What happens in parents' lives after implantation in regard to the experience of the use of different therapies and interventions (AVT Auditory-Verbal Therapy, supportive signing, and sign language) is one of the main areas of inquiry I chose to explore because of how it allows a parent to become oriented

through ideas and experiences that can be generally termed as communication strategies.

Looking at the practice of pediatric cochlear implantation field globally, the situation in Sweden described above influences the rate at which these parents can come into contact with deaf and hard of hearing people and become aware of sign language and Deaf culture. These factors provide a context I have used as a starting point in studying parents' experiences in this socially intersecting environment.

A recent report from the Swedish Language Council on bilingual environments, in this case Swedish sign language and spoken and written Swedish, found that currently 85% of children who use CIs are integrated into regular classrooms to some degree (Lyxell, 2014). An earlier report from HRF, The Swedish Association of Hard of Hearing People, had similar findings, as did a survey from The National Agency for Special Needs Education and Schools (HRF, 2014; SPSM, 2014). Estimating how many hearing parents of CI users use signing with their children is more difficult. Enrollment in sign language instruction for parents in the TUFF program could give an indication (Personal communication M. Paulsson, 2016).

## The dissertation project

This project has had a wide range of influence from a number of theoretical perspectives, or in other words, different types of relations between ideas. I have seen this as a way of following the current thought and history of employed by other researchers. I began with seeing the body as a space, an idea to which phenomenology has contributed. I followed ideas from sign language scholars, which added paying attention to what happens between people who use space and body to communicate. To study parents who experience, from a first-person perspective, the body of the child and the space they share with the child is my departure point. What I witnessed in how parents embark on learning about their new world quickly landed in how I found a parental struggle in situations where a child was seen as different from them. In this situation, with their child, they were no longer able-bodied; they experienced difficulties which disabled them in their parenting. Viewing the parent in this way shifted the definition of disability as a non-typical characteristic, i. e. deafness of an individual, and allowed for a new approach for the study. Studies in ableism scrutinize the worldview that disability is a weakness or a failing rather than an expected outcome of human diversity. My researcher gaze is directed towards this assumed ablebodiedness as well as audism, an assumed hearing norm.

As the project proceeded and the methodology developed, the activities of parents merged with the goals of the communities they were turning to. Advocating and activism came into focus. I began to wonder what a social literacy of disability could be described as in this context of meetings between hearing and deaf individuals. How do parents become literate of **dis/ability**? This includes how they experience being abled, disabled, having a child who is different from them, and having a child who is likely to be understood better by others who have similar experiences of deafness. Dis/ability describes how the child, as well as the parent, is seen as being disabled in some instances and not in others. How parenting experiences can be described and reinterpreted into how people come to know about disability and relate to others in ethical ways will aid in filling a knowledge gap about the invisibility of normality.

I took the opportunity to step out of the Swedish deaf and hard of hearing social and cultural contexts and took my questions ‘back home’ to the southeastern region of the United States. The most significant discovery was made was when I went in search of parents of CI users who were using signing alongside speech based therapies as I had seen in Sweden. The definite conviction of the two university departments I was visiting, one in special education and the other in sign language interpretation said there were no such parents. ‘You won’t find any.’ If I were going to interview parents of CI users they would not have learned to sign. This had two implications: I knew people existed who did this that were living in the state. I had seen evidence of this on Facebook in the netnographic work and so have others. The impact of social media on uncovering alternative experiences and presenting testimonies of how these experiences were pulling clusters of practice together could not be underestimated. The interviews I had conducted in Sweden had given me a way to see how unique the Scandinavian experience with sign language instruction programs for parents is on the one hand and how it globally impacts the experiences of many more parents of cochlear implant users regardless of whether they sign and speak or only speak. It began to appear that there are as many ways to be a parent of a deaf child as there are ways to be deaf.

### What is the knowledge gap being filled?

This is a study about a process of parenting in everyday life. Through childbearing a parent actualizes views and beliefs about medicine, technology and many related social systems and institutions. The aim of this dissertation project is to describe the ways people with typical hearing experience parenting a deaf child who uses a cochlear implant (CI) in Sweden. The description includes a contrast with similar parenting

experiences and contexts in the USA. Within a framework of social science studies of disability this study is carried out by combining interviews, allowing me to analyze experiences of parenting from a first-person perspective of 19 parents together with ethnographic, and netnographic methods of participant observation. The parents' lifeworld is situated in different contexts, networks of people and objects, which seem to influence the parents' individual understanding of parenting.

It is important to state my own sociopolitical commitments, including interests, commitments and power relations, surrounding the situation in society in which my inquiry is situated for two related reasons: acknowledging any bias in my study and to emphasize how all researchers affect what they research. The way this project has started and proceeded is influenced by what I find to be underrepresented in the academic work that gets done and the knowledge which is produced today. These are political concerns about the lack of research in health, illness and disability in humanities and social sciences and the structural problems of the allocation of research funds aimed at investigating the lives of underrepresented groups.

## Chapter 2 Review of literature

Cochlear implantation more than any other audiology-oriented technological innovation has changed society because of how it has impacted the organization and access to education and thus the lives of deaf and hard of hearing (DHH) people and their families. For example since the implementation of pediatric cochlear implantation practices, enrollment in schools for the deaf in Sweden has steadily declined (Holmström & Bagga-Gupta, 2016; Holmström & Schönström, 2016 forthcoming). Due to the nature of cultural patterns and the role deaf schools play in groups who converse in signed languages, this impacts the possibilities of how DHH children are socialized, not just educated.

Padden and Humphries explain the distinction of using “Deaf” in contrast to “deaf” which originated in the USA (2009 p. 1). The use of the capitalized “Deaf” describes cultural practices of a group within a group. Referring to the condition of deafness, the word “deaf” is used and covers the larger group of individuals with hearing loss. It is important to note that Deaf people range from being hard of hearing to profoundly deaf. In Sweden the capital “D” is not formally used in this respect and instead the distinction is made in other ways by referring to culture or to being a sign language user. The Swedish term "dövkultur", meaning "deaf culture" refers to the minority language status and “culturally deaf” refers to its deaf or hard of hearing users (Sveriges dövas riksförbund, 2014). In this review of the research literature the D/d distinction is used, whereas the Swedish formulations are used in the present dissertational work.

In addition to how schooling is organized, the ideological core of linguistic groups is in flux. A Swedish deaf culture discourse during the 1990s is described by Jacobsson which provides an analysis of the arguments and logic in favor of sign language and rejection of surgery in the initial years of pediatric cochlear implantation (2000). Here, a different way of understanding deafness becomes constructed, primarily by hearing parents, in challenging this deaf cultural perspective, a change which comes about in the contact between established discourse and alternative discourse. The CI revolution led to the challenging of truths in the Deaf culture discourse. The advocacy of cochlear implantation brought with it a development in discourse in ways of referring to sign language and identity, and through

dialogical ways such as “the best of two worlds” and offering “freedom of choice” (Jacobsson, 2000 p. 216).

Patrick Kermit, a philosophy scholar, wrote about what is ethically necessary in order to offer the possibility of a freedom of choice for CI using children (Kermit, 2010c). A distinction between “choosing freely and becoming able to choose” which language to use as an adult relies on habilitation with the implant as a child where acquisition of language is not threatened (Kermit, 2010c p. 151). Kermit argues that choosing between raising a child as hearing and speaking and raising a child as culturally Deaf and signing is simplistically posed as a decision between two ways of being. Kermit discusses observations from a pilot study based on emphasizing language used in successful interaction instead of levels of hearing ability. To advance the bioethical discussion of pediatric cochlear implantation, he argues that it is vital to consider identity formation and adult expectation of technology in light of how language is used in social capacities in everyday life. Also, in review of the bioethical debate that continues on practices after implantation, Kermit argues that the skepticism of Deaf individuals is not primarily concerned with preserving culture and sign language (Kermit, 2012). They draw on their own experiences of the harmful effects of rehabilitation and ideas of normalization which gives this view ethical weight in practices surrounding cochlear technology.

Hearing parents of deaf children are challenged by the situation of not being able to communicate if they do not know a signed language. This makes them a part of a unique group in the world because they must actively engage in learning to communicate so their children will be able to acquire language and avoid preventable disability. This experience from the perspectives of parents is largely missing from the literature. In point of fact, 90 to 95% of the parents of deaf and hard of hearing individuals are hearing (Mitchell & Karchmer, 2004). There is understandably great variation in these families which impacts the research which has been funded and therefore carried out. This has been problematized by researchers in areas related to pediatric cochlear implantation and was the general concern of the participants in a recent international conference, Multimodal Multilingual Outcomes in Deaf and Hard-of-Hearing Children in Stockholm 2016. Researchers and representatives of NGOs repeatedly called for more focus on the needs and experiences of “the 95%”. The importance of multilingual communication from early on was also a workshop outcome which situates parents and parental-decision making about post-implantation as a primary interest. Krister Schönström, one of the researchers on the organizing committee stated

Models on early parent-child intervention based on multilingual communication including sign, speech and written languages need to be further established in the societies to better serve the needs (and variability) of the children and to promote their linguistic and cognitive development from a lifelong perspective (K. Schönström, personal communication, June 21, 2016).

Early childhood intervention, by definition, requires direct involvement by guardians and is intended to train, guide and support parents to reduce the risk of their child developing problems (Marklund, Andershed, & Andershed, 2012). There is extensive research about outcomes after early intervention for DHH children (Bagga-Gupta, 2004; Holmström, 2013; Moeller, 2000; Scheetz, 2012; Schönström, 2010; Yoshinaga-Itano, 2003; Yoshinaga-Itano, Coulter, & Thomson, 2001). In social science and humanities there is research about identity, deaf communities and culture (H. Bauman, 2008; Eriksson, 1993; Jacobsson, 2000; Ladd, 2010; G. Leigh & Marschark, 2005; Marschark & Spencer, 2003; Marschark, 2007; Monaghan, 2003; Paludneviciene & Leigh, 2011; Sparrow, 2005).

Current research on hearing parents of DHH children regarding cochlear implantation is dominated by medical and audiological perspectives (Mauldin, 2012; Perold, 2001; Scambler, 2013). Emphasis is on the effects of cochlear implant interventions on linguistic, communicative and learning ability in children (Bosteels, Van Hove, & Vandenbroeck, 2012; Pisoni, Kronenberger, Horn, Karpicke, Henning, Marschark & Hauser, Pisoni et al., 2008). Studies on children must practically involve the parents either for their cooperation or as a source of data extraction about conditions. They are often studied as a source of information for how their child is progressing for example in communication outcomes or socialization (Bat-Chava, Martin, & Imperatore, 2014; Incesulu, Vural, & Erkam, 2003; Watson et al., 2008a).

The prominent themes in qualitative parent research regarding cochlear implantation are the following: parental expectation, parental stress/coping, communication outcomes, experiences in support services, co-occurring disability, and parental decision making and ethics. The most significant results relating to this study are presented in what follows.

## Parental expectation

The earliest experiences of parents regarding pediatric cochlear implantation typically involve identification coinciding with childbirth. Newborn hearing screening programs and expectations of parents have been studied in relation to child communication outcomes (A. Young & Tattersall, 2005; A. Young

& Tattersall, 2007). This exemplifies how new approaches and technologies are implemented first and followed by studies which aim to identify how intervention practices change as do the needs of parents. In these contexts parent processes involving reactions, acceptance and future advocacy for the child are in focus from the perspective of counseling services in the medical model of deafness (DesGeorges, 2003; A. Young & Tattersall, 2007 p. 218). A common point of agreement is that early awareness is crucial for children to be able to develop if there is a lack of communication. Hearing parents' needs and processes and how they relate to participation in programs for the betterment of people who are deaf and hard of hearing is the primary reason expectations in families is studied. In terms of family involvement, the level of engagement parents exhibit has been found to correlate positively with positive development and language outcomes especially when it is combined with early intervention after having been identified early (DesGeorges, 2003; Moeller, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Hyde et al include parents' expectations and experiences in a study of outcomes of cochlear implantation in children (Hyde, Punch, & Komesaroff, 2010a). Their findings were in line with much of the quantitative research in regard to how parents often have high expectations for their children and how this often reflects actual outcomes (S. Archbold, Sach, O'Neill, Lutman, & Gregory, 2008; Christiansen & Leigh, 2002; Sach & Whynes, 2005). Of particular interest is that the qualitative findings reflect a wide range of diversity in respect to the child's social development and participation and the nature of the experiences of parents (Hyde et al., 2010a p. 337). The experiences of the time period after implantation when the device is switched on were also found to be varied in studies examining how parents viewed their child's progress (Perold, 2001; Watson, Hardie, Archbold, & Wheeler, 2008b). Perold's study based on qualitative interviews found that expectations are influenced by parents' responses to deafness, their anxiety about their family's situation and the outcomes their child has in being able to utilize the implant (2001 p. 53).

## Parental stress and coping

Parental stress is often studied to find ways to improve services in the care of DHH children which is directly related to how a parent experiences their life satisfaction (Hintermair, 2004; Lederberg & Golbach, 2002). In a Canadian study of 31 deaf children with CIs, Zaidman-Zait and Young found that in everyday situations self-reported sources of stress for parents were: implant drawbacks and failures, difficulties in communicating, their child's behavior, demands they felt in intervention programs, finances, educating others and advocating about deafness and cochlear implants, and academic concerns

(Zaidman-Zait, 2008; Zaidman-Zait & Young, 2008). Closely related to parental stress are both the expectations and hopes parents hold and outcomes of spoken language ability but the identified studies which were found rarely incorporate these multiple areas in the same study.

## Communication outcomes and choices in therapies

When it comes to communication involving cochlear implants, most of the research focuses on speech and spoken language development in clinical tests (Thoutenhoofd, Archbold, Gregory, Lutman, Nikolopoulos, Sach & Tracey, 2005). More recently modes of communication are studied in combination with a matter of choice by parents. Wheeler, Archbold, Hardie & Watson (2009) have studied what parents have chosen in light of the progress of the child who has been implanted and found that the parents prioritize effective communication but consistently have in mind the traditional goal of developing oral communication skills. They also found that after oral communication is established with the CI using child, a number of parents consider once again the use of signed communication which has to do with issues of deaf identity and its possible role in the child's future with others. Wheeler et al.'s study incorporates analyses of societal processes which determine outcomes in communication and education. Therapy experiences of parents of children who use cochlear implants have been described as: long-term, life style changes, techniques becoming daily habit and parent referral to clinic professionals in terms of family-like relationships (Neuss, 2006). Roles parents self-report to hold are connected to outcomes and therapy such as the role of: teacher, advocate, member of support groups and facilitator of their children's social interaction (Duquette, Durieux-Smith, Olds, Fitzpatrick, Eriks-Brophy & Whittingham, 2002).

In Hyde & Punch's study on the modes of communication used by children with CIs, interviews with parents and teachers were included in a mixed-methods approach to investigate views on the role of signing in facilitating spoken communication (2011). "The qualitative findings elaborated on the quantitative results and clearly showed that many parents who were dedicated to the development of their children's speech were also open to sign language playing a role in their children's lives, and, indeed, were determined to make use of signed communication if it benefited their children" (Hyde & Punch, 2011 p. 545). What they found, which was consistent with colleagues in the United States and the United Kingdom conducting similar research was that parents often adopt a pragmatic attitude towards the use of sign where many value it as important in their child's life.

They do this together with maintaining the primary goal of communication through hearing and speaking made possible by CIs (Punch & Hyde, 2011). This study included a diverse group of CI users which made it possible to include long-term outcomes in the analyses. Integrating many different factors, not only age, which figure in children's outcomes is a valued part of this study because of what it contributes to the role of modes of communication throughout life. This adds complexity to the discussion which is also lifted by the authors as an important goal of further research.

## Experiences in support services

Parents are ambivalent in their perceptions of the medical services they received in regard to deafness which appear to be as problematic as they are in experiences of disability (Mertens, Sass-Lehrer, & Scott-Olson, 2000). Analyses of the experiences of support services are used to identify main concerns of parents (Narr & Kemmery, 2015). Parents are also studied to understand their reactions and resolution to diagnoses (E. B. Adams, 2011) and to identify parental stress, coping and adjustment in experiences with deafness (Anmyr, 2014; Hintermair, 2006; Hintermair, 2004; Horsch, Weber, Bertram, & Detrois, 1997; Jackson, Traub, & Turnbull, 2008; Quittner, Steck, & Rouiller, 1991).

One study in particular stands out in regard to parents' perceptions of services associated with cochlear implantation practices. Three years after implantation the parents expressed seeing three things: a change in the abilities they saw in their child's communication, that they have a strong reliance on services to guarantee the functioning of the technology and that they have to persist in insisting on close cooperation between the clinic and educational services (Archbold, Lutman, Gregory, O'Neill, Nikolopoulos & Thomas, 2002 p. 38).

## Co-occurring disability

I have found that it is often the case that studies separate communication mode and language use from child behavior. Often it is explicitly stated in studies that additional disabilities were excluded in the samples which explains why 'other disabilities' together with cochlear implant experiences are underrepresented in the cochlear implant research. This is related to research on parents and their access to resources in disability contexts. An exception to this tendency is provided by Hintermair (2006) who has

discovered that assessing communicative competence rather than linguistic mode (spoken or signed) is a way to include holistic analyses of the overall service needs of parents and families. Hintermair proposes that a resource-oriented approach to deaf education includes focusing on a child's ability to communicate rather than what is provided in pedagogical practice. The results also show that high parental stress is related to socioemotional problems in children, which is shown in a strong correlation to experience of access to services and experience of stress. This implies that since early intervention facilitates communicative competence, studying the access to resource access by parents must go hand in hand with studies of DHH children's development. Additional exceptions in the research literature including experiences of disability co-occurring with deafness are found in studies which do not exclude parents from research for their children's discontinued use of cochlear implants (Hyde, Punch & Komesaroff, 2010a).

## Parental decision making

Stuart Blume points out how studies on parental decision making about cochlear implantation do not seem to investigate questions about the child's identity (Blume, 2009 pp. 152, 163-172). This exemplifies how trust in medical advice is characteristic of the modern world we live in and that the medical model of deafness focuses on the individual solution in families. According to Blume's research, this does not take into consideration a broad societal field of knowledge including the value of close personal communication with very small children (Blume, 2009 pp. 76-78). Referring to child psychology, it is identity, personal relationships, school environments and linguistic competence which are the focus of a child's development in a family.

Christiansen and Leigh cite two interview studies showing that a large number of parents in these samples who use signing to some degree were reluctant to approaching deaf people for advice regarding their children and remain to be so (2002). It was also found that it was also more likely that parents did not meet any deaf adults prior to implantation and that the views of deaf people which parents did come into contact with differed greatly in their views on cochlear implantation (Christiansen & Leigh, 2002 p. 266). The hearing parents, when making decisions situated in medical contexts, probably have not had contact with deaf people and had some resignation about establishing contact or trying to communicate with them. Others felt they knew the perspective of the deaf community or that they could expect criticism from them in some respect.

Research regarding hearing parents' individual experiences of social processes is less prolific but includes the aim to illuminate how they understand deaf and hard of hearing communities and what is known as the cultural linguistic model of deafness (Young, 1999). Zaidman-Zait & Young (2008) examined the role of parents in habilitation processes in CI use in two case studies. They analyzed behavior, internal processes and social meaning in order to describe how parents act and think in regard to their parenting of a child with a cochlear implant. They found that by being engaged in "parenting projects", these parents define their identity in a construction of being a parent of a deaf child. Emphasis on productive projects involved positive perceptions, pride and competence as a parent (Zaidman-Zait & Young, 2008 p. 208).

Interpersonal relations and experiences of parents in the field of hearing and deafness are often described in terms of intensity, newness and involving change for parents as individuals. Bosteels, van Hove & Vandenbroeck (2012) took a phenomenological approach to study individual relations and explore meaning in parenting a child who had a diagnosis where encountering different worlds are involved in constructions of parenthood and deafness. Their analysis develops a main point of critique of how support for families is often secondary to goals of rapid, efficient intervention for enhancement. Related to this is that they found evidence of parental positions between social and medical models of disability which enabled parents to embrace aspects of unpredictability in their parenting. Citing Fisher & Goodley's work in parenting experience of disability (2007), they argue the following:

As 'philosophers of the present and becoming', parents with deaf children can look at doubts and uncertainties in the light of chances and opportunities, can try to enjoy their child and parenthood now, can avoid unrealistic expectations for the future, and be prepared to resist if they have to defend their rights or those of their children (Bosteels, Van Hove & Vandenbroeck, 2012 p. 993).

This conclusion appears to be at the core of a concern for the lack of post-implantation studies involving family experiences alongside studies on causes of variability in outcomes of CI use. Laura Mauldin, among many others, identified a paucity in research and examined how parents' relationships through technology led to entering new communities (2012). The clinical structures shape decision-making and the integration of clinical practices in family and group environments. Community belonging in this sense is seen to be a way to increase compliance. Included in Mauldin's fieldwork were interviews with parents to explore the everyday experiences of CI use in families which led to discovering that there is a new strong biosocial CI community. Parents came into contact with this community through how clinic work and state authorities converge in what Mauldin

identified as anticipatory structures which led to the identity construction of becoming a ‘parent of a CI user’ (2012 p. 537).

There are disparities in outcomes of implantation. This perhaps is leading to conclusions about the use of ‘wrong approaches’ by parents or to individual or additional impairments in children which contributes to the controversy between advocates of speech and listening, and total communication allowing sign language. These disparities are also a part of what is known and what is not known about cochlear implantation which adds to uncertainty in the experience of parents. Mauldin (2012) believes that the investigation should continue in both communities in order to not lose sight of supporting deaf children in having access to language.

It is expected that parents are thematically at the center of the research to determine the best way to educate DHH children who are understood to be linguistically capable if provided with language exposure. An example of this is found in Knoors’ article on a study where parents’ objectives are studied as a part of children’s environment together with how parents are receivers of professional advice (2007). Decision-making processes in cochlear implantation, pre- and post-operation therapies and choices about communication are often examined in studies of children’s outcomes (Kluwin & Stewart, 2000). Repeated in the literature is that most parents find the initial process of deciding to be difficult and stressful and many see only one option (Hyde, Punch, & Komesaroff, 2010b). They also show that making decisions and following intervention programs is a major part of parents’ continuous experiences. The subject of a number of extensive works involving parents of CI users connect the issues of all three phases of the CI process, before, during and after, in light of the education and the future of the group DHH children (Blume, 2013; Christiansen & Leigh, 2002; Marschark, 2007; Meadow-Orlans et al., 2003; Monaghan, 2003; Moores & Miller, 2009; Paludneviciene & Leigh, 2011).

As mentioned, outcomes in speech and language have been found to be heterogeneous and vary considerably even when other disabilities are accounted for (Kral, Kroneberger, Pisoni, & O'Donoghue, 2016; Mellon, Niparko, Rathmann, Mathur, Humphries, Napoli, Handley, Scambler & Lantos, 2015; Niparko, Tobey, Thal, Eisenberg, Wang, Quittner & Fink, 2008; Yoshinaga-Itano, Baca, & Sedey, 2010). Variability is attributed to both internal and external factors such as age of implantation, family background in respect to language, education and socioeconomic status, family involvement post-implantation, cognitive functioning, other disabilities, access to schooling and access to health services. It is clear that the implications include the need to study attitudes towards disability, multilingualism, language mixing, new media technology, to name a number

of areas. The debates persist in the cultural, social, economic and political spheres and parenting relationships embody this intersection of disciplines. As for meaning in everyday lives, variability in outcomes is the core issue of uncertainty for parents of cochlear implants users.

Antagonism between proponents of opposing communication strategies can be explained by structural inequalities. Critiques of audism and ableism are figuring in the debate which impacts the experiences of hearing parents. Audism is a form of discrimination of deaf and hard of hearing people which privileges the ability to hear whereas ableism is discrimination of people with disabilities, both assuming a pathological view resulting in negative stereotypes and stigma (Alftberg, Apelmo & Hansson, 2016; Bauman, Simser & Hannan, 2010; Bauman, 2004; Campbell, 2008; Campbell, 2009; Castaneda & Peters, 2000; Eckert & Rowley, 2013a; Eckert, 2010; Rauscher & McClintock, 1997; Solvang & Haualand, 2014). Within the disciplines of deaf studies and disability studies these terms show the power hierarchies between groups which exclude from participation based on function and disability. It does serve a purpose to explain the complex relation between the underpinnings of these fields because of how parents must also negotiate these boundaries. Solvang and Haualand have introduced these concepts for those unfamiliar with deaf experiences and current social practices.

Sign language is the big difference between the Deaf and (other) disabled people. Sign language-using Deaf people have a wider ground for forming a community. Institutional practices such as language learning, poetry and theatre contribute to such community forming (Ladd 2005). It may even be possible to widen the perspective to three understandings of deafness. It can be seen as either an impairment to be treated, a ground for a common language or as a disabling condition. These three ways of seeing deafness are not antagonistic; instead, the interaction between them may contribute to a clearer understanding of deafness as a social phenomenon relevant to a wide range of discourses (Kermit 2009), one of them disability. Striving for treatment, fighting social oppression, and celebrating disability culture are important points of reference in disability discourse. These three positions are referred to as the (global) medical model, the UK social barrier model, and the US minority and cultural models (Goodley 2011, 7-17) (Solvang & Haualand, 2014 p. 3).

The Deaf Rights Movement followed in the wake of the Civil Rights Movement in the United States. The model of deafness held by members of deaf communities who share pride in a culture and a sign language rejects associations with definitions of disability. In respect to parents, learning about this controversy is part of their parenting experience which is described in Scambler's article in a critique of the cochlear implant debate and identity politics (Scambler, 2013). The literature on parents' views of

what they need when their child is identified as DHH often mentions needing to know more about the deaf community and about the differences of opinion on assistive devices and communication strategies (DesGeorges, 2003; A. Young, 2003).

Advocacy by parents of DHH children needs to be understood in light of different ideologies based on language. Bagga-Gupta & Holmström (2016) examines how a double monolingualistic norm is functioning in the practices and discussions about technology use in social arenas and particularly in educational settings. This norm builds on keeping languages separated and unmixed as opposed to polylingualism, i. e., the complex and strategical use of several language varieties and forms of communication together (Bagga-Gupta & Holmström, 2016 p. 7).

What is most at stake in the field of deafness and deaf communities is how hearing parents come to decisions about mode of communication (Scheetz, 2012). In *Deaf Education in the 21<sup>st</sup> Century: Topics and Trends*, family dynamics is discussed centering on the issue of choice. It has remained consistent throughout the past century that the use of one language is encouraged early on and also presented in simplified terms and remains to be the case even more so in respect to current use of CI technology. The point is argued that the decision, though it may initially appear to be straightforward, is not framed as a decision which is ultimately about the relationships between the acceptance of deafness and identity formation. The author also cites recent studies on family dynamics where characteristics of healthy families with children who are deaf are investigated (Scheetz, 2012 p. 82). Mention is given to the historical development of how parents are viewed moving from a pathological view of deafness with focus on grieving and loss and shifting towards viewing parents as having resources which can be utilized. This is particularly the case in the fields of education and special education. Rather than relying of the medical model and a negative view of parents' experiences, these fields have come to focus on parents' strengths as a resource to be used together with external support.

It appears that the individualistic and neoliberal trends of choosing in regards to the body are why the pathological view is receding in favor of a responsibility view of active citizens. As an example, the factors that contribute to healthy dynamics in the family are identified through asking parents how they would advise others to act who have a deaf child. These included encouragement to become an advocate, be informed about rights and to be focused on accessing resources guaranteed by rights (Scheetz, 2012). All of these actions are framed by making the right choice and result in parents being viewed as utterly responsible for outcome. Another indication to be prepared to make active choices is expressed as to have high

expectations, learn sign language and be involved in the child's education (Luckner & Velaski, 2005). Identifying successful parents is judged on terms of what they were able to do for their child which points out that education research remains to be designed with a 'for the child' focus where parents are seen as resources. This is problematic as well because of inequality in access to "personal" resources and privilege. Such social conditions require that we look at the complicated nature of identity, issues of relationships between identity based groups and structures of oppression in ableism and autism (Burch & Kafer, 2010).

## Ethics

The ethics of choosing a cochlear implant for one's child has been the focus of researchers in philosophy, social science and bioethics (Kermit, 2010a; Kermit, 2009; Kermit, 2010b; Kermit, 2010c; Neria, 2011; Peñaranda, Suárez, Niño, Aparicio, García & Barón, 2011; Valente, Bahan, Bauman, Petitto & Hall, 2011). The decisions parents are faced with actualize a number of ethical concerns. An analysis of ethical issues after cochlear implantation is the focus of Patrick Kermit's philosophical dissertation (2010a). He reviews the bioethical discourse on pediatric cochlear implantation and lays bare the construction of two dichotomies. The first dichotomy is a type of allusion to there being a sharp dividing line between two groups; deaf as in hard of hearing or Deaf as membership in a sign language using community. The other dichotomy is constructed between opting for, and rejecting cochlear implantation. It is the combination of these two which creates what parents become confronted with and results in either/or thinking where there is a decision between two ways of existing. Kermit regards these dichotomies together in four empirical studies using the philosophical concept of authenticity to come to the most ethical alternative regarding lingual capability, that being providing both a signed and spoken modality to DHH children (Kermit, 2009; Kermit, 2010b; Kermit, 2010c).

The cochlear implant ethics literature trails the issue of parenting deaf children (Christiansen & Leigh, 2002; Hintermair & Albertini, 2005; Kermit, 2010a; Kermit, 2010b; Kermit, 2010c; G. Leigh & Marschark, 2005; Marschark, Rhoten & Fabich, 2007). The focus on the ethics involved in decision making for deaf children is an important area to consider when investigating parents' experiences mainly due to the fact that it is under-problematized. The works that focus on ethical argumentation are aimed at broadening perspectives which are hindered by dominant medical discourses which is a major contribution of Blume's book *The Artificial Ear: Cochlear Implants and the Culture of Deafness* (2009). Departing from science and

technology studies, Blume writes about the development of the cochlear implant and reveals the marginalization of the groups directly impacted by the controversial revolution in auditory prosthesis surgery. He examines how the CI is embedded in a complex network where shareholders in medical arenas dominate. In so doing, he provides the historical background of how lobbying forces grew out of the contact points between deaf communities, research institutions and CI companies.

Portrayals of hope for cure and technological innovation in modern society underlies the relationship of the representatives of medical science with parents. Currently the matter of decision-making in reference to the use of medical technologies underpins many issues being addressed in social science research (Hintermair & Albertini, 2005; Kermit, 2010c; Mellon, Niparko, Rathmann, Mathur, Humphries, Napoli, Handley, Scambler & Lantos, 2015). Hintermair and Albertini address specifically the ethics of cochlear implantation. In *Ethics, deafness, and new medical technologies* (2005), the authors discuss a negative portrayal of deafness as a result of new technologies where “the problem” of being deaf can be cured once and for all. They refer to this as a public preoccupation with a misleading idea about deafness and disability. Hintermair and Albertini argue that the families can be seen to be pressured in undue fashion. The role played by health care professionals, in how parents are informed, needs to counteract these effects through adopting “inclusive and individualizing ethics”. This means helping parents achieve a broad perspective on deafness. The authors argue for authenticity and an individualizing ethics as does Kermit who points to the realization of a person’s unique potential. A distinction is made between either/or collectivistic ethics and both/and individualistic ethics. Hintermair and Albertini state that taking the best of both alternatives rather than choosing between advocating for sign language or for an all speech approach is the most ethical. They end their article in support of authenticity and allowing being “deaf in my own way” citing Stein Erik Ohna’s work (2004) as an example of this ethical choice (Hintermair & Albertini, 2005 p. 190).

Since hearing parents of DHH are mainly in contact with medical teams the question of what professionals should do and what type of advice to give is raised in the literature in all areas of research, primarily the need to consider negative effects of technology and the related practices. A critical view complementing the technological solutions is required to minimize negative impact in human life. Assumptions that deafness is meant to be overcome, and that there is a critical time for implantation and training also impacts quality of life where the early years of children’s lives are something to get through (intensive training) or form for another point in time (prioritize speech rather than communication). Hintermair and Albertini argue that “at

all costs” ways of thinking contribute to the negative consequences of implementing new technology and bring with them new risks (2005 p. 189).

What happens linguistically after implantation will exemplify the complexity of decision-making as it plays out in everyday life. Snodden & Underwood found that in an ethnographic study of children in an ASL and reading program, children negotiated their pluralistic identities (2014). They were also “readers of power”. They did not sign at preschool where ASL held a lower status (Snoddon & Underwood, 2014 p. 536). When the children were in the book reading group they did use signing which the authors attributed to being given the necessary inclusive environment where plurilingual strategies were used by others during the activity. Snodden & Underwood related this difference to how power relations impacted the children’s identities and relationships in different settings. The idea is that a social relational model including ASL modeled on this study would allow deaf children to be plurilingual learners.

## Deaf education and historical perspectives

It is important to be provided with an understanding of educational and language issues with sensitivity to historical developments concerning deaf and hard of hearing individuals. For example, the parental role has changed in respect to deaf education. An historical development towards parents becoming advocates and supporters of cognitive and linguistic development in the early years of life was found in autobiographical and biographical writings about successful deaf experiences (Marschark & Spencer, 2003 p. 15). The implication for parents and what they do in their parenting role is framed in such a way as to what is required of them based on the historical study of education of deaf individuals. These requirements are put in terms of the long term influence of parent-infant and parent-child interaction, individuality of the child and the necessity of becoming informed in reference to communication, language and academic achievement (Marschark & Spencer, 2003 pp. 18, 190-199).

The particular issues contributing to the motivation of pursuing an investigation of how parents engage with identity category groups which include their children has grown from the cultural and political movements of disability groups and deaf communities. The experience of a parent or family member of a DHH individual brings together a combination of these communities’ interests in real life situations. The interpersonal deaf-hearing relationship, between the parent and the deaf child, together with the

relationship between privileged and oppressed groups in society are the sites where this can be examined.

When discussing the role of disability studies and Deaf studies Yerker Andersson, the Swedish born sociology professor and Deaf studies scholar, refers to parent experiences as a starting point for investigation.

I should note that disability studies has been accused by critics of being a political weapon serving anti-business activists, radical social advocates, and even the medical establishment. However, in fact, it has helped us better understand human behavior. It has also helped parents, including parents of deaf people, to understand and improve their own relationships with family members who are different. My father is a great example of this improvement. He was a teacher, and he was shocked when he found out that I was deaf at the age of three. His friend, who was a teacher, gave him a book to read. It was about Helen Keller. That helped my father because it showed him that I, too, could be capable, that I could learn. Until that point, my father didn't know what was possible for deaf and disabled people. Parents in America and around the world are often shocked and disoriented when they find out that they have a child with a disability, and here, I am including those who have a deaf child. Engaging with them and encouraging clarity on what being deaf and/or disabled means is an incredibly important part of the work that both political and scholarly groups pursue. This kind of work has affected not only education but also people's awareness about this disability and deaf people (Burch & Kafer, 2010).

The debate of how to educate deaf children, which continues largely unchanged dates back to 1880 to the Milan congress on deaf education when sign language was banned (H. Lane, 1989). How communication is really about existential issues for the parent and the child answers why there continues to be a strong polarization between oral and signed approaches. The shift has occurred in which therapies and advice that are made available in respect to who the parents are and their plans for the child's future. In the sociological study *A Battle of Words - Competing Truths in the Deaf World*, the debate and controversy in Sweden over cochlear implantation is explored (Jacobsson, 2000). When CI technology became an option for parents of deaf children during the 1990s it changed the landscape of hearing and deafness as well as deaf education. This revolution made it necessary for people in this context to form an opinion on the use of an invasive measure on children. Jacobsson uses discourse analysis to reveal how deafness is talked about in the time period when the conflict was at its climax in Sweden, the conflict being whether parents should have their children implanted or not.

The main research question, how parents experience living with a child who uses a CI and how they are socially engaged with others through that experience will serve to clarify and narrow in on works in other disciplines

interested in this group. This will allow for reinterpretation and a synthesis of what is known about the broader subject of parenting, deafness, and disability (Anderson, 2006; Linikko, 2009; Meristo, 2007; Midbøe, 2011; Nelfelt & Palviainen, 2004; Schönström, 2010; Wennergren, 2007). Other doctoral theses in the Swedish context were important for understanding how parents are involved in the cochlear implant process but have focused on improving utilization of the implant and attaining desired outcomes from the implantation process itself (Anmyr, 2014; Ibertsson, 2009; Karltorp, 2013; Löfkvist, 2014).

School placement is mostly a decision made by parents after evaluating their family's overall situation and the child's educational and developmental needs. Holmström's compilation thesis *Learning by Hearing? Technological Framings for Participation* examines everyday lives of CI using children in mainstream schools with focus on technology's role in communication and identity issues (2013). She analyzes technology use and how language ideologies are manifested in everyday lives of children with cochlear implants. Holmström identified strong educational implications of the use and reliance on hearing technologies which have come to light from the ethnographic data in classroom settings which provides many possibilities for further research on classroom interaction, as well as in home and leisure arenas.

A debate among scholars and medical practitioners under the current circumstances of pediatric cochlear implantation and sign language is an area of research which crosses multiple disciplinary boundaries. The current North American context can be understood in this "Ethics Rounds" article *Should all deaf children learn sign language?* published in the journal Pediatrics in 2015.

Every year, 10 000 infants are born in the United States with sensorineural deafness. Deaf children of hearing (and non-signing) parents are unique among all children in the world in that they cannot easily or naturally learn the language that their parents speak. These parents face tough choices. Should they seek a cochlear implant for their child? If so, should they also learn to sign? As pediatricians, we need to help parents understand the risks and benefits of different approaches to parent-child communication when the child is deaf. The benefits of learning sign language clearly outweigh the risks. For parents and families who are willing and able, this approach seems clearly preferable to an approach that focuses solely on oral communication (Mellon, Niparko, Rathmann, Mathur, Humphries, Napoli, Handley, Scambler & Lantos, 2015).

This ties in with the discussion of ethical reasoning related to communication with small children and emphasizes the importance of parents' needing perspectives from a diverse group (DesGeorges, 2003).

A study of parenting building on this example cannot begin by simplifying or reducing experience to be instrumental in normalization processes. This objective can be read as using the critical disability studies lens to shed light on how the parent is disabled in communication with the deaf child. Another aspect is that parents, as members of majority culture are examined as contributing to disabling environments for DHH people. Departing from these assumptions follows the principles in examining normativity to interrogate structural ableism (Campbell, 2008). The aim of the study is to address one major challenge, that research in the field of deafness and hearing be inclusive of the experiences of people impacted with the intent of understanding better how lives are lived and the meaning is derived from processes under their life conditions. Speaking to the problem of how inequality is perpetuated motivates using resources in studying how parents of children who live "between worlds" are carrying out the informal work of parenting (Najarian, 2006 p. 101). Najarian shows how this informal work involves both the enactment of political decisions on and activism by individuals for their families and the advocacy of educating others about disability and deafness. This type of labor is the labor of social justice and is vital knowledge in all sectors of society. For example, the work of adopting and upholding language is a major part of the 'invisible work of mothering' (Najarian, 2006 p. 11) and using 'normalizing' strategies to work against the stigma as a type of resistance.

Najarian's work pinpoints the issues of becoming and belonging to be addressed in this dissertation in how one's child's language and schooling in informal and formal contexts is connected to ideas about group belonging and is part of a becoming parent experience. Also, how the hearing parent develops skills for advocating for their child can be seen as advocating for themselves. This relationship within a process can be understood more clearly in comparison to this group of Deaf women's experiences. Also of interest is how the deaf women who had hearing children changed how they communicated with their extended families after the birth of their children. The current study includes examining families' lives as they are socially re-organized because of language choices and overarching goals of their children's participation in society.

Related to issues of belonging through language is the focus on attitudes and work to changing attitudes which dominates the ally development literature (Adams, Bell & Griffin, 2007; Ayers, Quinn, & Stovall, 2009; Curry-Stevens, 2007). Identifying ally characteristics is one important way to

understand parenting experiences and to focus on how changes are connected to disability conceptions (Evans, Assadi, & Herriott, 2005). The work on the intersections of deaf disability studies is examined through an exposition of audism and ableism as they intersect in lived experience and perceptions of difference (Bauman, Simser & Hannan, 2010; Bauman, 2004; Castaneda & Peters, 2000). This includes analyses of understandings about the normal body, particularly in familial relationships. These works come together from disciplines in cultural studies, psychology, sociology and education which enable analyses of complexity concerning disability and culture as alternative perspective construction phenomenon (Eckert & Rowley, 2013b; Eckert, 2010) and define the definition of audism “as a schema of audiocentric assumptions and attitudes that are used to rationalize differential stratification, supremacy, and hegemonic privilege”, an area of concern this dissertation hopes to address.

To see how the parenting process and role contribute to participation of individuals in society can be developed through identifying characteristics in a becoming process involving a situated and experiential form of knowledge. The present study can fill a gap in identifying how particular experiences centered in parenting are ideal for a description of a type of social literacy which deals with ethical commitment in action towards others. Using a social justice education lens from other sectors of identity will aid in this description of lived parenting experiences in deafness and disability.

To summarize, there is a paucity of research on parenting processes in intersecting situations of differentness, in particular in respect to technological developments, Deaf culture and disability experiences. There is also a lack of research that examines the experiences of hearing parents of cochlear implant users regarding their new circumstances and what role it plays in their development through the child and with others. The current study on such transformations and becomings in adulthood experiences through parenting will investigate a type of situated learning in everyday contexts. How the parent of a CI user seeks knowledge and support requires an objective to analyze how a parent understands their situation in regard to language which involves deaf culture contexts as well as medical impairment contexts. In the present study the experiences of parents will be examined by how they orientate from communication ideals and the people they meet who appear to be in one of two ‘what is right for the child’ groups. These are concentrates of ideas; one about spoken language only and one about adopting a bimodal approach. Research in the field of disability, like other social science research dealing with the medical field, is disproportionate in terms of what gets financed and how it is viewed as useful research with impact (Lindberg, 2016). This work will fill a gap identified by researchers interested in the state of affairs of disability

research in Sweden which follows these global trends. My study addresses and contributes to interdisciplinary, social and democracy rights based scholarship.

This dissertation is in dialogue with problems in society through the concerns of parents of CI users exemplified in situated learning in everyday life. The aim of my study is to investigate parenting as experience and describe it in terms of an individual and shared process in interaction with others. Three areas I have identified that this study will contribute to are the area of parenting and disability to understanding meaning-making in everyday life, the role of social media in instances where parents seldom have physical social contact because of the uniqueness of their situation, and lastly, how parenting as a relationship can be used to study allyship by way of care which is transferred through the development of skills to other areas of life promoting participation in society. For example, there is a lack of knowledge regarding how parents' new encounters with deaf and hard of hearing related issues lead to a need to find experiential knowledge on the Internet and how this impacts both deaf communities and disability communities. Parenting in these everyday situations makes possible an added awareness and alertness to futures, which regularly negotiate overarching issues in the lives of deaf and disabled people. The study of the everyday lives of people is a locally bounded concern connected to political and social circumstances.



# Chapter 3 Theoretical framework

In this study parenting a child is understood from a theoretical meaning-making perspective. Meaning-making is seen as a complex process involving both individuals making sense of personal experiences and social sense-making. There is a connection in this study which assumes that ideas about normality and disability are socially constructed because people's lived experiences are profoundly divergent but at the same time socially organized according to similarities in positioning and exchange of experiences. As a consequence, parents whose children use hearing devices for example, share some socially constructed understanding. Parents' everyday lives, embedded in systems, structures, definitions and language use are the site of examination of 'lived parenting'. In this way, weak social constructionism and first-person embodied phenomenological experience describe the everyday lifeworld of these parents. The individual parents' experiences and perspectives themselves are vital for this study and the primary focus of a critical position grounded in everyday life.

I will explain how I utilize a constructionist view of both deafness and disability in this research project motivated by axiological commitments using an interpretive approach. My interpretation aims to utilize the knowledge that some groups are seen to be more knowledgeable about certain phenomena than others because of individual experiences in societal roles. The viewpoint of individuals who are parents draws on their subjective experience of a phenomenon.

There are ways of knowing that are not constructed through action and speech, namely the way subjective meaning is socially established.

A critical position, intrinsic to the reality that is its object of investigation, is essential to the viability of a feminist theory and critical interrogation of social structures and practices that is committed to the idea that reality is, to a greater or lesser degree, socially constituted (Zeiler & Käll, 2014 p. 10).

This is a way of proceeding from seeing the body as the primary site for knowing the world. How subjective meaning comes into our world is used to analyze how meaning is negotiated. My position, a strain of weak social constructionism, acknowledges that there are different interpretations of the

world but that they are organized in the same way because of our human condition. Both an interest in structure of existence and the social texture of how things are experienced are necessary in this critical theoretical approach.

The first meeting I had with a parent of a cochlear implant user was in a café. When the espresso machine was running she used it as an example of a place where her daughter would be deaf even if she were wearing her cochlear implants. When the machine stopped, the differentness between her use of senses and her daughter's transformed. The machine was no longer in the mix and the cochlear implant appeared. When the espresso machine was making noise, then the CI was cancelled out. Seeing differentness as a process allows for a new way to analyze parent accounts. Machines are not only an example of what gets plugged into an environment in the form of noise source or enabler of electronic sound. I point out these machines' material qualities in relation to sound in order to show how it opened up a way to see parenting a deaf child. The cochlear implant is a machine that gets plugged into relationships between parents and deaf children. To stop here though would miss the point. The way of seeing 'on' and 'off' and 'in' and 'out' of different ways of existing is opened up by contemplating activities as processual. If we see the fluidity of the use of senses in interaction with all that *matters* in the activities between people and objects we can preserve the complexity of lived parenting in sensorial differentness.

Differentness, seen as a process between people and objects in an environment, is investigated to reveal constitutive conditions of parents of children who are deaf and use cochlear implants. The analysis presented in the chapters stays very close to the empirical material offering descriptions of phenomenological themes about relationality and corporeality. Experience of parenting in sensorial differentness is the study object for the foundation of the analysis.

Zeiler and Käll state in the introduction to *Feminist Phenomenology and Medicine*:

It indicates the relevance of feminist phenomenological perspectives to the field of medicine and health by highlighting difference, vulnerability, and volatility as central dimensions of human experience rather than deviations, and vitalizes the field of feminist phenomenology, as well as the field of phenomenology more generally, by bringing it into conversation with a range of different materials, such as empirical research, case studies, cultural representations, and personal narrative. It also takes into consideration and examines normative cultural practices and structures of meaning that situate different bodies in different ways and with different conditions, and seek to lay bare the constitutive conditions of experience (Zeiler & Käll, 2014 p. 2).

The above quote summarizes a commitment to diversifying the type of perspectives used in studying the body by bringing studies of experience into conversation with different types of empirical materials. It serves well as a basic tenet underpinning my theoretical stance.

## Disability models and models of deafness

The medical model of deafness (also referred to as the pathological or infirmity model) defines deafness as impairment. In opposition to this understanding, the cultural model presents the view that emphasizes belonging to a culture where being Deaf opposes labels of disability. A third model, the social model of deafness is comparable to and inspired by the social model of disability but is considered to be in opposition to the cultural model. The cultural model is set apart from the social model in these respects: The social model still views an individual in a state of being disabled by the environment whereas the cultural model operates with a definition of deafness as a shared trait of a linguistic group and not a definition of lack or lesser abled, regardless of the circumstances. The trait of deafness indicates a specific visual gestural language sharing culture which is not compatible with any view of deafness as disability, medical or social. The concept ‘culturo-linguistic model’ is a widely held idea in signing Deaf communities about an existential situation of being a minority based on a signed language (Ladd, 2010 p. 15). Being culturally Deaf and the corresponding goals of being recognized as such are the basis of group identification. The social model of disability is seen as suitable for meeting needs based on *individual* impairment, the medical concept of physical deafness and the surrounding environment. These aspects place the social model in opposition to a group identity category which is inherently about how the Deaf exist as a *collective* based on shared language, behavior, values and beliefs.

A critical social constructionist model of disability has inspired this study. Firstly, the analysis aims to center on challenging ableist assumptions which shape reality. Social research is a critical enterprise to discover dominant and taken-for-granted understandings of reality in order to produce a particular form of knowledge about life conditions from the perspectives of the people being studied. Secondly, this critical model infers that disability is understood as a relation between an individual and their social environment i.e., the embodied relationship in a family with both hearing and deaf members. Another example is how societal institutions can construct disability through practices based on expectations of function. Reduced function is seen as a natural variation among humans, “everyone is

impaired” (Shakespeare & Watson, 2001 p. 25). Both social and relational perspectives address the issue of personal impairment placing emphasis on experiences of disability being contingent upon environmental, social and cultural factors. These models also implicate the facticity of impairment in understanding disability as a relationship between both individual and contextual factors. Core features of a relational model point to disparity between an individual and an environment, that disability is situational i.e. the interplay of using (technical) objects in specific situations and that disability is a relative concept on a continuum, not a dichotomy, which is influenced by these relations to environments and situations (Gustavsson & Tøssebro, 2005 pp. 34-37).

## A critical perspective in disability studies

The term critical implies an interdisciplinary framework in disability studies. There is a particular social objective to analyze in order to reveal circumstances and conditions of human lives which are contingent upon power structures. The focus on the daily lives of people in contexts of disability is used as a lens to not be limited by the existing structural biases in society. Critical theory is not only explanatory it is intentionally practical and normative and politically aimed at social transformation (Bohman, 2015p. 1).

A part of disability research branching out of the critical approach is to study ableism as well as disability (Campbell, 2009). Ableism is the knowledge system which produces entitlement and exclusion based on negative ideas about disability. This term also points to the taken for granted normality of the healthy body as the norm. It includes the ontological underpinnings of what *abled-bodied* in its most opposite form produces: a binary of life and death on a continuum where sickness in terms of impairment is dehumanizing. I utilize this concept to see ability and disability as interacting with what it means to exist in relation to others. When writing *dis/ability* the focus is on placing differentness between bodies. Body and culture in interaction is complex and beginning to state questions in this way assumes that there is no objective category of what is normal or typical, only what is a human experience. This focus could then be utilized to show how lives lived in *sensorial differentness*, constitute and make evident other ways, non-ableist ways, of looking at impairment and disability for which we seem to be lacking language. This may appear at first to be a study of parenting in a problem framework but there is an important difference which separates this research endeavor from priorities of most existing research involving families in disability contexts. The problem is not located within

the disabled body of the child, nor in the courtesy stigmatized adult. Ultimately, the problem lies in the dominant views held by society of the disabled body which is how ableism will be interrogated. A significant objective of this project would be to present positive ontologies of being human in differentness, in dis/ability, which is one way to contribute to a more socially just society.

The overarching view on disability as a subject for academic endeavor and critiques of social exclusion employs a critical stance toward the master narrative of disability (Ayers, Quinn & Stovall, 2009 p. 380). This draws on a minority group model connected to civil rights movements in the USA. Critical disability studies in this case is part of a framework of transformational knowledge towards social justice particularly in education. Recognizing ableism in disability studies aims at interrogating unquestioned and invisible norms. “Able-bodiedness, even more than heterosexuality, still largely masquerades as a nonidentity, as the natural order of things.” (McRuer, 2006 p. 1) The term ableism points to what sets individuals off from a socially constructed norm. Ableism is described in Ableism Curriculum Design Education in *Teaching for Diversity and Social Justice* which explains that this is a phenomenon described with other terms such as handicapism, disability discrimination, physicalism, mentalism, and ableism (Adams, Bell & Griffin, 2007). Ableism or disability oppression is the exclusion of people with disabilities. The use of the term is often described in comparative terms to racism, sexism and oppression on the basis of non-heterosexuality. This places ableism within the framework of social justice issues/theory building. Like the other types of oppression it is described at functioning at three levels; individual, institutional and cultural. “Temporarily able-bodied people” are privileged. People with disabilities are disadvantaged. The systemic form of oppression emerges in patterns of treatment that discriminate in, for example, access to education, health care, and employment opportunities. Communication in families using signing comes into focus through starting with the able-bodied hearing perspective of individuals and the exchanges between the identity groups of the hearing, the deaf and the disabled. The related phenomenon of audism, the dominance of societal norms of hearing over sign language use, is a specific case of ableism. A deaf community is a source of identity for its members based on cultural beliefs and values through sharing a signed language. In this way audism operates on both ideas about not being able-bodied and belonging to a linguistic minority (Lane, 1992).

## Feminist research perspective

A socio-political commitment of feminist research is a defining premise under which I have worked (Mertens, 2010; Mertens, 2012; Scott & Usher, 2010 p. 171-189). Such commitments are articulated through drawing on the theories of feminist, disability and deaf scholars (Campbell, 2008; Campbell, 2009; Ladd, 2010; Mertens, Sass-Lehrer & Scott-Olson 2000). The theoretical approaches in these works have helped along the way in order to open up understanding necessary for interpretation. In these approaches there is a commitment to interpreting the world and arguing that we must take into consideration how and why and by whom research is carried out and to what end and “researching the everyday world as problematic” (Smith, 2002; Smith, 1987). This has impacted the theoretical perspective in combination with: choice of parents as experiencers, the fields of deafness and disability, and participant observation/observing participation drawing on personal experiences. The theoretical perspective as it is implicated in methodology guides the researcher’s gaze through the type of inquiry or purposes that underlie the project as well as the written form and style of the work (Johnson, Onwuegbuzie, & Turner, 2007). Feminist phenomenological understanding of embodiment and relationality have guided the choice of research questions, the use of multiple methods and engagement with standpoint epistemologies and care ethics (Denzin, 1980; Denzin, 1997 pp. 53-89, 274- 279).

## Orientations, queering phenomenology

Sara Ahmed’s theoretical framework brings together scholarship from different traditions such as phenomenology, psychoanalysis, cultural theory and cultural geography (Ahmed, 2006b; Ahmed, 2013). She connects these works to studies of non-normativity which provided me with an example of an approach to study both experience and social interaction from a critical perspective. Orientation refers to one’s place in the world and is a concept which utilizes the directionality and spatiality of being in the world (Ahmed, 2006b p.21). When we lose our orientation, we lose are place and the feeling of being at home (Ahmed, 2006b pp. 134-135). A related concept of belonging is used as an entry into the subject of parents who experience sensorial differentness. Ahmed’s writing struck a chord with how I had been reading and working with phenomenological works together with feminist theory and research in anthropology and sociology (Anspach, 1997; LaChance Adams, 2014; Mol, 2002). I was able to see how the initial aim of my study could be theorized and made understood to others by using similar approaches.

A concept developed in my empirical analysis of parenting experiences, communication orientation, is borrowed from Ahmed's *Queer Phenomenology: Orientations, Objects, Others* (2006b). Being a theorist of difference, Ahmed makes orientation into a query of how we are orientated towards certain objects and way from others both in body and in beliefs, thoughts and values. In this way phenomenology is a set of tools to think about orientation (Ahmed, 2006b p. 181). A subject orientates in a mutual arrangement with the world and objects. Close objects within reach have consequences for becoming through orientation but our desire motivates our reach. To see a parenting relationship in this way means to see how the parent through a desire for a child's existence foregrounds other objects bringing different ways of existing into view. A theoretical concept of orientation starts in a description of the relationship between embodied experience and the situatedness of experience.

Ahmed also interrogates spatiality, how different bodies we reside in space, namely how certain bodies feel comfortable in certain spaces when orientated. Disorientation is when we encounter something overwhelming in the social world through bodily action. Ahmed demonstrates space as actions between bodies and objects which was how I began to see what was transpiring in the empirical material. The space I was contemplating came to be called *sensorial differentness* in this work. Viewing activities in this way makes it possible to study how certain things become available to us through experience when we have been disoriented. That experience of the overwhelming brings other paths into view. Together with new circumstances, objects coming into view, it is a way to become reoriented through others.

Intentionality, that consciousness is directed towards something, creates lines which point in directions according to Ahmed. Directions shape perception which is needed in order to become orientated. Actions are how we follow lines.

The lines that allow us to find our way, those that are "in front" of us, also make certain things, and not others, available. What is available is what might reside as a point on this line. When we follow specific lines, some things become reachable and others remain or even become out of reach. Such exclusions—the constitution of a field of unreachable objects—are the indirect consequences of following lines that are before us: we do not have to consciously exclude those things that are not "on line". The direction we take excludes things for us, before we even get there (Ahmed, 2006b pp. 14-15).

I utilized this idea of (dis)orientation as a way to see how a person, through their own experience, learns about how others exist and in what way this is social and cultural, particularly how parents orientate in sensorial

differentness where their children have a different way of existing in the world than they do. A child's existence becomes thematized in the parent's existence. Answering the question of why some parents follow different lines to different objects can be answered and will include internalized societal views about technology, language, and disability.

The project has been designed to investigate becoming in parenting and where Ahmed is discussing whiteness, I am discussing hearing. When she discusses queerness, I discuss deaf ethnicity and disability. Ahmed's language allows for a way to interpret how the parents and the interactions between parents are ways of being in the world when the expected path forward takes a turn. Her concern with social relations and following paths we can find and ones we don't find on our own will be how I make sense of parents' lifeworld and networks.

Overall I hope to contribute to a deeper understanding of the group closest to deaf and hard of hearing children using a specific social context in differentness where meaning is constructed. Situatedness in studies employing critical theory draw on the strength in the particularity of what is lived, embodied and practiced. This also links the following discussion of situatedness to situated learning (Lave & Wenger, 1991). In focusing on groups in positions of normalcy, in this case hearing parents, identifying how their situated learning as parents can develop into cooperation with a group they differ from in senses or function, is a contribution to theorizing parenting relationships. To a large extent, the social meaning-making of the parents can be understood as a case where similar embodied experiences are the fundament of shared understandings and engagement in similar actions of advocacy in their everyday lifeworld.

## A social theory of learning framework

The concept of Communities of Practice (CoP) can help us understand situated learning and shared meaning-making in groups negotiating the use of senses, languages and technologies. Start from the sense-making of individual parents and how they share their experiences with others is an example of how this learning framework can be applied to parents in online support groups and social media groups. I see learning as a fundamentally social process (Lave & Wenger, 1991). This framework provides a way to see the intersecting levels of analysis in the project as a way parents first become aware of and then begin to exhibit a type of social literacy in dis/ability informed by a 'sociology of the superordinate' (Kimmel & Sykley, 2010; Kimmel & Ferber, 2014) and racial literacy development

(DiAngelo, 2012; Sensoy & DiAngelo, 2012). These include personal processes of becoming, social processes of belonging, a focus on affectivity as a form of practice, group interactions and a process of experiential learning. In utilizing this framework I will be able to show how personal and social relations situated in a particular kind of parenting can aid in increasing our understanding of fundamental social processes of participation through examining everyday practices with a range of qualitative methods (Wenger, 1999 pp. 11-15).

## Advocacy, activism and allyship

In Conceptual Foundations for Social Justice Education, in *Teaching for Diversity and Social Justice*, Hardiman, Jackson & Griffin utilize the term “allies” to refer to members of an advantaged group who recognize that they have a power privilege (2007). Allies work together with marginalized group members because they recognize that everyone in society is harmed by oppression but in vastly different ways depending on having different identity categories. Being an ally underscores that the relationship is to an issue and a struggle, not to individual people, which distinguishes it from advocacy. Allyship involves adopting the role of change agent through activism in a relationship to an oppressed group but also to other change agents. It is in the enactment of working towards a common goal that is an important part of what defines allyship with disabled citizens. The system of oppression is the target. The domain for allyship is the essential aspect of eliminating inequality.

In my study, a social justice education framework is applied in examining the descriptions of parenting as a process. Becoming, belonging, communities of practice, advocacy, and activism are described through lived parenting and doing parenting which is situated knowledge through connecting with others. How parents become personally engaged through the act of using Facebook is used to study the imagined and conceptual belonging to other groups through social networking sites, a type of befriending intersecting with activism. As an analytical tool, the concept of allyship can magnify the points where the key to the shifting perspective is found in becoming knowledgeable about lived disability. New perspectives through interaction are seen as a way of developing literacy and a way to be considered an ally to a group’s concerns. To become literate in this way is a prerequisite to allyship. It was this working definition of *parents as allies* which led to the notion of befriending the adult version of one’s child who uses a cochlear implant. The framework is utilized in describing that type of transformation process which is taking place in social circumstances of

inequity where children as well as their parents are seen to be occupying positions in boundaries between identities.

## The role of theory

My study is an empirical exploration of lived parenting. The role of theory in my study is one which provides a theoretical lens which informs the understanding of a phenomenon from important meta-theoretical points of departure in the phenomenological movement. In order to “do phenomenology” I learned to reflect in an attentive manner on the meanings of everyday experiences and events originating in the body, I also approached the study by continuing to read texts and developing a style of thinking which is used in the disciplines of the human sciences or *Geisteswissenschaften* of phenomenological sociology, anthropology, and psychology (Van Manen, 2014 pp. 15-25). My first priority has been to stay as close as possible to the experiences of the parents themselves. When patterns in the material demonstrated how the personal experiences were anchored in practices and the interdependence between materiality and experience, my theoretical orientation followed these discoveries. Turning to social phenomenological and critical, cultural and feminist theoretical languages I continued to explore different vantage points of lived parenting. I have also continuously related my empirical findings to earlier research and utilized other scholars’ theoretical languages without leaving the overarching theoretical lens in the dissertation project. An essential expression of my primary interest in the experiences of the parents themselves is also my critical theoretical perspective on “normative cultural practices and structures of meaning that situate different bodies in different ways and with different conditions” (Zeiler & Käll, 2014 p. 2). This can be described as a feminist, phenomenological position closely related to a social justice education perspective.

# Research aim and questions

The aim of this dissertation is to explore and describe experiences of parenting a child who uses a cochlear implant.

Certain basic characteristics in the resulting descriptions will aid in describing the development of a social literacy of dis/ability.

Research questions illuminated in the present study are:

- I.     What first-person experiences do parents have when parenting a child who uses a cochlear implant?
  1. What is it like to become a parent of a child who uses a cochlear implant?
  2. How do parents come to understand their child's use of senses?
  3. What are a parent's initial experiences of a hearing technology?
  4. What experiences do parents have regarding the future of children using a cochlear implant?
  5. What ideas about language and communication emerge when becoming a parent of a CI user?
  
- II.    How does the lifeworld of parents of children who use cochlear implants become shared or connected in networks of people, objects and experiences and what does this sharing mean?
  1. What contact was found between parents of children who use CIs?
  2. What are the major themes found in social media sites in parenting children who are deaf or hard of hearing?
  3. What characterizes the atmosphere in parenting online support groups in social media?
  4. How can parenting a child who uses a CI be described as a social learning process?



# Chapter 4 Methods

“I don’t buy that disengagement is the best way to study a subject.”

Andrew Solomon

## Introduction

In this dissertation I am investigating the lifeworld of individuals becoming parents of children who use cochlear implants and the related networks which connect people, objects and experiences. This is my knowledge interest in studying the situated meaning-making, the act of making sense of experiences involving parents, children, the technology used and practices surrounding them. Meaning is co-constructed in everyday lives involving complex technological systems. I start my empirical analysis with descriptions and interpretations of how individual parents understand their own experience. The next step is to further the study into an exploration of practices by studying networks including parents, materials, and ideas using ethnographic and netnographic methods. I have worked using a design that has two main parts. The first part is an interview study of *lived parenting*. The method used here focuses on individual experience in everyday life departing from a first-person perspective. The second part was designed as a study of *doing parenting*, by observing and participating in parent encounters. The method used here was developed to utilize ethnographic tools which focus on activities involving materials and networks. These two parts of the project aim at describing individual processes and shared meaning in practices.

The fieldwork supporting this design began with participant observation and exploratory conversations and included identifying the study objects of the parents’ lifeworld and networks which are constituted and interwoven with cochlear implants and adhering practices. It was in these situations, inhabited by parents of deaf and hard of hearing children, where I searched for participants to recruit for the interview study. The interviews and later the interview transcripts were utilized in designing the ethnographic network

study by selecting materials and specific situations actualized by parents. This is what I refer to as ‘following parents’ in the study design which indicates exploring similar parenting practices of other parents of CI users as well as first-hand engagement in real life situations and in online discussion forums.

In short the methods used move between a study of experience and a study where practices, in a broad sense, are included. A concrete example of this is how I track actions referred to in parents’ accounts of unsettling incidents into other situations i.e. from tangible hearing device materials through digital and visual materials. Building on the idea of the body multiple and how being is both representation as well as enactment (Mol, 2002 pp. 54-55), I used connections of actions to investigate how parenting in certain respects is shared. I call this *material affectivity*: a term to comprise how material, affect and activities are involved in how a parent practicalizes, a way of going about parenting emanating from the grasping or apprehending the senses and needs of another human being. Studying how practices involving objects like computers and cochlear implants as a part of everyday life requires different techniques to take on the task of describing how events take place simultaneously and in different settings (Czarniawska-Joerges, 2007).

## Entangled pedagogical research

The study designed for this dissertation project in many respects began with thinking about participatory methods namely how to harvest earlier experiences and combine them with situations to which I could gain access to do unique research. The idea to study parenting in a particular situation where the social sciences in health and illness meet deaf and disability studies placed the current project squarely in an empirical tradition of researching everyday life. This is one of the most defining characteristics of the theoretical framework and the methodological choices. The best way to describe the approach is through laying out the connections between the study object and my position as researcher. Faye Ginsburg and Rayna Rapp, two American anthropologists describe their own research to be what they coined ‘entangled ethnography’ (2013). In the article *Entangled ethnography: Imagining a future for young adults with learning disabilities*, Ginsburg and Rapp add to the vocabulary of ‘engaged anthropology’ and have provided me with a way to unpack the current project by using a framework which insists on being explicit about how researchers always have stakes in the processes they are describing and studying. In this respect,

research in this field is interwoven with activism and development of practice.

## Researcher entanglement

My own research is characterized by similar entanglements with several centers. Although these overlap I present these entanglements with the following headings: existential, education, linguistic, deaf/disability, research-advocacy, and social literacy.

*Existential entanglement:* When I became a parent of a child who connected me to habilitation programs focusing on interpersonal communication with infants, I was able to see how these ‘early in parenting’ occasions grew in significance as time passed. This was because of the type of future relationships made possible when combined outreach programs involving signed communication starting from infancy were embarked upon. This is best described as an existential transformation: my child and family exist as they do today, socially and culturally, because of how we benefitted from these involvements which is connected to the next point.

*Pedagogical entanglement:* The instance which provided the idea for an area of study came about through being involved as an educator in Swedish liberal non-formal adult education contexts (folkhögskollärare) and then becoming one of the adults in this type of learning process situated in a life-long learning environment. Being in a new learning situation, to know more about signing as communication with children was contemplated and observed from a teacher perspective, a learner perspective and a parent perspective. The pedagogical entanglement in these relationships led to being able to formalize these experiences into a research aim.

*Linguistic entanglement:* The intersection between signed communication and signed language was demonstrated for me by a signed communication instructor who was a hearing parent of an adult deaf child. In addition to this she was an ‘extra parent’ to a person with Down syndrome from an early age. She demonstrated language and taught language through continuously giving examples from these relationships. She was teaching that you need to learn about the other person in order to be able to convey your own cognitive idea to them, and this realization about communicative competency came to be seen by parents as much more valuable than the signing vocabulary they would retain. This entangled instructor (deafness, disability and language) connected cognition, expression and modalities of language in how parents can relate to their children and what that means for the child as a grown individual. Willingness to understand another person has to override your feeling of inadequacy in a new language system. This teacher’s outlook on

languages became combined with my own view where learning more language is inherently enriching and desirable. These experiences provided living examples of descriptive linguistic knowledge unhindered by language ideologies or equating language use as intelligence.

*Deaf dis/ability entanglement:* Through personal experience, the access to signed language and to deaf sign language users presented an opportunity to examine broad inclusion in disability and deaf communities and found these communities to have common goals. The individuals I came into contact with who encouraged and facilitated projects of using sign language with other categories of people than those who are deaf and hard of hearing demonstrated openings in boundaries that are seldom investigated. These people lived their lives in entangled spaces and in so doing offer realness to an intersection which was difficult to grasp, namely deafness/Deaf culture/disability because of historical oppression and persistent stigma from all directions.

*Research-advocacy entanglement:* I was invested with power when I was able to independently choose a research interest after being accepted to a doctoral research program in Education. When I decided on examining meaning-making in parenting and disability I engaged in putting the spotlight on an area I personally felt was under-prioritized in scholarship which in itself is an act of advocacy meant to benefit these groups in society. Advocacy entangled in research is also demonstrated in how the aims of a doctoral study coincide with the aims of special interest groups for families and individuals in deaf communities and disability communities. Familiarizing myself with the field, looking for answers to exploratory questions and searching out people who could share their stories increased my personal involvement with individuals and increased my advocacy efforts. The two separate processes of research and advocacy grew tighter together through my growing knowledge of lives lived in similar ways to my own. This indirectly resulted in becoming a member of organizations offering activities geared towards my own needs and wishes for my family which then led to increased engagement in special interest politics from a personal standpoint. All the while declaring for others the original research interest and researcher position, these new affiliations became vital parts of the fieldwork.

*Social literacy entanglement:* An inductive research approach process led me to examine the findings of this study at increasingly higher and broader levels to identify the main contribution of the dissertation. Asking how this knowledge can be understood in local and universal ways required that I used Internet based forums for discussing societal issues. In addition to this, interconnected and globally spread online groups were a part of the

empirical study. The terms and discourses in these groups offered a way of thinking about the research contribution as it was emerging in the groups in focus and groups in similar struggles. I came to see the project's contribution as a way people, particularly parents, may become knowledgeable about others' life conditions. The term 'social literacy' entered through social media use. A parent literacy idea entered through how one learns through a child. The different statuses and areas of identity a person holds intersect with the unquestioned norm and invisible privilege that they hold in similar respect to other positions and belongings. White racial literacy, examining heteronormativity and acknowledging gender power relations require similar types of self-examining and experiential knowledge as does a literacy about disabilities and deaf communities. The internal entanglement of different factors of oppression as targets of social norm criticism became more apparent throughout the project because of social (media) engagement between individuals figuring in the study but not least my own engagement with these issues through personal relationships.

In addition to this I can identify some other entanglements that have been of importance to my study. From the beginning of the project I intended to combine my expertise in academic disciplines by building on the training I have received in linguistics, psychology of second language learning and adult pedagogy with the methods and objects of study in anthropology and ethnology. This was done to realize an overreaching social science endeavor to interrogate medicine and disability. As a project proceeds, others' definitions and identifications of what you are pursuing are also interwoven. Groups of researchers in different departments lay claims to the emerging dissertation which reinforces entanglement with others' objectives and perspectives in research. Who becomes interested and how this leads to opportunities to engage outside of one's immediate departmental affiliation provide new sources of legitimacy for interdisciplinary projects. It can just as well reveal structures which will continue to hinder cooperation. These opportunities interact with how I intend to communicate findings as well as what analytical conclusions are possible through differing perspectives.

Supervisors and researcher colleagues influenced how I identified my project in terms of theoretical perspective and approach. What these experts say and do in their role to ensure the quality of a doctoral dissertation led towards formalization in stating what the study is about and what needs to be understood about how it was carried out. This includes how these scholars locate similarities with other established researchers and is an additional way to become entangled in ways of thinking and doing research. Articles and studies in close lying approaches and areas of interest become a part of the project when formalizing the written text. Connections to researchers through research networks serve to tie one tighter to a theoretical

commitment which insists on being clear about having stakes in the research project, both personal and professional.

## Phenomenological method and hermeneutical awareness

My use of the notion of the lifeworld involves departing from a phenomenological approach as a part of a method that strives to include the embodied lived experience of everyday life in what becomes a socially shared reality (Hydén & Olin Lauritzen, 2007). The lifeworld enables a focus on both the body and the social in *lived parenting* and *doing parenting* through phenomenological awareness. Conceptualizing these notions developed into a method for organizing this project circulating around the cochlear implant. I began by including physical, sensible, social and imagined elements in ideas about the lifeworld. This allowed me to pay close attention to including both the virtual and the material of technology like the Internet and cochlear implantation as parts of parents' own perspectives of every day practices and the networks of parenting they engage in.

My focus on lived parenting makes it natural to build my analyses on the parents' first-person perspectives of the meaning of their own parenting. However, there are also other significant perspectives expressed in the interviews about the parents' ways of understanding and caring for their children which provides material which transcends individual experience. These include numerous examples where the parents refer to other parents, professionals and children as well as objects and practices. In my analysis, an in-group or 'we-perspective' came to be of considerable importance because of how it illuminates a need for parents to share experiences, views and strategies with other parents in order to understand their own experience of sensorial differentness.

A *hermeneutical awareness* has sharpened my attentiveness for and understanding of the parents' perspectives emanating from a phenomenological departure. The purpose of cultivating this awareness is to interpret meanings hidden behind what is said and done. Some of the meanings are deeply personal but my hermeneutical awareness aims at disclosing social, cultural and linguistic influence on what the parents expressed in statements and actions. In methodological terms, I use hermeneutical awareness to guide the steps which begin by first grasping the meaning in parents' accounts from their own sociocultural and linguistic vantage point and then relate this to the rest of the material including the social, cultural and historical context in which the study is placed. To be hermeneutically aware is to utilize how the deeper understanding of the

empirical material as a whole is established by the reference to separate accounts and situations. These individual parts are understood in reference to the whole material including the larger context of interpreting everyday life. The following methodological discussion of hermeneutical awareness outlines how this was carried out in respect to the current study.

The first interpretive move is to use this phenomenological point of departure to go from description of what one person experiences to discover meaning that isn't immediately apparent. The second interpretive move is to put the individual first-person perspective into a social context. Interviewing numerous parents allows an entry into what individuals share. In order to understand the parents' interaction with others, it is necessary to transcend their experiential perspectives and interpret the interaction from a third person researcher perspective. Utilizing the interpretive and the descriptive methods are how both the first-person perspective and a study of situatedness are used in analysis to account for the issues the parents begin to reflect upon and where this leads them.

Hermeneutical awareness in an ethnographic approach has also been the means to link the fieldwork and the interview studies in an overall interpretative analysis. Thus, in the analysis of interviews I am supported by my previous knowledge of situations studied in the fieldwork. I use it in an interpretive cycle which oscillates between a holistic understanding of findings from both the field studies and the first-person perspective interviews. The central criteria for interpretation are a convergence between the whole and the parts. The parts are the build up to the comprehensive understanding which then is used to interpret each piece. A concluding main interpretation is reached through this conceivable reading which is supported with both internal and external plausibility criteria. All interpretations are constantly checked against the data which is a unique collection of excerpts and descriptions as illustrative examples. An additional external criterion draws on eliminating other interpretations and utilizing accepted knowledge in qualitative social science investigating everyday experience (Lange & Westin, 1985).

An awareness which is both critical and interpretive is often described as being a product of a circular or spiral process. Such a process uses internal and external criteria. An example of this used in education research and disability studies is the interpretation process of experience-near and experience-distant empirical sources as described by Gustavsson and Bergström (2005 p. 199). They describe a relationship between interpretation and social science research endeavors. There is a specific interest in social science to reach the type of historical interpretation which is given meaning through the actor's world and experience. Gustavsson and Bergström see this

as a type of tracking activity or a following of tracks. Lived parenting and doing parenting are a parent's world and considered as experience-near. The theoretical and existential elements in interpretation are characterized as experience-distant and include how social theory analyzes culture as a shared phenomenon. What parents are experiencing can then be analyzed with the shared values, beliefs and thoughts in this type of organized meaning anthropologists denote as culture. The practices through which meaning is given to what a parent experiences is interpreted through the pendulum movement between experience-near 'tracking' of what an individual's actions mean for them as life conditions and experience-distant readings of tracking with theory. This is the basis of the validity of the interpretation. Since there is always the possibility of embarking on an additional revolution in the hermeneutical circle, the analysis is working with ever changing and fluid materials.

Zygmunt Bauman writes about how both Heidegger and Gadamer make the point that the basis of a hermeneutical analysis will be found in 'understanding as the work of life' (Bauman, 1992 p. 149). This is to say that understanding is a problem in the world, to be solved in the world, which points to the impossibility of absolute truth free from prejudice or other pre-conceived human notions. There is no understanding or interpretation free from history since human existence is related to the past and future. Bauman discusses how thought and language function hermeneutically quoting Gadamer: "Speaking remains tied to the language as a whole, the hermeneutic virtuality of discourse which surpasses at any moment that which has been said" (Bauman, 1992 p. 171). This motivates the ambition to study meaning transcending what is said in interviews by applying hermeneutical awareness. This understanding of real language is exemplified in what happens in natural conversations (spoken or signed). The meaning of any action is situated in the actor's own project. To access any meaning in human action, there has to be an element of thinking what the other person means as if you were that other person. Words, their meanings, are woven together with 'the texture of life they share' and 'life shows through the words' (Bauman, 1992 p. 30). Here, *Leben* is the central ontological concept in understanding through interpretation since it leads methodology to investigate a totality of life in context which includes both structure and texture.

In the same way, hermeneutic awareness in the analysis refers to utilizing and successively developing an informed and nuanced interpretation from the spoken, written and observed material. Here, holistic interpretations of the accounts of all the parents were founded on comparative analyses of the individual parents' interviews, first in relation to the entire interview material from one individual and then in relation to all of the accounts from

each person interviewed. In the initial phase of the interpretive work the foundations of the general interpretations were controlled against the excerpts from the individual parents. On a more concrete level of analysis, each individual interview was first thematically analyzed and then all themes were compared with themes from other interviews in order to identify important similarities and differences. This process of interpretation can be described as a successive process from experience-near interpretation of the individual parents' accounts towards more experience-distant i.e. theoretical interpretations of the lifeworld and networks of parents (Gustavsson, 2001a).

An example of how the hermeneutical awareness has contributed to interpretations on different levels is how my understanding of the parents' account, presented in the chapters initially focusing on first-person perspectives, were completed by knowledge from investigations into parental practices and activities. These endeavors are not explicit in the parents' own accounts. This is a third person perspective from fieldwork. As a result of this, the overarching terms indicating a transcendence of individual experiences are used: material affectivity, becoming, be/longing and orientation. Traditional methods where a researcher is in one place and time are not able to capture practices, objects and people in parallel action (Czarniawska-Joerges, 2007). Following Czarniawska-Joerges's arguments in *Shadowing and other techniques for doing fieldwork in modern societies* the methods to study everyday life require including the shared domain in the descriptions to provide a comprehensible account.

Charles Westin has written about his reflections on the genesis of his hermeneutical dissertation (Westin, 1994). He describes the concrete steps he took starting with a decision to interpret what immigrants wrote about their experiences which required using inductive methods and general knowledge and ideas from theories about identity. There was a dialogue between parts within the same person's letter with parts from other's letters and then with themes i.e.; 'arrival', 'encounters' and 'looking back'. Seeing possible ways to organize experience with themes in the letters contributed to the steps from empirical data to generalization and then to a theory of an immigrant's experience.

In the analysis of interviews I am supported by my previous knowledge of situations studied in the fieldwork. I use it in an interpretive cycle, a dialogue between parts, which oscillates between a holistic understanding of the field studies organized by being parent centered (where parents are and carry out actions) and the first-person perspective interviews. This hermeneutic awareness has been utilized in successively developing an informed and nuanced interpretation of the interview material as a whole vis-à-vis the individual parent's interview, excerpts from other parents on emerging

themes and the backdrop of the project in its entirety. This process of interpretation uses the parents' understandings of their lifeworld, an experience near account, and my experience-distant researcher understanding of what phenomenon they are making sense (Gustavsson, 2001b). In short, the participant observation provides ethnographic texture and is a wider perspective which moves beyond the lifeworld of people to discover properties of structures in the shared world (Smith 2002; Smith 1987).

This method of phenomenological and hermeneutical awareness is utilized differently in the empirical chapters depending on how the data was generated. In this way the method founded in phenomenological theory is focused on practices of parenting while also allowing for insights which borrow from attending to material, affect and networks to investigate the space where differentness resides.

## Problematizing method

When using different types of empirical material, the methods as well as the empirical focus shift but the primary research interest to understand parents' sense making in their lives in sensorial differentness with their child is unchanged. Different methodologies are drawn on in order to access multiple perspectives of their lifeworld. The feminist and critical theorists I have drawn on reiterate the value of beginning in embodiment and lived experience which is how I have chosen works with methodological and conceptual links. For example, the analysis of parents' accounts showed how closely connected their experiences were to the technology of the cochlear implant. This necessitated transcending the first person perspective in trying to understand the interconnectedness between the sense making of technology, the child and the parents. My in-depth analysis of the process of the parents' sense making also demanded that this process was understood against the backdrop of their interconnectedness with other parents and professionals engaged in similar sense making projects. In addition, the netnographic studies of shared parenting were used to explore how the phenomenological first person perspective is constituted in the interconnectedness and communication between parents which required a social phenomenological approach. In summary, I chose to continue my analysis by including new contexts and methodological perspectives of crucial importance to my understanding of what parenting a deaf child who uses a cochlear implant means.

Although the theorists figuring in the dissertation have different ontological, epistemological and axiological assumptions I utilize them in the overarching interpretation project. The separate parts organized in the five empirical chapters are brought together to form a 'whole' which is constructed by using a certain degree of innovation in order to advance the analysis. In this way the findings are brought together leading to a result which is greater than the sum of its parts and is what enables the abstraction. Interpretive integration considering many perspectives strives to approximate the most accurate way to understand the study object of the experiences and networks of parents of children who use cochlear implants.

The questioning of truthfulness of first person accounts is answered with pointing to how beliefs, prejudices, everyday thinking, formation of identity and cognition are what influence and shape experience. It is the exploration of the lifeworld of the individuals which is central and not an ultimate truth, correctness of content or isolated motives. In answer to the criticism of how a researcher intervenes through interpreting interviews and observations, every act of knowing is at the same time an act of interpretation. This reiterates one basic tenet of critical hermeneutics: a researcher's endeavor involves keeping track of one's own prejudices, not to judge them but to acknowledge and draw on them in the study (Bauman, 1992). A related issue is that the empirical materials used in the qualitative methodology analysis are made accessible for scrutiny and the methodological steps are thoroughly and systematically described in the following section. Also, any claims of generalization refer to being able to extend the findings to other similar socio-cultural contexts and situations.

## Data generation

Data was generated in order to answer questions about parents' everyday life. I started with participant observation in groups where parents have found the need to learn sign language in the non-formal education context referred to as TUFF (TUFF Regulation for national grant for sign language instruction for certain parents, 1997). I used notes from fieldwork to formulate investigative questions for a pre-study on cochlear implants and parent organizations. I interviewed four parents in this pre-study, one with a deaf child, one with a child who uses hearing aids, a parent of a child who was implanted with cochlear implants after the age of 3, and a parent of two children who were implanted before the age of two. This last parent's interview is included in the chart of the 19 parents in the interview study. I also interviewed one CI using adult who was recently implanted after suddenly becoming deaf at the age of 20. I presented these exploratory

findings in seminars and proceeded to design the main study. My initial training in researching medical technology in the lifeworld influenced my choice in using the CI as the central artefact to delineate the study by including this technology use as a unifying element in a parenting context.

Parents of children who are implanted early are often a secondary part of research interests about children, their development and cochlear implantation (Anmyr, 2014; Asker-Årnason, 2011; Ibertsson, 2009; Karlsson, 2013; Löfkvist, 2014; Magnuson, 2000). I decided to delimit the group of parents to be interviewed by utilizing age of implantation as a factor. When the age of implantation dropped after the implementation of universal hearing screening of infants in Sweden in 2007, a new group became available to investigate. The literature also identifies this group as new often mentioning the fact there are still a very small number of children who were implanted early and have reached adult age. I chose to only include parents of children implanted during the first two years of life in the interviews to be able to describe their early experiences which are historically unique due to the practices leading to early cochlear implantation. I discovered the significance of how this group of children is seen and portrayed differently in respect to their hearing status and technology use and I drew the conclusion that I would be able to add to the knowledge of every day experiences of cochlear implantation from parents' perspectives. The study was designed to then investigate how parents learn from parents in broader groups under the umbrella of parents in sensorial differentness.

Because of family ties and prolonged stays in the area, I was able to establish contacts with several universities in the United States. I took the opportunity to include this fieldwork material to expand the variation and reach of the study. Two interviews with one parent from this context are conducted in English and are included in the interview study material.

In line with a preliminary interest to explore if parenting of a child with a CI was different in (spoken) bilingual families, my invitation to parents to take part in the study was written in both Swedish and English. At a later point I abandoned this objective but it did result in that some of the interviews were in Swedish and others in English depending on the participant's preference. In one case a participant was interviewed in Swedish in the first interview and in English in the second.

## Overview of the empirical material in the dissertation project

In this project I have generated several kinds of data. Apart from the pre-study, ethnographic study and the main interview study, digital observations from computer mediated communication (CMC) were conducted. The collection of empirical material started with participant observation in parent groups. The decision of what type of parent experience to investigate was a result of this physical participant observation. The digital participant observation developed out of discoveries about the parents' presence online. This was a significant part of their everyday parenting in respect to the research interest (Murthy, 2008). The 19 participants frequently use information and communication technology (ICT) and social media related to their parenting a child with a cochlear implant.

*Table 2: Overview of empirical material. See appendix 8 for complete listing.*

Type of study	Participants	Data collected
Pre-study	2011 Four parents and one CI user interviewed	Recorded interviews and ethnographic protocols
Interview study	2011-2015 19 parents interviewed	Recorded interviews and ethnographic interviews (written notes) See chart below
Physical participant observation	2011-2015 Parents of CI user-centered contexts	Ethnographic protocols Appendix 8
Ethnographic interviews	2011-2015 Approx. 30 informants	Ethnographic protocols Appendix 8
Digital participant observation	2013-2014 10 SMS groups	Netnographic protocols
Analysis of digital images and films	2013-2014 40 entries	Netnographic protocols

# The interview study

## Recruiting participants

A ‘call for informants’ in English and Swedish was posted physically and distributed electronically in contexts connected to CI clinics, hearing rehabilitation clinics, on bulletin boards in schools, centers and organizations frequented by parents of DHH children (Appendix 1, 2, 3). The text appeared in both languages in social media site groups directed towards parents of children with cochlear implants or hearing impairment as well as on special interest organization websites. The ‘call for informants’ letter was also distributed through email contacts to these organizations’ board members and three hearing centers in a southeastern region of the United States prior to planned fieldwork which occurred during the spring of 2014.

Nearly all the parents who contacted me who had a child who was implanted early were interviewed. Time constraints hindered two parents from being interviewed. I asked all of the parents who contacted me if they knew of other parents who might be interested in participating and this snowball effect resulted in further recruitment. On several occasions personal contacts led to distributing the ‘call for informants’ letter through social media messaging as well as other informal social ties. After 15 first interviews were conducted I stopped actively recruiting but was contacted by three more parents and included them in the study. One parent from the pre-study is included in the interview study totaling 19 parents in the interview data.

In a preliminary conversation prior to the interviews I explained my project, verbally or through email. I asked individuals what they thought about the study, if they knew of other parents who had children who used cochlear implants and similar questions to begin to introduce the project to them. When I approached parents after they had contacted me I continued to inform them according to the ethical guidelines (Gustafsson, Hermerén, & Petterson, 2011).

## Conducting the interviews

A greater part of the work involved in interviewing was conducted in Swedish. Since 1984, aside from short intervals of study in the United States, Swedish has been my primary language of communication. I have lived, studied and worked in Sweden intermittently from the age of 17. My research training was primarily in Swedish. Two participants have English as

a first language and their interviews were in English which included Swedish terms and phrases like names of Swedish institutions, places and concepts they were accustomed to referring to in Swedish. One participant spoke primarily English in her home. The language used in establishing contact was English. The first interview was in Swedish. In the email contact in between she suggested doing the second interview in English. All in all six of the interviews were conducted in English, two of which were conducted in the USA.

The interviews were approximately 1 to 1 and ½ hours in length. They were digitally recorded and are stored on a hard disc and flash drive/usb memory. The interviews which were not recorded are kept in handwritten form in field notes and typed in text files stored digitally in the same fashion. Of the three interviews in the pilot study, only one was transcribed and the unrecorded interviews were summarized in notes. Four interviews were conducted on Skype where the participants were in their own homes.

I have had email or social media messaging contact with each of the participants after their interviews to either set up a second interview or to ask additional questions for clarification after transcribing the interview. I conducted a second interview with 11 of the 19 parents. The other seven parents were only interviewed once due to their time constraints, interest or feelings of having contributed what they could but even in these cases there is additional material in the form of emails, text messages, links to websites and social media postings.

## The interview guide

The interview guide (Appendix 4) developed out of the first interviews I had conducted in the pre-study. I adjusted the interview guide after findings from the pre-study to be able to include significant practices connected to parenting which included preschool choice, school situations, contacts with rehabilitation teams, therapies, medical encounters, and dealings with the insurance and school authorities. This adjustment added attentiveness to when parents were in contact with other parents to incorporate the interview study into the ensuing fieldwork. The second interviews were used to expand questioning in areas explored in the first interview.

I applied an open-ended technique in conducting the interviews with the parents drawing on the list of questions in the interview guide. At least once during the interviews I would pause our exchange by reading through the guide I had in front of me. I would check that we had addressed all the questions and at times used this as an opportunity to redirect the interview to

maintain content uniformity of what would then be the transcribed material. An open ended variant of a semi-structured interview implies that I intended to investigate yet unknown areas connected to their experiences and by doing this I was able to make discoveries of how parents ‘do parenting’ in these particular circumstances involving sensorial differentness. This led to the second step in the development of the design of the project: to follow activities and participation similar to the ones described in the interviews. This shaped the fieldwork by investigating connectedness into other forums for example different types of participation in social media groups, activities organized for children and medically or therapy related encounters.

I made efforts to not let the interview go longer than 1 and 1/2 hours and would often ask to get back to them to schedule another interview instead. Some participants felt they had shared as much as they could at this point but agreed to let me contact them in the future when the child was older or if the study led to other projects. This interview method also aided in developing relationships with the participants where the issue of trust was instrumental in the formation of parts of the data, namely the fieldwork. Examples include how I was given permission and access to use blogs, invited to join Facebook groups, and meet family members in informal settings. I was also invited to participate in social activities as well as advisory forums and meetings organized for parents of deaf or hard of hearing children.

## The participants in the interview study

The group of 19 parents shares a number of traits. They range in age from early 30s to mid- 40s. They have more than one child. The CI using child was implanted at the age of two years or earlier. 18 of the 19 parents in the interview study were in a Swedish context i.e., they either were currently living in Sweden most of the time or they were Swedish. Swedish is used by 18 of the participants but in varying degrees. The children of the parents interviewed were currently enrolled in a preschool program or compulsory school where Swedish was either the main language of instruction or Swedish was one of two languages in a sign bilingual school setting. The one exception in relation to sociocultural context is William. He was interviewed during the two-week fieldwork in the north-eastern United States.

There were a number of different languages used in homes. Coincidentally, the homes where the only spoken language used was Swedish had connections to or acquaintances with people who knew and used Swedish Sign Language.

The biographical information in the chart of participants includes first the alias of the parent followed in parentheses by the letter S for spoken orientation or B for bimodal orientation. This is a general indication of a parent's communication orientation. Twelve participants are described as primarily bimodal in orientation. Then follows a name of the child if it figures in the material and age of the child at the time of the interview, assistive hearing devices, spoken languages used in the home, whether or not signs or signing is used at home and finally the number of interviews conducted and type of interview data. Additional children with typical hearing are not included in the chart. All the names have been changed. Details like sex of the child, geographical places or school and hospital names are omitted or changed in the excerpts presented in the study.

*Table 3: Chart of interview participants*

	Name of parent (CO)	Age of child(ren) name figurative	Assistive devices	Spoken languages used in home	Signing or sign language used	Number and type of interviews
1	Ebba (B)	Adam, 2	CI+HA	Swedish and English	Yes	2 semi-structured (1 in English)
2	Daniel (B)	Siri, 5 and Kajsa, 4	CI+HA (both children)	Swedish	Yes	2 semi-structured
3	Josef (B)	3	CI	Non-European	Yes	2 semi-structured
4	Mari (B)	Andreas, 12 and Elin, 14	CI (both children)	Swedish	Yes	2 semi-structured 2 fieldwork
5	Håkan (B)	13 and 16	CI (both children)	Swedish	Yes	2 semi-structured 1 fieldwork
6	Leif (B)	Nina, 10	CI	Swedish and European	Yes	1 semi-structured 1 fieldwork
7	Ella (B)	Hugo, 9	CI	Swedish and European	Yes	1 semi-structured
8	Hillevi (S)	Sanna, 11	CI	Swedish and European	Yes	1 semi-structured
9	William (S)	Oscar, 3	Bilateral CIs	English	No	2 semi-structured (English)
10	John (B)	Hannes, 4	CI +HA	Swedish and English (Scottish)	Yes	1 semi-structured 1 fieldwork (English)

*Table 3: Chart of interview participants*

	Name of parent (CO)	Age of child(ren) name figurative	Assistive devices	Spoken languages used in home	Signing or sign language used	Number and type of interviews
11	Catherine (S)	Emil, 11	Bilateral CIs	Swedish and European (French)	No	1 semi-structured (English)
12	Olivia (B)	Elias, 4	Bilateral CIs	Swedish	Yes	2 semi-structured
13	Peter (S)	Sam, 10	Bilateral CIs	Swedish and European	No	1 semi-structured
14	Mario (S)	Sanna, 11	CI	Swedish and European	Yes	1 semi-structured
15	Ilona (S)	Michael, 6 and Ben, 13	CI (6) HA (13)	European	No	2 semi-structured
16	Erika (S)	Theo, 8	Bilateral CIs	Swedish	No	1 fieldwork
17	Tomas (B)	5, 7	HA (5) CI (7)	Swedish	Yes	1 fieldwork
18	Anneli (B)	Johanna, 6	CI and HA	Swedish	Yes	1 semi-structured
19	Tess (B)	Anton, 2	CI+HA	Swedish and European	Yes	2 semi-structured

Semi-structured interviews were digitally recorded and transcribed. The interviews referred to as ‘fieldwork’ were of varying lengths, thematic and not digitally recorded. Notes were taken during and/or after these interviews. Unless specified the interviews were conducted in Swedish. When conversations in the field were extended to being able to ask specific questions following themes in the interview guide, they were then regarded as part of the interview study. The reason these individual encounters were included in this way is motivated by the similar criteria in experience as parents and the length and depth of the exchange. Compiled interview material listed in the table is analyzed using the same steps and procedures. A much broader range of subject matter gathered in connection to these interviews is considered to be a part of the fieldwork.

## Transcription conventions and translation

The level of detail in transcription notations is relevant to the thematic analysis of experience utilized in the interview study. In order to be able to remember the interview as an event the conventions in the transcriptions serve as a mnemonic device for interpretation purposes. When the excerpts are presented in the result chapters, they appear mostly in conventional written English and Swedish with fewer notations. Paralinguistic information including intonation, gestures or signed words or concepts borrowed from a signed language are included in the excerpts if it is significant for the analysis. The more detailed conventions used in the original transcription documents follows the notations in the appendix (Appendix 7).

In preparation for the presentation of the manuscript at the final reading seminar the majority of the excerpts were then translated into English. Up until that point the Swedish excerpts were presented in the analysis in Swedish. The motivation for this was to allow for transparency and understanding when seminar participants, readers and supervisors had Swedish as their first language.

The layout of the format for the printing of the dissertation made it impractical to include the translations side by side in the empirical chapters as was originally intended. These excerpts and their translations are digitally stored in a separate file with the empirical material.

## Presentation of interview material

The interview material in its entirety is used in the analysis, however certain parents' accounts are used to demonstrate central themes in the empirical chapters. Excerpts from two parents' interviews are presented in Chapter 5. In Chapter 6, the excerpts from three parents figure in the analysis. All 19 participants are discussed in Chapter 7. Chapter 8 incorporates all the data in the study, netnographic, ethnographic and the interviews through using a composite conversation method outlined below. In the last empirical chapter, Chapter 9 I conducted a case study where I reconstructed one parent's history over time to understand why his account and views differ in a particular respect regarding parenting. This holistic presentation of one individual is an instance of a parent who has developed a type of proficiency in relation to disability which I then use to reflect on and identify characteristics in the other interviews where I then refer to seven other parents.

## Fieldwork

The interview study and the fieldwork were to some extent used together in the generation of empirical material and are steps in the analytic process where the thematic content in each are compared which served as an organizing tool. For instances, I began participant observation to acquire background information about pediatric cochlear implantation and related practices. As I increased the fieldwork sites and began to find participants for the pilot study I was able to develop a detailed understanding of the different groups and actors involved in the everyday life of a parent who has a child who is deaf or hard of hearing. After delimiting the study to focus on a smaller group of parents I concentrated fieldwork to be organized around parent to parent contexts in regard to cochlear implantation. The strategy for fieldwork has always been to stay close to what parents experience in what they do and where they reside.

I organized the fieldwork using two sources for method. One is taken from *Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography* (Marcus, 1995) and *Shadowing and other Techniques for Doing Fieldwork in Modern Societies* (Czarniawska-Joerges, 2007). In order to provide a detailed and nuanced understanding of parenting a cochlear implant user seen as a particular cultural phenomenon, I utilized participant observation as well as ethnographic interviews to be able to grasp and use the language as it was used in the parents' semantic references. In ethnographic interviews I used strategies aimed at getting people to talk about what they know intuitively in order to make cultural inferences from what they said as well as what they did by combining it with the participant observation (Spradley, 1979). I saw it as essential for understanding, to include a cultural focus on for example use of terms in the communities. It is part of what I see as a requirement to comprehend meaning in the different social and cultural contexts. This is what I mean by the study being 'ethnographically informed'. A naturalistic setting is accessed where the informants are engaging in practices of parenting which are to a large extent utilizing tools and language, for example CI technology and signing. What was undertaken to produce the description includes both the socio-cultural contextual terms and meanings used by the actors as well the researcher's own style for communicating (Spradley, 1979 p. 24). Parenting, as a part of a cultural practice includes the encounters with people and practices as a cultural group experience. Three main arenas are the medical contexts, the educational contexts and the cultural historical contexts of deafness and disability.

This compromises the ‘fieldwork on the move’ utilized from an adaption of shadowing techniques, not to describe parents or their ways of life but the nature of this particular type of parenting experience situated in disability (Czarniawska, 2004; Czarniawska-Joerges, 2007). I chose to involve myself as a participant as well as an observer in the new situations these parents had found themselves. Including the cultural meaning systems and the way society is structured relating to these is how the goals of describing experience and sense-making have been reached. I use the fieldwork as an internal validation system of my descriptions.

### Ethnographic interviews within the fieldwork material

I have conducted ethnographic interviews with people other than parents compiled in the list of sites and contexts where field notes were generated (Appendix 8). The term ‘interview’ is used in a very broad sense including informal conversations and fact finding inquiries. These were written by hand or on mobile devices during or after the fieldwork day ended. This material is dated and labeled by event and/or informant and can be found in the overview of the contexts that have been included in the fieldwork (Appendix 8). At times appointments were made with individuals and in other instances conversations evolved into interviews like in waiting rooms at clinics or where short questions led to offers to take part in meetings or consultations. These interview notes were combined with field notes for each separate context. Field notes and photographic images were also compiled in digital file form on computers, tablets and mobile devices. Photographic images were also included in the fieldwork protocols.

### Networks of parents

The online sites I included in the fieldwork follow the same method as presented above. I either carried out similar activities to the ones reported by individual parents or investigated information they believed I would be interested in. This fieldwork was shaped by what a parent would be likely to be engaged in when searching for information, browsing content online and visiting social media sites. I carried out Internet searches, read online material and followed how visual data was shared and linked through social media sites by parents like the ones in focus in this study. I often asked parents what sites they use and sources they recommend to other parents they meet or were themselves given recommendations about. An example of how I worked was to investigate specific details that were part of parent interviews. As my network of contacts grew as a result of the study I proceeded to send emails to people I had come into contact with and was

guided to Internet sources which they as parents, professionals or activists identified as reliable or helpful. Again the aim to describe parenting in this computer mediated communication situatedness drove the method. It is in this way that the netnographic approach I used is mixed. This part of the study is not restricted to online interaction but interwoven as it is engaged in by parents in day to day living (Kozinets, 2010 pp. 59-73; Kozinets, 2015 pp. 15-18).

## Netnographic fieldwork

I have conducted participant observation in social media sites (SMS) and online support groups (OSG) which comprises the part of the digital fieldwork through computer mediated communication (CMC) and is specified as netnographic. During an 18 month period, between the beginning of 2013 through the summer of 2015, I conducted participant observation in ten closed groups and five open groups which parents had reported using. My researcher role in the netnographic fieldwork depended on my access in each specific group. The closed groups required approval by the moderators which in some cases required specifying my role as a parent and details about my children. In each case I was required to offer personal information I included my research motives. If I participated actively involving more than reading other members' posts I posted information about my research project. This social media arena was delimited to ten groups, both open and closed, used by parents of deaf and hard of hearing children both in Swedish and English. Some of these groups are affiliated with special interest organizations and others have been started independently by individual parents. The majority of these SMSs are situated in a Swedish context with the exception of three groups using English. The three English language based groups were added to the participant observation material when the re-posting of articles and links in the Swedish based groups from these sources were found to be significant.

Blogs and vlogs (a form of blog often including embedded video links, supporting text, images etc.) on the subject of parenting and hearing impairment or co-occurring disability were included in this nethnographic material when it was connected to the SMSs. Material from special interest organization websites in this Internet web based fieldwork were included in the data when it was linked to online posts and discussions in these groups.

The process of finding these sites and delimiting this part of the field study took two months. The next step was to visit these sites once a week and take notes by hand to record observations of the activity. After the half point mark, approximately nine months I identified the main issues that repeatedly

emerged. This resulted in the development of three themes which were prominent in how the users actively contributed to posting content. I then began to use these themes to re-read and re-visit the groups. I used the search word field in each group to locate discussions back in time as users are often encouraged to do by other users of the SNS. The themes were labeled ‘Thoughts about signing’, ‘Something else disability’ and ‘Technology (in)dependence’. The first theme deals with how and if to use forms of signing with a child who uses a cochlear implant. The second theme deals with how references to additional disabilities or co-occurring conditions are seen as ‘something else’ than hearing-related and discussed as potential problems or areas of concern about child behavior or diagnoses. The last theme ‘technology (in)dependence’ actualizes how humans think of technology as two-fold where it has both negative and positive consequences for its user. Being dependent on technology is a drawback, whereas gaining independence through the use of technology is the advantage and that both phenomena can be present in the same enactment.

## Composite conversation construction

The analysis is intertwined with how both the physical and digital data were collected. I applied methods of composite narrative construction in an adapted form to generate *composite conversations* since the exchanges on SMSs are commonly referred to as ‘conversations’ and the most widely used site was Facebook.

Initially this construction was adopted to solve issues of respecting privacy of individual parents which soon showed promise as a method to analyze a large amount of data from naturalistic settings (Lind, 2013 p, 18; Robinson, 2001). I followed works which adopted techniques in composite narrative construction and ethnographic fiction (Davidson & Letherby, 2014; Fisher & Goodley, 2007; Inckle, 2010; Solorzano & Yosso, 2002). The goal was to maintain a level of authenticity in the exchange in online discussions while following ethical research guidelines (Buchanan & Markham, 2012; Markham, 2005 pp. 272-274). The methods used are to ensure that the focus of lived experience of disability did not get lost in the solutions to ethical dilemmas of studying ‘vulnerable’ groups and ‘sensitive’ issues. This is a cloaked approach where I chose to use a composite technique rather than testing direct quotes in search engines (Trevisan & Reilly, 2014). In this way key themes were realistically conveyed without the disclosure of personally identifiable information. I find this to be in support of my composite conversation construction adopted in this study of the social world of parents of deaf or hard of hearing children in online communication.

The construction of a composite conversation in the empirical chapter begins with one of the major themes identified. By following the typical form and length of a Facebook conversation in the material I choose a thread starter from one of the actual conversations as an organizing tool to present the issue. After this first step I assembled original conversations on the same theme in a text document. I detected patterns in commonly occurring views, insights and opinions about the theme.

Each comment in a composite conversation is an actual quote from a user of one of the SNSs as it appeared in a discussion categorized in one of the themes. The comments are taken from multiple sites and groups, both open and closed. The exchanges between commenters came into focus and served as how the individually extracted comments would be presented. This composite method involves first collecting multiple individual entries expressing similar experiences which were found to be commonly occurring. The authentic comment which was used in the composite also represented the same function and intent of these multiple entries i.e. posing questions, stating opinions, explaining, sharing experiences, offering or enlisting support etc.

Comments from similar but separate actual conversations were extracted singly in some cases and in authentic groupings of comments as they appeared in other cases. These comments express the experiences, opinions or intent in typical exchanges in the theme. This gives the conversations an appearance which follows the pattern of the exchanges in the data. This implies that the assemblage is fictive but mirrors the existing patterns and content in the compiled material within each theme. The lettering of comments (A1, B1, B2, B3, C1...) indicates that the comments have been extracted singularly or in authentic groupings. The two composite conversations appear in Chapter 8 Networked Parenting. The first is lettered A-Q and the second is lettered R-U. This was done to provide a presentation of commonly occurring SMS group conversations in a descriptive and comprehensible form of netnographic fiction. To portray how the meaning in comments becomes shared and emerges from negotiations in communicating ideas to the other commenters, each comment is traceable to an authentic form, function and content in the data. The composite conversation as a cohesive unit represents both individual and shared meaning as it commonly takes place. Presenting realistic exchanges relays the concern, problem or question frequently posed by parents of cochlear implant users. This enables the analysis of an extensive amount of data through this netnographic method.

The majority of these SMSs used predominantly Swedish/Scandinavian. English was used on the largest sites in respect to number of members. The extracted conversations and comments were in both languages but the

construction was recorded in handwritten English and then typed out in a separate document.

This netnographic method includes taking account of modes of social interaction both online and offline (Kozinets, 2010). To do this is to add, not reduce diversification of the many ways parents make sense of the perspectives of what it means to be deaf or hard of hearing and how people they encounter transgress boundaries of models and constructions (Young & Temple, 2014).

## Analysis

In the results chapters, excerpts serve as empirical grounding with an introduction of what was being discussed during the interview. After the excerpt I point out the significance in what the parent was expressing to provide a description of how they experienced it. The interpretation includes this emphasis of significance in relation to the entire interview material from this particular parent. It is then used with excerpts from other parents analyzed in the same way to clarify the finding.

To summarize the analytical steps I have done the following: I used readings and reflections of the entire interviews in order to inductively produce the important themes and to give specific excerpts preliminary interpretations. I then discussed and tested preliminary interpretations against the entirety of the interview data and the fieldwork. Interpretations which were not supported were abandoned or reworked as the chapters were written. I present more critical interpretations together with argumentations as the chapters have been adapted. In seminars and through supervision, validity of the critical interpretations and claims in the empirical chapters were discussed in order to judge the research quality and present adequate arguments and evidence to support them.

I am studying a small number of people, their related communities and situations by pursuing different modes of existential inquiry in everyday life which motivates the unique combination of empirical material used in the presentation and analysis of each of the five empirical chapters. The generalization of these particular parents' experiences and related networks is based on similarities to other situations of parenting in disability as well as situations of differentness where the child is unlike their parents in group identity category (i.e. ethnicity, sexuality, gender, or race). Studying what it is like to be human on the one hand is a type of universal project. Studying enactment of networks on the other hand has its strengths in visualizing the

particular, the technological and the imagined in practices. My intention with using these methodologies, interviewing and participant observation, is to access authentic sources in lived accounts, as they are perceived by individuals who exist *in the world*. This includes interpretation of how a person is able to share what it is like to be this subject and how meaning is constructed in a shared social reality. It is a description of how meaning becomes shared and includes an investigation of human lives and material things, and it is useful to imagine this as what is *of the world*. An integral objective of the project is to account for complexity instead of eliminating it.

### Self-reflexivity as method

I have chosen methods that emphasize the significance of acknowledging values and experiences of who is doing the research (Zeiler & Käll, 2014). The methods draw on my positionality and have been critically assessed in each step (Mertens, 2010). Entering the sociocultural setting provides a high-quality and reliable account through detail. The method used in the fieldwork often took the form of being ‘close observation’ rather than participant observation (Van Manen, 2014 p. 318). I wanted to remember and utilize how parents physically inhabited situations as they were participating in activities alongside their children by also participating in them. I utilized different researcher positions depending on the fieldwork site. This is described by Dwyer & Buckle in how parent research involves inhabiting insider and outsider roles of the studied group (Dwyer & Buckle, 2009).

I have relied heavily on being self-reflexive through participation so as to draw on direct experience in the shared situations. I have studied lived parenting through lived parenting. I am a parent of a child who has brought me into situations which include sensorial differentness in a way which is similar to becoming a parent of a child who does not hear. This includes going back and forth from this perspective to an overarching researcher perspective which means there are multiple researcher perspectives to utilize and to question. The researcher roles through this perspective switching have been impacted by my previous life experience which serves as a sensitizing tool but must be critically examined. Much of what determined if the involvement was participant observation or observant participation rests on this type of awareness and ability to be open, sensitive and in many respects vulnerable (Adler, Adler, & Fontana, 1987; Ambert, Adler, Adler, & Detzner, 1995). A phenomenologically ‘close observation’ (Van Manen, 2014) of parenting while parenting is to utilize an embodied method. Lois Wacquant explains the implications for method which come from a conscious utilization of one’s vulnerability.

To make the most of ethnography, the field sociologist must methodically mine and thematize the fact that, like every social agent, he comes to know his object by body; and he can leverage carnal comprehension by deepening his social and symbolic insertion into the universe he studies. This means that we can and should work to become - "vulnerable observers" in our practice of fieldwork (Wacquant, 2015 p. 8).

Wacquant calls this approach enactive ethnography where to do sociological research is not only *of* the body as an object but *from* the body methodologically speaking. The flesh of how we experience is utilized in method. Wacquant explains this with Drew Leder's revision of Merleau-Ponty and the visceral in embodiment as well as the ideas from Lakoff and Johnson that when we are focusing on the embodied, thought is mostly unconscious; thought and reason are metaphorical, imaginative and affective. In short, there is emphasis on the embodied action as a way to do research. "It situates itself *not above or on the side of action but at its point of production*. Carnal sociology strives to eschew the spectatorial viewpoint and to grasp action-in-the-making, not action-already-accomplished" (Wacquant, 2015 pp. 4-5). Wacquant compares sensual ethnography with his carnal ethnography where the latter is not a study of the senses but the utilization of sensory formations as the means of study. The researcher in this way is situated in the action as it is being made. What can be grasped by being a vulnerable observer adds to the validity of the description in concrete and lived ways. In the present study, which focuses on sensorial differentness, methods developed from contemplating the sensual and sensory as ways to know, have contributed to how experience of parents is interpreted and described. Pointing to the lived experience as an insider researcher is not only vital for understanding the results, it is how 'carnal comprehension' is used in validation. Vulnerable experiences of being othered, as an immigrant, a woman, as non-Swedish, and relational situations of disability were used primarily in designing the study to capitalize on and accentuate these embodied ways of knowing. This is a way to understand how personal experiences are involved in interpretation which requires acknowledging them as a resource which needs to be controlled. Description involves sensitive portrayal and requires both method and purpose to utilize interpretation in analysis. In the article *Participant Objectivation* Bourdieu says

This does not mean that anthropologists must put nothing of themselves into their work, quite the contrary. Examples drawn from the author's own research (with special focus on field enquiries carried out concurrently in the far-away colony of Kabylia and in his home village in Béarn) show how idiosyncratic personal experiences methodically subjected to sociological control constitute irreplaceable analytic resources, and that mobilizing one's social past through self-socio-analysis can and does produce epistemic as well as existential benefits (Bourdieu, 2003 p. 281).

What is here referred to as a 'self-socio-analysis' includes presenting the steps a researcher takes in how they remain in control of knowing whose experience is being described where the researcher's experience is examined. I did this in showing how the material was generated as well as how it was analyzed. I had the following questions as guidance throughout the project: Is a particular theme central to the parents of CI users and why? In what way are these situations unique for these parents and in what ways are they shared by others? Having control of my knowledge and knowledge production was accomplished through identifying an object I knew very little about (cochlear implants), a phenomenon of which I had partial knowledge (deafness) and practices in which I was immersed (sign language use, a disability context and parenting). What is objectivized is how I came to participate in the research. Here the social world and origins of personal beliefs are examined and how they influenced my position in the social order of the research endeavor (Bourdieu, 2003 p. 283).

## Ethical considerations

For this dissertation project I have chosen methods to organize a study of everyday experiences of medical technology using a design that allows for and makes accountable a researcher's involvement in what is produced.

One specific ethical consideration in this project has to do with the cochlear implant field in Sweden being polarized by language ideologies (Holmström, 2013). The issue of competing ideas in groups related to deaf and hard of hearing experiences has been studied for the very reason that they are ethical dilemmas (Blume, 2009; Jacobsson, 2000). This can be placed in the larger context of examining practices utilizing professional knowledge, for example the medical paradigm where one expects tension in the field (Anspach & Mizrachi, 2006). The role of ethical dilemmas in social science research are well represented but studies involving language choice, technology, education with parents living in this polarized field are less so (Christiansen & Leigh, 2002; Leigh & Marschark, 2005; Leigh, 2009; Marschark et al., 2007).

A major issue discussed by parents of deaf children is whether or not to use sign language and to what degree. Throughout the project, I intentionally explained how we use sign language because one of our children has a language and learning disability but is not deaf or hearing impaired. I offered this information in order to be totally open about experience and knowledge about sign language because of how it matters to the parents in this polarized field. It also served as an opportunity for the participant to find out how this study had begun, that my research interests were about everyday experiences and technology, and that my knowledge of the controversy about language that exists in their encounters as parents of cochlear implant users was new and limited. I also represented an exception. Using and learning sign language because of language disability and not the presence of deafness presents an anomaly.

In the beginning of the study when I approached parents I had been tentative about providing any information about my personal involvement and professional motivation. Doing this became ethically problematic because it disturbed the level of trust building between the participants and me which I felt was required to do this work. I then chose to offer this information very early in the correspondence and conversations prior to interviews and participation. In many cases, the step to share information about my personal interest in the research project was initiated by questions from the parents themselves.

### Process consent

Each interview participant was emailed and/or given a copy of the research project description/call for informants (Appendix 1). Informed consent was obtained verbally from interview participants at each separate contact. This practice is called process consent (Ramcharan & Cutcliffe, 2001). The parents were in this way reminded of the possibility to discontinue participation including the use of any interview material and ethnographic material from fieldwork. Before interviews were started I gave them a new copy of the project description, a consent form (Appendix 5) and an interview record form (Appendix 6) to either fill out or update with contact information and details relevant to the study. I then repeated that I am the only one who has access to this information and that I would be keeping it in a coded version in order to be able to contact them for possible research in the future. Using verbal and written reminders of the possibility to discontinue participation throughout the process is part of the research method. I stated that in research of this kind steps are taken to ensure confidentiality but cannot guarantee anonymity (Gustafsson et al., 2011).

My primary ethical consideration during this study has to do with studying a group as an outsider even though I identify with the groups of parents in disability and parents in a signing community (Bridges, 2001). I have used my affiliations and personal relationships to access the field. Nearly every part of the study is connected to affiliations I have outside of my role as researcher. One specific example of this is my access to closed Facebook groups regarding issues concerning parents of children with hearing and communication disabilities. These groups intersect with other similar disability groups, special interest groups, NGOs and other forms of computer mediated communication. How I use information about these groups or from these groups is a recurrent ethical concern in this project.

Expanding the netnographic and ethnographic fieldwork to North American contexts was a step I took to use contrasting and similar experiences. This was done to shift the focus from such a small group of parents within one country to a larger imagined community that is very much a part of the technological and global impact of the devices and connecting information, forums and movements related to being a parent of a cochlear implant user.

In each contact with a new person I wished to include in my study I have taken steps to be sensitive to their situation and wishes. In a great deal of the fieldwork I seldom mentioned that I was gathering data at the time. It was often after the event that I made the field notes. I weighed the necessity of informed consent to the level of involvement of individuals. If their individual experience or opinion could in anyway become relevant I would take measures to notify them of my project and take steps to ensure that they could not be directly identified. The ethnographic work in this respect is not about individual experience but of what is shared, co-existing and creating a part of what I have studied in networks.

In the event that I have participated in events in order to be able to do fieldwork I have informed the organizers via email by including a current version of my research proposal abstract. At actual events I have verbally or in sign language informed groups when it has been possible and appropriate. In smaller meetings within events or activities I have introduced myself or repeated my reasons for being there. I have also participated in events that I incorporated into the fieldwork when I accompanied family and friends. This part of the data collection is clandestine. The reasons for not wanting to inform others in these instances ranged from not wanting to disturb the field to not knowing it would become part of the project until after the fact.

## Digital materials

The challenge of doing fieldwork in contemporary society is discussed in terms of how to deal with space when studies of culture and meaning are circulating globally (Czarniawska-Joerges, 2007). Instead of considering observation as something that takes place in one room at a time, solutions employed by social science researchers are presented to construct ‘mobile ethnology’. An example of this is how a shadowing method evolves and changes from an outsider position to participant observation. In this study I began to gain access to a wide array of these spaces after physically and virtually shadowing individual parents in the locations and situations listed at the end of the dissertation in the appendices section. The goal of the online fieldwork was to widen the description of this situated parenting. With this intent each encounter evolved differently as I gained entry to different spaces, the empirical material was generated with different methods which explains the varying nature of the chapters.

I adapted my netnographic approach from ethnographic approaches to studying online interaction as presented in Annette Markham’s *Life Online: Researching Real Experience in Virtual Space* (1998). The aim in her study was to make sense of peoples’ social experiences in computer mediated contexts by applying a participant observation technique where she took part in the same type of activities based on the experiences of the users themselves. “People know they are not really transcending their physical world; their body is the place where they live” (Markham, 1998). Markham is in an explicit sense a co-creator of the material and is involved in negotiations with her informants. I chose to use a similar technique but to protect privacy and confidentiality of individuals, composites of conversations from numerous sites were constructed. I did not participate in any of these exchanges. In this way I maintained a strict boundary with the online parents. I considered that anything posted in these groups could be used as data, a position which resulted in the composite conversation construction method. In using data from open and closed Internet based sources I have taken steps to inform the participants in Facebook groups by introducing myself and my research project and by posting the ‘call for informants’ letter in open and closed groups (Netnographic fieldwork protocol 12). The moderators of the groups commented on my post in the forums which was followed up with discussions by users visible on the site. These discussions resulted in allowing or denying this type of post and interaction after evaluating the contact information and description I had provided.

When using Internet based ‘print screens’ and images I have used material generated by search engines that are not connected directly to any person in the study but rather to how parents explained what they did. I have also judged the content to be specifically illustrative of the enactment in question which is how it is related to the people in the study. The decision to exclude visual materials in the present monography generated in this way were based on gaining legal and ethical expertise in what can or ought to be reprinted and what benefit it would bring to the people being researched. This shows how each step in the inclusion of data has been taken with the research ethics guidelines in mind along with specific consideration for how content was meant to be shared and used in each forum by the users. In this evaluation I have used *Ethical Decision-Making and Internet Research Recommendations* from the AoIR Ethics Working Committee (Buchanan & Markham, 2012).

### Storing the empirical material and informing participants in the semi-structured interview study

The material gathered and generated in the study from fieldwork is kept in digitalized protocols with references to field notebooks. The identifying data is stored separately from the source where the material is included. The interview recordings have been coded and the identifying information for contact purposes is kept in different files and in a different location. The participants in the interview study were informed of the way the recordings would be stored and used as empirical material for this project and for further analysis in separate academic articles and related works for broader distribution.

## Presentation of the empirical chapters

The empirical chapters will explore the experience that parenting a child who uses a CI entails. Chapter 5 examines affect and materials in the becoming process initiated from two parents' interviews with focus on entering a different world through being engaged with technology surrounding the cochlear implant and computer mediated communication. In Chapter 6, the beginning of becoming a parent of a CI user is described and analyzed in terms of lived parenting, i. e., what parents experience in sensorial differentness. Chapter 7 introduces the communication orientations creating the particular landscape in this process of parenting in terms of longing for a future belonging for the child. Chapter 8 explores the themes most prevalent in exchanges about parenting a child who uses a CI in social media interaction. The final empirical chapter, Chapter 9 presents the idea of dis/ability literacy through the case study of one parent who appears to demonstrate transcendence of a conflictive atmosphere through experiential knowledge of disability. This chapter concludes with examples of similar characteristics of other parents in the empirical material and is developed into qualities of a social literacy in dis/ability.

# Chapter 5 Materials and affect in becoming a parent of a CI user



*Figure 2: Image of plastic colored covers for hearing devices.  
Photograph taken by author.*

## Introduction

The use of a device like the CI enrolls parents and their children in ongoing interaction characterized by a series of discoveries of life in sensorial differentness involving technology and people. This takes place in clinics, hospitals and rehabilitative service centers. In this chapter affect as a part of the interaction associated with the experience of these discoveries, is described and analyzed through the trackable ideas, notions and beliefs. As part of the sense-making, technology, parenting and sensorial differentness are constituted. Affect is seen as a productive entity of motivation and drives

the action in practices. The materials in focus forefront objects: the body, sound and the physical circumstances. Parents' accounts are the entry point to bring into view practices involving technology, senses and disability as sets of experiences.

## Material affectivity

Parents are connected in networks through *material affectivity*. The term first emerged and was then developed to be able to examine the complexity in parents' accounts. Material affectivity enables an approach to the question of what parents *do* which appears to be related to an expression of emotion about their new parenting experience. *Affectivity* refers to movement and activity through experiences marked by emotion. To state that this type of affectivity involves materiality is to track affect that travels through bodies and objects. This way of intervening foregrounds objects and experiences in studying parents' accounts of activities they engage in by allowing joint attention to materials, affects and practices in parenting. This is necessary so as to connect the parents' experiences of emotion in everyday life to social and material phenomenon. By using a combined first and third person perspective through focusing on material affectivity the social, cultural and individual circumstances of the becoming parent of a cochlear implant user can be studied together. The materiality of the CI in respect to the quality of being a thing conjoining different social relations assumes that human lives are not individually impacted by technology. An analysis including what is socially shared requires attending to the 'ongoingness' in what people do because of how they feel (Wetherell, 2012 p. 23). I have utilized both the material from the interview study and the data from the ethnographic and netnographic field study. In reenacting what the parents reported to have done, for example accessing images and information on websites, illustrates what can be understood as affective practice (Wetherell, 2012). These enactments include doing similar web searches, viewing similar images on websites and reading the computer mediated texts which figured prominently in these parents' narratives.

The question of what happens in respect to material objects and affective expressions in the initial steps of lived parenting is investigated in this chapter. Material affectivity will be tracked in how culturally shared notions connect to actions these parents report and are seen as being held together in how they circulate through emotions expressed in interviews (Ahmed, 2004 pp. 117-119). This involves focusing on affect underpinning parents' advocacy in the analysis. The chapter begins with description of particular artefacts from the accounts of one parent, Tess, what she sensed when she saw and touched them. The investigation follows the circulation of

affectivity between objects and through bodies. It includes physical sensations and verbalized thoughts in a type of narrativizing where events and experiences were communicated in a storylike form in order to better understand them and make them understood in the interview. A second parent's accounts, William's, will then be used to illustrate further how a material affectivity focus on practices result in how he does parenting in a context of disability.

It is important to keep in mind that the conjoining nature of affect builds on the notions of connectivity and connectedness and is part of the research perspective. In this chapter as well as the coming chapter on Networked Parenting, the notion of how individuals are connected to others in networks through computer mediated communication has been borrowed from recent studies on Internet use after the social media revolution often referred to as Web 2.0. This refers to the cumulative changes in the way webpages are made and the Internet is used to enable interaction and collaboration between users in social media communities (Van Dijck, 2013 p. 4). Networked individualism refers to how a person participates in communities and affiliates with others in network society through the use of digital information and computer and mobile device mediated communication technology (Rainie & Wellman, 2012 pp. 6, 12-18). An important aspect of focusing on networks of material and affect is how they become shared and felt by individuals in ways that substitute or complement face-to-face communication. The notions of connectedness and networked individualism widening the first-person perspective used here, focuses not just on the parents' own view but trying to understand their views and experiences in relation to the key interaction of parenting a child with a cochlear implant, i.e. the interplay between the parent, the child's body, the technological device afforded by the implant and images and information on the Internet. This means the first-person research perspective is interchanged by a third person perspective where the parents' experiences constitute just one of the parts in a complex network. Drawing again on Ahmed (2004; Ahmed, 2013 p. 202), I take a close look at the role emotions and affect play in connecting the technology with the child's body, the parents' experiences and thoughts and how emotions open up the future and lay the ground for new orientations to others.

## Tess and a box of colored plastics

I will start with presenting a summary of Tess's personal account relayed in her first interview. Here the exploration is of a network of interactions involving the materials of hearing aids, the colored covers for hearing aids, audiologists at the CI clinic, web sites with relevant information and others parents through their written texts online. Tess went to the clinic to get Anton, her infant, fitted with hearing aids. He was approximately three months old. The audiologist Tess met with had been responsible for administering audiological tests on Anton. She mentioned numerous times throughout this interview that this audiologist was 'non-communicative' and felt she was unable to get enough information from her. I include this detail here since it is part of how Tess accounted for her frustration which influenced the mood of the interview. It was apparent from the outset that this supplied the intensity of how she was feeling which connected her narrativizing to the material objects and was a way of introducing the critical event she was about to describe. During the fitting the audiologist gave her a case which contains different colored plastic pieces for the outer part of the hearing aids. The audiologist was going to order the hearing aids in the color Tess was asked to choose. This is the moment around which this analysis circulates.

Tess: Yes, so we got an appointment to try out hearing aids and I remember the feeling that day when we were going to make the molds so she gave me a case or a box with all the different colors of the hearing aid. 'So now you can choose a color' and I remember that it felt really strange and caught myself thinking that here I am sitting and choosing the color of my son's assistive device.

Liz: You thought that.

Tess: Yes, it was a really strange feeling to sit there 'All right, should it be this color or this color?'

Liz: What did that thought lead to? That there were colored assistive devices? Did you think about something else?

Tess: It felt (pause) I just thought it was surrealistic. It was a surrealistic feeling to sit there and choose between different colors of devices my son needs. The whole situation felt very strange.

Material affectivity is first detected when I ask Tess what she 'thought' or about her 'thoughts'. She answered and continued to elaborate saying 'felt' and 'feeling' and described those feelings. This makes it possible to recognize how thoughts about objects were involved in her emotions. Here is where I connect her experience to involve affectivity. The situatedness of the materials is concrete, visible and touchable and it was this concreteness she referred to. Tess was striving to account for what brought on these feelings and wished to dwell on them longer in her account to be able to formulate

words about her emotions. This is how affectivity in the account reveals how she is connected to other bodies in previous situations.

I remember vividly during the interview with Tess when she stretched out and cupped her hand as if holding the box of colored plastics, the hearing aid casings, while she spoke. She held her other arm tightly around her rib cage. Through her body, she communicated her mood. The subject content of the interview had intensified through affect and revealed that she was experiencing this mood emerging as affectivity as she spoke. For this affectivity to surface and be trackable there had to be social interaction in a conversation and the mood experienced by Tess and by me is involved in how her stream of consciousness is imbued with embodied images from this incident she is recounting.

When Tess began to realize that what her child will need is a visible aid, an assistive device, the words ‘surrealistic’ and ‘really strange’ were attached to choosing among colors. I came to see this choice of wording as signaling a rupture connected to how material objects were involved in her view of her situation. A previous way of understanding had been permanently altered. Tess’s outlook began to include a viewpoint from an outside angle, a gaze. The point of focusing on this moment as a rupture is to point to the fluid movement of her subject position where she sees herself and her child as they would be seen by others. A back and forth movement of seeing and being gazed upon pass through this ruptured boundary. In this moment she became a parent, entailing a certain social position, of a child with hearing aids. The hearing aids are a product of social practices in a particular kind of parenting in sensorial differentness.

## Rupture makes experience visible

‘Rupture’ can be related to what has been called a ‘break’ in illness narratives of chronic conditions. There is a clear and irreversible ‘before illness and ‘after illness’ which changes the world of the experiencer. The focus is on descriptions from within a way of being in illness (Kleinman, 1988) or in a biographical disruption (Bury, 1982) after realization that there are permanent and lasting changes in conditions of life. Tess gives us the opportunity to see that this point of realization is connected to other ways of seeing and other practices of receiving help and assistance which is akin to being permanently changed through bodily harm or illness. What comes out of this rupture is what enables a new form of experiencing the world. The metaphor of the rupture is to make the experience visible. A rupture is productive in the sense that affectivity is set in motion and changes what

appears on the surface as materials, the plastics and the body of Tess's infant. Much like a critical incident, this rupture, is used to track a transformation of self that continues to be trackable in Tess's actions and thoughts (ADD REF Todd & Jones 2005). Becoming a member of a disability category or 'at risk for exclusion' category can be a drastic, intense type of experience. I am depicting Tess's experience by using the illustration of a rupture in an earlier taken for granted belonging to a category of ordinary people.

The idea of whether the color choice should be picked to be noticed or picked to be hidden emerges through ideas of yet another concept, one which involves stigma (Goffman, 1963, 2009).

Tess: It was only partly that he actually needed hearing aids and that I thought was a little tough. Then it is suddenly so visible for everyone else and absolutely nothing about hiding the hearing impairment because I have no interest in that and I never will either and I will always encourage Anton to show and to tell that 'This is me.' But it became so obvious that strangers, people I don't know will notice 'No, ugh, that child has a handicap. He's handicapped. That felt (pause) it becomes so *final*. It made it so very clear in a way.

Liz: When you got that box?

Tess: Yes. It was before that, in a different way, very theoretical, very abstract. Yes, he has a hearing impairment and that means this and this. Nothing we can do about it more like we have to relate to the reality we find ourselves in. We have to make the best of it all. But that particular, that particular (pause)

Liz: That others would see?

Tess: Yes. That very moment when I really sat there with this box and it felt like such one of those trivial things of picking a color.

In Tess's account the significance of the color of an assistive device and the significance of the actual device are placed side by side. What was it in the colors or the fact that the choice presented to Tess was about color that triggered the rupture? The outside part of an electronic piece of equipment, like the cases and holders for mobile phones, electronic gadgets and accessories is about presentation of who owns and uses the device, not about how the device works or why you are using it.

The issue of surface (color) and depth (quality of technology for hearing) led thoughts to what Tess would be allowed to influence and in this case it was the color. This is a choice about what is decorative, playful, or individual expression having little or no bearing on what Tess's role as a patient advocate for her child in this health care situation calls for. At the same time it is a choice which comes through in a narrativizing style. She insists she does not want to hide a hearing problem or would ever encourage her son to

hide who he is. The meaning of color chosen to be seen or chosen to camouflage is being made here and Tess connects it to existence. Tess is forced to decide on a presentation of disability for her son and for herself. She vicariously puts herself in her son's "situation" which at the same time becomes a rupture in her own being

Tess contrasts the triviality of choosing color to the 'there is nothing we can do about it' reality of life-changing, hearing impairment. This contrast also signals the rupture and the inhabiting of ways of being. The rupture enables a tracking of material affectivity, moving through a realization of disability, on a social level, through the personal level of the incident in the audiologist's office. The combination of Tess's previously held notions of disability and actions of choosing to show or hide a hearing aid demonstrate this. The circulation through emotion in Tess's account enables a fastening down of intensity of the movement in the plastic material and perception of color. This is the important aspect that there is a flow between material things and previously held thoughts and by pinpointing this moment of rupture, an opening to what more can be seen in the transcript excerpt can be followed into other spaces where it is socially shared. The rupture is the opening through which other social worlds enter. This is the main point of this analysis, i.e., to put the affectivity to work in identifying experiences of activities, hearing aid fitting and stigmatization through gaze and encounters between actors. The rupture shows in a new, narrativized understanding of her child and is linked to her future with the materials and social and political ideas of hearing technology.

A sense of shock like Tess relays can pass without having an impact on what she ends up doing at the moment. However here there is a transformation, marked by the rupture, continuing on in Tess's narrative. Through sharing it in an interview, the rupture accumulates meaning for Tess as it goes another round, around this point in time. As it gathers meaning for her, for the interviewer, for other like parents and later for the readers of posts online she may share it with, it solidifies an important part of becoming a parent of a CI user.

Ideas about disability involving aversion and fear are part of what Tess is simultaneously reaffirming and resisting. Narrativizing seems to be a way to speak something into being and make it part of the world. In so doing it shows how it is both an activity and affective practice. How these affects and actions are intertwined can be described as laden with intensity which connects past experiences with socially shared ideas in a recognizable but unfamiliar field of disability for an individual. By not labeling affect or emotions as positive or negative but rather as a relation of circulation allows for an interpretation of how Tess and parents like her act and react to

socially held notions. Societal structures position who is disabled, and economic structures determine who decides what a device can cost and what it will look like are how affect is found in these circulatory relational structures.

## Networked extensions of the first-person perspective

My aim is to enter the parents' experiences through the first-person perspective, but to transcend its scope by adding an understanding of how personal meaning-making relates to the parents interaction with other people and things in networks. This third person analysis is inspired by Ahmed (2004) and refers to a tracking of affect as how emotions are important in binding—in my case—the parents to important materials and other persons.

I argue that emotions play a crucial role in the "surfacing" of individual and collective bodies through the way in which emotions circulate between bodies and signs. Such an argument clearly challenges any assumption that emotions are a private matter, that they simply belong to individuals, or even that they come from within and *then* move outward toward others. It suggests that emotions are not simply "within" or "without" but that they create the very effect of the surfaces or boundaries of bodies and worlds (Ahmed, 2004 p. 117).

Another way of describing the widening of my perspective is to say that my study of the parents' meaning-making related to the new conditions of lived parenting demands both an exploration of their first-person perspectives and an exploration of their meaningful interaction with other things and people, who take part in the production of meanings concerning sensorial differentness. The surfaces or boundaries of bodies with technology and worlds of sensorial differentness emerge through affective practices of narrativizing 'ruptures'.

Margaret Wetherell reminds us that in studying affect a set of points needs to be taken for granted for the analysis to lead to contributing to clarity. When summarizing the concept of affective practice Wetherell states this intent.

I have been trying to identify a set of points to be taken for granted such as that emotion is culturally constructed, that bodies/brains are plastic, that affect involves flows of bodily perturbation that have become quite organized, that everyday meaning-making is situated and practical activity infused [...] with sedimented social and personal history, and so on (Wetherell, 2012 p. 96).

Continuing with the role of the concepts of narratives and interpretative repertoires Wetherell says that

Narratives of affect mobilise shared communal and cultural interpretative repertoires of sense-making, as indeed does most talk about affect in a situated performance. These form a kind of backdrop, available to be called in to formulate and describe any instance of affect (Wetherell, 2012 p. 94).

In light of narrativizing, focusing on affect allows us to study everyday meaning-making and sense-making and how it is implicated in what later becomes shared with others because of how it is recognizable to other parents' personal experiences. Shared social meaning fuses affect and meaning-making practices. When Tess searches for information and support from other parents in online environments she is turning to a sub-group where these types of reoccurring activity are distinctive of parent to parent social relations. Tess's narrativizing contributes to this networked community of affect where intensity, through parenting relationships contributes to the construction of meaning and circulates.

The detection of hearing impairment in her infant is revealed and transported through the materiality of the hearing screening technology and affords new situations where Tess became an interactor with health care professionals who would be co-providers of care. By going to appointments, knowledge of multiple previous tests along with multiple understandings of others (parents online) accompanies Tess and her child into the clinic. Added to this are also the other sources of knowledge Tess acquired in different ways through Internet, websites and information searches through her networked individualism (Wellman & Rainie, 2012). Her actions are entwined with the upcoming procedures generated by her need to feel informed and prepared as best as possible. These situations were presented in the interview as how Tess saw her role to be as a parent of a child who needs medical care. Tess's faith in her own ability in these respects, translates into being in control of an idea about herself. Her confidence to be able to care for her child without specialists is a part of her former world which halts abruptly but is still there as a type of background noise or shadow Tess uses to understand her new world. The consultation with the audiologist was the beginning of a concrete reliance on hearing aids as well as reliance on others' actions and expertise and it transforms Tess's world.

The following statement from Tess's interview points to when the physicality of wearing hearing aids was becoming a fact. An imagined image entered into the narrative ...*then it is suddenly so visible for everyone else*. Here the affect through imagining the hearing aid in place became possible to track when it was uttered. The boundary of what Tess could

choose to portray about her son's body and what she concealed was ruptured just like her way of seeing and experiencing was ruptured. The control over presentation of self is lost which is signaled through the affectivity of material circumstances. The event yet to come, when the hearing aid is being worn in and on the infant's ear, is already felt by Tess to be seen by others. Instead of choosing a time to disclose information about deafness, it is materially "outed" through the clinical practice. Here the excerpt illustrates how two ways of seeing are simultaneous and it is this which shows where the computer mediated affectivity latches on to the empirical material of Tess's account into the empirical evidence. Tess is imagining that this gives visible information about belonging to a category about which others will have immediate judgments.

This excerpt is used to point out where the material affectivity continues into another of Tess's excerpts about images.

Tess: No, you don't always see that [infants with hearing aids] and it is also that I had a really strong feeling that when we were waiting for Anton's hearing aids I saw a picture of a baby who had just received hearing aids and it hurt so much! I can't say why and what it was that did it but it was just so [moaning] almost a physical reaction [...]

Liz: Describe that some more.

Tess: It made, it is so hard to put it into words. [...] It hurt inside me. To know all that this is going to bring onto Anton, because it is of course he who has to live with it. He is going to live with it every day. He is the one who will have to struggle.

Awareness of the gaze of strangers and the stigmas in society about hearing impairment, being disabled, and being deaf are actualized and emphasized in this excerpt. Thus, the process of meaning-making referring to the sensorial differentness can be tracked through the hearing aid, the computer image and the infant body. Affectivity carries on from the excerpt about what took place in the audiologist's office. Tess's previous way of existing was punctured by new bodies, images and future struggle which continue to flow through the rupture. Affectivity circulates into a new collection of circumstances leaving the colored plastic coverings and moving on through information and communication technology (ICT) and computer mediated communication (CMC) on screens. It is in the very specific situation and detail of this rupture event that makes it possible to take into account that the material affectivity evolves from one display of interaction in an interview with me, interconnected through mood, and to another practice represented by the Internet image in a web browser image search.

Material affectivity reveals how signs sticks to some things and slides off of others which creates the boundaries between bodies (Ahmed, 2004 p. 120). What continues to circulate can always return but it will not appear in the same way. This makes it sound very close to how interpretation never rests in one place to be considered completed or finished. As soon as the sudden visibility of disability is fastened down in Tess's world, stops her previous way of existing, and sticks to the plastic hearing aid case, it defines boundaries between a previous and a present world and the body of her child and other children.

To gain empirical concreteness for the purpose of this analysis I used Internet sources to show the web browser image search resulting in the depiction Tess spoke of. I entered the words 'infant with hearing aid' which resulted in a row of images on my computer screen (Netnographic fieldwork protocol no 111). The image depicted of how the barrier between what is known and unknown to others about the inside of the infant's body breaks down. Seeing a hearing device on an infant signals the presence of disability. Similar images described by Tess were referred to as causing emotional pain in her account, and seen as affectivity there is a bind of body surface (of infants and her child) to signs (of disability and views of disabled groups). This binding is used to show how the emotions become concrete in different affective parenting practices. Tess includes a description of the image in her account which I re-enact and the image appears. For a new parent this is a way to see a future event through a networked social system. Tess's experience is imbued with the realization of a not yet materialized future. It is real because of what she sees and how that connects her to other parents and practices that preceded her Internet search. The existence of things like assistive devices and hearing aids, fitting practices, the choosing of color, bind together the materials of body and plastics. The incident evolves into a meaningful and tangible reference point accessible to others. In this exploration affectivity is tangible because it contributes to distribution of understandings which are socially organized through interaction between and with other people and things. Tess is thinking about the information others then would have, what judgements they make from it and how it can determine how her child and she, directly and indirectly, will be treated. For Tess this has already taken place which we detect through her emotion.

## Resources, presentation of choices and resistance

To further demonstrate how material affectivity connects a first-person perspective to a shared social reality, i.e., interactions involving factors of societal structures, the following finding about choices, resources and resistance is analyzed. This excerpt leads into how Tess shares how she is

thinking in relation to available resources and what power she will have in relation to these resources. Tess relates her dependency on economic systems to what she is allowed to make a choice about.

Tess: Yes that very moment when I was really sitting there with this box and it felt like such a trivial thing like to pick a color.

Liz: Okay.

Tess: It felt very (pause)

Liz: With this feeling about how others see my child?

Tess: How others see and also these types of thoughts that this, is this the hearing aid that is best for Anton and is it what the county has to offer because they had bought it at a good price. Is it really the best for him? These thoughts are also, that I can't influence what type of hearing aid he gets but I am invested with confidence to pick the color.

There is a distinct shift in meaning from visibility of disability to influencing a choice of technology. The shift starts with the finality of disability and a feeling of powerlessness resulting from what others will think. The expression of powerlessness continues on in a separate but related issue, not being able to influence the grade or quality of hearing aid that will be provided by the county for her child. Departing from the moment when given a choice of color of the hearing aids, Tess is dwelling on themes of powerlessness and vulnerability in relation to not being able to impact the choice of technology. This narrativizing circulates around a different materiality of economic and political systems but is bounded together through affect. The interview continues with how Tess feels about having no influence on what matters to her, the quality of the technology, after I repeat parts of her expressions.

Liz: Then I think about resources. You had already thought then, it seems like there is a lot in this experience, as you said, surrealistic, 'Final.' Other people are going to have thoughts that you can say are negative. Something you can't influence. And then the resources.

Tess: Exactly. This, 'You have nothing to have a say in'. You think that this device works better than this one or that this one can work better than this and here you have this choice, you can choose the color. And I know that it is about procurements and budgets and money and resources.

Liz: That's stuff you know something about. [Tess works with budget management.]

Tess: (laugh) Yes, I know that, I have complete understanding for that but it's still difficult that you can't be a part of it and influence when one alternative is what you have to choose from. You can influence the color you want. Good, huh? Kind of. And it is probably great for some people. Not as good for others. Maybe I want to be able to be more involved in the decision process around what is needed. Not just to be presented with a decision that has already been made because we [the hearing center] have bought them. It maybe isn't necessarily the best there is.

Liz: You are thinking about choice and influence.

Tess: And it was also this thing that led to that we actually switched out our audiologist.

This is an example of how a difficult fact for a parent surfaces through affect. The theme expressed by Tess is about being a certain type of person who likes to read up, be very informed, go through the options, think things through and discuss alternatives. Tess contrasts her preferences with others, who she means would like to get it (hearing aid use) taken care of and focus energy in a different way. What is the same among parents is the frustration of being in the situation in the first place. It makes Tess feel incompetent or not trusted to know enough to influence the decision which has to do with her personal characteristics and preferences and is where she begins to exhibit resistance. Powerlessness and resistance are connected in Tess's account and are exhibited in affectivity both in the action in interview and in the topic of the excerpt. She reacts to not being able to exhibit power by turning to other sources and experts which then led to feeling more informed and justified in changing her immediate situation with requesting to see another audiologist. What she comes to know through networked individualism are strategies which increases her autonomy.

Tess is educated in business and economics. She is knowledgeable and has previously worked with public procurement. She knows why certain things work the way they do and what type of power is governing others in this respect. Tess has the impression that systems of organization seldom can be swayed by individuals. There are binding, instrumental structures limiting what can be influenced by patients in a social welfare medical context. She realizes she will *not* be successful in influencing the significant parts of a medical decision making process and it becomes part of her parenting reality. 'Wanting what is best for Anton' and not always getting it translates into a frustrating situation which determines new life conditions. For Tess, the choice of color was just as much about what choices she will not be given, resulting in feelings of powerlessness. An economic system becomes personally lived. She says she completely understands why it is about budgets and money but it is still difficult to be in that situation. Being offered to make a choice that is so banal made this very obvious and subsequently more painful for Tess.

## Resistance as a part of parenting

Resistance is found in the affective circulation between colors, plastic, assistive devices, impairment, attitudes towards disability, and assumed roles in parenting. Being able to have other choices, about other materials and about personnel, shows how Tess strives to exhibit control over treatment.

Dealing with the earmold materials and the difficulties with fitting the ears of infants since they grow quickly placed a ‘critical for accessing sound’ change within the body of the infant. I interpret Tess’s descriptions of the inside of Anton’s ear, the difficulty of getting the hearing aid to stay on and the importance of making sound available to have accumulated intensity. The material circumstances were highly affective creating strong emotions about not being listened to or being ignored. The legitimacy for switching out a health care professional had multiple motivations that are material and affective. These are related to issues such of harm, avoiding pain, enabling comfort to access sound and meeting medical needs appropriately. This is how Tess narrativizes her resistance.

Tess: There was this as well. I wasn’t completely convinced that it was the best solution for Anton. [...] Babies grow so much, very very quickly and we had huge problems with it. And we had to make new molds, tried new materials and we found a material that worked really well and we said to our audiologist ‘Well go with this now, this is just the best.’ and so she orders something completely different that didn’t work. So back and forth. And I read a lot and talked to other parents who actually had experience with other types of hearing aids-

Liz: Was it this group [discussion forum on Facebook]?

Tess: You bet.

Powerlessness was transposed in form from previous clinical encounters. To explain how these feelings followed with Tess into the continued dealings at the clinic there is a material affective link. In this way a trivial issue of color is re-contextualized in a new decision which was *not* trivial but dealt with parts that go inside that ear of the infant’s body; comfort to enable hearing.

Ensuring the exposure to sound to attain stimulation is the central goal of pediatric audiological practice. This goal is communicated to parents from the time of detection of hearing impairment and is associated with individuals in health care encounters. For instance, if the infant isn’t comfortable or content the focus is directed to materials. The part that enters the ear, the earmold can be made out of a number of materials and the everyday living situation of getting a hearing aid to stay in place is a major concern for parents who are responsible for this step to provide an audible environment. Tess expressed difficulties with this particular matter. She searched for information online in Internet searches and discussion forums. Tess finally found a suitable material which she suggested to the audiologist. When the audiologist orders something different, feelings of not being listened to or ignored led to switching out their audiologist. This is also the point in the interview which connects Tess’s experiences to social media sites and other parents’ stories of medical encounters.

## William and totally implanted devices



*Figure 3: Image use granted by Michael Pringle  
(Netnographic fieldwork protocol 4 and 106)*

The theme of parenting in sensorial differentness is further illustrated through contrasting the tracking of different objects and affect in William's experiences, a parent who has a child who has already received a cochlear implant. The material from William's interviews differs from the others in that he lives in the southeastern part of the United States. His interviews are interpreted through additional ethnographic interviews with other parents and professionals and participant observation in the same socio-cultural context. This section also includes analyses of online material in William's Internet searches. These interviews centered on choices at a later stage in pediatric cochlear implantation treatment which already exemplifies how decision-making is ongoing in these practices. The account begins by referring to how he and his wife are considering a second implant. He explained that his child had already tried hearing aids but did not get use out of them. It is also notable that for William choice of technology is connected to minimizing visibility. He has experiences of his child's implant and how visibility of devices has set affect into motion. The deliberation about a second implant interestingly raises both new and old questions. The intensity of affect deals with negative views about disability combined with personal financial concerns. How visibility of devices is connected to cost, damages and new technologies not yet available will be explored in this section. This first-person and third person perspective analysis will show how affectivity in this section primarily occurs through how ideas about technology and stigma are intertwined in William's narrativizing of events.

Connectivity refers to being systematically connected via technology in ICT and CMC. Images of children wearing hearing aids and cochlear implants are one of the forms of material connectedness between individual parents made possible through connectivity (Van Dijck, 2013). The concern about

how the hearing technology is viewed from others is a prominent theme in William's account similar to how it was for Tess. Providing how William's ideas are presented in a different way leads to actions of prevention of harm in his parenting. Where Tess is driven by striving to counteract a feeling of powerlessness through resistance, William expresses fear of how his child will be treated. This fear prompts him to search for solutions on the Internet. William's account, in a chronological manner, picks up where Tess's left off. She was still in the stage of making sound accessible by testing hearing aids in a process of candidacy for cochlear implantation. Below in William's interview he immediately refers to (online) reading about what is available on the hearing technology market. The connection I will illustrate is in how the affectivity in William's case leads to choosing not to get a second implant for his child.

William: I will say after reading about different companies what they offered, our experiences with the hearing aids, what they offered in the cochlear implants, what they offered and we've even been asked you know, are we going to have a second cochlear implant because he's a bilateral hearing loss.

Liz: He has one now?

William: He has just one.

Liz: And he doesn't use a hearing aid.

William: We've tried hearing aids but they are more of a nuisance for him to wear versus the amount of information he's actually retrieving.

Liz: That's interesting. Okay.

The indication that the decision whether or not to get a second implant would lead to the central theme of William's interview is when he says, 'we've even been asked.' This inscribes how decision-making is an ongoing dilemma for William. He does not want his son to have a second implant. Instead of focusing on how this would improve his son's ability to access sound, it is seen as hindering the possibility of a better technological solution in the future, one that would be invisible. William is motivated by limiting the impact of a stigmatizing condition, first by only having one side implanted and then by 'saving' the other side for use with advanced technology. Also, the advantages of the possibility of 'invisible hearing' weigh more heavily than what would be afforded by a second implant which is exemplified in this excerpt.

William: Looking forward to the future we do a lot of research on the advancements moving forward. I know stem cell research is something that they are looking at. I know that totally implantable devices are something that they are looking at.

Here William presents two possible developments for providing hearing in the future. Information about these possibilities which are being researched is Internet based. How these ongoing advancements are impacting his decision in the present is where the narrative shares similarities with Tess's reaction to the visibility of devices on other infants. They differ in that Tess's connectedness through images and then OSGs leads to positive and valued interaction with other parents. For William, the image searches and website information present a problem; the technology he hopes for is not yet available and puts him in the situation of waiting. Seeing only images of adult trials with new devices provides him with knowledge of an imaginable future which is out of reach. The idea of a totally implantable device provides a possibility to hide what causes a stigmatizing effect in William's view. This is similar to the affective reaction around which Tess's account circulated.

Liz: Totally implantable devices. How does that work?

William: Similar to a pacemaker it would be. And in this world and I know this may sound very shallow but when our child is out there with a cochlear implant on people would stop and stare. Some would point and some would ask questions 'What is this?'

Liz: What do they say?

William: Initially, the uneducated people would be like 'Well, what's wrong with him?' And 'Is that Bluetooth on his head?' or is that some other device that was totally unrelated to his hearing loss.

William spatially describes the situation with 'in this world' and 'out there' in a way that characterizes a vulnerable feeling he is experiencing. Like Tess saying she would never encourage her son to hide his hearing problem, William discloses that he knows that it 'sounds shallow' to point out his concern. These two parents express knowing that this disability made visible is stigmatizing and they make efforts to distance themselves from holding these beliefs. William sets himself apart from others again in referring to and mimicking others' 'uneducated' views. He then continues with how children react to seeing a CI also stating that their curiosity is understandable whereas comments from adults are criticized. These attitudes appear to make William irritated and uncomfortably aware of how his child appears to others.

William: And we had to explain to children.

Liz: What do children say?

William: They would ask 'What's that on his head?' And we would say 'That's his special ear. Without it he can't hear.' Usually that would resolve

the children's curiosity and they moved right on. But they were very curious which I understand.

Liz: But what does it do, what did it do to you? You know what I mean, because you said, 'This may sound shallow.' I want to know what that felt like or what it feels like because it might still be something that you think about.

William: Oh it is. It is. Today's society we hear about it a lot on the media and we see it in other children and other adults for that matter. Bullying is a big concern in today's schools. And if you give another person that little power over you, they will use it against you. Here's something that's going to be blatantly obvious to someone with sight that they can use as some sort of way to hurt my son verbally.

Here William refers to 'today's society' and 'the media' and 'today's schools' that add to how he is experiencing vulnerability which he labels as bullying. What is visible to others is his son's weakness which puts him not only at a disadvantage but in danger. Now the affect which is surfacing is the emotion of fear. This fear lies in the possibility of William's son being harmed emotionally or physically because of the visibility of a hearing device. The excerpt below shows how this harm is connected to financial harm to the family.

William: And as well as that I have to concern myself with the fact that if he were ever to get in an altercation, there's a very expensive piece of hardware on his head that could get smashed, destroyed, and I have no recourse.

Liz: What happens if that happens?

William: It's about 8000 dollars.

Liz: You pay?

William: I pay.

Liz: Out of pocket?

William: Out of pocket.

The strongest theme up to this point is about vulnerability and providing protection from possible consequences. The references to Internet are about finding solutions to material circumstances of signs of disability revealing weakness to others.

## Vulnerability through technology

Soon after his son was implanted William went with his wife and son on a trip to Disneyland. Within the first hour they were there, his wife realized that the CI was missing. It was still during the phase when they were getting used to putting it on their son and having a routine for how to use it and keep it on. After a number of hours they were able to pick it up after someone had turned it in. This experience is very significant for what develops in

William's narrative. Very early after implantation they lost the device. They had a back-up but in the event that the other one would be lost too they would have to buy a new one. The cost involved in accessing sound was the earliest and most prominent part of his account and shows how this is part of the fear of becoming vulnerable through the use of technology. How this fear circulates in the narrativizing will relate to what can be seen by others and the project of finding out more about 'invisible hearing' as it is phrased in the netnographic material. The possibilities afforded by the development of a totally implantable device make it conceivable that William's emotions about social and economic vulnerability coincide. Such a device on the inside of the body can neither be seen nor lost.

There are three ways William imagined that his son could be hurt. First in the way people have branded him as different ('What's that on his head?'), in potential situations of verbal abuse in bullying in school and lastly in a fight where the vulnerability implies physical harm but centers on an economic risk of having to replace the expensive hardware. Tess's account had also quickly moved from what others would see and would think to economic matters but differ because of social economic structures. Tess is in Sweden which has a social health care system and William is in the United States where medical insurance has to be purchased. They are both constrained by economic systems that they refer to when they talk about their child using hearing technology.

William: I have one other one [CI]. The company that we purchased ours from gave us two and the company that we have for a certain period of time if we lose one we can get another one back. But that's a limited time.

Liz: Limited time, inside a warrantee?

William: Yes, I think it's like five years or something like that, so, you know. The first five years of his life chances are that's not going to happen but as he comes into middle school and high school, perhaps even college, those could be things that will impact his self-esteem. And things that he will have to worry about. So for the idea of a totally implantable device in my mind, I think that would help him because no one else would use that against him to bully him or to make him feel bad about himself. I wish this was more of an uplifting society where people would support and care and nourish and help. And to some degree those elements still exist but (sigh).

The motivation to hope for a device his son could use that would not be visible is an affective connection to what could be gained if his son's use of technology and disability were not detectable by sight. Self-esteem can be protected in William's view if his son isn't targeted by bullying. Another reference to what the world is like, in how it seems to lack compassion and support which his son needs, is how he expresses resignation. In the account of how signs of affect shift and stick, as Ahmed says (2013 pp. 194-195), to different ideas about the world out there and what the assistive devices *do*

and not only symbolize are detectable in this material affectivity. This is understood in what William does in choosing not to get a second implant. There are two motivations why William makes this decision. The first is that a second implant would be even more visible and doubly expensive. The other motivation is how William understands what cochlear implantation does to the cochlea and the residual hearing. Implanting one device could make a newer (invisible) device impossible to implant.

William: I would be taking that chance away from him. [...] What would I say to him?

He has gone through a process which concludes in taking a position he could defend when his child is old enough to ask why he did what he did. This is further evidence of the complexity of ongoing decision-making. William believes that this is a decision that shows that he did everything he could to maximize his son's opportunities which he projects into the future.

William reasons, similarly to parents who make the opposite decision to implant bilaterally, that they have to be able to face their child when they are adults. The same reasoning is used in deciding to implant the first CI. Usually offering their child the opportunity at the earliest age possible to implant CIs is the more common form of this scenario which refers to results that exhibit higher levels of successful outcomes in learning to speak and listen. William's argument to wait to implant bilaterally keeps options open. This is a prominent theme in other parents' interviews when they were deciding on implantation. In William's case 'better' means not visible and not losable. Since the technology is not developed at present, William wants to wait.

This illustrates how circulation of affect involving the same thematic content, keeping options open, has different pendulum movements between material options involving technology and belonging and plays out differently in individual lives. The same emotion and the thought it results in, 'I don't want to take that chance away from him' can lead to different decisions. These decisions in everyday life, seen as affective practices, are analyzable through looking at the individual account and motivations for action in the specific social circumstances of meaning-making.

The broader shared social context of being a parent of a CI user provides the connections between Tess and William. In the following chapter another parent, Josef, actually makes the same decision as William, to not implant a second CI with the contrasting motivation of wanting his son to be able to access a language and an identity as deaf that would be taken away from his child if he got a second implant. The explanation lies in the material

circumstances of belonging that are linked to the aspirations a parent has for where the child will be able to grow and develop. Where does the child belong and what hinders the child from achieving this belonging status?

To understand this disparity in how the same decision to not implant a second CI can be motivated differently, the following excerpt reveals how William feels about the cochlear implant and what it does to his son's life.

William: Part of me feels I owe it to my son to offer him as best an opportunity as I can and be as involved with him as I can and to help him through this time because even though to him it's normal, just a normal day, I foresee his future with things that will help him and hurt him. I think this, the cochlear implant device in some ways is going to help him with relationships with those who are truly compassionate. And I see where it will hurt him where people who are truly mean and devious.

The fact that the cochlear implant is being used for his son to be able to use sound and acquire speech is taken for granted. Nowhere in the interviews with William is hearing the main point of discussion because of the deeply lying assumption of the need to be hearing in the society William is describing. It is notable how this unquestioned goal made it possible for these ensuing meanings, associated with the CI by others, to surface through affectivity in William's narrativizing. He acknowledges that their day to day routine with the CI and going to the hearing center is 'just a normal day' for his son. This means this is not the case for William. That William says the CI 'in some ways is going to help him' is based on other people's compassion and not on being able to listen and speak. It is indicative to the intensity with which William is struggling with emotions about what is safe and what he fears. There are also parts of the excerpt which take on a religious message of struggle: 'helping through this time', 'truly compassionate' and the word 'devious'. Such phrasings are often used in prayers and sermons in William's sociocultural context in referencing being tried in hardship, how one should treat others who suffer and evil intentions related to sin and temptation. The deafness and the cochlear implant are in no uncertain terms problematic in existential ways for William.

In many parts of his account, William has identified obstacles that make the world unsafe. Particularly for his son it is connected in three discernable ways: self-esteem, physical harm and economic hardship. When William mentions his son's self-esteem as a concern he is actualizing how his son is denied normal treatment by others in society which is normally accorded to those who do not use assistive devices. The brand name of the totally implantable device William refers to coincidentally builds on the concept of esteem and appears in four of the images linking to more information on web

pages involved in either marketing or researching the development of the totally implantable device.

To envision William's parenting experience, the Internet search for current information about cochlear implantation was re-enacted starting with the images appearing from a web search of 'totally implantable hearing device' (Netnographic fieldwork protocol 105). Affectivity is tracked by following William's actions from his accounts which illuminates the themes important for him through his online activity. These included hearing technology companies, healthcare blogs and popularized scientific news sites. Gaining empirical concreteness through images illustrates what a parent investigating future technologies for hearing would see. There are computer images of the ear and how the devices are implanted, a photograph of one of the devices being implanted during surgery and a picture of the implant from a system that has no external wearable parts. Each picture serves also as a link to the webpages where the image can be found in its original context, for example a private web page about a totally implantable cochlear implant. Another image leads to an abstract from an article on a first experience with the surgical technique to implant the 'totally implantable hearing aid' which is the case for another brand name as well. A reference to 'invisible hearing' is what prompts the reader to think about an alternative to visible hearing aids which is the main theme of countering vulnerability in William's interviews.

Affectivity is tracked in the practices of searching information on the web and decision-making which is connected to William's thoughts about the future for his son. The theme about vulnerability in the form of self-esteem is intertwined with the economic hardship that is possible through being a cochlear implant user. In the interview references to losing or having the implant damaged through getting into a fight or in a physical accident were actualized as a financial problem that William sees as likely since it was one of his first experiences with a cochlear implant. New developments in hearing technology, as with most technological innovation, are associated with exploration, innovation and high expense. The question of whether or not it is available to his son is not only about advancements in development. It is about being able to afford it through an insurance company where the expenses for this technology would be covered.

This closes in on an issue Tess's narrativizing circulates around as well. The procurement process determines what will be available and what decisions she is allowed to influence about the hearing technology her son has access to. In this way Tess and William end up in a similar place. If you have the resources you will be able to ensure a type of economic independency which is interwoven with the circumstances of how society views visible hearing technology.

## William's world changed

A theme which was found in the interviews and observations of all the parents was how they felt that their lives had dramatically changed through engaging in practices connected through cochlear implantation. For William the materialism of a CI carries affect which is discernible in how he describes relationships of helping and hurting. William engaged in seeking out knowledge in the expertise of practitioners' and had decided to commute two hours each way to bring his son to a specialized hearing preschool. He has changed his work situation and as he describes it, every aspect of his day to day life. He said that 'my world is anything but normal' and reasons in this way.

William: Back to your question regarding Caleb [his son] and why I am involved in volunteering and all of that

Liz: The community thing.

William: The community thing. I think the reason why I do that is A. I want to become more knowledgeable on the subject so that as I am approached, I can explain and help others and [...] And B. I want to strongly be there for him in whatever capacity I can. If that requires me driving him to and from, so be it. I want to get him to the point where he is independent, strong, comfortable and prepared for whatever may happen.

Liz: Mmm

William: And the only way I can do that being a new dad is to get involved and understand the type of scenarios he's going to get in.

The way life has changed for William exemplifies how his individual experience and the social circumstances are bringing him into contact with experts. He uses words like strong, independent and prepared which reinforces his earlier statements centering on vulnerability and fear of what could happen to his son or him. Much of this fear is related to finances and when discussing his career refers to how finances are a concern by saying 'I'm not where I'm supposed to be in life'.

The excerpt below shows how William is less concerned with the impact of hearing problems when he believes there is a possibility that there are other 'defects' and can possibly contribute to an explanation for why he is skeptical to the second implant.

William: We've informed people that [bullying] is a concern of ours. Um, but it's more of a concern now not so much for the hearing loss as it is other uh, defects that could possibly be happening.

Liz: Did you think about that with the first one [CI]?

William: We didn't think about the hearing loss or [disabilities] at all till we found out about it. We were worried about if there were any other things and we are still concerned that there may be some, uh, not necessarily behavioral issues but maybe sensory based issues that could possibly be happening.

Here William is broaching the subject that his child may have a learning disability, problems with retaining focus. In the interview I searched William's use of other words to talk about his suspicion of additional or occurring conditions which adds clarity to why he wants to be involved on a daily basis with the educators so he will not miss the signs of problems in development.

William: Yeah and I don't want that to happen because that will, those little ripple effects will impact him throughout his life and how I handle those now at an early age can make his future much more brighter.

Ripple effects refers to how falling behind or missing out will have an increasing impact on his child's development as he grows. How he wants to avoid these effects is stated as a type of strategy to know what is normal.

William: Typically I, the concerns that I have that are related to hearing or related to behavior, which because they are hand in hand in numerous ways, are the educators because they're going to be the reason why I choose them. They're the first line of offense/defense recognizing what is normal. What is baseline.

The major theme of vulnerability can be found in the above excerpt through the use of the words offense/defense. William is experiencing a struggle which requires a strategy and the best way to do this is to rely on experts who know what is normal in this new life situation. William expresses it as gaining a better perspective through the help of these professionals.

William: And by going to the people who are working with him and understand his hearing loss on a daily basis, I can gain a better perspective of (pause) I'm seeing this strange behavior at home. Is this A. normal three year old? B. abnormal three year old or C. normal three year old with a hearing loss and figure out, ok if it is what it is-

That William has organized his life around having daily contact with these educators can be interpreted to be a way to cope with feelings of not being in control of knowing what to be worried about. These feelings are directly related to the actions he has taken. His narrativizing consistently presents open ended possibilities in the future. This can also be accounted for in how he reiterates thoughts about the future, about not having control of what others think or say and the technological developments that he refers to which present both possibilities (of hiding) and limitations (too far in the

future, too expensive). Towards the end of the interview I wanted to hear William's view on signing and how he regards this modality as a possibility or a limitation.

Liz: Do you think he's ever going to want to learn sign?

William: I don't know that answer.

William's answer and tone make clear that signing is not an approach that is desirable. It confirms that the hearing impairment per se is not an obstacle to be by-passed with using signs. William's main concern is to disarm impact of the stigma of being disabled in any capacity. Signing would be a highly conspicuous sign of being deaf. William never uses the word deaf during the interview. He changes the topic by saying again that they have been asked by many others to make a decision about the second CI. This last excerpt functions as an explanation. William, through emphasizing what he regards as possible and desirable future scenarios makes clear that using sign language would not solve the problems he worries about, namely how others see his child and how this puts his child in a vulnerable situation by being different.

## Affective aspects of becoming in sensorial differentness

The way a parent makes meaning about their new world is illuminated by using the term material affectivity. Bringing in materials makes visible parents' meeting a new world through hearing device use and how this is connected to notions in the culture about disability. Societal organization through connectivity, connectedness and networked individualism are important to include in the type of affectivity parents are entangled in.

Tess and William have provided illustrations of how parents' daily lives include reaching beyond the face-to-face world of small, tight groups and can access diversity in relationships and social worlds through communication and information gathering capacities (Rainie & Wellman, 2012 p. 11). The ability to do this fundamentally changes parenting, particularly under special circumstances. This extends the possibility to be in the virtual presence of others through computers and handheld devices, and makes them aware of reachable and unreachable goals for their children and the use of technology. Tess and William's entrance into an unexpected and unknown world through technological hearing devices is tracked through focusing on material affectivity in their descriptions of their experiences. This alien world is characterized by differentness and social discreditation (Goffman, 1963, 2009 pp. 41-42) associated today with what is called

disability. For more than three decades, research has shown that disability and its meaning are socially constructed. However, the technological devices and equipment used in cochlear implantation practices are material things which cannot be avoided or go passed unnoticed. The world of disability is to a certain extent familiar to both of them but what is entirely new is how the technological devices enter their lives as becoming a part of their children's bodies causing them worry and concern which emerges in different affective ways. Tess's experiences circulate around a theme of powerlessness and resistance whereas William's accounts circulate around vulnerability and defense. Both parents' are making sense of these technical devices.

The material affectivity perspective has helped us see how personal experience, technical devices, and computer mediated forms of interaction with others and objects are woven together through the thoughts and emotions of these two parents. The resulting description illustrates a type of intensity in circulation actualized in their accounts. The world of disability now appears to totally occupy Tess and William's immediate existence. Disability concerns them in very real ways. When Tess is asked to choose the color of *her* son's hearing aid, she is forced to link the world of disability to her own taken for granted world of typical, ordinary people. This is the rupture. The invisible boundary between her own world and the world of disability was irreversibly dismantled and made visible through a child's body and device coming together. Both she and her baby broke through into the alien world, a world they occupy in vastly different ways. Tess becomes unordinary as a parent of a child who can't hear and her child who will to some extent always be exposed as unordinary to the 'othering' gaze of ordinary people. The hearing aid and then the CI will signal the attribute that triggers social discreditation. Tess could see the others' gaze because of how the normal and the stigmatized are actually perspectives shared by everybody (Goffman, 1963, 2009 p. 138). This implies that Tess and William can hold multiple perspectives by seeing themselves and their child as divergent both through a perspective of courtesy stigma as well as through the normal gaze on the stigmatized "others" like their children (Goffman, 1963, 2009 pp. 28-31).

William's first words in his interview are illustrative of the social implications of how difference is publicly noticed. He felt very strongly about being subjected to rude comments and questions which appear to be the lasting image of when his world changed. The rupture experienced by William is interconnected with being denied privacy generally accorded to other parents which figures prominently as a discreditable dilemma adding to the realness of being in a new world. However, Tess and William did not just encounter a new dimension of disability in their own socio-cultural

community. They also inhabited new positions in a social economic system as well as a globally connected computer system. They found out that the devices their children would be dependent upon are steered by arbitrary, bureaucratic systems which become connected to their bodies. This led to the discovery that they were even more vulnerable than they had understood in relation to their new belonging to the alien world of disability. For Tess, this coincided with the plastic covering incident. For William, a search for being able to manage stigma with implantable devices leads to resignation. It is here that the real and tangible materials of devices are connected to their strong emotions which guided them in connecting with other parents and professionals through social network systems who could assist them and their families.

This can also be understood in terms of parent biographical disruption and reinforcement (Todd & Jones, 2005). As an example, Tess begins with an event which momentarily disrupted her expected path forward but has begun to connect with others which indicates that she is finding a way leading to others like herself. She emphasizes the importance of this way of informing herself and helping others and reinforces a sense of self in this way. William enlists the help of others who are better able to detect problems and deviations in behavior to continue to minimize stigmatizing effects. In his narrativizing he returns to motivating a search for better and less visible remedies for hearing loss and puts this in terms of having to protect and defend which are strong existential themes for him. William sees his entire life as changed for the worse signifying his ‘loss of self’.

The affective practices of narrativizing reorientate parents’ relations to norms of social ideals of ability. They become aware of how these norms impact them and their children which compels them to engage with sympathetic others to enlist support. What I have aimed to do in this chapter is to show the role of materials and affect in everyday life of parents intertwined with others through the materiality of computerized networks. That affect is something that can be followed in actions has been shown in how lived parenting is inseparable from the actions and practices of others.

Showing how the bodily and sensorial conditions are part of what is involved reveals that there are considerable emotional aspects in becoming. These parents are trying to come to terms with a world changing experience. This struggle with uncertainty, involving the sense of self as coherent, is how parents exist. The feelings of not being in control, not having sufficient knowledge and coping with suffering, occur simultaneously with feelings of love and care for another human being. The role of affect in becoming has been explored.

This chapter has shown through Tess's and William's examples manifestations of existential parental uncertainty. This can further be explored by examining how they exist as both experiencing subjects and objects of social constraints. This duality is expressed as the self being ambiguous, an idea developed in the philosophies of Maurice Merleau-Ponty and Simone de Beauvoir (De Beauvoir, 1948; Merleau-Ponty, 2002). How ambiguity is related to ambivalent feelings will be developed in the discussion chapter.



## Chapter 6 Becoming a parent of a child who uses a cochlear implant



*Figure 4: Posted photo on an online support group. Permission for use of the image was granted by the parent. (Netnographic fieldwork protocol 3)*

## Introduction

The previous chapter presented a description of what the beginning of becoming a parent of a child with a cochlear implant entails and what meaning this has for parents. The initial arrival through a rupture in the taken for granted world, through the encounter with technology, characterizes this beginning. This chapter will present a more detailed picture of lived parenting and how the parents come to understand their child's use of senses. The becoming process in focus has to do with a particular mode of existence which involves the body. I am approaching this task of examining the phenomenon of sensorial differentness through the use of the existential themes of embodiment, spatiality and relationality. I developed the terms apprehending, practicalizing, consolidation and narrativizing to use in a description of a becoming process.

The experience of the parents who were interviewed are represented by David, Peter and Ebba's accounts and are explored to describe what it is like to exist as a parent who finds out their child senses differently than they do. All of the other 16 parents in the interview study have shared these themes in their accounts on the issues explored in this chapter. The interviews have included 'beginnings' of what a majority of the parents referred to as journey, a trip, traveling from one point of being in one way to a new point described as a type of experiential and practical awareness. Initially I had an interest in describing experiences of technology rather than describing their experiences from a starting point, a beginning or as development. It was however the strongest pattern in the material of these parent accounts. The foundation of living with the CI technology in everyday life is explored through examining the start of going in and out of ways of experiencing one's own and others' senses and what choices these early experiences led to.

In order to see the accounts through a phenomenological perspective I draw on Drew Leder's notion of *dysappearance* as a departure to investigate how individuals attempt to make sense of their infant's world through their own (1990 pp. 69-99). I use this notion together with entering into understanding the inner workings of another person's body. I use a first-person perspective of parents where the way another person exists is thematized, namely grasping how a new human being uses their senses. Going in and out of ways of existing when contemplating another person's senses in body thematization (Leder, 1990 pp. 94-95) directed the way the interview material was approached. This was done through developing a way to focus on how unanticipated events become the focus of experiencing. Oliver Sachs, a neurologist, writes about deafness as "an unexpected perspective on

the human condition” which directed him towards imagining perceptual ability (Sacks, 2009 p. xiii). The work on his book, *Seeing Voices: A Journey into the World of the Deaf*, began with his interest in how deaf children acquire language in the absence of sound. His focus was on what is possible through vision. He states that the book is “as much about visual perception and imagination as it is about deafness; [it is] a meditation on what it means by necessity to be intensely visual on every level” (Sacks, 2009 p. 57). These ‘meditations’ about perception and imagination about what it is like to sense differently is paramount in investigating the becoming experience of parents and has inspired this particular study.

There is a beginning of becoming a parent of a child who uses a CI that parallels the general ‘becoming a parent’ process. In the interview material there is a consistent, often implicit presence of having gone through a shock, a trauma like event or an incident that remains central to their early parenting experience with the child who is discovered to be sensing differently. The child is found to be either deaf or hard of hearing with references to being or having a handicap or a disability. This is a fundamental aspect I do not describe at length in this chapter in order to access the way parents comprehend their child and their thoughts about how their child exists with them. My focus for this project is to bring along these experiences of unwelcome circumstances and go beyond and deeper into what is involved in exploring experience: the existentiality of a lived relation, a lived body and lived things. Van Manen uses these elements to exemplify an existential inquiry. “The notions of lived relation, body, space, time and things, are existentials in the sense that they belong to everyone’s life world” (Van Manen, 2014 p. 302). This chapter utilizes accounts from such notions, the lived parenting, to attend to the detail of senses and abilities. I am assuming that a deaf parent of a deaf child, apart from belonging to a minority in living in a hearing dominated world, will have a similar experience to the hearing parent of a hearing child in respect to the senses and communication (Lane, Hoffmeister, & Bahan, 1996). The parent who becomes a ‘hearing parent’ does so when they have a child who uses their senses differently.

It is the initial relational parent-child beginning through birth which sets the starting moment of becoming in lived parenting. Becoming is characterized by a shifting from continuity to discontinuity in existence discussed in terms of rupture in the last chapter. This object of human consciousness, *sensorial differentness*, the striving to make sense of another person’s senses, involves going in and out of ways of being. To depict how parents are in a process of becoming, I draw on Sara Ahmed to concentrate on their disorientation and movement towards reorientation as relational embodied experiences (2006 p. 157). In this chapter this is found in the experiences of perceiving the child and perceiving what the child perceives. The shared spaces the parent and

the child inhabit are used to explore how parents contemplate a new human being's uses of senses. Ideas about sensory use and soundscapes (Alftberg, Apelmo, & Hansson, 2016 pp. 9-30) and how relationality changes how they are experienced is found between individuals. Understanding a parent's experience of a communicating, desiring infant is at the core of this investigation which foregrounds the parents' lived experience through facets of existing in the lifeworld, namely body, time, space and relations with others. One example of a type of account utilized for this is when a parent of a child who uses a CI has observed practices framed by medical technology where the infant is tested for having or not having the ability to use sound on several separate occasions. This procedure known as hearing screening of infants is the beginning of a parent's experience of contemplating hearing which initiates their own process of becoming hearing. A parent is first made aware of being a hearing person by becoming a parent in this specific situation which starts their orientation in this *sensorial differentness*, a type of reorientation. The parent 'becomes hearing' a realization that their hearing is a capacity. This was previously taken for granted but now ceases to be assumed and will be a part of their mode of existence.

This chapter deals with descriptions of what parents experience when asked about their becoming a parent of a child who does not use sound as they do. Understanding the reality of what an infant hears is approached as being a conceptual challenge to parents. In short the descriptions of the events that led up to their children using a cochlear implant are analyzed. From this material I have developed terms to describe and maintain a focus on orientation following Sara Ahmed (2006). These particular experiences include the senses in medical and technological practices. I see the terms as tools I was compelled to design for this particular investigation because of what I found in the material how parents were orientating. The developed battery of terms is used to attend to sensorial differentness in descriptions of existence. The primary focus is on how parents come into existence through a becoming process of orientating. I use the terms *apprehending*, *practicalizing*, *consolidation* and *narrativizing* to describe these different aspects of becoming found in the material. The excerpts which comprise the empirical material are analyzed with these terms to get as close as possible to parents' lived experiences which is also a way to utilize the parents' narrativizing accounts in providing ethnographic description.

## Making sense of early detection of hearing impairment



*Figure 5: Newborn hearing screening with automated otoacoustic emissions  
Permission to use image granted by Public Health Wales, Child and Maternal  
Screening, Newborn Hearing Screening Wales.  
(Netnographic fieldwork protocol no 9)*

This is a description of how I have understood these parents in a beginning of becoming state who are attending to the senses of sight and sound as abilities. Often in my eagerness to know more about living with CI technology, the concrete use of verbal and visual strategies or the everyday encounters with professionals, parents returned to telling about the process on the way towards cochlear implantation. This was such a common occurrence that it is a distinct characterization of the interview material. The participants steered the interview back in time away from the ‘living with’ experience to ‘how it came to be’. I interpreted this movement as their efforts to get me to understand where they had been, what that process means to them now and what significance it has and will continue to have for their lives with their children. This is what one parent called the ‘hearing journey’ and what I describe as becoming a parent of a child who uses a cochlear implant.

The main events that depict the situation of becoming a parent of a CI user are testing situations, detection and approval of candidacy for cochlear implantation of which all the parents in the study have given accounts. In this chapter excerpts from interviews with Ebba, David and Peter will be used to present how the larger body of empirical material can be understood with the use of these examples in respect to becoming in situations of *sensorial differentness*.

Hearing tests of different kinds at frequent intervals and numerous occasions characterize the parents' introduction to hearing impairment as it is understood and talked about by doctors and technicians. Inaccuracy, fluctuation, variation, subjective experience of audiologists and interpersonal relationships contribute to what parents learn about how much you can know about another person's hearing and what to do with that knowledge. Ebba and David discuss this at length and in a recurring manner in their interviews. The focus of both the first interviews with these parents was on learning about their child's hearing impairment. Their second interviews and Peter's initial interview dealt more with therapy, language choices and schools. It is part of the 'coming to terms' experience. Reconciliation is the acceptance and understanding of what hearing is and how it works and how variations of it form *sensorial differentness*. These parents learn about 'hearing as missing' where the ability to use sound is suspected to be impaired.

### David's account of hearing screening

The first type of testing the parents come into contact with is called automated otoacoustic emissions or AOAE which is a hearing screening of infants. For this test, a miniature earphone and microphone are placed in the ear, sounds are played and a response is measured. If a baby hears normally, an echo is reflected back into the ear canal and is measured by the microphone. There is no echo that can be measured when a baby has a hearing loss. David started the first interview with explaining what they were told the first and second time the test was administered. He did not remember the name of the test until later but explained what was being measured in general terms. The excerpt starts with a quote from a nurse or midwife and symbolizes how he and his wife found out there was a problem with the baby's hearing.

David: They said 'No there's no reading but it's probably amniotic fat.' This wasn't an audiologist who did the testing. It was an assistant nurse who did it. So we just had to come back after a week or two. So we came back after a week or two. Siri was alert and happy and healthy just like any two week old baby but they didn't get a response then either. Then they said 'No, it's surely still amniotic fat but you are going to go to the audiology clinic at the hospital [next time].

David's concern about the accuracy or reliability of this test grows after the second try seemed not to have worked either. It is important to note that David refers to Siri as being alert, happy and healthy as a baby is expected to be. This utterance shows a way of how the body of the child 'disappears' when it is in good health (Leder, 1990). The contrast to the third screening

marks a significant incident which contributes to David's understanding of the testing experience, his child's hearing and the reliability of later tests in how he begins apprehending, namely the way he contemplates and attempts to grasp the way another person uses senses to experience.

David: She was probably two months when we went there [audiology clinic]. Then they did the test the third time and it was the same thing. No answer and we had to wait a little bit and then we got to meet, it was the same nurse, the audiologist who did it. We had (pause) no we had to wait to meet the audiologist, the doctor, yeah, which was the same day. And the doctor looks in her ears and beeped with some thing and said also 'No here, here we aren't getting an answer. The girl is deaf' he said. Really, just like that. That was like our first news of a result and also our first contact with our hearing habilitation center. So that was a really bad meeting. A very unsympathetic doctor [details about the doctor]. All the others we have met there have been really great luckily, but this was our first appointment so it was, it was horrible.

For David this event actualized a life with a disability, which for him was a traumatic instant. It is presented as a critical point through the dismissive and matter-of-fact fashion in how David mimicked what was said. David's experience of detection is also marked by irreversibility. This is a screening practice but David understands it as a diagnostic practice because of what is said by the doctor. This exchange stands out in the material both in relation to what happened in other parents' accounts where there was much less direct disclosure of detection by a medical professional, as well as what David will experience in test results and changes in his daughter's hearing. It is first after many evaluations that David will later find out the nature of his daughter's hearing impairment as well as its medically defined cause.

David describes his experience as 'horrible'. It denotes the description of the deliverance of a message in a medical setting and frames his entry point into dealing with doctors and test results as an advocate for his child. To him, this was an abrupt exposure to facts which the doctor insensitively disclosed. The standard procedure reported by other parents was to confirm suspected problems through undergoing an *auditory brainstem response* (ABR) a test which gives information about the inner ear (cochlea) and brain pathways for *hearing*. Experiencing carelessness by a doctor with serious emotional consequences develops into David's refusal to have his daughter treated by him again.

David: We called all over Sweden [during these months] to find a, or we called to all the university hospitals to find an earlier timeslot [to do an ABR]. We thought that it was an extremely long time to wait, a month, to get this result. Or to get any result for that matter. But there weren't any times so we had to wait this month out. So we go there again. That time we didn't meet

with [the doctor who said ‘The girl is deaf’] because we had of course said that we don’t want to meet that doctor anymore.

Later in the interview he told about the complaints he had filed about the treatment they received in how a test result was relayed. This set of connected events: the screenings, the experience of being given an off-hand diagnosis likened by David to a ‘sentence to a life of deafness’ and the formal complaints he filed, makes up the context of how David started to become a parent of a CI user. Events like these, testing situations and disclosure of deafness events, are significant for many decisions and actions that are described later in interviews. In this excerpt where David talks about his refusal to be treated by this doctor and the feeling resulting from never having heard back about the complaint from the authorities lingered in how he shared this personal narrative. An interpretation that results from David’s encounter and the following process can be connected to how a parent comes to trust certain people and distrust others as well as the procedures associated with them.

### Peter’s contrasting experience of the hearing screening process

Another parent, Peter, told about his experience of the hearing screening. His process of becoming takes a course through an experience of an immediate and definitive detection of deafness. This may have contributed to why this description of detection is so different from most others in the study. A conclusive result is linked to a diametrically different narrative of how he came to trust the medical care and personnel so much that he considers them family and very good friends, a point that will be taken up in the conclusion of the interpretation of detection experiences.

Peter’s narrative is marked by how he appears to regard the deafness detection event as uneventful. It was not relayed as traumatic or problematic. The AOAE test readings were explained to Peter by the chief physician and understood them as a test result that was definitive. I understood Peter as having a reason for downplaying what is often considered in terms of shock or trauma. He resisted the idea that he was traumatized, that parents need psychological help. He describes the parents he shared this experience with as people who practicalize, want to begin addressing issues as solvable problems. ‘They don’t go around feeling sorry for themselves.’ Peter’s adamancy of not being changed by the experience on a personal level can be related to how he understands deafness. When summarizing his conversation with the chief physician he states this matter-of-factly:

Peter: ‘His hearing was between zero and nothing’ [at two days of age].

Peter, like all the parents, starts his account from a beginning of being a parent of a CI user. His beginning led to recounting the time when his wife was expecting their child. It dealt with how they could not count on knowing which maternity ward in the large city they lived in would be able to admit them when it was time for his wife to give birth. Access to delivery and maternity care were seen to be unpredictable. They had decided to plan to go to a smaller regional hospital close to his home town when their due date for delivery was getting closer. A strategic decision to increase the possibility of receiving good care had already been made. Peter continues to frame the event by having been very lucky to be in a hospital setting where they had implemented the neonatal hearing screening (AOAE) quite early. This led to the earliest detection of deafness as possible, in how Peter understood it. It was a combination of extremely fortunate circumstances.

Does receiving this news along with trusting the smaller hospital environment, the knowledge of the luck of being in the right place where they could detect deafness so quickly and being close to home and family members have meaning for how the news is understood? In Peter's case it certainly does. He never expressed any difficulty with understanding the screening or testing procedure as David had. Peter said another doctor later had declared his child to be 'the deafest baby they had ever come across.' Peter also describes follow-up testing and attempts to get use out of hearing aids, explained by Peter to be another step in the testing process. He emphasized the baby's total disinterest in the hearing aids as opposed to extreme alertness in all other situations. This was how Peter says he was apprehending his child's deafness and what the child was sensing.

The contrast to David's drawn out and negative experience of finding out about deafness is striking. Peter quickly came to an understanding and summarized his early experiences leading towards cochlear implantation for his son like this:

Peter: The first months [with the baby] were mostly a project, to understand what the best path [plan of action] would be.

The act of practicalizing was undertaken almost immediately by Peter and can be a conclusion drawn from how the doctor explained the AOAE test and the cochlear implant from the first screening experience days after birth. This is unusual which stands out from the other parents' narratives. How these experiences translated into a sense of trust is traceable through Peter's account to his pragmatic style of dealing with a clearly defined problem whereas David's was a problem presented after a relatively long series of tries with an abrupt conclusion.

Peter describes a nearly immediate detection message being delivered directly from a head doctor involved in a research program in charge of having implemented the hearing screening program in that hospital. This is connected to being told about cochlear implantation at the same time as detection. His account is one of reliance and trust in the health care system embodied in this doctor and the doctors in the clinic they later would attend. This was how he understood his own choice to plan a delivery of his first child in a smaller regional hospital to be connected to reliability in specialized health care. There was a story of coincidence and luck that they ended up in a hospital where the hearing screening practice to enable cochlear implantation was being researched and implemented earlier than in other hospitals.

Peter: Then it appeared like pretty obvious. It was going to be a cochlear implant and there was never something, never some decision about it. We almost didn't make a decision. It was already like it, it seemed so totally obvious really.

Liz: Mmm.

Peter: So there wasn't any trauma at all in making a decision about it. Nothing that I remember.

Liz: If it at all was a decision.

Peter: It was like just, it was just to continue. We just got down to it. There wasn't any like 'Really? There's like this [CI]? Okay. That's settled. We'll take that then (laugh).

Liz: It didn't feel 'yes' 'no'?

Peter: No, like there was no such (feeling)

To emphasize the point that his decision-making about cochlear implantation was straightforward, not a difficult decision but a natural continuation of the screening process was important for Peter. It is connected to how he said he could be agitated that people expected him to feel like he was traumatized, that deafness was tragic, or that others would think he felt sorry for himself or had a right to feel sorry for himself.

Throughout Peter's interview he repeatedly explained how he understood himself to have the same outlook as the CI-clinic personnel had and how these are connected to practices inside and outside of the clinic. He shared their way of seeing things in how deafness should be treated. Similarities like this, in outlook and in handling situations are what exemplify Peter's experience of trust. In addition to this, the process of his beginning of becoming was emphasized and concentrated to a much shorter time period through how he sensed clarity in what could be known and done.

These two parents' experiences have dealt with infant hearing screening leading to detection. It is important to note that it is unusual to receive a diagnosis of hearing impairment from the results of only AOAE measurements. Most of the accounts in interviews and fieldwork report it as

an indication to investigate the possibility of deafness. Peter and David share experiences of sensorial differentness in their becoming but approach it differently. Their strategies are grounded in trust or lack of trust in professional judgments. This is intricately related to how they both express issues of care in how they were treated and exemplifies how they are similar beyond or beneath their apparent and explicit differences in their accounts. Their beginning of becoming signifies how relationships in the intimate sphere of parenting are intertwined with relationships with experts.

Seen as *apprehending*, being directed towards making sense of how another person, here an infant, is experiencing and therefore existing in regard to senses is the goal of these testing situations. These are examples of how a parent tries to understand what an infant hears or can be shown to sense.

When these parents then act on what they made sense of is termed as practicalizing. *Practicalizing* is the usage or enactment of strategies and materials in caring for a child or in goals of interpersonal communication with the child. This is made evident in parents' engagement in practices like getting tests performed and using hearing technology. For David practicalizing was to embark on making appointments, getting explanations and dealing with professionals to get clarity. When apprehending was impossible he turned to actions to be able to continue grasping the situation.

### Ebba's account of detecting hearing impairment

I would like to continue from David and Peter's experiences with another testing situation leading towards detection. When Ebba's child was diagnosed, it occurred after the ABR (auditory brainstem response). Ebba's account is interesting in how the suspicion of a hearing problem was relayed but never explained. The non-verbalized messages of what the reading could mean was described as causing more and more concern as time passed and the screenings were repeated.

Ebba describes a drawn out process around the screening and realization of hearing impairment. By the time they would be scheduled for the test that would be in Ebba's view 'a definitive answer', she had experienced four AOAЕ screening occasions with their audiologist. This is how she presented the four tests:

Ebba: At the obstetric ward [...] the hearing screening. He didn't pass that. We didn't think so much about it because it's really common that you don't get a reading from that test. OAE is what it's called.

Liz: You were still there [after giving birth] when they did it?

Ebba: Yes. We were given a new time and went back in later and there still wasn't a reading. Because it just shows yes or no. It doesn't show any levels or anything like that. So we went back two weeks later and still nothing and we thought that he had been very sticky when he was born. There was a lot of amniotic fat on him. [...] Yes the audiologist we had then [...] was very non-communicative (laughter) putting it mildly.

Liz: Okay.

Ebba: The middle of December was when we got the third appointment. [This was for the fourth screening attempt including the one done at the maternity ward.] He was a little over a month and it was still a little bit like we were thinking that 'Yes well now there is probably something after all.' She [audiologist] still wasn't saying anything. I tried asking her, 'Is it showing anything?' 'No, no, no.' [the audiologist answered]. I thought, 'this can't be normal.'

Ebba's son failed the infant screening four times. The gradual realization of hearing problems was marked by not receiving information. Ebba spoke about the absences of communication from the audiologist. This, together with a long waiting period during the Christmas holidays before an ABR could be done, characterizes her experience. Before this next excerpt Ebba explained that during an ABR measurement the baby needs to be very still and her baby wouldn't sleep. She breastfed the baby and after one and half hours the test was over. Ebba and her husband waited ten minutes and were then able to meet with the audiologist and the clinician. This is what Ebba said then:

Ebba: And then the doctor said that 'Yes, he does not have normal hearing.' [a noticeable increase in tempo when Ebba continues] 'So we will book a time next week and talk about this' [dismissive tone]. Then they send us home. (Pause) Um, I, what does it entail that he doesn't have normal hearing? Is he deaf?! He has a hearing impairment? What does this show? 'No, no, we can do this- we can take it next week.' [in the voice of the clinician] He wanted to like, he didn't want to give, he didn't want to answer how much he thought that Adam could hear. [...] That was an additional week we had to go home and wonder 'Okay. Is he deaf? Is he not deaf?' All of these thoughts. A lot? A little? What does this mean? But they just send us home.

Ebba expresses leaving this testing situation with great uncertainty. The doctor's manner is a continuation of what Ebba had already experienced in the non-communication from the audiologist and a feeling of not being given information is reinforced. However, she does reveal that her understanding through this battery of testing situations over time has given her information that '*There must be something wrong*' and '*I thought that it can't be normal*' when talking about the infant's capacity to hear. She puts into words what the doctor could have said from what she gathered the clinic personnel already knew.

Ebba: And from our perspective I had much rather heard that ‘Yes, he has a serious hearing impairment. We can talk through it next week because then we have time put aside for it.’

To say Adam doesn’t have normal hearing was diffuse to Ebba but led her to draw likely conclusions with her own knowledge based on going through this testing and detection process. She expressed that she had already figured this out since he reached the age of five weeks by the time the last hearing screening was conducted. The possibility of amniotic fluid or matter blocking the ear canal was highly unlikely. After a number of AOAE readings Ebba had begun to use Internet searches to investigate what could be expected and concluded from these readings.

### An immediate concern about the future

Here I want to show how Ebba experienced the moment of detection and what it initiated in her thoughts. When they found out from the doctor ‘*Well, his hearing is not normal.*’ Ebba said

Ebba: So we [her husband and she] talked a lot about it, a lot about what’s this going to be like now? How is this going to turn out? Immediately thoughts about ‘What will happen in school? Friends? All these thoughts just came [...] at the same time as ‘Okay. He doesn’t hear.’

At numerous times during the two interviews with Ebba she describes herself as always prioritizing education and emphasized how it is very important to her, in her life and a view she shares with her husband. It is her main focus of presentation when it comes to how she sees her role as a parent, to see to it that her children get the best education possible. This part of the interview exemplifies how this was a thought that immediately came to her when she heard that his hearing could be problematic through wondering ‘*what will happen in school?*’

Ebba and her husband spent a considerable amount of time discussing these future issues concerning who their child will be friends with and how his education will be impacted. Then she turned her account towards what she was feeling at that time and directed these questions to herself:

Ebba: ‘Will he ever hear me say I love him? Will he hear when I sing him a lullaby?’

It is apparent that Ebba is learning about hearing, deafness and disability by imagining what it will mean in her life through apprehending. It is an alien feeling to wonder if she will be able to use her voice. She shows concretely

that speaking and sound are deeply involved in deep feelings of intimacy and care and how she and her child will exist in the world.

During the interview Ebba returns to this point in time, the week of waiting during the winter holidays, on numerous occasions. It contains how she anchors her personal narrative as an expression of thoughts about the future for her child and how she was attempting to imagine her relationship with a child who may not hear. The incident of detection, however vague Ebba describes it to be, was a definitive circumstance of her apprehending. Situations where anomie is present, pinpoint how parenting in this context changes. There is a breakdown, a sense of alienation which makes certain points in time permanent in a narrative of apprehending disability. Her description emphasizes points in time like the vague message of a hearing problem and the time at home spent contemplating. Ideas about consequences in future times like in school settings and friends of the child circulate around in the way she experienced time. In her account, the detection, the alienation and the waiting period led to a type of meta-reflection about why she thought about the future. She expressed that concrete thoughts about the future are not usually a matter of concern when caring for an infant.

Another aspect of the vagueness of what they found out about Adam's '*not normal*' hearing is how Ebba drew conclusions about having to schedule a new appointment instead of being allotted time with the doctor when the detection of deafness was revealed to her. Ebba's thoughts about the imposed waiting period before they could discuss this, is an additional circumstance of the experience of time.

Ebba: I think I assumed the news was pretty bad already when he said we'll meet and talk about it next week.

At that point, when they weren't allotted time to discuss the results Ebba understood this as a part of the diagnosis about Adam's hearing. The doctor required a waiting period before a diagnosis could be fully disclosed. Her conclusion was that a larger amount of time is required to be able to reveal such a serious diagnosis. Needing to have enough time, for Ebba, is the part that signifies the seriousness. It is a signal of the degree of impairment. This time set aside to talk and get explanations is understood by Ebba to be related to the gravity of the situation requiring preparations of different kinds. One preparation was to come back so both parents could be there without having the baby with them. Another was seen by Ebba to be given time to be mentally prepared where she and her husband could be at home and talk about it and not in public or in an unfamiliar environment in a hospital. She understands the intent but the result is described mostly as a

frustrating and emotionally painful effect of not being given information immediately.

David's encounter, in comparison, was characterized by shock and a waiting period which was much too long. Peter's account lacked any element of shock, disappointment or waiting stage. However this can be interpreted to be a reaction to how he is viewed by others as an object of sympathy or pity. Ebba deduced the diagnosis indirectly. These three experiences put side by side exemplify different scenarios of how parents enter into becoming the parent of a CI user. What they do have in common though is that they engage in apprehending by making sense of tests, professionals' statements about test results and evaluations of tests. How parents do this differs from case to case but always requires thought about senses.

A matter revisited throughout the interview by Peter was that he strongly contested a view of disability as a tragedy. He exemplified this in his story by referring to a potentially tragic experience, a situation he found frightening: seeing his son put under anesthesia as if he were gone or had died.

Peter: Yes then he was operated on and that was also. And the only, the only thing that was difficult in this whole process that was when they put him under, when they put him to sleep! That's like, like when your little child who isn't even a year old, disappears from the world. You see his eyes want to just go blank and he isn't there anymore. Then that was like oh.

Liz: But you were with him?

Peter: Until he was asleep.

Liz: Until he fell asleep then when he had fallen asleep-

Peter: Then we weren't there later.

Liz: To have experienced that.

Peter: Yes, that was really difficult.

Liz: Yes it was. Wow.

Peter: Because then he was gone.

This operating room experience with his son came up in the interview as what part, if any in this subject of deafness disability, could be genuinely fateful. This story by Peter exemplifies what he describes as the possibility of death as an example of what was truly difficult. This and not a disabling factor was what he found to be a potentially tragic experience.

An additional way in which Peter contested the tragedy of disability was the way he felt deafness should be treated medically and therapeutically and that he has gained insight over the past years by reading the latest research and recommendations on pediatric cochlear implantation. His view of deafness and his pragmatic approach saturate how he gives his account of detection of disability.

Peter: Let's just get on with it and sort it out and fix it and it is more like check out what technology there is and just go with it. Stick the stuff in and get going. [...] It seems like the CI clinic and I are the ones who know what is going on and what works.

Peter felt like things were getting done to solve the hearing problem from the first screening occasion. He viewed this approach as being much like his own in dealing with any difficult situation and gives examples of another parent who has a child with Down syndrome who has done the same, i.e., doesn't see his child's disability as a tragedy or feel sorry for himself.

David, this being his first child, mentioned in different parts of his interview the slew of tests for other syndromes and conditions they were referred to take. This exacerbated his experience of testing practices but also framed how hearing was possibly going to be the least of the problems his child would have. In their frequent visits to the hospital and hearing center, David came into contact with families and children with disabilities that influenced his understanding of his child's situation.

Ebba was able to compare her experiences of her second child with her first. Her accounts included a calmer and more matter-of-fact approach to going through the battery of tests that ensue after the detection of hearing impairment. She also relied on her own judgments of 'home hearing testing' and was mostly concerned with not getting enough information from professional caregivers. Her account was characterized as an attempt to get facts and be more informed. She viewed the calls to come in for other testing for syndromes as meeting this need for more information rather than being additionally concerned about other problems. Ebba had the additional apprehending work of contemplating how having a normal hearing child and a child who was probably deaf would change their family life and the life of her other child.

These examples are provided to add detail to how apprehending involves contrasting ideas of practices, encounters and previously held ideas about how to solve problems, what disability is, comparisons to 'normal' babies and comparisons with the occurrence of multiple or complex disabilities.

## Consolidation through apprehending and practicalizing

After experiencing detection of hearing impairment in hospital settings, parents' continuing becoming process takes on the nature of adjusting to new circumstances in the home and with others in their lives. They are then directing themselves to what is new in their environment, the sensorial differentness. Their lived parenting involves a new relationship to changed surroundings again emanating from the infant and the infant's different abilities. This section provides an analysis of how becoming is characterized by these parents' new directedness of intentionality to soundscapes with the child through consolidation of apprehending and practicalizing.

After showing results from descriptions of reorientation in sensorial differentness through apprehending I will further the analysis to exemplify how a consolidation of experiences is enacted in practicalizing in the usage of strategies and materials for communication.

*Consolidation* is a strengthening of a parent's particular understanding involving their child's senses (apprehending). It comes about through the accumulation of different sorts of knowledge and experiences through practices and encounters (practicalizing) in situations which merge together and become strengthened into one general idea that is embodied by their child who uses a CI. Consolidation relies on experiencing the child's hearing in everyday situations and is used in the parent's everyday life as their idea of how their child hears, senses and exists. Apprehending becomes stabilized when it is no longer being contemplated and takes on the form of a more internalized and taken for granted idea about the child. This stabilized idea is the point from which parents continue to act (practicalizing) on what they know about their child and in particular the sound they can utilize.

When Ebba returns home after the ABR testing with the new appointment the week after, an attention to *sensorial differentness* is described. Her thoughts turn towards the child's body and expressions by talking about senses and ability.

Ebba: It was still 'Of course he can hear.'

Liz: Okay.

Ebba: We can see that he hears, it shows on him. He happens to be extremely visual and very, very visual and he has been that way since he was a newborn.

Liz: When you say that he has been so visual since he was a newborn can you describe that?

Ebba: Very um, very clear facial expressions, very clear with that he was conscious of what was happening around him. And I think that those signals were interwoven with the signals you could get if you were, as if he were

hearing if you understand what I mean. It was so obvious that he was following in exactly the same way as a hearing infant but in hindsight we get it that he was like that he was not deaf. He has a severe hearing impairment. So he does hear. And he hears and it seems as if he hears when you are very close and it was a thing like this-

Liz: When you say that do you mean with a CI or?

Ebba: Without. It is still that if we are rather close to him, this [shows a 10 centimeter distance with her hands from her ear] we can speak with him and he can repeat words.

This exchange is an example of apprehending another person's hearing as an embodied space. Ebba is clearly directing her attention to how her infant is experiencing sound and looks and interprets signals about what the infant is able to hear. She experiences sound differently as well because of her motivation to find out what she can about the child's sensory world. This way of detecting senses was not previously contemplated by Ebba. It was taken for granted and it is the emergence of hearing as problematic that prompts her to make sense of another person's experiences through reorientation to senses.

Proximity, nearness in place, is part of the *sensorial differentness* that is important to include in this analysis because of the inherent necessity of closeness of parents and infants. As the child grows, the distance from a parent's body and voice grows as the child can begin to move around on their own. Ebba, Peter and Daniel talk about this so I understand this proximity to be important in how the parents are apprehending the testing situations they go through with their babies which involves making sense of the body of the child in respect to 'sense' ability. When parents talk about their child still being hearing even without a CI it includes this element of proximity. Daniel had said: '*She hears if I am close*'. This conjures up images of parents being near, directed towards the child, perhaps the ear and movement towards the child to be in the area that can enable them to use sound. In this way intimacy and hearing contrast with the future situating of less intimate relationships as less access to sound which contribute to the sound environments in social interactions.

Below Ebba continues to explain about a feeling that has been a part of the experience of going through multiple testing situations with consistent results.

Liz: He can do that? [referring to being able to repeat words]

Ebba: Yes. And it has also been such a thing that has been there the whole time so it is still regardless of us having done so many tests and including under anesthesia and there have been different hearing evaluations so it has been relatively clear, very even like. But even like 'He hears too well to be where he is' [on charts and readings].

Liz: What do you mean ‘to be where he is’?

Ebba: Like hearing-wise.

Liz: Okay. On an audiogram?

Ebba: Yes. Exactly.

Liz: Is that how you think of it?

Ebba: His audiogram.

Liz: Okay.

Ebba: According to his audiogram he shouldn’t hear what we think he seems to hear. But that is also the type of thing we are going to find out the older he gets that he can tell us.

Adam’s tests are ‘relatively clear, very even like’. With this she means the general evaluation of hearing impairment based on an audiogram. Ebba sees stability in what the tests show but believes that the evaluations underestimate her son’s hearing ability. She believes her child hears better than what the audiogram shows. Again, proximity to the child and verbal interaction in the home environment are used as a type of proof. This shows how different sources of knowledge ranging from those from intimate spaces to technologically mediated spaces are involved in apprehending.

The concentration on apprehending includes wishes and hopes that lets Ebba interpret that Adam may hear more than audiological evaluators think. She talks about the experience of focusing on the infant in a highly attentive way. In this struggle to come to know about the baby’s senses she describes how she is being more attune to his bodily movements and actions.

At first, this exchange seems to be a type of denial of accepting a tentative test result. She is answering to the phrase she quoted from the doctor ‘He does not have normal hearing’ and her question she later articulates ‘Is he deaf?’ She says they can see he hears; that it shows on him. Quickly after that she uses the term *visual* and that her child is extremely and very, very visual since birth. This came very quickly after Ebba said that ‘it shows on him’. How he shows he is getting a communicative message and how he takes it in are described with the words ‘shows’ and ‘visual’. The act or quality of ‘being visual’ in Ebba’s experience includes vivid mimicking and expression from the infant that can be seen and compared to previous experience of other infants, particularly Adam’s older sibling. How this can be understood as apprehending the infant, being directed towards the body and towards *sensorial differentness* are a type of knowing that is described by the use of both her own and her husband’s sensing of the child’s sensing in a close human relationship.

## Apprehending through his child's body

After a certain age the child can give an indication of what they hear during tests. For instance Daniel reports his daughter as being able to say that the CI side is better than the HA side when asked about how well she hears. This is a 'development of the child' focused experience, the child as becoming. It includes a dimension of being able to 'read' one's child, as exhibited in Ebba's account of 'seeing' her son hear, above. Other occurrences in parent accounts in the home include reading facial signals like raised eyebrows and head tilts.

Peter describes how he understands his child's 'normal' way of being as 'with a CI' which is illustrated in this situation in a bathtub. His son is not using the CI.

Peter: He ignores what his little brother is saying most of the time. Sometimes he sees what [his little brother] means. He isn't good at lip reading. He hears too well. That normally [with the CI] he hears too well so he can lip read a little bit but he isn't good at it.

Liz: Does he like to see you when you talk?

Peter: No, no. Not like you would notice it. He says 'Huh?' Wrinkles his eyebrows and says 'Huh?' He says 'What?' sometimes. And surely he does that more often than a normal child. But on the other hand, there isn't that much difference than when you talk to other kids either because they are just as absentminded and distracted. They are like 'Huh?' I don't know how much has to do with hearing and how much has to do with that he is nine ten years old. They are just as scatty.

Peter normalizes the act of hearing in two ways. He contrasts his child's normal way of being (wearing a CI) with not wearing a CI. He considers how his son is similar to other children in being non-attentive to verbal messages. Aside from the 'normal case' of his son's hearing being with a CI, Peter also reads his child's responses of not listening as something most children his age do, that they need time to focus on what is being said to them because they are young children. These ideas of his child being like other children interact with his way of apprehending his son's sensing and signals of sensing, if they mean he didn't hear or is confused. Peter also stated that his son doesn't need to see his face to understand him and does not read lips because he hears too well. This interplays with how the signals from the child's body are perceived.

Peter goes in and out of a way of being together with his son. Here is an occasion he describes of how his son shows his way of sensing with an example of his child pretending to be listening.

Peter: Really, the difference is that he has the best weapon when it comes to argumentation. When he has had enough [Peter says 'click' and makes a motion of shutting off a switch behind his ears].

Liz: Wow. He does that? How does that feel?

Peter: Most often he does it with a smile. He doesn't do it when he's mad. He thinks it's a little like 'Yeah, go ahead and stand there yelling.' It's just a cover that you open like this so it turns off the batteries so then he can't hear a thing. So there he sits and looks at me with a big smile on his face when I'm really mad or he's already turned it off ahead of time because he knows that I am angry at him. He's already picked up on that I am going to yell at him so he has shut it off and sits like that and doesn't say anything and so he looks at me and then when my mouth stops moving, then he does like this, [Peter says] 'click' so he turns them on instead and it flashes on his ears then. [laugh, gestures 'I give up'] He sure has enough irony.

It is first when Peter saw his child put the battery lid back on the CI, functioning as an on-off switch, that he knew he wasn't listening to a reprimand. He describes the behavior with how he understands his child's feelings, happy not angry, waiting for his father's anger to subside. Mischievousness when he smiles at his father yelling because he has turned off the mode of communication his father is using. He describes knowing the child is aware of what is coming and how the child just calmly looks at him throughout the lecture. He explained how he watches his child watch his mouth and when Peter's mouth stops moving he notices how that is the signal the child uses to turn his hearing on again by closing the battery compartment.

Peter exhibits this apprehending and practicalizing as how he adds his knowledge of his child's personality, the use of material and devices and how his child is developing interactional strategies, to what he knows about the child's hearing. This part of *lived parenting* involves consolidating, knowing how the child works and copes, and is intertwined with the apprehending of 'sense' ability. This leads into how parents develop strategies that they talk about as shaping the environment at home, offering opportunity in school choice or giving language skills as tools to the child; in other words, practicalizing.

## Monitoring and the child's body

David gives an account of how he is combining the information of how testing functions together with his child at different ages. As a parent of a CI user tests and treatment are continuous and the child's development in all aspects is monitored. This illuminates how the decision-making part of

practicalizing is a continuous process. Discrepancy remains in what his child can hear and what is measured by an audiologist and is expressed as a significant concern by David. He engages in trying to make sense of measurements by discussing techniques and shortcomings with the doctor which, is a major element of his apprehending.

David: It was partly, it was a frustration is what it was, there was always a discussion and so we saw also the different audiologists' technique was very different, in doing these evaluations. We saw that if it was a curt, less agreeable audiologist who was doing the evaluation on the small child then the child wasn't interested and didn't want to follow along either and then you got a worse result on the tests [...] Then there were the audiologists who were like fond of children and very capable in this testing of children. It is very clearly another technique to get them interested so long. Then we got better answers, test answers. We also had long discussions with [name of doctor] as well so that's why we all agreed and she [doctor] as well, that these tests, they are not completely reliable but they are the best we have. 'We can't do more' is what she means. And that's the way it is then.

David's experience was described as always having to engage in a discussion about measurements. This type of negotiating, and the observation that personnel who aren't good with children in eliciting responses for evaluations, led to frustration about two things. The first is not getting consistent answers. The second is feeling like he has to engage in a negotiation to understand because of the lack of technique by an individual who he feels causes the inconsistency. This is an expression of David's vulnerability in relation to the technological medical knowledge in this passage.

This is a prime example of a parent who then engages in apprehending by observing a child's hearing in the home. There are no definitive answers for David. Frustratingly, he has to make sense of something he thought would provide answers by making his own observations and acting accordingly. What can be known about David's daughter's hearing involves subjective judgments where these judgments are shared with others involved in the project of apprehending, usually the other parent. In this part of the interview the others involved were his wife and the clinic personnel drawing on different sources of observation and sense-making. Here, the communicators of what the child senses/hears are the audiologists and doctors who have to step up to 'fill in' via technological instruments by providing answers the infant can't. This is one of the main beginnings of becoming a parent of a CI user *inside* the larger becoming experience when parents are constantly interpreting an infant's signals and body. David's account exemplifies how discussions with professionals about tests are a vital part of apprehending and his becoming parent experience. He came to a conclusion about why some of the testing, the ones directly performed by an audiologist, could

give different results or how the instruments even fail to register any results at all.

Below, David gives a detailed account of how the first time with the CI was experienced. The focus is on how the child reacted and then got accustomed to the device and how the engineer was involved in the process. In terms of apprehending the technology, the personnel and the child's body and senses are present in how David consolidates the different elements.

David: You start out very cautiously [activation and programming of a CI] then we were given different programs with this remote control that comes with it so we were supposed to turn it up ourselves every three days but then-

Liz: But could you do with-

David: Yes, with the remote. So even though we turned it up less than recommended so we were still careful so when it was way too loud in the end after a few days from having gone pretty well and she had had that [CI] on... a few hours a day so, no. So she started to be scared of it and refused to use it and it was like. She was almost panic-stricken as soon as we brought it out. And a really strong reaction. And we kept on like that for a number of days and coaxed her and things to get her to even [...] She wouldn't have it on even though we were so, uh, we went down to the lowest, lowest program even so in the end we managed to get her to put it on and then when she realized what it was like, it wasn't too bad really since we had turned down the volume. And readjusted it. You can readjust this [electronics] in a lot of different ways.

David deducted that the CI must have been doing something to her that caused discomfort or a sensation she wanted to avoid. Even when it wasn't being worn or turned on she was wary of it. These reactions taken in by David, added to the impressions of how she experienced sound. It was a 'learning through the child's body' experience that involved electronics, settings on the CI, volume, the initial programming and the parents' efforts to acquaint her with this new device. David continues to explain.

Liz: How did you figure out what to do?

David: No, it was of course, we discussed it with the engineer. For one thing we were there nearly every other day because he, then he hooked up his computer to the processor and then –

Liz: Now this is at [name of clinic], right?

David [...] Yes. Then he adjusts it. You do everything much softer and more careful and like bring it all down.

Going back to the clinic to the engineer and the frequent visits to the clinic add a set of practices to incorporate into David's apprehending.

David: We kind of wanted to start over with a new tuning or like we had from the beginning. And then, but then of course we are the ones who know

Siri and are with Siri so it is we who see her reactions but in cooperation with the engineer of course and the doctor.

It is mainly the engineer who is instrumental in how the CI enters into the environment which changes the soundscape, but also the doctor who implanted the device is consulted. David points out that 'of course' they had the knowledge about how the device was actually experienced, in his and his wife's view because of what they know through caring for their daughter. To start over, from a lower or less strong level of sound is a way for David to reenter the process and avoid the problems they started with.

David: But then it was then it took an additional week or so after two weeks when she dared to start using the implant then already after three weeks she was wearing it all the time and seemed to understand [...] she was being helped by it. Then in the coming months it was turned up carefully once a month. Something like that. But now since a year back we have found a level, and a programming that we haven't changed or that the engineering hasn't changed so now it is consistent and we were there just last week to see what uh, if we should make any adjustments.

David says the new level of adjustment is stabilized, there are no changes made to find the right settings or to increase the level once a month. There is permanence to the way David says this, and emphasizes it by saying they were there last week and the right level has been found according to the engineer, the parents and the child.

David: But the engineering didn't want to and we all felt that it was good and Siri is six so now she can explain it herself.

Liz: She says how it is?

David: As a two-year-old already or, maybe as a three-year-old she realized that she needed this [HA and CI] and was very careful with them and never ripped them off or anything.

That she didn't want to remove them and was careful with them are expressed by David as Siri needing them. But he makes a distinction between the CI and the hearing aid she uses.

David: It was like her thing and this with the hearing aid she has on the right. That [side] you test for hearing regularly to see if it disappears.

David makes reference to the possibility of hearing worsening or disappearing. On one side, the CI side, things are stable; on the hearing aid side there is still a risk that has to be monitored.

Liz: Hearing ability can get worse there? Has it?

David: It could well very likely get worse but no, it has been constant maybe even gotten a little better. I mean the test answers have gotten a little

better with the years but on the other hand children are more cooperative.  
Then you will get a better result (laugh)!

Using the term ‘constant’ and that the test results have gotten better as the years have passed indicates that he understands the maturity of the child as a missing answer. The results have improved because Siri has been cooperative or motivated. In this way her development is brought in focus and shows how the young child, from a very early stage, is part of how the technology is understood to work or to fail. This is communicated through how David understands her as being cautious and kept the devices on as a two year old. Now as a six year old she can explain to the clinic staff what she hears and what levels are best for her. As the child grows and matures, the parent has been apprehending and practicalizing and successively adds to what they know about the child’s use of senses. It also requires reflecting back or doubling-back to understand past events, parts of experience which didn’t make sense at the time but are used in the present. This notion will be developed further down but important to note is what is revealed to the parent through the maturing of the child’s body together with the developing use of the hearing nerve stimulated by the CI. Consolidation is redone. An interesting detail is that David compared and thus consolidated experiences of both of his children who had similar occurrences of deafness where he uses his apprehending of his older child to understand the younger.

### Accounts of struggle and problem-solving

David’s account can again be contrasted with how Peter’s account lacks this sense-making activity characterized by struggle. In the hospital Peter had gone through similar testing situations and was given, in his view, clear messages. As previously demonstrated, he experienced receiving definitive information from the hospital to how he was able to move quickly from apprehending to practicalizing early on in the first weeks and months of his child’s life. This is an example of how practicalizing should not be understood as a stage but as a parallel process to apprehending when plans of action ensue quickly. During the first year of his son’s life Peter started immediately reading what he could find on pediatric cochlear implantation.

Peter: Then we went through all the tests and in the end it wasn’t especially hard to decide [to operate] since he couldn’t hear a thing. It was like clear but then I had been sitting and learning a lot of things during that time on Internet and all that then. And read.

Liz: That was how you went about it. Your wife too?

Peter: No, it was me who had done that, she was working and I was reading.

Liz: [laugh]

Peter: I read, started reading like dissertations and things about pediatric cochlear implantation and ten years almost ten years ago. Starting with things from 2004 is what I read [...]

That the year is significant is to explain to me that this way of treating deafness does not include the pre-pediatric cochlear implantation era. Early implanted children are put in a distinct category and this is the group Peter is understandably concerned with. His embarkment on knowledge gathering was his practical plan and began when he found out about the cochlear implant at the hospital where they gave birth. It led towards his understanding of the process and what is called for in getting a cochlear implant for a child.

Peter: Me and those who are at the CI clinic at [name of the hospital] it feels like we are the ones who know about the state of the present situation and then you have to educate the rest kind of who are all around whether it be family or school or other social services or situations.

It is noteworthy to include how Peter does not view himself as having changed who he is or having transformed in anyway. For him it is better described as a project that required that he adopted expert knowledge on what he found necessary.

Peter: No. I don't know. No I don't think that [having a child with a CI] changes me much especially. I think I have, compared to before, a subject that I know very much about now. I have never had as much expertise [in a special area] as I have now. It's really fun in a lot of ways for me personally I mean and getting asked [to sit on discussion panels] in this area. That's really good.

Living with the technology and reading the literature on cochlear implantation made it possible for Peter to share this information together with his own experience with others. Again the practicalizing Peter exhibits is put into focus when he feels the need to explain that his child doesn't change how he lives his life in any significant or exceptional way even though he has leading expertise in this area unlike anything else he has experienced.

Peter: I don't feel like I have a child who demands or changes something in the way I live or anything. It is more, it just feels like there are practical, technical adaptations.

The general theme of solving problems and getting on with life are how Peter portrays his everyday life in sensorial differentness. This is exemplified through practices of technical adjustment to do what families and children normally do in daily life.

Earlier in his interview, David had told about how one of the ABR tests, described as the most reliable test there is, had failed to give any readings or measurements at all. For David the technology failed completely. The doctor, one who he had grown to appreciate and respect, had even reassured that the technician, who had conducted the test, was one of their best and most experienced. This at least would rule out a certain type of dependences on a factor of human failing which was a manner in which David described some of the medical professionals.

In my interpretation these consolidated experiences David accumulated led to a desire to not make the child overly reliant on the medical technology. His expressions of what was seen as unreliable and diffuse point to issues of trust in people, processes and technology. In this next excerpt David frames what he has drawn conclusions about by situating his thoughts on his daughters' futures.

David: You wonder what it will be like, of course. What type of hearing do they [Kajsa and Siri] have? Now it seems that they certainly are going to go to this regular school with a hearing profile [which includes sign language instruction]. That's going to work really well since the reason they hear is because of technology. [...] A computer makes them able to hear and what will happen with it and so on.

Liz: What do you mean, what will happen with it?

David: They aren't what would you say? They aren't self-sufficient in hearing. They hear of course but if the battery isn't in they don't hear. And of course you wonder like what is this. That's why we feel that signing is important as well of course and not just depend on the electronics and the technology.

Liz: That is an interesting thought. That they are dependent on something that you maybe might not always be able to influence, or? I mean the battery, it can die? The device can break.

David: Yes, precisely. There are these practical things too. Sure, you can have an extra battery in your pocket and of course we do but I mean something can happen to the electronics and you have to re-operate. Then [the possibility exists that] 'Now it isn't possible to re-do the operation.' Like it's surely happened. Everyone can, all children can't be operated on for example. Some doctor maybe does something strange during an operation, we have heard of parents who after two years had to re-operate because the implant broke. That happens too.

'They aren't self-sufficient in hearing' leads to associations to producing (natural) resources and not having to rely on a chain of technology to meet one's needs. It seems to be in line with how David views how technology will play a role in his children's future and how it shouldn't be the only solution. His reasoning takes an even further move into the future where technology can fail or illness could hinder his children's ability to use sound with a CI altogether. The choosing of a school where they will learn signing

is a strategy that builds on a consolidation involving views on technology, the body and language but also the possible failings of humans in being able to address situations surgically. This makes the act of choosing schools an example of practicalizing that reveals what ideas the parents have about the future and worlds they strive to achieve for their child to be able to inhabit.

## Narrativizing in parent experiences

The parents in the interview material have shown how they think about their child in the present, as they are now, how they had added information about their hearing from previous testing situations, and are able to imagine future scenarios. The combination comes about in a consolidation of what their child was able to do then, at that point they return to in accounts, and to where they are now. In my view this can be described in different ways in using metaphors of a trajectory and doubling-back, anticipating and reminiscing about ability as narrativizing techniques. These techniques fill the function of fusing together the parents' thoughts and consolidating them into a comprehensible telling of a story.

*Narrativizing* is a description of the sense-making pattern made visible through expressed accounts in interview situations. Narrativizing puts events into an order that reveals the instances of apprehending, practicalizing and consolidation. These include 'doubling-back', a term to describe how events and resulting apprehending from events are returned to and used in consolidation. Another example is 'anticipating ability'- using experiences of present events to understand future circumstances. This focus on narrativizing is a way to follow a parent's account in putting different events together to express what they know and what has happened to them. What a parent knows in this lived sense is part of a construction of the parent's self. Three examples are developed below.

### Doubling-back

Examples of where consolidating occur in these parents' accounts include Ebba's way of expressing how her child can repeat words when she is close to him as a way of explaining what she experienced when he was a newborn. She uses both an apprehension of her son in the present and of when they were going through the initial testing period during his first year of life. It is an example of how parents *double-back* in thinking to pick up moments of apprehending to put them together. Ebba's reference to events then and now are put into a chronological narrative form but the apprehending is a process of combining which travels back and forth. In the excerpt above Ebba gives

an account of facial expressions communicating how her child is aware of his surroundings. She describes them as interwoven embodied signals that he was following like a hearing infant which give rise to comparisons to her older hearing child. Ebba is apprehending from a reference point inside her child's body. Then she gives proof that if you are close to him, now, without his CI he can repeat words back to them which is how Ebba doubles-back in apprehending. She goes through narrativizing, to gather up experiences, which makes it possible to combine them with new circumstances.

Why does Ebba give an account of the first news of their child's hearing impairment to talk about how they presently experience and think about their child's hearing? The account returns to the first time in the home after the ABR but before the scheduled consultation. She tells about remembering how the baby uses facial expressions very early on and there is a comparison to other infants. She returns to the present and oscillates between what signals her child gave, what signals hearing infants send and uses these to define 'not deaf' but severely hearing impaired. This is an instance of *doubling-back* that is part of how becoming parents of CI users give accounts of apprehending and come to conclusions about disability categories.

Part of the becoming parent experience is reconstructing past experience and doubling-back, an indication of a type of living with sensorial fluctuations and related uncertainties. A parent can make sense of or find explanations for what the child can do now, was able to do before and contrast these events of apprehending. This also exhibits how a parent goes in and out of ways of being through apprehending. Ebba offers examples of how she gives accounts of how she puts her apprehending to work which also means you have to leave apprehending and the object of it, i.e., sensorial differentness, to act. It would seem that you can't be doing both apprehending and practicalizing at the same time but the one is also part of the other. Through narrativizing this way of experiencing is detectable when the parent verbalizes thoughts and actions and exhibits how the two interact.

This is different from the before and after point of biographical disruption (Bury, 1982) in illness narratives in a particular respect: it has to do with the senses that allow language acquisition. Ebba, like Peter, shows how the commonly occurring descriptions in other parents' interviews describe children as visual, gestural, and using their bodies expressively. To double-back to detection is not only to revisit the rupture. It is apprehending that comes through a narrativization of experiences in *sensorial differentness* which are aimed at reaching understanding about deafness and sharing it.

## Anticipating ability

In other parts of David's interviews he uses descriptions about how the maturity of the child will be the final proof of what they actually are able to do with and without technology. He also compares his two children's situations, communication and test results. They differ in age and he thinks about this as well and what it will mean for their hearing in the future. Through apprehending two differently embodied spaces of sensorial differentness he is able to anticipate ability of his younger daughter. His children have had the same combination of technology, one CI and one hearing aid, but he knows more about the older daughter because of her age and what she is able to tell him at the same time as he can observe that his younger child has better use from her technology. In this way he anticipates his older daughter's ability as more challenged than the younger daughter. This can also be related to how David saw his children's testing results to be more accurate as they matured. Accuracy and maturity are connected and he uses these experiences to anticipate a future act of knowing through consolidating which comes out in his narrativizing.

## Different paths and different futures

Peter shares how he wonders about how life for his son would have been different without a CI. He uses ideas about being born at a time when the CI technology exists and his grandparent's view of deafness as isolation at another point in history. These historical contexts are placed side by side in his account together with the stability of the physical body of his child, and his child's personality. Wondering if his child would have been the same person if they had chosen a different path, occupies Peter's thoughts. This, in one sense, illuminates the idea of choice as creating a certain type of sensing and what that means for who a child becomes. In the excerpt below Peter shows how that, through narrativizing, consolidation comes undone temporarily, as he again considers what deafness is and does. Different choices seen as paths lead to different bodies and different lives. The choosing becomes a question of how his child exists and could have existed. The way these contemplations combine with apprehending both his child with a CI and when the child turns off the CI are everyday reminders of different ways of being which extend beyond the use of hearing and senses. The mechanism on a device actualizes existential themes in Peter's narrativizing.

Peter: What you can wonder about sometimes is if Sam had been the same person. It would be more interesting for me to know but it is impossible to

answer. It would be interesting if he were the same person if he had been the same person without these problems he has had. Or whatever you should call it.

Peter knows that accessing sound has changed his son's life through being able to learn language through hearing. He knows that sign language is a complete language that does not depend on utilizing sound. This actualizes whether or not you are the same person depending through which mode of language the child develops. The question of whether this set of circumstances expressed as problems or 'whatever you call it' has been part of who a person becomes is a part of Peter's mode of existence as a parent. These ambiguous circumstances creating the sensorial differentness are a central and continuous theme in Peter's becoming experience.

Peter: It's a little like this, both me and my wife speculate about it, if he is the same personality he, that he would have been had without [CI] but we are never going to find that out.

It can be understood that this couple, sharing in parenting, engages in this type of contemplation and are able to discuss it when they discuss their child's, in their view, exceptional personality. Would he have been this humorous, ironic, outgoing, entertaining and kind without a cochlear implant? Sensorial differentness is the springboard of adopting an existential attitude which includes uncertainty or confusion about who a person is or will come to be. In these parents' situations their choices have bearing on existence and thoughts about modes of communication are part of this way of being in spaces of sensorial differentness.

## Multiple bodies in narrativizing

'Doubling-back', 'anticipating ability' and 'different paths through different bodies' all involve gathering up perceptions about a child's senses through their bodily signals and actions both when they are using devices and when they are not, and using them in a unceasing reconstruction of ideas about the child. The thoughts about what helps the child, how that can be known and what the child is like because of the body they have are occupying the parents consciousness when they engage in this type of sense making. An important distinction to make is that there are multiple bodies of the child in the apprehending of the parents. One uses CI hearing. One is deaf when the CI is not worn. One positions them in a hard of hearing category. Aside from these there is the body that does not exist other than in their contemplation, the one that did not get a CI.

The narrativizing techniques used by these parents combine these multiple ideas about the body in order to consolidate their experience and make sense of it. Comparing these parents' experiences to when people tell about their experiences of health and illness as before and after onset of a chronic condition helps to see how non-linearity characterizes apprehending and practicalizing in the specific cases of parents who have a child who uses technology to hear which impacts human language. This is made visible through investigating physical and sensory conditions in parents' accounts but also conditions of what may have been, the imagined. In the case of chronic illness, wishing and wondering what life without illness would have been contrasts to how parents have engaged in a medical technological practice to enable a certain type of language acquisitions in the beginning years of life.

## A continuous and uncertain process

Apprehending work demands accounting for contradicting information about the child's hearing. These changes impact plans for the future in the thoughts of the parent. The consolidation of apprehending comes undone and practicalizing is altered or stopped. This weakening or disjoining of the ideas of the child's abilities, then has to be worked back together, resulting in new goals for practicalizing.

Excerpts from David and Ebba were used to demonstrate that there is an inherent desire of hoping for a definitive answer, not only to understand but to be able to know what to do. David had previously heard from the doctor that his child was deaf which led to preparing himself for an upcoming implantation for his child.

David: Well she was six months, around a half a year old. And we were set on operating to implant a CI from the start really since she was very likely deaf. But then some time around a half a year 'No the operation isn't going to happen, because she doesn't have, she has pretty good results on the test here.' That she was hearing impaired, there was no doubt about that but they call it moderate hearing impairment [...] 'The way it looks now she definitely won't be operated on *but* it does happen that the hearing deteriorates so you should be prepared for that.' [in the voice of the doctor]

This is an account that reveals how understandings about hearing impairment change when new test results are added to what is already known or declared about a child's hearing. David explains that they were prepared for an operation building on the idea of 'probably deaf' but now the child's hearing was categorized as moderately impaired. This information

built on evaluations carried out after the infant was given hearing aids. Again we can see areas of apprehending that are in flux here: the evaluation by the professionals, the technology usage and the news about the nature of hearing in this type of impairment. These are all derived from the enactment of measuring involving an assistive technology together with the body of the infant. After David describes his experiences of getting the news that the operation was not going to be performed he tells about how the technology can be improved and a different technology can be implemented so there are two technological factors which can and will change. He then concludes the event with what was said about the possibility of his daughter's hearing worsening and that they should be prepared for this.

David experienced finding out that Kajsa could hear with these devices and that adjustments and better hearing aids could be all that she needed to hear well enough. At the same time that David gets this news, surprising and positive when previously thinking of their child as deaf 'period', he is told that this new status of hearing is not definitive, only as it looks or seems to be now. One can stop and ask if the news was experienced as positive by David. It stopped a candidacy to cochlear implantation. Also it was presented as a temporary and likely to change state of being able to hear. In essence this means they found the child to be hearing in some respect after all but that it means she could become deaf again.

David: And sure enough at about a little over a year old, no she had started daycare and been going there for about a half a year she was two, so the hearing disappeared for a couple weeks. It wasn't connected to- she didn't have a cold either so we didn't connect it to a virus. So there was something strange and it was that [name of doctor] had described that something happens. They don't know what it is. I think you call it something like a chemical decomposition of the auditory organ so they don't know why.

Uncertainty is challenging and disappearance of hearing relieves one type of vagueness. This is an important exchange David presents here for understanding the experience of the becoming parent of a CI user. General understandings about hearing loss and deafness in society are no longer just facts about hearing and not hearing as an either/or state. They become *lived*, directly experienced in daily life including a struggle to understand what is said about how hearing can disappear. David is apprehending through doubling-back in *deaf* and *not deaf*, *hearing aids work* and *hearing aids don't work* and *approval to get CI*, *unqualified to get CI* and *maybe CI if things change*. This doubling-back characteristic of becoming is a way of using what reality the parent goes in and out of in how they consolidate what they come to know about the child and hearing impairment. Going in and out conceptually and situatedly, is different but similar to how the child's going in and out of being able to hear is perceived by the parent. It is part of

apprehending and has consequences for becoming. These consequences are related to time, planning for the future and trust. At times David experienced the situation as stabilizing through consolidation. He had divided up his story into different stages of knowing. At the time of the interview he spoke of how things are in his family in the present. A large part of this is when the child receives a CI.

These examples are connected to ideas about ‘cutting edge technology’ and ‘upgrading’ and ‘lost time’ and opportunity. There are opposing desires in wanting the child to be able to hear as much as possible and simultaneously hearing poorly enough to be approved for cochlear implantation. Note Ebba’s elated reaction to a second ABR testing situation with her child.

Ebba: So I don’t know who came out, the doctor came out and talked to my husband and me about it and she goes ‘Well, it looks like this *is* what his hearing is like.’ So basically giving [...] us the news that our son was profoundly deaf. And we already knew that. And we were hoping to hear that ‘cause that’s what we wanted to hear so we were [arms up, clenches fists and pulls down towards body] and she also said that he’s a clear candidate to continue with all the other tests. You’ve got to have an MRI and a CT and all those.

Ebba avoids a situation that David experienced, which was getting the news that his child hears too well to go ahead with an operation at that point in time. When Ebba expresses how happy she is it is because of a decision about a plan of action she and her husband had come to when reading about cochlear implantation. Her elation about their son being profoundly deaf was only used this way when it pointed towards being approved as a candidate for cochlear implantation providing her with a definitive answer. This use of the word deaf again to describe Adam is similar to when she opposed the comparison of a CI to eye glasses. She uses different terms for her child’s hearing in contrast to how she uses the word deaf to categorize. Here she is in a medical encounter that requires clarity and ‘profoundly deaf’ represents this in the exchange.

### Being at risk for lost time

Ebba continues with an explanation first referring to the negative in-between state, being ‘borderline’, as a category. She explains that this categorization would have negative consequences.

Ebba: Yeah because I think it’s called an unusual way of looking at it but we were both so scared that he was going to be borderline. So they’d say ‘Well, we’ll go with the hearing aids and see how that goes’. And then he would have lost time. [...] We were like ‘ah that is so good to hear’.

Something along those lines and she just kind of looked at us and she goes ‘Well that’s an unusual way of responding to it’ but we already knew that he didn’t hear much and we just wanted to hear that his hearing was bad enough so that he would get a CI.

Ebba uses the word ‘borderline’ as a category she most definitely wants to avoid. What she is referring to is the type of situation that leads to the kind of uncertainty exhibited in David’s description of varying and changing test results and the resulting state of uncertainty. That their baby would be in this ‘borderline’ state, an area marked by being on the verge of belonging to the category where Adam would be approved for cochlear implantation, was the worst case scenario for Ebba and her husband because of how Ebba combined this state with worry about losing opportunity through losing time.

There is a concern for how long a child or any person for that matter is without auditory stimulation when it comes to candidacy for cochlear implantation. This implied message in the idea about ‘the earlier, the better’ when it comes to cochlear implantation is an important part of what Ebba says ‘and then he would have lost time.’ In becoming a parent of a CI user the fact that there can be ‘lost time’ points to language development and stimulation as well as clarity in how to proceed with therapy based on the child’s abilities and needs. ‘Losing time’ is part of the struggle, frustration and emotional suffering surrounding testing situations of hearing impairment that for many reasons is often in flux. In this medical context, what needs to be known is if the baby is getting access to sound that can support speech and oral language acquisition. This determines also what should be done in respect to visual communication strategies. This explains why Ebba and her husband were so pleased to find out that her baby’s hearing was ‘bad enough’.

The testing and evaluation experiences of parents of children under a few months of age with hearing impairment and deafness, depicts what parents are hoping for in a diagnosis: clarity. From these accounts more suffering is associated with not knowing and the use of hearing aids is part of this experience. Less suffering is associated with early definitive answers and a confirmation of becoming a candidate for cochlear implantation. Most of the parents in focus for this study have been able to compare in some way how both of these types of experiences are felt. To have moderate hearing loss involves a prolonged time period of uncertainty since it is over a longer period of time that the use of hearing aids is evaluated which is exhibited in David’s account. Cochlear implantation practices reported by these parents are aimed at finding the children who benefit from this technology as soon as possible because it gives the best results if it is done early.

Early detection is a tool leading to confirmation of becoming a candidate for cochlear implantation. Having a moderate hearing impairment to a severe hearing impairment that fluctuates is understandably a less concrete experience which keeps the apprehending and practicalizing of living in sensorial differentness in motion. This is less definitive and involves a ‘wait and see’ element as described by David in his detailed accounts and in Ebba’s sparse words as ‘lost time.’

### Making sense of change in sense use

The following excerpt describes the continuous process involved in making sense of changes in a child’s hearing.

David: So she wasn’t deaf but how much she would hear in the future that we couldn’t know since she was so little. It could improve but it could also deteriorate so everything was really uncertain [...] It was an additional answer that wasn’t an answer. It was more like ‘Wait a couple months or wait a half a year so we know more’ and that was pretty much what we heard from birth really. You have to wait, come back, or from the beginning it is surely nothing at all, just amniotic fat to that she was likely deaf but like, more and more indicated that it was a severe hearing impairment. That’s what they all said but how severe it was no one knew really.

In this account he was given information about potential change at the same time as he was expecting a clarification. David is attempting to consolidate findings about hearing but it fails. They are in essence saying ‘Here is a result for today.’ It guarantees nothing about tomorrow. What’s being expressed here is uncertainty, a lack of being ensured about a solution on which to base a plan of treatment. It leaves the parent’s question of what to strive for or to do unanswered. Again the element of time and its importance to the parent to achieve conclusiveness intersects with other people’s understandings of time and urgency to enable hearing or to undertake sign language learning to communicate with one’s child.

David’s account points towards a finding about how parents do not come to definite conclusions about what hearing impairment is and what is done when that happens. Similar to David, there are reports from all the parents interviewed of numerous instances of trying to understand the degree of deafness, whether or not to call their child deaf or hard of hearing and to explain this to me, their listener. These efforts they make are signs of their own struggle in apprehending disability and ability. Apprehending the infant in respect to hearing begins at a period of time created by the detection of hearing impairment through infant hearing screening. Handling this early

knowledge is a part of managing *not* knowing in their becoming as parents of CI using children.

At some point in the approval and implementation of one's child being given a cochlear implant the experience of hearing impairment as a problem lessens for a parent. The frustration lessens because there is a definitive course of action. This excerpt sums up how David started his re-orientation into hearing impairment as disability and where he was emotionally when the interview took place. Both of his children had received cochlear implants.

David: Absolutely. But it like, works of course. It is clearly a handicap. But you deal with it as you go along kind of. Now we see it because we have changed our way of seeing things so we see it as a small handicap today. But of course that it is a big handicap but we see it as a smaller handicap. It isn't as difficult and tough. But the main thing is that the worry is detached from it.

What is 'working' for David refers to living their lives with CI technology and that his children are able to use sound. He states what the challenge is: the handicap. This is the apprehending he does, what is there, in his child, involves something which is missing: The inability to hear is expressed as a disability. The practicalizing is found in what they do about it, in disability, along the way, as the problems arise. He then says they have gone through a change that has affected how they see things. These things include more than the disability he is referring to which is made clear through how it has transformed from being something traumatic to being a minor handicap in how he perceives it. To say in one sense that it is major but that they see it as minor because it isn't as difficult now is how the apprehending and practicalizing result in less worry and uncertainty. This forms a path of existing which leads to more stability and certainty aided by personal adjustment.

How apprehending and practicalizing relate to frustration and relief leads to depictions of how trust has developed over time in these parents' becoming. David concluded his interview with expressing that only people who live what he has lived will ever be able to grasp what his life is like now. He is referring to hardship and suffering which he sees has many positive sides. The importance of being understood by others, especially other parents of CI users who know what it's like, grows in importance for David as well as Ebba. Peter's experiences of disability are seen as similar to other natural parts of life in everyone's lives. He puts his trust in groups of people who hold this view.

## Reorientation through narrativizing and consolidation

In this chapter I have shown how the beginning of becoming can be described in terms of a process of multiple simultaneous attempts from the parents to make sense of sensorial differentness which entered their lifeworld. The process is characterized by a close ‘reading’ of the child’s body distinguished by the way parents explore and understand sensorial differentness. These actions in the becoming process are described as apprehending, practicalizing, consolidating and narrativizing. It is the idea that the parents through lived experience are using their senses and conceptualizing to do this sense-making work. Their becoming is illuminated through the meaning sensorial differentness takes on in their lives and can also be described as developing understanding about their child as a part of their new life circumstances.

*Becoming in sensorial differentness is an orientation concept to denote the type of learning process these parents go through, which builds on their embodied experience of interpersonal relationships, objects and others alongside developing goals to share language.*

This chapter answered the question of how a parent starts to realize their new life conditions by studying first-person perspectives of experience and how this redefines who they are, namely hearing parents, and what they will do. It depends on how they understand a child’s senses through their own. I have investigated how the contemplation of a reality of what an infant hears is an intangible challenge to parents providing a specific theme of uncertainty. They learn that the process of grasping what deafness is takes time; senses and the use of them change and will likely continue to change. The intersection of the clinical practices and the parent’s becoming are affected by the child’s embodied fluctuation of ability to use sound due to embodied variation of the functioning of cells and organs which makes it difficult to identify as something that is permanent or stable. Parents’ accounts present this challenge to grasp which I describe as apprehending. My conclusion is that the process that proceeds from this point in parents’ accounts is a continuation of imagining what the child hears with the cochlear implant.

Consolidation is a meaning construction process which is a product of apprehending and practicalizing. When a parent brings parts of their understanding from these two parts of their lived parenting there is a strengthening and unifying of how they experience in regard to their child. Narrativizing appears to be how consolidation emerges in the use of a type of strategy to bring what they have grasped and what they enact together in a coherent story which consolidates experience. In terms of orientation,

consolidation stabilizes and offers a foundation to stand on. This description is one avenue to observe how parents think about disability and deafness and is presented through these parents' renderings and how they merge their experiences into a way of being in the world with their new child and their new situation in sensorial differentness. Their encounters and engagement with medical technology demand specific types of consolidation characterized by beginning in disorientation and continuing in their reorientation. Becoming is enacted through the pendulum between disorientation and reorientation. It includes seeking out encouragement and support through people who have experiences similar to them.

Narrativizing reveals this process of orientation in becoming and can further be understood with Ahmed's words:

Moments of disorientation are vital. They are bodily experiences that throw the world up, or throw the body from its ground. Disorientation as a bodily feeling can be unsettling, and it can shatter one's sense of confidence in the ground or one's belief that the ground on which we reside can support the actions that make a life feel livable. Such a feeling of shattering, or of being shattered, might persist and become a crisis. Or the feeling itself might pass as the ground returns or as we return to the ground. The body might be reoriented if the hand that reaches out finds something to steady an action. Or the hand might reach out and find nothing, and might grasp instead the indeterminacy of air. The body in losing its support might then be lost, undone, thrown (Ahmed, 2006 p. 157).

Narrativizing is human activity which helps the parent to reorientate. Giddens also points to what happens to our ontological security in the shattering or unsettling of a coherent life. When interpreting parent experiences, there is no straight path to understanding their existence in sensorial differentness. The terms I use to describe the becoming process are sense-making terms. They were reachable through letting the individuals begin with their understanding of their experiences in a narrative form, a fundamental way for people to make sense of their situation. This chapter continued from Chapter 5 where there was an exploration of becoming focusing on the roles of materials and affect tracked in parents' accounts. Redirection in life after a rupture, takes a path through disorientation to connected spaces with other bodies and things, namely technologies of the CI and computer mediated communication (CMC). The parents, the child and the CI are part of a material network as part of their social world.

# Chapter 7 Parents' be/longing and communication orientation

## Introduction

This chapter explores another aspect of the lived parenting of cochlear implant users that I call communication orientation. Focus is on analyzing the social world of parenting concerned with how language as communication is contemplated in new ways due to differentness in the use of senses. Orientation in this chapter refers to the transformation of a parent's earlier attitudinal position about language and communication based on what they have experienced before and after they became a parent of a child who uses a cochlear implant.

Communication orientation involves attitudinally directed language goals acquired and developed in the social world that parents share with other parents, professionals and other persons with relevant experiences. The objective of this chapter is to investigate what this process of orientation means for parents' continuous becoming when a child does not hear. I use *be/longing* to denote a social process involved in contemplations of where parents long for the child to belong in social groups. This state of longing for one's child to be in a desired social place primarily concerns how they will be able to communicate and participate. The inquiry of this chapter is about what the parents' actions from affect (affectivity) mean for the parents' continued process of becoming. Orientation turns out, to a large extent, to be something that people do together with others in experiencing social relations about language which creates various types of belongings for the children and for parents themselves.

## Belongings and be/longing

Belonging, when studying the experiences of hearing parents of deaf or hard of hearing children, exemplifies how the child belongs to the family in one sense. In the other sense the child belongs in characteristic or distinguishing categories; a social category (hard of hearing, deaf or CI user), a cultural

category (language user) etc. as does the parent. It is then helpful to think of people as having multiple belongings in self-identification.

To distinguish from these multiple belongings, *be/longing* involves the directionality and desire of the parent, a term highlighting how a parent incorporates the relationship to their child- who uses sound and communicates using senses differently- into his or her way of acting, striving and making choices for their child's future belonging. This *be/longing* of the parent emerges as a specific communication orientation towards, as well as for, their child. Orientation, in Ahmed's meaning, involves existential meaning-making and the phenomenology of social relations. In applying this relation between theoretical ideas, parents' way of being in the world can be seen to change with giving birth and then detection of hearing impairment but what's more is that how the child exists is a life condition for the parent which sets them apart from others. Parents also encounter new possible belongings, for instance, in the communities of deaf people. These potential belongings can be experienced as contradictions to their current taken for granted belongings and belongings they were anticipating. Senses, communication and identity in language enter into the parents' world which put new things in reach while others recede. Parents in in certain respects are defined by their children at this time in life. When the child has membership in other categories of identity than the parent, the work of apprehending and practicalizing are undertaken in the parents' orientating to include a 'parent of' belonging for themselves.

When a parent orientates toward what they want for their CI using child as a future adult, the most contingent factor is communication. Belonging to groups which hold similar ideas about language - be those ideas based in ideology, attitudes or beliefs - is embedded in the larger notion of *be/longing* by parents situated in a deaf and hard of hearing context. Togetherness and cooperation with others like oneself, who understand the specific sensorial life circumstances involved, are in focus in the actions of the parents in this chapter. This is significant for a number of reasons that parallel attitudes toward language and child language acquisition. What is done in the family, communicatively speaking, is primarily intended for use outside the family towards communities. Which communities are longed for or become undesirable, for oneself and one's child, undergoes a transformation as the child develops and the parent's understanding of deaf dis/ability develops.

## Parents' perspectives on communication and cochlear implants

Communication orientation builds on existing language-user categories the parent belongs to. This also goes for disability categories. What was present in parents' everyday lives is the starting point of communication orientation in respect to parenting. The parent is going to be incorporating a different sensing child into their way of communicating, as well as the complex social meanings which emerge in sensorial differentness. Seen in terms of orientation, a re-orientation involves trying to set the world upright again. In the world of the parents in this study, this involves situations where parents of children who use CIs have come into contact with, or otherwise become involved in, deaf and hard of hearing sociocultural groups in meetings with other parents.

A spoken communication orientation and a bimodal communication orientation are identified in my explanation of how these parents of CI users are understood to be exhibiting be/longing. Seeing these orientations as directedness aids in understanding how parents do not necessarily have an orientation as one has a characteristic or quality but rather are turning toward it and use it as a compass and to extend their reach. How meaning circulates in ideas and practices related to two types of opposing markers were identified as the two orientations which are placed in view of these parents. The way parents turn in one of two directions is investigated by re-examining material from the parent interviews.

The chapter has two parts. Part one is structured to present excerpts from interviews showing examples of the spoken and bimodal orientations, with the main characteristics and socialization examples of each. The analysis in this first part then shifts in the second part to investigate the conflictive atmosphere created by the fact that the two orientations tend to be regarded as dichotomous and even antagonistic belongings in relation to the dominating sociohistorical ideas about desirable language use in the present context. This is done in order to understand how antagonism influences the parents' experience.

### Spoken communication orientation

Catherine, Erika, Hillevi, Ilona, Mario, and Peter in a Swedish context and William from a North American context are the parents in the interview material who were presently exhibiting characteristics of a spoken communication orientation at the time. This means they may change their

orientation in the future for example by changing schools or when the child in some way prompts the use of signs or signing. The spoken orientation can be indicated by three main characteristics. The first characteristic is that the parent's first choice is a mainstream preschool and school. The reasons given vary but include being close to home, the same school attended by siblings and going to the same school as other children in the neighborhood to be able to make friends.

Hillevi: But I wanted very much more that she would be in a home environment [regarding school as part of what is close to home]. I mean it isn't just all that. Mostly that she has friends where her home is. Put her in a taxi, sit and ride to [name of a specialized school] every day, I had no desire for that.

Liz: How did you pick a preschool? What kind of information did you get?  
A regular preschool?

Hillevi: Yes, regular.

Hillevi was explaining the reaction she had when she realized the children in her daughter's new class in the school close to home came from all over the county.

Hillevi: I felt that partly because these kids are spread out over the whole [name of area] so none of them [the students who are in her daughter's speech and language class] would live close to her. I wanted her to have, you know, just be able to go to the neighbors' and ring the doorbell of her classmates. Friendship is so important.

The assumption here is that her child's friends who live close by are hearing. To have relationships in a 'close-to-home' environment means that communication needs to be spoken. Even though Hillevi's daughter would still be attending the school in the neighborhood, the children in her daughter's new class would be coming from distant neighborhoods which would impact how her daughter would be able to spend time with children close to home. This adds a dimension to what a school close to home is chosen for. A spoken orientation is developed from the objective of accessing friendships close to home environments.

A second characteristic is that a parent is involved in rehabilitative activities to support speech and listening e.g. Auditory Verbal Therapy (AVT). This involves rigorous training and practice in the home and in school.

Liz: But she had practiced signing before she had a CI but after the CI operation they wanted to work with another therapy?

Hillevi: It was speech of course. That is what they say at the cochlear unit that, they are like separate worlds. If you talk to someone who supports hearing and signing yes then bring on the sign language so the child has a way to express themselves. It's like 'Don't rely on the technology.' Whereas if you

are at the CI [clinic] then it is ‘You have to give it your all in [spoken] language and speech and listening because otherwise they won’t learn. There is so much to do [therapeutically]. Take away signing.’ So you have to find a balance and choose on your own.

Liz: What did you do then?

Hillevi: We spoke.

Depending on the age of the child and intensity of the training a major assumption in therapies for speech and listening is that a rich verbal communication environment is vital. It must be practiced, it is prioritized and prioritized over other learning areas. Visual support is seen to hinder opportunity to facilitate listening ability with a CI. Visual cues are not used in structured therapy sessions for this reason.

Another parent, Ilona, explains how the therapy is carried out in their everyday life and home environment which she learned from and is supported by staff in the CI clinic. As a parent she has a coordinating role with teachers and an extra tutor to make sure speech development stays in focus for her child. To state that everything she does is aimed at speech is an expression of her focus on strengthening her child’s abilities in Swedish throughout the day.

Ilona: With the youngest, Michael we read a lot, we work with pronunciation and things like that, games too. Everything I do, it is a little less now that they have gotten older, but everything I do has to do with speech. I am trying to develop their speech. To the largest extent possible. He has extra tuition in Swedish in school.

Liz: Good. And he is going to a different school? Where does he go?

Ilona: [name of school] It is a regular county school. A small school, very good school. Close to home. The closest.

Liz: Do they use a microphone?

Ilona: Yes, they are really ambitious, so they want to! They are very enthusiastic. They want to use the microphone. They want to do their best. So that is really impressive.

Liz: Can you describe more concretely what you [Ilona and her husband] do?

Ilona: I help with homework. I hire a teacher who works with Swedish with Ben [the older sibling]. So I actually pay a teacher, help with homework. I explain things. I understand that he [Ben] doesn’t have any friends so I try to fill that role. I talk and play with them and spend time with them. Choose different activities. Talk to teachers. So I give the support that is needed. And with Michael-

Liz: You give the teachers support? You communicate about how you should, how things can be as best as possible for the children?

Ilona: Yes.

When Ilona states that everything she does has to do with speech she exhibits orientating with specific goals for her children and gives many examples of this here as well as throughout the interviews. There were many school changes for her first child which provided Ilona with a set of requirements for her second child guided by this developed communication orientation towards speech.

The third characteristic is that signing in some manner impacts negatively on CI using children or their hearing families. This is exemplified in two ideas: one is that to be able to fall back on signing would make a child dependent on a back-up system. The other is that dividing time between different modalities is seen to make it harder to succeed in attaining fully developed spoken language and full knowledge of a target language. Included in these ideas is also the understanding that signing elements are not compatible with speech goals and future needs.

Catherine shared an account about how a friend asked her why they didn't learn sign language which illustrates this.

Catherine: A friend of mine, when she first introduced herself said 'I'd be very interested to know why you decided, you know, to not go ahead with sign language.' But anyway no, we haven't [used it as a back-up]. The thing is I think that you have to look at your child and think what's best for them and yeah, there are no guarantees with any of it but we felt that if we did the sign language A) I'd have to do it in French, B) [his father] would do it in Swedish and our families would have to learn and Emil would become more [dependent]. It would always be there as a back-up. Whereas with the speech, that's the thing he has to use, so that was our thinking.

Raising children bilingually as Catherine and her partner do in French and Swedish adds an important detail. The different languages are seen as relationships to family members. It is likely that thoughts are actualized about jeopardizing these relationships through adding a language none of the relatives know. Also there is a distance factor, living in different countries which would make it very difficult to learn and that the national sign language for each culture would be involved is an indication of this dilemma. It is noteworthy that in the interview material, parents like Catherine who considered their home environment to be bilingual, could have either a spoken or bimodal orientation.

Since Catherine's son Emil has a CI he is using speech already. It was a prerequisite of CI candidacy that he uses speech which is the reason the device was implanted. Since this is already what the family has committed to they had made the judgment that sign language would complicate their child's situation.

Ilona demonstrates how the task of securing a stimulating spoken language environment in a systematic way recommended by the CI team is time consuming. She says this about signing.

Ilona: He tries to sign with me. But I am totally uninterested. I can't learn sign language.

Liz: There you set a, there is a limit?

Ilona: [Exactly] No. No. No. I can't do everything.

Liz: No, you say you do very much to stimulate their language.

Ilona: But I am not at all interested in learning sign language. I can say that I don't want to. I know there are a lot of parents who want to and who are very good. I feel like I don't have time.

Liz: It takes time too.

Ilona: It takes a lot of time. But I feel that primarily that the Swedish language is very important.

The effort Ilona exerts towards helping her child learn Swedish is partly due to the fact that they use a different language in the home. Swedish is a second language for all of them. Through stating that she can't do everything she is saying that this is why she does not want to learn. It is out of the question because of the time it would take. She already spends what she described as a full working day helping her children with homework and games to use spoken Swedish. When the children were in preschool and school she dealt with practical issues related to the same goal to stimulate language. She puts herself in a different category than the parents who do want to learn and who have done well. She differs in that her time is already taken up with a dual project in regard to language: speech and Swedish. Signing would further disadvantage her bilingual children.

## Socialization into a spoken orientation

During fieldwork I was made aware of a common practice used in CI clinics where parents of children who were candidates for cochlear implantation or recently implanted were provided with the opportunity to meet with a family who had previously gone through the process (Fieldwork protocol no 33). I was interested in early encounters with other parents who shared similar experiences so I asked Peter to talk about an early meeting with other parents.

Encounters in the clinic are often a parent's first meeting with another family where both a parent and their child are present. What is illustrated here is how influential these organized meetings in this clinical environment can be for socialization towards a communication orientation. Peter begins by describing the other parents' school choice.

Peter: Well, she went to a sign language preschool first. Here in town you can choose. When you live in [name of a small town] you can't choose quite as much but they had put her in one of these hearing [specialized] preschools and they spoke partly sign language but then her language [development] took off when she moved to a regular group with her little brother and she was in the same place with him. That was like their best decision. That she came to a place where they only spoke instead of them signing and speaking alternately. That has definitely, had influenced a number of decisions that I have made too.

Liz: Yes.

Peter: And then they have also seen [...] when you have read reports then you see that there is scientific basis to believe that there is an advantage with it.

Liz: With this, to get as much-

Peter: The advantage of focusing on spoken language early or over all for that matter.

That a 'spoken only' environment for this child using a CI will result in beginning to speak and develop spoken language represents what these parents understood as a best practice for children with cochlear implants in general. There are similarities with other categories of learners (hearing aid users, language disabilities, behavioral disorders) where determining what group constellation is best is based on understandings of disability dispersal. In the case of the CI user, being around other children who don't have language disabilities is seen to provide an environment where the complexity, quality and amount of spoken language used will be high.

Liz: And it was of course that which helped you to choose? [...] So it was the choice of where he should go to preschool, what was it you wanted to have, what were the criteria for you then?

Peter: Good preschool. [laugh] Someone who, what is it called, who could be seen to take him seriously and see him as an individual. Yes, the director there 'Yes but that will be great!' [after] I explained about CI. 'Exciting, wow that is exciting, we have to have him here! [It was] the first encounter outside the family, 'This is going to be really fun!' [...] How great that we get someone who is unusual, kind of different.'

Emphasizing being seen as an individual is in contrast to being categorized as a disability group member. The socialization parents of CI users go through in their first meetings with preschool personnel and other parents is how they come to know what others think about a CI using child. What is expressed by Peter above is a typical indication of how parents hear that their child is welcome, is a source of positivity for the group of children because of the CI child's difference. Being an individual who will stick out is spoken of in these positive terms. Below is an excerpt which illustrates how 'different' children provide something valuable for the typical children.

Parent: The other parents ask a lot of questions and are glad our child is in the group. We felt really accepted and that our child is accepted. Every child is different. A lot of the time parents tell us how important they think it is that kids today are mixed with kids who are different. (Fieldwork protocol number 22)

Every child is different is an expression often used to emphasize sameness and normality of the needs of children. Important to understand is that the child with the disability is seen to be provided with role models, in this case for speech, the parent. In the experience of these parents, their children are accepted by other parents and personnel and are seen as an opportunity for the other children to learn that everyone is different and has individual needs or reflects that society is inclusive. In this case, kids who are different, means children who have an individual impairment or a diagnosis with a need to be dispersed among others not like them. The child who uses a CI is categorized in such a way that they represent disability acceptance. This parent in the fieldwork and Peter were likely pleasantly surprised and relieved at the attention and acceptance by others, a pattern of interaction which often led to parents of CI users hearing about the other parents connections to others in their lives who had a disability. In other cases the parents who knew about deafness and deaf culture would share those stories which often involved questions about sign language. That their child who uses a CI is filling a type of need for other normal children provides either a valued status position for the family which was probably not expected or gives rise to how their child represents a potential signing language group even when they don't use sign language. Another contributor to status which is not entirely a positive experience is that parents become informal educators about hearing impairment for other parents.

Parent: We get a lot of questions from other parents why we don't use sign language. You end up having to teach other people a lot about that if you get a CI this early your child isn't deaf. Most people forget that Diana can't hear without them. I even forget. (Fieldwork protocol number 23)

The way a CI child is then normalized as a group member in a class is exhibited in this statement.

Catherine: The teacher when we have a parent-teacher conference says she forgets about Emil's disability.

That the child no longer is noticeable as representing disability is a common way for a CI parent to express how well they are learning, adjusting and are accepted by students and teachers. The following excerpt was delivered as a highly positive outcome for this parent.

Peter: His soccer coach didn't even notice that my son uses CIs.

Peter's experience is that his child was seen as any other child on the team and not defined by his disability, treated differently or required special accommodation. This is how parents in the material would express how well a child was able to merge into a group where their deafness was not noticeable or significant in their everyday lives.

The next excerpt shows a contrasting experience where a CI using child of parents with a spoken orientation isn't accessing sound to the degree she needed to be in a regular classroom. The reason they chose the class was to 'give her a chance' at having friendships with hearing children as was presented in Hillevi's excerpts above. The following excerpt is from an interview with both parents, Hillevi and Mario.

Hillevi: They have [different] difficulties. It is a group, she is the only one who has a CI, so it is like a regular class needing extra support. [...] It is 'Speech and language' [specialization].

Mario: They work with speech and language, just a little smaller [in class size].

Hillevi: There are fewer kids with only five kids in the class. In ordinary classes there are 30 kids and they can't concentrate on one child at a time. She almost has a teacher next to her all the time when she is doing something.

Liz: Does she like it?

Hillevi: Yes, now she does.

Liz: Was it difficult maybe?

Hillevi: When she switched classes it was exactly that, really difficult, because she had been in a regular class. She was completely lost. She wasn't following at all. It was the teacher who said that when they talked about something, then when they asked Sanna about it, then she talked about something completely different. She hasn't been following along so it wasn't a good alternative. But we still wanted to like give her a chance.

Liz: Mmm.

Hillevi: So that was one hard thing. Then yes, I think that you also know, you don't want her to be treated differently. It was just hard to accept. But then you realize in the end that I think that it is the best for Sanna.

Regular means spoken language when Hillevi and Mario describe the class. Hillevi's excerpts above demonstrate how parents of CI using children deal with attaining a spoken environment which has to be adjusted for their child to access communication. Hillevi has hoped for her child to be able to benefit from a normal classroom environment. Learning that one's child profits from a special preschool or school setting, to the parent, means having to accept belonging to a category of parents whose children need to be with other children with challenges because of different types of disabilities. The parent experience of their child having to switch to a special group or classroom is unusual, strange, and perhaps even devastating. The above excerpt is exemplifying a type of secondary rupture between two school world settings. It is feasible that Hillevi and Mario have not heard

others say they forget that the child is hearing impaired or has a CI in the same way. In other parts of the interview Hillevi describes the tactless treatment by school personnel who made official statements to others about her child's difficulties. To her the chain of events represented an extreme feeling of her child not being accepted but blamed for causing problems for the school. Hillevi appears to have struggled to advocate for her child's right to be with others and then to accept that her child had a need for a different classroom structure in that school. Her child then resembled other children who had different disabilities. For her, the uniting factor for the children in this specialized class was having a similar need of one-on-one teaching, not that they shared a type of belonging with each other. This indicates a struggle with accepting likeness to others who are disabled. Hillevi and Mario primarily understand their child as needing a better hearing environment for learning.

### Be/longing in a spoken communication orientation

Regarding spoken communication orientation as a whole, it is a general implication that any use of signs is only meant to be temporary and complimentary. Once the cochlear implant is in place the focus will be on practicing listening and only using signs initially to support an unclear auditory message. One major goal of an auditory-verbal approach is to make listening automatic and to eliminate the need of dependence on verbal cues. In the cases where the parents did use signing, the way it came to be used changed. Many parents adopt the practice of speaking or naming objects first and then following up afterwards with a sign if they are unsure if the child grasped it. Previously they may have been signing and speaking at the same time. Communication orientation for a parent gradually reorientates as the child's body changes and sense use is altered.

Be/longing of these parents with a spoken communication orientation is directed towards being included in regular preschool groups and classrooms. The parents repeat versions of 'every child is an individual' and the CI is part of that individuality. In mainstream classrooms these parents understand how being with hearing children is possible and are given a type of confirmation that they have done the right thing when their child develops clear speech and is able to play well with others. A common message is that spoken language development is often achieved, even surpassed at times and the cochlear implant works very well. An example of this is how Catherine is very enthusiastic about her child's interests in music and how the world of dance has been made possible for him. The be/longing for these parents can be explained with two types of experience. One is in the present where the parent sees that the child has a given place in their social groups now. The

other is a recollection from their own past in that they see the child as having many of the same types of experiences as they had as children. Furthermore, their child's deafness becomes unreflected at times represented by 'I sometimes forget that without his CI he can't hear a thing.' That these parents have children who gladly tell others about their CI and let it show is also an indicator that being different in comparison to the group is positive and unique. The parent also downplays the technology like when comparisons are made to Bluetooth, earbuds (in-ear headphone), and headphones for listening to music or using mobile telephones. Music interests, sports activities, academic achievements, and dancing are highlighted as successes in a parent's be/longing for their child in a hearing world. Be/longing to the hearing world builds on an idea of the CI as a part of the child. This is an intertwined idea of the child's body with devices that downplays deafness and emphasizes likenesses to hearing children.

Parents who emphasize aspects of a spoken communication orientation speak very highly of the teams and individuals they meet in these settings. Having a close relationship with the CI clinic is likened to a family feeling. These relationships with personnel in clinics is crucial for parents be/longing towards a hearing society. This future project is sustained and maintained by a type of medical community available for the child's lifetime to the age of 18. One parent expressed it in this way.

Parent: A doctor who makes it possible for my child to hear me is part of who my child is. That's what they do, they create a sense of hearing in a human being. (Fieldwork protocol 24)

For this parent, the technology includes a personal relationship with a doctor. Implementation through surgery by a person to be able to use sound is thought of as a part of the relationship made possible to their child. An additional aspect of how technology creates kinship like ties was in Mario's outlook during the interview. Often referring to other health care encounters he had expressed that the relationship with members of the team at the CI clinic differs from other medical care-givers. They were more personal with him which he did not expect.

Mario: They are super nice to us. The really know us.

Ilona shares a common experience many of the parents in the study have of hearing how the professionals in the clinic express that the children are 'our kids'. The frequency and length of contact for the duration of a patient's childhood makes it possible to develop a closer familial type relationship with the staff. Also, CI practices include recurrent testing of hearing and language skills and discussions and documentation of progress in school and the child's social environment. Discussions of cases of the families in the

clinic setting also extend feelings of familiarity by parents when they meet well informed team members (Fieldwork protocol no 37). This broadens the areas of life which are relevant for the follow-up appointments conducted by numerous members of a CI team. This is illustrated in these four separate excerpts.

Ilona: They see my child as one of their CI kids. That's a good feeling to have that type of support, encouragement and praise that I am doing the right thing [in respect to communication].

Peter: They are like our family. They know everything about Sam and he has never ever not wanted to go there.

Catherine: They are absolutely wonderful and gave me the best advice about to wait to have our second child.

Hillevi: They really give you a sense of being a part of what they do, like when they say our kids.

Ilona feels recognized for her efforts. Peter views the absences of negative behavior or resistance to be at the hospital by his child as proof of why the clinic is like family. He said also that it was like coming home. Catherine deems the connection between family-planning and the clinic's advice as converging which strengthens a type of kinship with the clinic. 'Our kids' provides a sense of a joint project in parenting with the personnel for Hillevi.

Gratitude to what you are able to share with your child and how you are able to do that go to the core of many of these parents' identities. This symbolism is important to explore to understand how parents experience gaining an existential connection with their child that was made possible through a medical practice of providing hearing for speech and listening in a shared language. Pediatric cochlear implantation is involved in a fundamental transformation for these parents. An understanding of the spoken communication orientation's origin is rooted in this transformation. What happens as time passes impacts the communication orientation in different directions. Some examples to be discussed in the latter part of the chapter related to be/longing, the hopes and imagination for the future of the child by the parent, are how growing up and school situations will reveal new needs and interests as the child gains autonomy. Also the contact parents will have because of their role as a parent of a CI user will bring them into contact with other views involving bilingualism and biculturalism.

## A bimodal communication orientation

Bimodal is the term I use drawing on parent perspectives of using both spoken and signed communication. Often the term is used together with bilingual and bicultural to emphasize the community, history and culture of a sign language using group. Other terms include multimodal, multilingual and plurilingual to described environments and capacities. For hearing parents in this study, contact with deaf culture occurs sporadically and infrequently in some cases and in others the contact may become established through existing acquaintances. What they have in common is that deaf/hearing intercultural contact of this kind, one that involves their newest family member, is a new phenomenon for them. I have chosen to only refer to modality in this communication orientation to illuminate the hearing parent's experience of learning about and using a new modality in their parent-child relationship and how it impacts their ideas about communication and disability. The parents who exhibit bimodal orientation characteristics are Anneli, David, Ebba, Ella, Håkan, John, Josef, Leif, Mari, Olivia, Tess and Tomas.

One characteristic of a bimodal communication orientation is that, if available, a specialized preschool or school is chosen where some form of signing is used. In the case that the child is in a regular preschool or school, the parents strive towards getting the educational staff to use signs as well as spoken communication.

One of the parents, Leif, told about how they started with what he calls a deaf-hearing class. Sign language, as it was pointed out to them, is their child's first language and that since he would use both Swedish and Swedish Sign Language (SSL) in preschool, they as parents needed to learn it. This finalized the aspiration of learning to sign for Leif and his wife. His description of his daughter Nina being another person in sign language showed how complex the language situation for his daughter appears to him. It is clearly necessary for him to have both modalities in order to know her. He described his child as wanting, needing and preferring to be signed to, in different degrees depending on the situation, even though she is using her CI and chooses to answer verbally. This is especially the case since Edvin, her older brother, doesn't use sign language but is one of the people closest to her. Leif says his daughter always speaks when Edvin is present to maintain a connection to him but asks her parents to sign what he says so she doesn't miss the part of the family conversation she is most interested in.

Leif: I think that it depends on what you are brought up with at home since spoken language is her natural home language but sign language is her first

language however strange that may sound. [That is what she is] most fluent in or most secure in that you [Leif himself] are a little laid back since it is the home language. It simply makes you a little lazy [about learning sign to keep up with her].

Liz: Which language does she prefer to use?

Leif: That is hard to say! That is really hard. I think that she is kind of like another person when she signs. She is calmer. Concentrated. It might be connected to the language. You have to look at the other [person], be clear with your hands. Yes, she is a little calmer, a little more focused. In some way that it is that it demands more focus when you sign than when you talk, you have to look the person in the eye, precise hand movements, when you talk you can do it a little more, from laziness, you don't have to look the person in the eye.

Liz: How has this influenced the family's language use? You said that you interpret what her older brother says, when you are sitting and eating food.

Leif: When Edvin says something, Nina says to me 'Can you tell me what Edvin is saying?' She can't follow along really. You try to sign what Edvin says.

Awareness of modality allows Leif to see how language is interwoven in expressions of mood or composure. He then adds detail about views about a visual modality as more present, more attention being given to the other, as opposed to a less attentive or concentrated hearing way. It is reasonable to consider that visual modality offers his daughter a type of security which contributes to her calmness.

Another characteristic for an orientation towards bimodality is that parents engage in both types of early intervention and post-implant therapy. These are speech and listening based like AVT and sign language based courses like the county run introduction courses and the national TUFF sign language tuition for parents. One difference is that sign language courses are not as necessarily concentrated to the first years after implantation and early in the child's life. In fact, the older the signing child gets the larger the need of parents for sign language instruction. The opposite appears to be the case for AVT since it is primarily an early intervention practice concentrated to the early years after implantation. Sign language courses with personal language fluency maintenance goals continue to be included in what a parent engages in since the signing often proves to be difficult to keep current and active. This is pointed out by Leif to be due to the spoken home language environment which includes hearing children.

Leif is involved in an organization which lobbies for an increase in the number of hours in the TUFF program in Sweden. After the 240 instruction hours are completed the possibility to have access to courses geared towards hearing parents is limited. Since Leif's daughter goes to a bimodal/bicultural school they are often in sign language using contexts and come into contact with many deaf people. This is an example of where school choice creates a

need to continue to be able to use both spoken and signed communication for the parent as well as the child.

The third characteristic is that the parent exhibits a commitment to supporting sign language and the sign language using community in order to provide a connection for themselves and their child to signing environments. The connection provides opportunities to use sign language. This commitment is likely to involve social efforts on a practical level. Due to how these efforts reach into other groups like others who sign and who are deaf or hard of hearing, the interests of these other minorities become a part of what parents are aware of and engage with. The group CI users is added to a more diverse collective in coalition with other groups needing situations that are made accessible for hearing technology and/or through offering signing and interpretation.

Leif: We are active in supporting an organization that is about communication as the main goal. This communication idea is inclusive because of the diverse groups in the organization. Sign language, sign supported speech and optimizing environments to be able to use audiological devices like CI is part of that. And smaller groups and more time and emphasizing the visual support or if someone is partially blind through tactile communication.

The struggle connected to this social commitment, to supporting accessibility for all, becomes apparent when parents realize which types of policies support or hinder the use of alternative communication or sign language. The quote below is how one parent summarized difficulties in educational contexts.

Parent: You have to fight for your child to get instruction in sign language and sometimes that doesn't even work. I have a right to learn it but he doesn't.  
(Fieldwork protocol no. 21)

Being bimodally orientated in communication means a hearing parent adds a new modality into their understanding of what is possible and desirable human communication, but does not necessarily mean they become bimodal/bilingual themselves. Often the parent's perspective departs from making actions they take towards situations and groups accessible to their child or others like their child who sign. Being able to sign then means that the child will have more access to more people who they are likely to be with in the future. For these parents the important aspect is seeing to it that their child has the means to participate. This is not the same as a bilingual/bicultural perspective where the rights of the group are in focus. However, this orientation involves embracing ideas which coincide, where sign language is necessary and positive because they understand their child

to need and/or benefit from it in the present and future when spoken communication is unintelligible for them.

These parents of a cochlear implant user who exhibit a bimodal communication orientation want their child to continue using signing so they will be able to choose the modality which will serve them best in different situations. In this way they will be able to access knowledge most efficiently. Enabling an ability to choose is an ever present rationale parents with a bimodal orientation display.

Håkan: I want my child to be able to choose [now when they are in school] and when they compete in the job market.

This choosing between sign language and spoken language for the future is initially about letting the child have numerous possibilities to be secure, informed and able to participate fully on their own terms. This way of choosing for Anneli and for Olivia was presented often in terms of identity. What I see in the material from Ella, Leif, Tomas, Håkan and Mari is an idea of being versatile in environments. A space of sensorial differentness can change suddenly when a battery dies. Other examples include how many people are talking in a room, if the child is familiar with a person's voice which affects intelligibility, or of course, noise of any kind and lighting as well. This is what Leif meant by being comfortable with certain people and 'able to read us' even if they are in loud environments.

Leif: When she is at home she speaks and listens more, she is more at ease and comfortable. She knows our voices and can read us.

Mari expressed a similar idea about how her daughter appeared to her. She experiences her as being able to change who she is through changing languages.

Mari: She transforms when she signs, she becomes more alive.

Mari attributes this change to a level of comfort and to feeling secure with people who know how to sign. Also when her daughter speaks and is in charge of instructing or showing, she has a similar way of conducting herself as well. In these cases it depends on a role change, as a coach or baby-sitter leading the communication as well as the people she is engaged with who are younger or familiar to her.

Another parent had a similar experience when her son changed his demeanor in midsentence. They were discussing his younger brother, whether he liked a movie or not. When her son switched to what he thought about the movie's stronger points he switched to sign language.

Parent: He gets further, deeper into things when he signs. He expresses himself in a way he just can't or doesn't when he is speaking. I saw his facial expression awaken or you know, he was in there. The pronunciation came through his face as well as his signs. Maybe that's why I think that. (Fieldwork protocol no 34)

That this parent's son has a personality that can be more deeply engaged through signing is her point. Ella reasons similarly when she later associates this to how her child will be able to excel in life. These examples are language and identity related but are used here to demonstrate how they have a modal quality that the parents are addressing and presenting. This is an intricate relation between modality, identity and personality. Communication, engagement and flexibility in group interaction situations which fluctuate are conditionally related to how the CI child can choose a combination of language modality systems.

One way of understanding this is that parents see environments as changing both from the outside and within the bimodal child. They believe their child should be given the opportunity to enhance these skills and abilities to adapt to and change with these spaces of sensorial differentness they inhabit and embody. This is connected to ideas of different modalities in the parents' be/longing ideas for their children.

Nearly all of the parents with bimodal communication orientation characteristics expressed wondering what schooling would be like if their child had been in a hearing only environment. This can be related to early sections where parents engage in possible lives that have not been pursued for the child and their parent role in this. Below Mari had started by sharing concerns about written texts and how close a spoken language is to a writing system. When having misgivings about quality of instruction and how it has impacted learning to write she clearly laid the causes of this to be on teachers not having expectations that deaf CI using children could reach as high academically as typical students. She felt it was not due to the children's ability but to teachers' low expectations and adjusting course goals to the class's weakest students. These pre-conceived ideas held by others shaped the environment. Mari described it in this way:

Mari: Tests get cancelled and projects take much longer. They don't reach the learning goals for their grade because of changing demands and lowering requirements. At the end of the term they said they might not pass a number of subjects! I asked 'Why didn't you tell us at midterm?' They just said they ran out of time, not that they couldn't reach the goals or weren't doing well in their studies. Every time we complain the teacher would often answer that they [both her children] were at the top of the class. So it's hard to know what they are learning really. Or what they would have learned if they were in another school if they had to just use their hearing.

The relatively small classes include students with other disabilities. There are considerable gaps in progress between many of the students and often students differ in how they progress in school subjects. This can also be influenced by newcomer students who were not in signing environments before and were not progressing in mainstream environments. For Mari this combination causes a lack of drive or stimulation which is a cost of being able to learn and use sign language in the child's schooling. It brought Mari to wonder how their learning would have been impacted if they were in a larger group and had to use their hearing but at a higher pace. She exhibits through this account that bimodality generates contemplations on the best way to learn in regards to access to different types of signals and social relationships for their CI using child.

Tomas spoke of these environment changes in terms of technical malfunction, societal availability to supporting systems like manufacturing and how municipal and state funding affect the use of technology like speaker and microphone systems. Even national crises and political climate are mentioned as fluctuating circumstances which can impact or inhibit the use of sound with CI technology. This type of worry reaches into more encompassing levels of society such as who will pay for health care in the future in these global capitalistic systems.

Tomas: Politically, anything can happen. There are no guarantees for funding.

The connections between health care systems and CI technology are anything but certain in Tomas's view. Håkan had ideas about what opportunities are open and closed because of being able to sign and speak. Going to a specialized school to be able to be instructed in sign language was framed as putting his kids at a disadvantage because of the time it takes. They attend one year longer than regular compulsory school. On the other hand, he was convinced that knowing how to do things in different ways was not only a marketable skill but vital when they come into the changing and competitive labor market.

Håkan: Other kids are miles ahead already when they leave high school. Our kids' strength will be in their versatility and signing is a large part of that. You see it isn't just language, it's about competing for jobs.

The issue of environments that use visual senses for communication and future occupations was expanded upon by a number of parents like John Håkan and Ilona. Ella thought more about how far her son can reach in respect to each modality.

Ella: I think he will reach higher by using sign language. It's about potential and I think, I know he already chooses activities depending on which language he can use. So that is surely the case for what he will work with. But I don't know. Maybe what he'll be interested in will be more important than signing.

Here Ella sees that her child is already making adjustments to what he engages in based on modality. Håkan hopes that his children will be able to profit from being flexible. Ilona, having a spoken orientation towards communication can be contrasted to these ideas of versatility. Her hope was for her children to reach further than other hearing children because of how advantages of the hard work, concentration and extra tuition would make them more competitive. This view is included here because of how it summarizes what parents see as an embodied versatility which comes from the notion that their children's struggle makes them stronger. Because hearing parents have to struggle to be able to communicate through signing they make assumptions about their child's situation and how communication like this can be formative. It makes understanding harder for their child in communication with them which in turn may lead to thinking that it must be as hard for their child to use hearing and perhaps also signing since the child is hearing with a CI.

## Socialization into bimodal communication orientation

John, Tomas, David, Josef, Leif and Ebba give very positive remarks on their first sign language learning experiences that have been connected to the hearing and rehabilitation services centers in which their children were enrolled. These first meetings with sign language teachers and with deaf adults are recurring stories offered by these parents in highly positive terms in their interviews. It characterizes the material as a whole when parents have positive educational encounters as presented in these separate excerpts.

John: Everyone loves Felicia! [the sign language teacher who is deaf]

David: Our teacher was an extremely empathetic and enthusiastic person and opened up the world of sign language for us.

Tomas: He told us how lucky we were to have kids who were deaf because it gave us this opportunity.

Ebba: It was 'language is language' and that is when I realized it.

Josef: We learned it and used it and we saw that he liked it and could sign with us. It's his first language.

Leif: She told us it will always be our child's first language, that we should remember that even though she was given a CI.

In these excerpts there are important affective connections between parents which are represented by signing experiences. These can be through their own use of signing, meeting signing individuals, courses they have attended which were transformative for them or witnessing the results of signing in how people connect which are positive. Being able to sign with a small child provided valuable experiences about who the child is made possible to be through the signing adults they had interacted with. In a comparison with the spoken communication orientation, parents have expressed similar positive experiences or feelings of gratitude of having met helpful and positive people usually connected to the personnel in the CI clinic teams or in educational teams who give them valuable insights about their children.

The majority of the parents interviewed and encountered in the fieldwork exhibited characteristics of a bimodal orientation. This is understandable for various reasons. First of all, having a deaf child who uses a CI in Sweden brings with it the offer to learn sign language through a nationally funded program. Secondly, the parents were generally motivated to be interviewed because they experienced a struggle to access the support their child needed since they did not fit the category of normal hearing. Primarily, these struggles in economic terms are a fight to access resources to make the environment accessible and were situated in school contexts. Secondly, nearly all the children were in regular classrooms. The domination of a spoken modality requires special curriculum plans to learn sign language. Since all of these parents know they are entitled to TUFF, they question the lack of similar programs for their children who are mainstreamed. Another reason for finding most parents to be orientated towards bimodality is that having a CI using child is not a commonly occurring experience so joining groups and accessing information from multiple parent groups will cross the categorical borders drawn by audiological device use. This means families with deaf and hard of hearing children ranging in their use of a number of different technologies will meet in diverse groups and include the language modality diversity which follows with it. In addition to this, the majority of the parents in the data generated saw their child as sharing qualities with various other groups of children with different audiogram readings, technology use and conditions outside of strictly audiological diagnoses. Contact with other parents in physical and virtual forums exposed these parents to the use of alternative communication strategies and when deafness is the main determining trait, visual strategies dominate in informal and everyday use. When parents found commonalities with other parents, the diversity of disability presented multiple possible ways to compensate and accommodate. One example of this is how most parents in the study believed their children would benefit from small instruction groups in schools.

## Be/longing in a bimodal communication orientation

Since all the parents in the study have CI clinical experiences in common and speak of the treatment they receive in a positive manner if not outright praise, it is necessary to try to understand how socialization proceeds from this point. Above we read about Peter's experiences of meeting another CI family. His account exhibited how he was given evidence and arguments for choosing a spoken communication orientation. In the material as a whole, the question of what to do or not do in terms of signing is revisited continuously by parents in their lives after implantation. Parents try to understand the nature of the debate which exhibits a foundation that separates the spoken from the bimodal orientation. It is a confusing situation for parents to continually be in. It is worthwhile to consider this tension through how a parent reasons about re-orientating in communication.

The following excerpt has to do with making a decision about a second cochlear implant for Josef's child. Josef's parent-to-parent meeting differed from Peter's in that he was the one to ask to meet other parents whereas most of the accounts relayed in interviews told about having been offered this opportunity as part of a series of regular appointments with the different professionals on the CI clinic team. This is likely due to Josef knowing that translators can be arranged and that would require needing a more definite appointment guaranteeing that other parents were available. Josef's meeting, like Peter's had a large impact on solidifying a path forward when faced with two choices. What is most interesting about this account is how he balanced this information with conversations he had in other contexts. He searched out meetings in alternative places and groups to weigh in other opinions in this act of consolidation.

Josef: I had read a lot and tried to meet other parents [...] before I decided on a second operation. I had asked at the CI department 'Is there a possibility that we can meet parents [who have a child who has] two CI?' So they arranged it for us. We met at the CI department. Mom and dad and the child with CI. We asked the parents a lot of questions. [They were] volunteers they [CI clinic] had talked with. They had arranged so that we had an interpreter so we would understand perfectly. [...] The mom said to us that we should do this second surgery. 'You have gone half way so of course you should do it.' There was something about the second [CI] so he can hear better with the first. She wanted us to go on with it but the dad said that the second operation 'It doesn't help that much.' He hadn't noticed much [significant] difference than with the first. Maybe a little that she knew [from where] the sound was coming, on which side and maybe a little [better hearing] maybe. [...] He didn't think, he had checked a lot as well before [like Josef] but she [the mom] wanted us to go ahead with it. So I read something else, a lot more also in this group [on Facebook].

Josef's excerpt adds nuances to what takes place in meetings between parents. A child's two parents will not always have come to the same conclusions. Parents share their fact-finding activities with each other and they offer accounts of observing how their child hears and behaves in regard to the use of a CI. These early meetings are when parents first become aware that there are different ways forward in raising a child who uses a cochlear implant and that even within a family there are different ideas i.e. if one or two cochlear implants is best. It becomes apparent that what a parent chooses will also be a rejection of something others believe is best. Josef had been in contact with parents in waiting rooms, at deaf community events, at sign language classes and as the excerpt concludes with referring to a Swedish Facebook group for parents of children who are DHH.

To further exemplify foundational thoughts on my understanding of the relationship between belonging and communication orientation, we can look again at Josef's scenario. Josef already has knowledge of cochlear implants and had been through having his child implanted but what the meeting resulted in was a way of understanding categories he believed his child would be able to belong to. He saw that if they opted to give their child a second CI then they would perhaps risk harming part of the child's identity as a sign language user and potential deaf community member. Understandings of the body, that a child was born deaf and new insights about a group in society who wants to use sign language and be deaf, result in Josef adopting a bimodal orientation. Technology made the auditory based modality possible but too much of that technology risks the development of the visual modality, in Josef's understanding. If a CI malfunctions in such a case where only the spoken modality was used, there will be a considerable problem. If sign language is in place then the security in belonging to a signing community eliminates the impact of that problem.

Josef: In the beginning like I told you we had not had much experience, we had decided that he, if there were possibilities we wanted to have two [CI]. We had decided on two. They said that they would only operate on the one ear. Otherwise we would have decided on him being operated on both at the same time. [Because of this we] met with different [people] that you can know a little more about [what others think about] this with CI. ‘What is the conflict then? What is the problem? etc.’ But it is good that he just has one CI. And if it breaks too, *if he becomes deaf the next time*, then it is nothing. There is no need to worry. For us. Then he knows sign language. It is like in the beginning when we had these feelings I mean, that it was bad, a problem. We didn’t know then.

Liz: Can you tell me again about the people you met or talked to?

Josef: We met many who were deaf, children too. I was there with my son [a festival]. So many said to me ‘Why did you do this [implanted a CI]?’ That was difficult then [to be questioned]. Yes, but I am satisfied. We had checked this, what is it called, noticed that he spoke and understood everything [with a CI] but then I just thought ‘Why should he still have two of them? Why should he be operated on again?’ I have talked a lot with relatives too. My wife’s sister, they don’t live here but live in Germany and so it is better that he only will have one [CI]. That he signs too. If he signs then it is better with only one CI. We have decided on that. He signs. It is enough [with one CI]. He still can’t hear, he needs sign language. So it is better with only one CI.

That he considers his child to be deaf at the same time as he may become deaf again due to a malfunction illustrates how a parent uses meanings of the word deaf as a category for belonging on the one hand and as a condition the child was born with and can be returned to if the CI stops functioning.

Josef’s account gives witness to how learning about identities and medical knowledge intersect. The decision was based on a combination of seeing that the CI had worked for listening and speech and that without it he was still not able to hear. He perceives his child’s body as permanent in that regard, as deaf. Josef’s son was able to learn and use signing as a one year old which was strongly encouraged by the deaf adults and children he met. To be both speaking and signing he decided one CI was all that was needed and that a second one would still not make him hearing but could make it more difficult to learn signing. Josef had been encouraged to place his child in a regular preschool which he did. For a number of reasons this was not working out well, mainly because he viewed them as lacking competence about hearing impairment. After meetings with parents learning sign language and deaf adults and children, Josef decided to switch to a bilingual/bimodal preschool to ensure that his son would learn sign language.

A bimodal orientation is not commonly demonstrated through choice of schooling according to this study. Many children who use CI technology live far away from specialized preschool groups for hearing impairment. Anneli

is an example of such a parent. The orientation forms out of contact with others who use sign language. What distinguishes a bimodal orientation in these cases is the parents' account of a struggle. What is mostly significant here is how Anneli, confronted with negative attitudes towards visual language modality and sign language. If the unarticulated goal for Peter was to make spoken language as accessible as possible for his child, for Anneli the goal is to ensure that her child has access to both hearing contexts and sign language using contexts because of understandings about identity categories. Belonging here is illustrated through how Anneli had hoped for and been disappointed by how hard it would be for her child to be able to incorporate 'sign language user' into her identity.

Anneli: There is a specialized education preschool where the children go for two days a week and [it] used to be a signing environment but today isn't because there are of course no deaf children [sarcasm]. And today you don't need sign language if you have a CI. [sarcasm] So there. But that is the way it has been.

Liz: I hear just in your tone, [Anneli laughs] because your tone means much more. You hear more in the tone than in the words.

Anneli: I understand kind of like why you don't, it's like she is deaf. That is how we have reasoned. She is deaf. She has received an assistive device that enables her to hear but she damn well has to have that language. That is just so obvious.

Liz: Why is it so obvious for you?

Anneli: Because she is deaf!

Liz: Yes.

Anneli: It is like if she were paralyzed it would be obvious that she should have a wheelchair! So that she could be, yes, it is wrong to use the word normal. But so she could function better. I mean, we live in the hearing world and we of course want to give her the assistive device so she can hear music. That is to be able to hold a conversation at all. (sigh) Yes you can, I don't know at the same time she is deaf. And as far as we can make possible we want her to have that part too. The choice is of course hers later on. When she is older she has to find her own identity but you have to give her the tools for it. We have to make the decision about the operation when she is young so that that can make it easier for her. [...] so for us it wasn't so much of a choice. But we didn't want to take away that part. She still has to be secure without assistive devices as much as that is possible and can work. And she is for the most part anyway.

The comparison between a CI and wheelchair is a stark depiction of how Anneli views deafness from a hearing family perspective. Anneli believes that a person born into a family using spoken language would want to be able to function through hearing as much as a person would like to be able to get from one place to another if they couldn't walk. This is the hearing perspective from which Anneli's orientating departs.

In this excerpt, we learn that two days a week children in this geographical area gathered in a special environment organized around their category of being a group who could benefit from sign language and have hearing impairment. What becomes apparent is Anneli's understanding of her child as deaf, and therefore is an essential prospective user of sign language. This requires that Anneli self-identifies with being a hearing parent of a deaf child which she also discusses in terms of entering into the TUFF program for parents to learn sign language. Anneli wants her child to have 'that part too', meaning to be able to belong to the deaf sign language using community which Anneli and her partner cannot provide. Her child would have the opportunity of having a shared language with a deaf community which Anneli clearly sees her daughter to belong to. Immediately prior to that she describes *where* the family lives, in the hearing world and had earlier pointed out that they wanted her to be able to hear music. These ideas can be understood against the background of Anneli having reexamined her own belonging to a cultural and linguistic category which comes into view for her. She now understands 'hearing' to be a category with a culture and a spoken language where music is a vital part of hearing culture. In that her daughter has a CI she has been let into this world. This fact constitutes that it will take considerable effort for a manual and visual modality to be added to Anneli's child's world.

The main motivation for learning sign language detected here is about security, making it possible for the child to feel 'at home' without assistive devices. This is a common idea about the child's body that a number of the parents I interviewed expressed. Among them are David, Ella, Tomas, Olivia, Josef, Mari, Ella and Håkan. Interestingly, parents like Hillevi, Catherine and William report regularly using sign language or home signs even when a child rejects it or doesn't use it in their own communication. The parents of young CI users often mention ensuring that their children feel secure when they aren't wearing a CI in the event that batteries run out or the CI gets lost or stops working especially when they are not with them. This idea of 'feeling at home' is feeling secure in one's body without technology in different situations. Communication orientation determines which strategies a parent most often intentionally uses to do this. Security is an important theme in the idea of be/longing by parents regardless of modality.

Two communities or groups would mean two belongings for a child. The security in communities is in exchange for freedom to become something not determined by a group. The question for parents is to attain security for their children without giving up too much individual freedom at the same time as this freedom may cause feelings of not being like others in respect to senses. Here the parents' understandings of belonging are put in terms of their child being connected and engaged with others, but always at risk of alienation or

being ‘lost’ or isolated. Again future belonging of the child steers the parent’s be/longing through their actions and efforts. These parents position themselves towards what can counter a feeling of ‘homelessness’. Anneli and Olivia exemplify the group of parents who prioritize ‘feeling secure without technology.’

## Understandings of the ‘right path’ in an orientating process

Identifying how parents have understood the desirable environment for a CI using child can be explained in how they are presented with ‘right path’ thinking which is a result of the debate on the mode of communication used with children who receive cochlear implants (Gale, 2011). The ‘right path’ in CI clinic environments for cochlear implants users designates a world of speech and listening. What this entails for a parent’s initial stages of be/longing is significant. The right path is singular in this respect where only a spoken modality can be used for communication in preschool and home environments. The ‘right path’ for spoken communication orientation is led by the speech and listening principles of AVT therapy and pediatric cochlear implantation clinics. The ‘right path’ thinking which contributes to steering a bimodal orientation requires a bilingual/bimodal/bicultural setting preferably starting from preschool and continuing up through higher education where the languages are both used in instruction but separately. Bilingual approaches in rehabilitative and schooling settings including sign language do not discourage the use of assistive device technology. However, there is a core assumption in these instances that mixing or blending a spoken and a signed language, as it is often expressed by sign language users, is not beneficial to learning sign language or making oneself understood in sign language. This is connected to the idea that the spoken language will lower the level of intelligibility of the message. This disadvantages deaf individuals who largely or exclusively use a manual and visual modality and is considered to contribute to oppression through hegemonic structures between hearing and deaf communities (Ladd, 2010 pp. 75-82).

How goals of spoken and bimodal communication orientations are formed similarly through ideologies is presented here and is part of what constitutes a conflict. The common idea is that there is a right and wrong to how language should be taught and that there is a linguistic ideal for the target language(s). For the spoken orientation, visual support of speech of any kind decreases the amount of exposure to auditory messages. Listening to discern

speech has to be practiced and anything detracting from this will have a negative outcome. For the bimodal orientation, use of speech and mouthed words from the spoken language mixed with sign language interfere with discernibility for the other person who can't hear or does not use spoken language. Combinations of signing and speaking will confuse the person reading the signs and especially disadvantages deaf signers. There are mouth and facial movements in signed languages which carry linguistic meaning. There is an added moral dimension in that this disadvantages the group who does not and/or cannot use sound and spoken language (Hauser, O'Hearn, McKee, Steider, & Thew, 2010 pp. 487-489).

Often, if a parent, before having a deaf child, had previous contact with a deaf community member, an interpreter or there was disability in the family related to deafness or language then sign language and bilingual environments are viewed differently. What they have in common is that they have had exposure to scenarios which include using multiple language modalities. Aside from one parent's experience, John, where language development was problematic for a sibling in his family, there are a number of examples in the interview study. Anneli has a neighbor who was an interpreter. Olivia's cousin knows sign language. Ella had witnessed a drastic change in the access to public television via sign language interpreters in her home country. Tomas' aunt worked at a day care where basic signing skills were used. Ebba's cousin is an interpreter. These are not an exhaustive list of examples in the material but show how these parents have a common experience. Many have memories from childhood of a Swedish television program teaching basic signs and from a card game with Swedish Sign Language illustrations. They have previous knowledge of deaf or disability contexts where sign language had either been learned by someone relatively close to them or there was a previously positive interest in signed languages and related civil and minority rights movements.

Language prescription and ideology in goals of both orientations add to the antagonism between groups. The signed language in relationship to the dominant (spoken) language is grounded in a historical struggle of language preservation and is closely tied to cultural preservation of a group of deaf sign language using people.

## Parents experiencing opposition to strategies they choose

Some parents like Peter, Olivia and Josef come away with different experiences that may or may not have led to decisions about communication. However they are all made aware of how they will soon be faced with choices and alternatives that will be viewed differently or even harmful by others. When parents interact with other parents they are made aware of alternatives in the form of different paths taken by others which increases the feeling that they are and will continue to be faced with more choices and have to defend them.

The idea of the competition or conflict between verbal and sign language can be further explored in Anneli' discussion of the advice she got from the hearing rehabilitation center.

Anneli: And during that time, when the hearing care education professionals visited us at home they believed that we should not be in such a hurry with sign language. We could start with a few signs anyway. Yes, that's the way it was and it has been her viewpoint the whole time.

Liz: Because?

Anneli: Yes. She or her argument is actually, here comes the cliché, if you sign then they won't talk because she thinks that it makes them lazy.

It was quite clear that Anneli does not share this view where one language makes you less proficient in another. Her point is that this view has caused problems in providing sign language using opportunities for her child. She goes on to explain that it is clear to her that it is easier for children who use cochlear implants to use speech when they are given a choice between signing and speaking and believes that the opposite opinion, that they become reliant on signing, is ungrounded.

Liz: Is there any evidence for that?

Anneli: No. And I am so tired of it. What I would have wished for to begin with, is that you get objective information. Not that you just say that 'but they get by with TSS.' [supportive signs with speech] Because nobody knows that. They can't say that when they operate on them. Johanna's [CI] hasn't worked optimally. She can't hear. She hears really well I think when they test her in these soundproof booths. Then she hears sounds I can't hear. But not otherwise. It doesn't work optimally. Of course they can't say why.

Liz: In noise?

Anneli: At all! Yes, with speech [the child's own speech] it is relatively alright. Then again I don't know if she is lazy. I can refrain from listening even though I hear. You kind of, it just goes by you. But if you had been given objective information from the start and because they mean of course that you should not suggest sign language because many parents can't handle it. That's bullshit. Or 'Many aren't open for it.' No. But objective information at any rate is good. And then that she should have been given, her and us in a

certain respect, *help* with sign language that we could focus on. Because we still have to instruct them in hearing and speaking. But to do both is damn hard. And so both practice hearing and speech and sign language. There.

Liz: Is that why then?

Anneli: Yes.

Liz: That they think that it will be overwhelming for parents?

Anneli: I don't know but that is exactly what I mean. [to get help to teach the child] That is, she should have the right to it.

The message Anneli is given by the supportive education services worker is that children like her daughter will manage with just using or learning signed speech (TSS), sometimes called simultaneous communication or total communication. With this method only the most important words in an utterance are visually supported by using single word signs borrowed from a signed language. The grammar of the language is not taught or learned and TSS is not adequate to communicate on anything but a rudimentary level. This means that they advise parents to focus solely on speech until it becomes apparent that their child isn't benefitting enough from an auditory and verbal approach. TSS also results in enabling communication in hearing environments with people who use some type of hearing which makes it more difficult for the deaf signing person to understand signs used in this way.

Ebba, Anneli, Leif and Ella have shared ideas of being able to use interpreters as a goal for their children's future education. The mixed discussion forums related to hearing impairment on Facebook, on websites and in parent organizations embracing the use of sign language have regularly recurring discussions about how to ensure higher education. The choice to pursue sign language for one's child is part of making higher education accessible to DHH individuals. This is part of school placement decisions for possible future learning environments. For most of the parents of cochlear implant users in this study, a bimodal communication orientation incorporates the specific language learning goal of making higher education accessible. The distinction between TSS and sign language is significant for them for this reason which impacts their children's opportunities in adult life. They need to repeatedly emphasize the difference between the temporary nature of forms of supportive signing to actual sign language proficiency.

For parents of CI users with a bimodal orientation, the benefits of concentrating solely on speech are outweighed by the benefits of learning sign language. This is to point out that a bilingual/bicultural approach in compulsory education to ensure acquisition of a signed language is essentially an idea of possible belongingness in a cultural group. It is based on the idea that since there is no way to know how well the child will be able

to utilize sound then both languages should be taught to the child at a very early age. This argument is often presented together with research findings in linguistics on cognitive benefits of multilingualism and lack of evidence in neurolinguistics competition models distributed in online environments by parents. This summarizes an ongoing debate that has been discussed at length at interdisciplinary conferences about bimodal (sign) bilingualism during the fieldwork period (Fieldwork protocol no 29).

## Elements of competition

There are a number of elements of competition that contribute to the conflictive atmosphere parents of CI users experience. Here are excerpts demonstrating this.

Håkan: We will see who is right. We think we chose the right way.

Early in Håkan's experience he felt that the debate was about who will be right about how well children will do in school and work life. He saw a battleground where the two forces were the deaf organization on the one hand and the proponents for mainstreaming for all CI using children who lobbied against sign language use.

Peter: This is what all [CI using] children should get [latest microphone system in his child's classroom].

Peter's experience of his child exceling in school and adjusting in extracurricular activity groups provides a basis for his judgment that the therapy and approach they were given and adopted is how all early implanted CI using children should be habilitated. He sees this group who are implanted before one year of age like his son as a different category having very little in common with late implanted children and non-technology users. He demonstrates an element of competition between therapies through language environment. Also, that the schools and environments requiring signing are using resources which should be reallocated to provide the best microphone systems and equipment for all CI using children in Sweden. Here the competition is for resources.

The disagreement on the use of national and regional resources extends to which types of technologies should be developed for accessibility for DHH people. Technology and medical advancement for audiological science is pitted against technology to distribute and make accessible interpretation for sign language users which has been found in printed materials and online discussion groups (Netnographic fieldwork protocol no. 13). These posts and

links are often in the form of having been denied access through the decision of school leadership or special service authorities. Equipment for hearing technology and specialized hearing educators set against the cost of specialized bilingual schools or interpreters and assistants in schools is a recurring discussion in parent organizations.

The reasoning to concentrate on one language to attain the highest possible proficiency is complemented by the emerging notion of the existence of competition for neural resources. This is portrayed as a ‘modality competition between languages’ where areas of the brain needed for language learning in a hearing modality can be taken over due to the use of a visual modality. It is a current manifestation of how the importance of one language is viewed superior to others in CI treatment contexts. This often is expressed by parents like Ilona who repeated “Swedish is the most important”, and which she elaborated by explaining that her time is not unlimited. She has to use what time she has on what is most important, and places the emphasis on Swedish in her children’s education and reasons that this is what will afford them status in Swedish society. The need to concentrate on one thing, one language or only spoken languages is pitted against using cognitive effort for learning a signed language, both by the parent and the child in question.

This competition for neural capacity is linked to the messages from personnel found in the interviews with Anneli, Tomas and Ella. The parent is seen as having a limited amount of resources to dedicate towards language stimulation of their child. A parent engaged in learning to sign will understandably have less time to stimulate their child’s listening skills. Olivia also provided an example of how the different contexts provide different ideals for therapy and early intervention. In the end it is the parent who has to choose and weigh in all the factors in these competing views.

Olivia: *You [as an individual parent] chose the right thing! Stand up for your choice and feel proud!*

An additional element of competition involves the needs and rights of the parent versus the needs and rights of the child. There is an implicit dilemma between the responsibility of the parent and the rights of a child who *potentially* belongs to a cultural and linguistic minority community. This is an expression of how the hearing world and the deaf world are made to be seen as dichotomous and therefore competitive which threatens the weaker group’s right to exist.

A closer examination of how a parent develops a communication orientation in a conflictive atmosphere is presented in the following excerpt. Olivia’s

interviews returned often to school environments. She shares her reaction to how to what other parents write in a discussion forum about ‘not making it in mainstream’ as opposed to environments adapted for groups of children with similar hearing disabilities.

Olivia: Because I, I react a little to, in some way, this is a feeling I have. I don’t know if it is correct, that they in some way look up to being integrated that ‘Oh my god, my son is so clever. He can be integrated! He is like normal children. His handicap is so small that it’s like, or he is going to get over it.’ And this is a super exaggeration on my part as you probably can guess.

That Olivia chooses to tell me about others’ opinions that she doesn’t share can be a way of understanding how parents who have children with cochlear implants all meet at some point with opposing viewpoints. This is part of what can be described as the conflictive atmosphere parents come into contact with. What it means for be/longing for parents can be seen to be intricately tied to educational environments the child is in. I would say ‘chosen by the parent’ but depending on where the family lives it is less a matter of choice for some than for others which Olivia brought to my attention. It is likely that the ‘choices’ made are really everyday circumstances of where a parent lives. Olivia was living in a place ‘where the possibility’ of attending a school more accessible for her son existed. She experiences this as the best possible scenario, that she was lucky which is demonstrated in the excerpt below. It can be intuited that Olivia is able to understand that she should see herself as fortunate whereas others are not. Regardless of this she also experiences that other parents’ satisfaction with the more common integrated school solution transforms into a majority view about school placement. These posts Olivia reads spill over into interpretations of others being judgmental about one’s choice to take advantage of the specialized schooling opportunity. When she reads about how others view her child’s school environment she meets it with surprise and disbelief.

Through an online exchange she senses the conflictive atmosphere and it navigates part of her bimodal communication orientation. She becomes a proponent for an adapted school environment shared with others with disabilities integrated by the use of sign language. It is closely connected to where she feels her son belongs.

Olivia: But I feel that like on [name of organizations]’s Facebook pages that it is like that [integration means success]. [...] It was on there first or first and foremost there that I got this feeling of ‘Yes, we want our daughter in a normal school but with a resource person [assistant] and how many hours can you get?’ and things like that. In some way there are a lot of parents who go

'Yes, you are making the right choice!' and the few who comment 'In any case my child goes to a what is it called, a special school? And then-

Liz: Or a specialized in hearing class?

Olivia: Or specialized hearing school, but it feels like it comes in second place. But then there is also [...] So it is, I take a lot of it with a grain of salt. It is this 'Yes, sign language isn't good of course because it holds back speech.' It is like 'What?!' kind of. So of course you have to sift through it quite a lot.

When this effect of being taken aback is digested, she is annoyed. It aids the solidification of views Olivia is developing about disability and language and less about individual family situations. She then connects this experience of how others view what she sees as exposure to an identity notion 'technology wearer' which is intertwined with body, technology and a signed language.

Olivia: It irritates me. No, but in my case it is like— but seriously what about identity?! His identity as a technology-wearer really? Yes but, to see other kids who have it. That is damn well the most important thing for me plus the support he gets of course. But like really [...] to immediately strive towards that he should in some way manage like others. I see zero sense in that. Really. Seriously. But then again it's obvious. If I had a husband and children or a [ex] husband and other children, cows [farm] and everything and have to stay close to those roots then it is obvious [attend an integrated school]. Life decides for you but when you are not [limited in that way] its ok. Then you can move.

Liz: You said technology wearer.

Olivia: Yes, I don't know. I thought if you should say that he isn't well, deaf in a certain situation and he isn't just a hearing aid wearer he is like technical (laughs).

Both contact with a close relative who works with deaf sign language users and informal contact with other parents are involved in what Olivia builds on and continues to learn about what it means for her child not to hear as others do. The choice to enroll children who use cochlear implants in mainstream classrooms is supported in a CI discussion forum. The choice to have your child in a school environment that utilizes sign language is met with silence on a social media site is Olivia's experience. It reveals two strongly contrasting attitudes that influence the sharing of information between parents. This can be interpreted as an indication of how CI parents' activities are enacted in a polarized field and constitute a conflictive atmosphere.

Olivia takes a point of departure in identity, being a 'technology-wearer'. She prioritizes her child being able to see others like himself using technology. When Olivia says 'Identity is the most important for me plus the support he gets' it is a concentrate of a defense of a position in the conflictive atmosphere. She is trying to accomplish prioritizing identity and

prioritizing access to support. In being/longing terms, it can be seen that if a child is in a mainstream context they will be like the other children and can identify as ‘unique like everyone else’. The strengths of others, especially their verbal abilities are viewed as the optimal environment for their child with a CI to acquire verbal language which upends this identity in one aspect. To be with others who are like a child in the respect that they have a disability, is based on being able to see benefits to an identification to the category DHH impaired and technology user.

There is a discursive agreement that all children should be given the same opportunity to develop based on what they need. The online forums are used in some way by every parent I came into contact with in this study. What can be read and discussed there from parent perspectives shows comparisons of resources and practices that are far from uniform across the different regions and counties. This unifying idea that there are major inequalities is connected to the core issue of the conflictive atmosphere: accessing resources. Peter and Hillevi have a strong belief that all parents should be given the advice that their child should be in regular classrooms and be informed that they have a right to this. They also expressed that they have been given full access to the latest technology. Peter says ‘All I have to do is call.’ Both parents are very aware that other parents have to struggle very hard to get the equipment and support they need. Peter believes that success in advocating depends on both parents’ education levels. Also being Swedish, with all that it entails in knowing how society works, enables you to succeed in obtaining what you need. The support systems are inadequate for children from families who don’t have these types of background. Hillevi believes it is more like a lottery where if you live in the right area you luck out. She says ‘I just call the center and tell them I want this new digital FM system and I get it.’ She says she’s appalled at the unfairness of how people who already have a tough situation have to fight for the simplest most obvious equipment once a child has been implanted and encouraged to be integrated in a regular classroom.

Communication orientations are partially constituted through these elements of competition. To navigate a conflictive atmosphere the parent orientates and reorientates to solve problems in lived parenting contexts. The bimodal communication orientation is partly resisting this dividing line between having to choose between technology and sign language. This exemplifies the competition between ‘technology solutions’ and ‘dependence on technology’ ideas. What is ‘right for the child’ is contested because the early development years impact possibilities when parents no longer bear formal responsibility for the child. This is brought to the attention of hearing parents through the expressed opinions of adult CI users and DHH individuals who grew up in similar circumstances. These adults provide links to past

oppressive systems, narratives of personal experience of damage to self-image which resulted in unnecessary adverse life conditions. Also, parents of grown DHH children offer lived evidence of having endured an essentially similar conflictive atmosphere to the one CI parents are currently experiencing in limited access to resources for language development.

## Experiencing antagonism

Several of the parents in the study pointed out that the opposition between approaches to communication became so strong that it could be understood as a kind of antagonism between different parents' own belonging to a spoken or bimodal communication orientation. Below is an exchange where Ella explains the antagonistic atmosphere she has come into contact with. She shares why she believes a polarization has developed between different viewpoints. In the ten year period she has been involved in two different parent interest groups related to children with hearing impairment Ella has noticed that the division or antagonism inside these organizations is not as apparent. Sign language is no longer referred to directly as negative or harmful even though the fear new parents have of risking spoken language development is still the main concern many hearing parents need to discuss. She summarizes her understanding of the current situation like this:

Ella: There are completely normal parents in both organizations. Everyone wants to do the best for their children. You want to talk about it all with people who get it. But it is hard to understand that [others believe] developing Swedish can suffer if you use sign language. During one period [in a child's development] sign language is ahead, then Swedish is ahead. It's only an advantage. Why would it obstruct the brain?

Liz: Why is sign language considered different as language?

Ella: That people want to distance themselves maybe. They are afraid of it. That it would take away [success or progress] from speech, that is scary. The most common argument is that parents have to put all their effort into Swedish. But in your subconscious [sign language] is something that sticks out.

Liz: In what way?

Ella: So few people know it. It is hard to find friends. The child has no one they can sign with. They don't want to move. There are a lot of factors and there is no easy answer. Sign language isn't sexy or attractive. Parents are so busy [...] but sign language is exactly like all the others, that you can learn many languages.

That the parents in these organizations are completely 'normal', not antagonistic, implies that the atmosphere Ella has experienced due to the organizations' standpoints involves perspectives which are not 'normal', they are in opposition. She touches on the reason why sign language 'scares' parents. They see their child in a vulnerable position that could further be

jeopardized through introducing a new system of which they have no knowledge, and what they have seen signifies something strange that is not part of their world and perhaps feels threatening.

Most of the parents in the interview study can be described as having some characteristics which are bimodal in communication orientation. They displayed having struggled to access a balance in supporting both spoken and signed communication. Major themes in their interviews are comprised of wanting to share negative experiences of feeling hindered by antagonistic attitudes held by individuals in societal institutions and agencies. These attitudes are not necessarily verbalized. One specific type of encounter is feeling questioned about sign language in the disinterest or silence they encounter at their CI clinics or in parent organizations for children who use CIs.

Most of the parents who can primarily be described to have a spoken orientation were contacted by me specifically through websites and in fieldwork. They share a feeling of being questioned by society for not embracing sign language and not associating with the deaf community. Catherine's experience illustrates how this can be experienced in the following scenario.

Catherine: They were neighbors this other couple and um, they were really grilling me and they were trying to [or] She [says] 'What makes you think...?' You know really aggressive like this. It was just the weekend, I wasn't prepared. I just tried, 'I'm not going to be biased, well there is the sign language and you should explore those options.' [other parent answers] 'Yeah well, I'm surprised you haven't because you know, I've, we've been to this sign language house they have like drop-in you go and the people are so...' And I said 'Yeah well that's fine. You have to explore the options and you know make a decision and we made our decision.' And she said 'Yeah, but your son doesn't seem...' [Catherine's child did not want to play and was watching TV] And it was really embarrassing! I was really upset actually but I didn't show it. [I said] 'Well you know if you need any more advice...' And then they didn't say anything. 'Well, you know, [...] there's a lot of political stuff going on you know and they are in it to make a lot of money in these companies and technology. I'm not so impressed.' [I said] 'Well, you know it's a really difficult decision and you just get as much information as you can. But you know I feel, we are so happy with CI and it's really working for our boy.' And they looked at him and went 'Right. Sure [sarcasm].' And I was so upset. [...] It was a total disaster and I looked at [their] baby and just went 'Well music, to give them music?' And they went, 'Well, you know' and then I realized that this woman was one of these very kind of socialist lefty people very kind of like, earthy and go with the natural way and this technology is interfering with natural things and really different. You know they are going to make that choice for their son and it worries me. (laugh) You want to give every kid this opportunity.

Liz: Do they think they have to choose-  
Catherine: They can do both!

There is reluctance by these parents to put themselves in the position of being questioned which takes on the nature of accusations about limiting the child's future. A number of the parents have offered the explanation of the feeling that they have to defend their choices over and over again. One parent phrased this as how the development of CI technology brings attention to deaf sign language rights and historical struggles. He felt that he was seen as a guilty party for not letting his child learn to sign. This was one of the reasons I was given by potential participants who decided to withdraw their offer to being interviewed. This reluctance demonstrates how antagonism materializes in subtle ways in the study. There were strong reactions by parents to how a special interest organization representing parents of children using hearing technology makes sweeping statements about other groups, NGOs and perspectives in therapy to support communication. These beliefs mirror debates in international contexts and websites siding with medical technology and commercial interests and against Swedish special education experts and institutions (Fieldwork protocol no 35).

During fieldwork at parent functions and conferences organized by groups promoting oral language development for CI and HA users, school success is manifested through setting high academic goals where mainstreaming is often seen as both the key to success and the goal. Pride is taken in a collective ownership of high test scores that are attributed to mainstreaming environments, early intervention and high parental involvement. This is contrasted with specialized schools and school settings where school inspection reports, low average test scores, the use of sign language in the curriculum and too many children with additional disabilities are both overtly and covertly stated as problematic (Fieldwork protocol no 30).

David, Anneli, Mari, Håkan and Tomas express feelings of offense, anger and resentment that medical personnel clearly discourage using sign language. Their views express that the main reason there is antagonism towards sign language in society today is directly related to encounters they have experienced when visiting CI clinics.

David: It is rather that they are focused on the sound. That is their world.  
[...] Because we are of course confronted with, we have acquaintances who are partly, who are very much into signing, of course bilingual, the child must be able to choose when they get older. They maybe will take off their CI and only want to sign, they have to get two languages, and then we have other families we spend time with who like no, there is no question, here is the technology and the implant is what we have. We aren't going to complicate

things with any sign language. Because that is actually what you will hear as a parent when you are at the cochlear clinic at [name of hospital]. We were told that, other parents were told that, 'Don't make things difficult with any sign language here in the beginning, focus on [practice listening], here the sound is the primary concern.'

Liz: In the beginning?

David: In the beginning but even, it isn't that we have contact with two doctors at the cochlear clinic at [name of hospital]. Two people we have really, really great confidence in and both have operated on our children. In the one case it was [name] and in the other case it was [name]. But it, a lot is very good there but what we reacted to was the thing with their view of sign language. What? There isn't any connection at all that there can be something good about being bilingual rather there it is, it is sound that is primary.

Liz: So you can understand that or you know where to place it?

David: I can understand that but I think that it is strange or they should watch what they say. They should not say that. And it can be nice and like 'Good, nice, the expert said it, I will go with that, good. There is no sign language here.' That can be very comforting. I like have great confidence in, a great person in every way but it is just all that around sign language or not which is one of those things I do not agree on with the doctor but all the rest seems very good.

Liz: Except that-

David: So to, um, it was also her experience to 'Sure, have a [realistic] view. I believe now that it is a great idea if you believe in sign language but remember to not, that it can many times be a failure.' And that is maybe her experience.

David tries to make sense of why the doctors are not consistent with advice. He uses a comparison to how the doctors are not supposed to recommend one CI technology supplier over another.

David: Here are two doctors who are two individual people where either the one is completely, not neutral but at least doesn't say anything negative about sign language and the other doctor is actually a little more towards the negative side about sign language and asks questions like 'No, be careful with that, kind of.' It is that they have taken a course in how not to recommend things like, the county offers two suppliers of cochlear implants and there are procurements and laws involved, the doctor isn't allowed to say 'Choose Cochlear because it is better than MedEl.' Instead the doctor says 'It is up to you parents. I am not allowed to say.' 'But what is the difference then?' They are hardly allowed to say what the difference is. 'They are pretty much equally as good.' Which they probably are just as good since they chose these because there are ten different suppliers on the market. But I think it should be that way with sign language. [...] But when it comes to hearing and signs I mean, they don't have that way of reasoning rather, there the one doctor is even rather hostile towards signing.

Another parent who has experienced similar encounters with medical professionals is Tomas. He says that after seeing the progress of children who have been implanted early, the argument that sign language would

jeopardize that is ridiculous. Learning languages, including sign language and progressing in proficiency, is a type of proof he presents about the cognitive ability of his child.

Tomas: We usually make a point of mentioning how well our child is doing with sign language too. Then he [the doctor] doesn't comment. (Tomas shrugs his shoulders) (Fieldwork protocol no. 25)

This example summarizes how parents like David and Tomas make attempts to include a more nuanced picture of their child's language development when visiting the CI clinic. That language, both SSL and Swedish, should be seen as parts of a whole in respect to learning and understanding is the point of these parents' efforts. Tomas spoke about how he saw abilities in signing as linking languages and instilling a natural 'language awareness' in kids who use Swedish, sign language and English at an early age. Parents like Tomas, David and Anneli use their children's abilities as a type of argumentation against the messages they were given by medical personnel. It seems that it is in these instances a type of advocacy of the DHH group begins to be played out by hearing parents of CI users. These families continue their sign language use in a type of family based project which they themselves have secured in contact with deaf communities. What they are saying to medical personnel in their continued encounters appears to be aimed at ensuring a more adequate and correct portrayal of the role sign language may play in a CI using deaf person's life in order to benefit other parents and their DHH children. In many instances these are the 'high functioning' bimodal CI users' parents who are articulating their opinions. This sheds light on how individuals resist that sign language is reduced to a therapy, an assistive technique, or system associated with multiple disability. Typically, in the case that a child would have additional difficulties CI teams then make allowances for sign language as a necessary and last resort because of 'something else' disability.

How parents use or adhere to advice involves a complex act of trust, but practices of advising against signing have come to be seen by many parents and DHH adults as a type of misinformation. This is how many of these encounters are presented by parents on SMSs, as medical distortions of what bilingualism is. The majority of parents in the study said they signed with their children before implantation. Bimodal orientation implies that there must have been positive experiences around realizing new possibilities in visual communication as Mari and Tomas explicitly expressed. That other parents are deprived of this because of how it is presented as medical advice is a commonly held view these parents share and which David's excerpts demonstrate. The door to this way of existing, often expressed as having two worlds, one hearing and one deaf, is closed in this way. This is the root of

the conflictive atmosphere for many parents with a bimodal orientation. It is related to David's positive feelings of realizing the important matter wasn't whether his child has a cochlear implant or a hearing aid it was realizing there are ways to not be isolated or become dependent on technology which he found out from hearing people and hard of hearing people who knew sign language. This changed his thoughts about what it means to communicate and what it means to be deaf. In terms of the 'parent of' identity and be/longing, bimodal orientated parents have come closer to the group of DHH individuals and see how these people's lives are experientially similar to their CI using children.

As stated previously, all the parents in the study are highly positive to cochlear implant technology and the professionals' expertise that make it possible. The conflictive atmosphere experienced by parents emerges in encounters between opposing ideas about optimizing technology and directing parents' personal resources towards a goal of spoken language ability.

Sharing in the experience of others' parenting in a conflictive atmosphere and passing through life stages as children develop and become adults, offers new parents a chance to see how others have transcended the antagonism. A path pointed out by an experienced parent puts other ways of existing within reach. Eva's excerpt below is a parent story, a type of witnessing for the benefit of others in a narrativized form. It exemplifies the type of activity requested at parent to parent functions: to hear about what it was like to raise a child who is DHH. The ways these accounts are told in retrospect offer a new perspective for parents. It also is a source that can point to attitudinal shifts through real life, trial and error reports, and what one parent makes sense of retrospectively. Eva provides reflections on what happened in a conflictive atmosphere much like the one parents in this study report to be experiencing. When her children were born pediatric cochlear implantation was still strongly debated. Today parents grapple with the decision making process after cochlear implantation. This provides a unit of lived experience in a condensed form which tracks a parent's development of a type of social knowing or literacy in dis/ability.

This is part of Eva's presentation for new parents at a summer camp adapted from my field notes.

Eva: At first it was really hard to learn, then we learned and used sign language, I saw my daughter learn and grow with her brother who was deaf, their sharing in language since they were so close in age. I know I can't be fluent in sign language and I still feel guilty even though I know better after all these years. It was just what went on in our family, I already had [hearing children]. I learned over time, and being members of all the organizations we heard of. The people I knew who were part of the deaf world, none of them told me my efforts were too little in learning and encouraging [my family] in the use of signing, it was really the opposite. But you pick up on what is accepted and what some people think so my guilt can't just be in my head. But I am who I am, I have a hearing style of signing [laugh]. He [son] likes to tease me about it. Anyway, he took a taxi to school and loved it but we didn't! He moved to go to high school when he was 16 and is absolutely nothing I should have worried about like I did all those years leading up to it. He has a job and he is really close to his family. Things are so different now with texting, Skype and all that. I just wanted to share that, what it was like. That's the whole point of this organization. (Fieldwork protocol no. 31)

This interpretation can explain how Eva is presenting how she did things and that it may not have been what was 'right' according to the bilingual/bicultural approach. She was responding to a language ideology about sign language when it comes to the two languages by keeping them equally supported but separate. Eva saw this as an impossible ideal to achieve in any multilingual environment. 'My guilt can't just be in my head' portrays what opposing groups produce in positioning against each other.

The negative feeling some parents can get from deaf adults can have their origins in these deaf adults' individual upbringing and their relationship to their parents who did not, could not or were not given the opportunity to learn signing. Many DHH children may not have been allowed to sign, had parents who couldn't help them to learn sign language as a child or were not able to access learning in sign language for different reasons. These lost chances are reminders of 'what could have been if only my parents had done this' and is part of the shared experience many DHH adults have in common.

Eva believes no one gains from this type of focus from the ideological core of either group. The personal relationships she had with deaf and hearing parents were what she chose to focus on. She found those encounters to be supportive and positive. This is what Eva had stated as 'There are quicker ways to find your way'; if you have contact with others who can help with signing and communication and be role models, a parent's attitude is more important than their language proficiency. This provides a description of how bimodal communication orientation involves a specific personal

struggle towards a linguistic skill that will always be difficult for parents to reach or maintain. ‘Finding your way’ as Eva says is description of orientation, either through learning from one’s own experience or orientating through shared parenting experiences. How orientation involves transcending antagonism is a key element which will continue to be explored in the following chapters.

## Socialization through be/longing

Parents of cochlear implant users all experience being scrutinized by others because of what they have decided on for their children. They are living in a reality of dichotomies formed by medical practices, rehabilitative practices, discourses of inclusion and language rights struggles. Their experiences are not primarily rotating around the deaf and the hearing cultures but around interpretations of deafness and disability related to communication.

Socialization through a conflictive atmosphere presents at first glance only two opposing ways to go about parenting a child with a CI. One end of the continuum emphasizes a type of individualistic idea of the child, not as an identity group member. This builds on being unique as all children are and they are integrated in a normal classroom. The other end emphasizes access to sign language and relevant cultural development and environments which are created to make environments as inclusive as possible for deaf and hard of hearing children.

Being faced with making early choices brings about adopting views which parents then must motivate and defend. This can be seen as a force pulling parents towards one of two orientations from which they then proceed in parenting. The communication orientations serve as compasses the parent uses and thus finds other parents on the same road. Stuart Blume described CI related decision making as not really being a choice because of two things: a parent cannot know what his or her child’s best interests are and an abstract ethical principle is not much help when bombarded by contradictory advice (2009 p. 150). As parents’ have described it, it seems as if that where they lay their trust, based on beliefs and values in society about biomedicine and connected support services seldom characterizes a fully informed decision about communication for their children.

This ability to influence a child’s belonging in the future is initially rooted in the be/longing by the parent. They long for a good life for their child with others who will enable them to grow and develop into well-adjusted and successful adults. The ‘others’ are so far only imagined groups for the

parent but emerge in their interactions with other parents and children like theirs. Be/longing is significant and existential in the regard that it is a way of being *for* another person, a defining characteristic in the parenting role. Be/longing is cultivated in actions carried out, which are intertwined with so many other people. This is what is discernible in a parent's becoming and their orientation which circulates around the child being able to communicate with different desirable groups.

# Chapter 8 Networked parenting and alternative understandings

## Introduction

The aim of this chapter is to illuminate interactions between parents, the meaning-making of their exchanges and how this contributes to the co-creation of understandings about technology, language and disability by these individuals. This involves studying exchanges between networked parents to answer the question of how experiential knowledge and experience become shared in online encounters. In order to more fully understand accounts provided in interviews on the becoming process of parents of cochlear implant users, a netnographic study was carried out on social networking sites (SNS). These types of spaces afford the assembly of thoughts and concerns discussed among parents who share similar life conditions through enlisting online support in groups (OSG). This was done in order to further track connectedness involved in the construction of ideas between individual experiences of lived parenting. In this chapter I use and adapt concepts from works focusing on shared interaction and its place in meaning-making rather than the enlisted concepts in the previous chapters in order to capture how parents interact and learn through engagement. Engagement with social media gave rise to opportunities for parents to develop alternative understandings of themselves, their children, and conditions in sensorial differentness through participation in online communities of practice (CoP) (Lave & Wenger, 1991; Wenger, 1999) where issues about hearing and deafness are discussed.

Through computer mediated communication (CMC), the interaction between parents is not locally bounded to a physical community, district or region. Nor is it bounded by a particular category of parent in regard to the parent being hearing or deaf. The single conjoining criterion for participation is being the guardian of a child fitting a particular description: intersections of hard of hearing and deaf categories or conditions making human communication problematic. This criterion is often explicitly stated in these groups within SMSs concerned with parenting but less seldom in ‘living with’ or ‘living as’ social media groups. Individuals’ reach of experience extends through this combination of ways of gaining access to these groups

and communities. The geographically and temporally dispersed congregation is achieved through connected social media site units which are in many senses smaller than a community but reach much further beyond societal and cultural borders. It is accessible to parents after it takes place because it is in a digital form where search words can be used to investigate previously discussed topics. This medium may be providing stability necessary for new understandings to take form because the content is diachronic, available over time and space, and can be easily redistributed. Networked parenting can ‘bring a conversation to life’ after it has been lying dormant on the site. This contributes to an accumulative organization of meanings. When a new parent enters with an inquiry and then types in comments on existing topics in social media conversations it calls other parents back into awareness of an ongoing discussion. This happens through activating alert settings on the device being used, a computer or handheld device. Part of the analysis tracks how understandings of experiences through chains of personal interaction are available to others and influence them. Different forms of networks give rise to different chains of results in the form of influencing how a person sees their situation and their social world from the center of their own personal network (Rainie & Wellman, 2012 p. 55). Networked individualism, leaving tracks, becomes observable and shared in networked parenting practices.

Participation in social networking sites by parents in this netnographic material has been studied both online and in face-to-face encounters. Often the question was posed to parents in physical meetings about which sources of information parents recommended and if they used groups on social media. The most common way of engaging in any online environment is through searching and reading and this was mostly how the parents described their use.

In this chapter, how parents commonly engage in social media sites is illustrated by beginning with a single parent’s account as an entry point. Josef’s excerpts describe this entrance and how he used the information he had sought out. Focus is placed on the way other parent’s experiences became a part of how Josef reasoned about and managed their child’s CI use. The account illuminates the most common way social media has been found to be engaged with in the study. I have termed this manner of engagement as ‘legitimate lurking’ borrowing from the concept of legitimate peripheral participation from Lave and Wenger’s social theory of learning which emphasizes concepts of identity, collectivity and practice (Wenger, 1999 pp. 11-12).

Next the analysis turns to two composite conversations to explore how meaning-making takes place between parents in similar circumstances. This

form of presentation utilizes a method of ethnographic fiction to protect the integrity of individuals, preserve the typical conversation structure used in social media while including an extensive amount of netnographic material in a realistic and everyday way. The first composite conversation is set in a Swedish setting also utilizing Swedish based fieldwork materials. The second is set in an English speaking setting with a broader netnographic material base. The findings from the major themes in the netnographic material are provided through these composite conversations. The first is entitled ‘Thoughts about signing’ where parents discuss views on the use of signing. The second composite conversation is ‘Technology (in)dependence’ which problematizes reliance on assistive device use in relation to knowing and not knowing sign language. Constructing a composite of conversations from multiple conversation threads on one theme from entries on multiple social media sites (SMS) illustrates what a real social media conversation typically could look like. Each comment in the composite conversations represents an actual comment by a parent in a social media group discussing themes similar to the one presented in the composite. Inconsequential details have been changed. The form, function and pattern of Facebook conversations between parents in online support groups (OSG) serve as the structure where each interaction (i.e. statement-response-statement-question-answer-statement) also represents an actual pattern of exchange. This means that parts of data from one actual conversation consisting of one or more comments were extracted as they appeared and is indicated by the same alphabetic lettering (A1, B1-B3, C1 etc.). When the social media conversation source of a comment changes, so does the lettering. If multiple comments were extracted they were extracted as they appeared and are presented in the same way in the composite.

The chapter contains an analysis of how an alternative understanding is constructed (Gustavsson, 2001 p. 227; Hannerz, 1992) and how it becomes part of the understanding parents share in a Community of Practice as a type of situated learning (Lave & Wenger, 1991). In this theoretical framework, social practice is seen as a site for negotiating meaning through participation. Identity construction is likewise based upon participation in communities which can be analyzed through modes of belonging. This ties in with the previous chapter where ‘parent of’ belonging and be/longing by parents for a child’s future were described. Seeing one aspect of parenting as situated learning through legitimate peripheral participation will contribute to furthering the analysis of how an alternative understanding takes form involving social networking sites.

## Connecting through disability: group membership of parents based on similar life conditions.

In chapter 6 I have described what I call the becoming process of lived parenting in sensorial differentness, a learning process through embodied experience of relationships, objects and others involving human communication goals where objects include words and texts expressing concerns or offering support. Thus, other parents of hard of hearing and deaf children function as social support and contribute to development of views a parent holds about disability. Together with their previous views, the reception of others' views inside and outside the 'parent of' group leads to how the parent orientates with what comes into view in a new world. In fact, the reorientation described in Chapter 7 largely seems to depend on engaging with other parents. The orientation of individual parents is reached through a rich exchange with many others but others' parenting experiences offer a particular way to pull this exchange into their own orientation. Computer mediated communication, especially social media use, has special qualities which aid in this 'becoming stable' in orientation. Exchanges on Facebook are less personal, more direct and make possible discussions that address confrontational topics. This makes it different from the face-to-face encounters which exhibit more cautious types of sharing. Comparing these two types of events describes how a parent could be on a faster track to finding out about experiences of disability and attitudes towards them. At the same time confrontations could very well solidify standpoints about decision making as was demonstrated in Olivia's excerpts in the previous chapter. The exposure provided in a more candid style through social networking sites is a mechanism which forms a community of practice of parenting DHH children.

The first interview I conducted was with a parent who I had met at a sign language learning event for newcomers. His name is Josef and had recently come to Sweden from a country outside of Europe. He has two children, one of whom uses a CI. The excerpt below presents Josef's entry point into networked parenting.

Josef: We met many others who had done the same [an operation to implant a child with a CI]. I had read as well. I read in a group we have on Facebook. We have the same background, we are parents. We had a group so we could go in there, read and ask if you wanted.

Liz: Do you ask questions often?

Josef: No, I am not so good in Swedish yet. I only read everything others write questions about.

Liz: What group is it?

Josef: What is it called? A hearing impaired group or hearing impaired children group, there are different ones.

Liz: It wasn't an association or organization?

Josef: It isn't an association. It is *only* a group on Facebook. You go in there. Everything is there, there you can read. Everything, like experiences.

Liz: That would be interesting to read.

Josef: I can show you it maybe if you want. I have read a lot there. Some people, they say if you have a child with a CI, that makes it possible that he can talk well but you need signs too. So it is good if you go ahead with just one CI. Sometimes from other countries they say that it is better if you have both CI [on both sides]. I have read many things like this on this Facebook page, two or one [CI] everything about why. We met many deaf people too when we were at the course. There was something [strange, problem]. So sometimes it is hard for us too. 'What is the problem?'

Liz: What is the problem?

Josef: They say 'No, it isn't good because when they are adults they won't use it so much. It will be hard for them.' That's what people with [CI] say. I don't know. So we had some language problems [to understand the discussion]. So we didn't really understand. So we met with Swedes who had deaf or hearing impaired children. They didn't have CIs. They were still small. They had been given the possibility [to operate]. Why didn't they do it? They [the children] are going to ask later too. It was good to read instead.

Through physical meetings Josef and his wife had met others who had children who had gone through CI operations. These encounters appear to have led to the Facebook group. Once he had found this group he seems to have gained access to something new and significant for his orientation, a comprehensible way to take part in and understand other parents' experiences. Josef says 'a group we have' and 'we are parents' which are indicators of identifying with these other site users. Even though there are multiple groups like this Josef reads one of them more frequently. He mentions in his interview that different countries have different recommendations or practices regarding the use of one or two CIs. It is not clear if he found this out through the one group as reposts or through Facebook groups originating in other countries. It is an indication that the access to the information is dispersed through social media sites that reaches into other cultural contexts. Josef explains how using the site works, how a member is part of this practice and why it exists for parents. The group he primarily uses is not affiliated with a physical organization which he emphasized. This can be understood as Josef being aware of opposing views represented by NGOs. He wanted access to actual experiences of other individual parents and found that he could take part in other parents' discussions more easily when he could read them.

The introduction to a conflictive atmosphere was felt by Josef in face-to-face encounters. He met many deaf people and deaf instructors at a course and detected a type of controversy or a debate which he had a difficult time

understanding. When he and his wife had met other hearing parents they realized it was still problematic to follow these discussions both because of language difficulties and vague ways of breaching the subject of cochlear implantation. This excerpt ends with Josef reemphasizing that it is easier to read. The controversy is conceivably easier for many people to read about rather than ask other parents questions considered sensitive or private. The social media site use allows for people to disclose information in a controlled form through abiding to community specific netiquette rules. This appears to contribute to feeling more comfortable when sharing opposing viewpoints and decisions. The OSGs are designed to offer this supportive environment for discussion of sensitive topics about hearing impairment between parents in non-expert roles. It appears that OSGs play an important role for parents whose embodied experiences are difficult to articulate and difficult to comprehend. This includes situations where one's own experiences do not match what is said by people they meet, both parents and others. Taking part in conversations, where alternative understandings are presented most probably helps parents to maintain alternative perspectives and understandings.

## Legitimate lurking

On Facebook, Josef gained access to opinions and viewpoints mixed together with personal experiences which came from a combination of hearing, deaf and hard of hearing parents who also have children who are deaf or hard of hearing. Even though Josef relayed through his interview that he only read these sites and did not actually write any posts, he did participate in sharing the site through links, email or by word of mouth to others.

'Legitimate lurking' describes how a parent can and is expected to read without contributing personal information on a social media site especially OSGs. The informal definition for lurking refers to reading the postings in an Internet forum without actively contributing. Josef includes this way of participating in his description of how the site is used and why it exists. The way Josef uses the Facebook page exemplifies one of the forms of support most commonly used. That users will engage through 'legitimate lurking' is presumed. This SNS fits the description of one of the objectives of an online support group OSG: to spread knowledge and information. In a community of practice perspective this allows activity on the periphery to new members or members with the need to be able to take and not give in respect to experience-sharing. This is how these 'parents-to-parents' sites can be characterized and differs significantly from face-to-face encounters where

silence can be interpreted as non-participation or reluctance to support others.

Learning from others' questions which meet one's need in respect to factors such as child's age, device use, schooling situation, is made available. This pertains to learning from someone who is close to you in legitimate peripheral participation. When Josef seeks out parents rather than established organizations, this is what he is accomplishing. If you are new to a group it is easier to recognize oneself in a 'not so new newcomer' than a person who has the most extensive experience. Learning from others is a practice and negotiating identity is part of becoming a member of the community (Wenger, 1999 p. 157). What the OSG as a community can offer in range of experience can produce other tangential effects. The newcomer will see discussions between parents in positions they are possibly going to inhabit. This adds a dimension to how legitimate lurking of parents in different life stages through a child's age and development may be influenced in how they think and prepare for the future in terms of be/longing. It also provides a rich situated learning environment with room to accommodate both newcomers and 'expert' parents. However, the combination of experiences may not always benefit accessibility. Håkan exemplified this in his interview that the newcomer's questions were difficult to put up with since it reminded him of all the misconceptions about CI users he continues to have to educate others about. Another parent in the material, who was rather new in his parenting, presented his reason for not using Facebook as that he felt up-to-date knowledge was hard to access in this way when it was mixed with former experiences by older parents (Fieldwork protocol no. 38).

In the next section, a different type of interaction between parents is detectable through an OSG scenario where differing opinions on a particular question are shared. A controversial subject about sign language use intersects with parents' accounts of different types of life experiences and levels of legitimate participation in multiple near-lying interest groups.

## Thoughts about signing: a composite conversation

The first composite conversation begins with a ‘thread starter’ extracted from a social media group which serves as a way to thematically organize the construction. The form of the conversation resembles closed Facebook groups intended for discussing issues of parenting children who are deaf or hard of hearing. Anna, the parent who has the role of thread starter in this construction, has been in contact with personnel in a hearing or habitative center. When she shares her impression, it functions to elicit responses about other’s experiences with professionals and attitudes towards signing.

Anna: Is it just me or does anyone else feel like they are discouraged from using signing? And why do the counties have such different viewpoints on the use of sign language?

Here an individual parent who is not in the physical presence of others but in front of a screen initiates a conversation expressing a thought coming from a personal observation. She knows there are others who will eventually read this, has judged the content of the subject to fit the group’s description statement and waits for responses.

A request for an informal inventory of the existence of variation in attitudes is embedded in Anna’s second question about variation across counties. This can be assumed to come from having previously read similar discussions on these sites which include participants living in different geographical areas primarily across Sweden.

A1: The fact that no one at all signs when we are at our hearing checkups, at least no one we meet, sends a pretty clear signal.

B1: They want me to concentrate on his speech because they think it confuses a kid to use two languages. (!)

C1: I get the feeling that most parents are positive to signing in some form but the people who work with it aren’t. Why is that? This is really confusing.

C2: They told us not to use signing. Period.

C3: [Addressing thread starter] Where we live the team we have is very positive to sign language. This must depend on where you live and what center you go to, but should it???

The first four comments provide evidence of other parents’ feelings of being discouraged directly or indirectly from using signing. A, B and C indicate that these comments come from three different discussions, which began in the same fashion as the one Anna started on an OSG. The fifth comment, C3,

introduces that there are different viewpoints about sign language present in clinics offering habilitation services, a point commonly pointed out in the netnographic material.

The absence of personnel engaging in signing in their practice is reflected upon and C1 adds that parents are generally positive. It is presented and described as a feeling. A possible assumption is that C1 has read other conversations or has visited a number of sites where other parents show this positive view towards signing.

The conversation so far has reiterated the lack of signing as a problem but shifts from why there are differing approaches used in clinics to whether this is acceptable. The following comment reframes the motivation for questioning the lack of signing in terms of general knowledge about languages and language learning.

D1: Everything we know about language says that learning multiple languages at an early age has all sorts of benefits. There doesn't seem to be anyone saying that sign language isn't really a language anymore. Or do they? At least no one I come into contact with. So this is the confusing part, why sign language in particular is so controversial. Any ideas?

D2: Probably because it is a sign of failing to fix someone's hearing. That they *have* to use sign language.

D3: Yes, [addressing D2], they are talking about *needing* something like needing a crutch. Then you are using sign language because you can't walk, so to speak ;)

The commenter in D2 answers the initial 'why' question posed in the thread starter about different viewpoints and quickly cuts to summarizing a controversy they have seen discussed before on social media sites. Sign language differs in social status from spoken language because it sends a signal about a presumed failure of an intervention. D2's use of italicizing *have* indicates that using sign language is also a sign of giving up; a type of resignation to accept that the person's hearing is not going to work.

Why there is so little signing in clinics has been answered. This interpretation is that the personnel, if they were to sign would be assuming the child needs a crutch. This could be interpreted as a key to why parents believe there is a sparse overt use of signing. The types of locations, the clinics and centers, are places where many professions are organized in teams and each member has particular goals connected to the audiological care of the child. The discussion continues to form an assessment of why there are different viewpoints in medical settings led by doctors which are then likened to situations in schools led by principals.

E1: Our doctor pretty much just asks 'Who is he going to sign with when he plays and goes to school?' He has a point there.

E2: That's exactly what the principal at our kids' school said when we wanted him to pay for a school taxi for one week to take him to the sign language course. [addressing E1] If they end up having to learn sign language, if you want to put it like that, wouldn't it be good if they had some exposure to it with some type of fun positive experience with other kids?

F1: Our audiologist says we need to prioritize stimulating the hearing.

By sharing experiences and sympathies, the commenters confirm and develop an interpretation, thus supporting it as a shared viewpoint on the children's communicative needs. Gradually, this viewpoint grows stronger and is discernible as an alternative understanding. It is reasonable to believe that the network discussions constitute an important foundation for the commenters to question the reality, the main cultural understanding of professionals presented to them at the clinics (and schools) - a questioning they would not have been able to carry out on their own. This exchange in the conversation questions the dominance on maximizing listening to attain verbal language goals for DHH children while acknowledging the practical challenges which is typical of the way these problems are presented. Hearing parents share a hearing culture, and this is the issue in discussions with professionals of whether or not to use sign language when the child is integrated in regular hearing classrooms. We see this exhibited in the quote in E1 and the support this parent gives to it making it a valid concern of parents as well.

The nationally run specialized schools for the deaf have organized both theme weeks and part time schooling programs for children who are mainstreamed (Fieldwork protocol no 32). In comment E2 a parent is referring to this type of program. These programs also aim at providing an opportunity for children who use assistive devices to meet others like themselves and to try out sign language or learn it as a second language. E2 also appears to be arguing for exposing hard of hearing children to sign language in the possible case of 'having to' learn to sign, an opinion she does not share which can be read from the passage 'if you want to put it like that.' The next comment states the overall goal of audiological treatment but in the flow of the conversation it comes in as proposing a choice that has to be made about efforts in education and habilitation. This is signaling an understanding of a competition model between which senses to use and which communication skills to practice. Reading these types of exchanges may be the first time a parent is made aware of their own decisions as being controversial.

The focus of the conversation narrows in around language attitudes. Here we can read how a participant presents the cochlear implant as enabling the use of sound and comparing it to being able to use vision through sign language. Both have to do with letting the child choose which language modalities or combinations they want to use to communicate.

G1: Look at it like this. Most of the argument to give a child a CI has to do with letting them choose to use sound to communicate. Wouldn't it be pretty much the same case to let the child learn sign language at a young age? That lets them choose too, but using vision to communicate. Doctors tell parents that the earlier the better when it comes to [exposure] to language. I think most parents ask themselves the question why that wouldn't be the case here as well, to keep signing with them. Telling from this conversation, that seems to be a thought crossing a lot of our minds. I mean why is it that doctors in particular have this old idea about language not having room in the brain to develop?

Here, the commenter explicitly describes the function of the network as a space where parents question current ideas and perspectives, and invite other commenters to have a critical discussion. In comment G1, the parent is equating spoken and signed language as viable linguistic systems when lifting the fact that 'the earlier the better' must apply to all language learning. Stating that there is an old idea about language is referring to the idea that you can only learn one language fully, or that there will be interference and a delay in language development if a child is exposed to multilingual environments. That doctors in particular have this idea is the springboard for an exposé of language attitudes revealing which type of modality is desirable.

In the message below, a network of parents mobilize outspoken resistance and opposition. That a message about the existence of attitudes of undesirable language is being communicated by people in positions of authority becomes apparent in the next comment.

H1: It is just plain wrong to tell people not to learn language especially sign language if the child can't hear! You know how many people I've met who REGRETTED learning to sign? Exactly. None. You know how many people I've met who regret that they didn't get to learn sign language or any [second or foreign] language for that matter when they were young???? I can add to this list every day!

This comment is coming from a person who is knowledgeable of and perhaps uses sign language in daily communication, presumably a parent who is hard of hearing or deaf. Indications that there is a more widespread debate in society, is provided here for parents new to deafness and disability.

Engaging in the subject of being allowed to learn sign language appears to be a common occurrence for this group member. References are made to knowing adults who wish to have learned to sign providing a perspective which stretches over a lifespan. Through this the commenter demonstrates a personal experience. The dominant view point in the conversation is strengthened and clarified, that signing should be used if a child is hard of hearing or deaf.

The next passage first introduces a CI user who has shown a jump in language development in both modalities. It is a short comment but supplies an important detail.

I1: When our daughter really started to sign on her own, her speech really took off too.

I2: The focus of the CI unit is to make it possible to use sound and they know what they are doing. I haven't met anyone there who grew up with a hearing problem though.

I3: Me neither but at the hearing clinic there are.

The comment I1 provides evidence of two languages making a jump forward at the same time. It supports a bilingual approach. The three comments above are adding to the discussion of how lived experiences are becoming valued in individual ways by parents; first in I1, there is a positive parent observation about speech development being correlated with producing more signed communication. This is seen by the parent as a type of evidence that different modalities benefit one another. This is a valuable parent observation for other parents in this forum.

The next comment I2 confirms that the professionals at the cochlear implantation clinic know how to enable the use of sound, but emphasizes their own personal observation of what the clinic does not have knowledge of, lived hearing impairment. This provides an observation about how a parent connects personal lived experience to knowledge about DHH issues and the use of signing. It is a short but significant addition about valuing two types of knowledge which is crucial for the alternative understanding being constructed here. I3 is also an example of a parent providing their own personal knowledge through observation. It is obtained in direct interaction with medical personnel. In pointing to an assumption that the people who work at the CI clinic in the hospital who do the implantations and programming of the implants do not have personal experience with hearing impairment shows how this group considers two contrasting types of knowledge to be relevant: the direct lived experience of individuals with hearing impairment which in this case is missing in the medical clinic but

present in the habilitation clinic, and the medical and technological expertise of cochlear implantation. I3 supports this observation of the CI team but then contrasts it with the life experiences of people who work at the children's hearing habilitation center, who 'have grown up with' hearing impairment. This comment offers an observation that may signal to other parents that there will be different attitudes at the CI clinic located in hospital settings which is a separate organization than the hearing clinics. The comments are compiling multiple contributing factors to why there are differing attitudes about signing.

This exchange in the composite conversation introduces a 'dual lived experiences' value involved in an alternative understanding. I2 refers to the lived experience of growing up with a hearing problem, thus illustrating an experiential disability knowledge serving as a meta-orientation device for others. In questioning the professionals' opinions and discourses, the witnessing of lived experience provides parents with a new way to see with a differing perspective. Nobody questions lived "expertise" in these two types of experience by one person. The knowledge of a parent who has grown up with hearing impairment *and* has a deaf or hard of hearing child embodies the dual lived experience which is being valued. This serves as a catalyst in a developing alternative understanding in this mixed group of parents.

The way in which group members enter and engage in a social media site conversation can be contemplated. Sometimes it is obvious that the commenter is just answering the initializing question in the thread starter. Others read all the previous comments. This involves clicking at the top of the comment list in order to bring into view 'see all comments' or 'see previous comments'. This is important to keep in mind because it has implications for how a comment can be interpreted. For example, the following comment in J1 can be read in two ways, either as putting in an answer only having read the initial question or as an example of offering a 'growing up with hearing impairment' account alongside other similar accounts. This is the type of knowledge that is assumed to be missing in a cochlear implant clinic environment that was brought up in the last two comments I2 and I3 which supports that it is an answer from a person who has read all the comments in the conversation thus far.

J1: I grew up with one-sided deafness. No problem speaking, actually, the more I have the floor, the more I understand<sup>②</sup> so I was pretty motivated! But there were (are) so many times I couldn't use my hearing, like being far away or not seeing the person talking or just loud places is what I grew up with. I think signing in any form is a great compliment to the hearing I have.

The contribution to the conversation in this comment is how sign language is seen as a compliment to hearing. The person provides accounts resting on three important aspects, a claim to being hearing and deaf depending on context, having knowledge of and using sign language and having an embodied recollection from childhood of not being able to use hearing in everyday situations. Also the way this parent commenter expresses being able to speak so well, pronunciation wise or public-speaking wise is unclear but is seen to be attributed to the learned strategy of steering conversation to be able to hear the conversation. This is another lived experience with multiple meanings of what causes disability. ‘No problem speaking’, producing speech and contributing to social interactions with others, develops out of a motivation to compensate for the risk of not following or understanding due to hearing problems by talking more and inhabiting active roles in conversations. Then the ‘other times’ when this way of behaving can’t be utilized a pragmatic and positive embracement of sign language is presented. These two micro-narratives in the comment are substantial contributions to the complexity of the lived experience based knowledge being discussed. These phenomena this parent is expressing are not measureable or recordable through testing a child’s hearing with instruments, rather they must be lived and told about by others. In these forums parents are interested in discussing all possible situations for their children with hearing impairment to feel prepared, make good decisions and avoid causing problems inadvertently. In addition, the boundaries are blurred between categories of hearing and deafness. A CI user’s parent may wonder how similar one-sided deafness is to using a CI or hearing aid.

What happens in the rest of the conversation continues from two points: the affective ‘sign language knowledgeable’ comment (H1) and this comment (J1) from an individual who is hard of hearing. The first is about being deprived of opportunities to learn signing and the second is how an individual was given such an opportunity to learn, and feels helped by sign language when spoken language use is not possible or is problematic.

A reader of the conversation could see the following comment as a continuation of how to understand the use of sign language by people who are hard of hearing.

K1: I didn’t know what to expect after reading about sign language or not when you decide on a CI for your child. I was so happy when the doctor said that sign language has to be [considered] our child’s first language since she is most definitely deaf. It just made it so obvious to me. She said that nothing will change that. ☺

This parent offers a way of understanding a CI using child as hard of hearing, inherently deaf and a native sign language user. Since sign language had been used in the child's first years of life the doctor legitimized a permanence of personal language history in an affirming way. The doctor neutralizes the controversy the parent reports to have encountered in online group discussions which proves to be unexpected by other parents.

K2: [addressing K1] Do you mean the doctor was positive to sign language?

K3: [answering K2] Yes!

K4: [asking K3] Is it okay if I ask which doctor? You can inbox me.

K5: [addressing K4] You have a message waiting ☺

The next commenter engaged by enquiring directly to K1's statement. K2 focuses on their own experience or an assumption that all doctors discourage sign language use. K2 asks for a confirmation about this discovery of an exception. The answer 'Yes!' with an exclamation point affirms that this is either exciting or surprising. This reveals that the commenters have taken part in reading about the debate on sign language and pediatric cochlear implantation. K1 refers to this by saying they did not know what to expect from the doctor. Stating that they were so happy can be interpreted to mean *relieved* that the doctor expressed either a view that is close to their own or was generally encouraging of the baby's way of being. That it was made to be 'so obvious' was followed by the use of a happy emoticon which conveys the commenters reaction to the surprising and affirming news.

When group members want to discuss the actions or behaviors of particular people, they offer or request to use 'inboxing' which involves sending a personal text message through a chat function connected to social media sites. In this case, the 'asker' can be seen to be motivated to find out where or who this doctor might be. This supports the reading that K2 was likely to have had a differing experience; that their doctor is either indifferent or skeptical towards the use of sign language once a child has been given a cochlear implant.

That doctors are the subject of the conversation, is symbolic of the debate surrounding the use of sign language which is exhibited throughout the composite conversation. Medical knowledge is prioritized in meetings and consultations in the clinic settings. The concerns parents have about their children's future in the event that the CI would not benefit them enough are not felt to be adequately considered. Individual physicians and surgeons represent a type of adversary to a sign bilingual approach to language for children who use cochlear implants. Parents show in comments in these

discussion forums that this is their experience; medical knowledge overrides the expertise of all other professionals in the medical and rehabilitative teams. Implied messages from other professionals are that parents should follow the doctor's recommendations of how best to utilize the CI. When the conversation turns to what doctors say about what to do after a CI has been implanted it is to criticize this practice which is clearly what it targeted in the next comment.

L1: Personally, I think any doctor who says that a child doesn't need sign language is stepping over a line. Who is going to be living with this type of hearing and who knows if it is enough for what they want to do in life? I mean really, it's up to that person. I usually think about other friends he can have. I don't want him to be the one who never got to learn to sign.

Another signal of the resistance to medical knowledge interpretations in questions of development of language and cognition can be found in 'living with this type of hearing'. Language choice through ordination by a doctor is an action 'stepping over a line' of the reach of their expertise. The use of sound with a cochlear implant is differentiated from the type of amplified assistance provided by traditional hearing aids. Medical knowledge is contrasted to this parent's comments that represent a lifelong perspective of an individual, 'what they want to do in life.' It is then expanded upon to be a personal choice, promoting potential social relationships with others. Those others are signers or deaf people who use sign language. This parent is expressing an idea that this is a positive group to associate with and it indicates an understanding that the doctor who determines the non-necessity of sign language is actually discouraging association with people like their children. Here the in-group or the 'own' of this OSG includes individuals and their families who are disadvantaged by hearing norms (Goffman, 1963, 2009 p. 19). To finish the comment with 'I don't want him to be the one who never got to learn to sign' identifies a characteristic of the in-group: signing or signing as desirable. The parent commenting is not a native sign language user or even fluent in sign language having acquired it later in life. If the parent were a native sign language user the child could have learned signing in the home.

Signing or 'signing seen as desirable' understood as social practices can help to understand this networked parenting community. Wenger provides a definition of practice in *Communities of Practice: learning, meaning and identity*:

Such a concept of practice includes both the explicit and the tacit. It includes what is said and what is left unsaid; what is represented and what is assumed. It includes the language, tools, documents, images, symbols, well-defined roles, specified criteria, codified procedures, regulations, and contracts that

various practices make explicit for a variety of purposes. But it also includes all the implicit relations, tacit conventions, subtle cues, untold rules of thumb, recognizable intuitions, specific perceptions, well-tuned sensitivities, embodied understandings, underlying assumptions, and shared world views. Most of these may never be articulated, yet they are unmistakable signs of membership in communities of practice and are crucial to the success of their enterprise (Wenger, 1999 p. 47).

The foundation of the alternative understanding discernible here in this composite conversation is a conglomerate of this concept of a social practice. The tension between the educational access to sign language learning and the pediatric cochlear implantation specialist is the catalyst of this conversation which results in an alternative understanding of parents of DHH children; that what is right is what is good for the child in a lifelong perspective. This allows for multiple possible futures for the DHH child in regards to language use. A main concern in this alternative understanding is to access language teaching and learning resources these parents are not capable of providing on their own. Sign language learning is one of these resources.

## Versatility for participation

As the conversation continues the comments take on a more direct and clear message in expressing the issue of why signing seems to be discouraged. The following comment gets right to the message some parents were advised to do by professionals in the clinic; ‘Speak don’t sign.’

M1: [I feel the same way.] We’ve basically been told what to do which means of course speak don’t sign. That is what they say. We (mother and father) both think that language is language and more is better. I have a friend who without the devices is deaf, but she signs. She does both and it works for her. There isn’t any need to worry about all the situations that make it hard to use the technology, as long as there is an interpreter there, that is, or someone else who signs.

Directly after being told what to do, as a way of understanding the force of medical advice that is put in terms of prescribed treatment, the commenter juxtaposes two things: ‘doctor’s orders’ to the advantages of knowing multiple languages. By stating that they know a deaf person who uses hearing aids sometimes and only sign language at other times is to give evidence of the desired intention to subvert dependency on technology while at the same time admitting there is a different type of person-based reliance that would be necessary for participation, namely sign language interpretation. Multilingualism (signed or otherwise) and ‘technology plus interpreting’ are expressions of the approval of versatility and self-definition

for the deaf individual. Here existing as deaf in this way shows how a combination of resources increases the level of participation since the situations can be adapted to.

The symbolism sign language in the conversation is reaching adds a dimension to the alternative understanding of parents. It is implied that there is a medical goal to exclude a visual-gestural modality of language for early implanted children because of the need to invest in maximizing the time used to practice listening in order to be able to speak. Sharing this time and effort in early intervention therapies and services to learn a language that bypasses the hearing is seen as counterproductive by medical teams responsible for pediatric cochlear implantation. This is especially the case for families with hearing parents who do not have previous knowledge of sign language. The competition for the focus in the early years of life, when language develops, is presented in this next comment.

N1: This is just so infuriating. First they tell you not to use sign language because the child needs to practice hearing. Then they say if you do want to use it don't start until the child is older (!). There is only one individual who is questioned whether or not they should be given the opportunity to learn sign language in this whole group around the deaf or hearing impaired child and that is the one who can't hear well or at all! Parents or guardians can go to TUFF [Sign Language for Parents Program], siblings can go to some SPSM run thing [National Agency for Special Needs Education and Schools]. Even personnel at schools seem to have more rights than the kid they are supposed to be learning it for. What is this??? It's like you can draw this big circle around all the people who are protected by rights and when you get to the deaf minor you take a pair of scissors and cut out a piece that excludes someone from this, for the very reason the rights have been made into law. Because they are deaf and have language rights!

The (!) after 'until the child is older' questions the logic of waiting to learn signing when it will be harder. The content of this comment summarizes and reiterates discussions that are frequently seen in groups on social media sites which lie in the boundaries between parent support groups and SMSs like sign language learning sites and deaf culture issues. The main message is that there is a systematic injustice made visible by the existence of programs and services for groups peripheral to the DHH child; parents, siblings and educators. There is no effective, accessible program that guarantees or protects the language rights of a young child who is deaf or hard of hearing in Sweden to this parent's knowledge.

The conversation turns to normality, society and schooling when a parent questions what happens to how a child is perceived if they use sign

language. Becoming ‘even more different’ is understood here to put the child at risk of stigmatization or exclusion.

O1: Why strive to make your child even more different? The whole point of the technology and the testing to see how they are doing with it is to ensure that they are able to manage in normal society. We are hearing, our friends are hearing and it’s working. She is in the top of her class in all subjects. If this weren’t the case or if it changes then we will do something about it.

This comment represents this parent’s general understanding of the goal of assistive technology, to be able to participate in normal hearing society. In this sense, a sign language community is not comprised within what is normal or desirable for this commenter. Again there is a description of the ‘A’ CI using child. This is detectable in the phrase ‘and it’s working’ and a description of excelling in a mainstream school environment. Being ‘different’ represents hardship indicated by being able to manage. It is interesting to see these two comments side by side because of the focus on hardship for the DHH child in society. These commenters both express areas of difficulty, the former is emanating from the lack of equal opportunity within society and the latter on the apparent or possible risk of being doubly stigmatized by deviating from society in hearing ability and in language modality use. An additional dissemblance to avoid is being different within the hearing family.

A second parent supports this comment by stating their decision to prioritize Swedish because that will make sure they will learn what they need in an integrated schooling context and a Swedish speaking context.

P1: We’ve decided that the most important language to put effort into is Swedish even though we speak another language at home. If that is rock solid then they will be able to learn what they need to in school.

According to these comments Swedish is the focus because that is how you will best be able to access learning for a life in Swedish society. The following comment questions why knowledge of a visual-gestural language would jeopardize these goals. It also seems to be questioning the short-term time frame on ‘it’s working’ and the sole focus on Swedish in primary school.

P2: But why would it be a bad thing to learn some signing? It seems to me that you have to wait and see if it isn’t enough (the CI) which actually means the child isn’t progressing and then there is the whole issue of introducing a new language because you weren’t able to fix the hearing. Maybe not the best way to start learning a language. :S Because you don’t make the cut for being mainstreamed.

The leading question of the utility of signing is a cautious start to a comment that cuts quickly to a critical point of the issue where the ‘wait and see’ strategy is rejected. This comment contains the double risk that the child could possibly be exposed to. If the cochlear implant does not provide adequate access to sound for whatever reason that may be, the child will have been delayed in progressing in language development. The connection to cognitive delay isn’t stated but the risk of falling behind that the larger group of DHH children is assumed to have is an implied circumstance. What makes this situation doubly hard is to introduce a new language due to negative outcomes, failing in either managing in a mainstream environment or being able to utilize the cochlear implant for any number of reasons. That an emoticon for sarcasm, S:, is used after ‘the best way to start learning a language’ is most likely referring to the child’s individual situation but the task of introducing a new language will impact all family members and communication in the home environment. The main message of this comment is to relay the importance of avoiding a situation of feeling like you or your child are being forced into using sign language.

The developmental risk or cognitive delay implied in ‘not progressing’ actualizes a particular perspective on disability. Networked support in parenting in OSGs function to facilitate the construction of alternative understandings of what can be called ‘something else disability’. Online discussion groups are established to be able to ask questions and express views from different levels of experience. The entry point into networked support in parenting by each individual will differ in this respect. Seen as situated learning, the possibilities of accessing new knowledge at the appropriate level expand with the size and diversity of the participants. Legitimate peripheral participation (LPP), a process of becoming a community member through actions, works around core values and practices of a community (Lave & Wenger, 1991 p. 29). This is how becoming a parent of CI user can be seen as becoming a part of a community of practice of parenting in online networks. This provides exposure to how others argue for and report on approaching similar problems in different ways. That is part of what makes it possible to use and adopt alternative ways of doing and understanding things. For a new parent the mix of ideas, the opposing views and the diversity of experience are proof that there are alternative ways of parenting a child with a CI.

The nature of the OSG characterizes this merging of views into an alternative understanding. Personal support, in a broad sense, can be seen as sharing similarities and interests connected to them which are unique in comparison to the dominant culture. If there is a consensus it comes in the form of pre-understood ideas of providing and receiving support. The main theme here is that what is right is what the child needs. What is needed is

influenced by their family, where they live, taking into consideration who they are and what other disabilities there may be. Family internal diversity requires alternative solutions and combination of activities in each situation.

The acceptance of using sign language with children with a CI is possible because this is an alternative understanding shared in the group. An example of this is how the group is made up of parents who gradually become more familiar with the variation of ways of being deaf or hard of hearing. From this standpoint of differentness comes ‘something else’ disability into consideration by parents. ‘Something else disability’ is an example of a perspective on disability from a particular viewpoint, one which consists of already knowing about the first known condition of deafness constructed by the early hearing screening of infants. It builds on shared individual experiences parents of DHH children can recognize in others. This is a specific theme with underlying conditions of sensorial differentness with which they have come to understand their worlds and thus allows for a number of points of consensus about disability in a group from a particular technologically mediated perspective. In Chapter 5, William demonstrated how a parent wonders what is ‘normal three year old’, ‘normal three year old with hearing problems’ and ‘not normal behavior’. This is a ‘something else disability’ understanding to not know what is indicative to hearing impairment which was first detected. How a DHH child is expected to behave and develop is set apart from behavior that may mean there is ‘something else’ to be addressed indicating an additional diagnosis or condition. What can also be found in a ‘something else disability’ understanding is that sign language use can be adhered to or not, and that there is acceptance and understanding for others’ choices based on ‘something else disability’ which will be demonstrated below. Again signing is often seen as instrumental rather than cultural by the majority of parents who are hearing. The parents assess a familial situation where signing is deemed as positive or negative by parents depending on unique combinations of disability, ability and deafness.

### Construction of the normal CI child

There have been examples here of commenters countering ‘either-or’ argumentation and ‘wait and see’ reasoning by pointing out that these approaches to language learning and use can exacerbate the disadvantage some children may experience. The comparison in reasoning portrayed in this conversation makes visible how the ‘normal’ CI child is constructed. If the CI proves not to be sufficient then there is ‘something else’ causing the problem, i.e., an interpretation of additional disabilities or life conditions. One interpretation would mean that to let the ‘normal’ CI user use sign

language puts them in a group that is seen by some as ‘having to use’ or ‘needing’ sign language for a reason other than not being able to hear. This understanding builds on how sign language is seen by hearing individuals to be negative if it is needed and positive if it is an elective choice. The parents who promote the use of sign language early on in the child’s life alongside spoken language are on the offense to ward off possible disability by language deprivation or the same stigma of ‘something else’ disability which the parents against using sign language are trying to minimize. The stigma is not primarily about hearing impairment (Goffman, 1963, 2009), it is the association that is made between deafness and supposed intellectual disability which is a sociohistorical construct (Ladd, 2010).

By knowing sign language a child’s status grows in the ‘in group’ of signers. The ‘having to’ learn sign language is avoided altogether by already knowing or having started to acquire it of one’s own (or one’s parent’s) free will. The choice-based use of sign language is positive.

### Changing a polemic tone with an account of disability

A parent who is engaging in a portrayal of singularity is exemplified in the continuation of the conversation. A function of the next comment is to nuance the discussion with individuality to avoid continuing in a polemic tone. The following also exemplifies how a parent gives details including assistive device use and particularities to add to the coherence of the account. The comment adds details of everyday decision-making to what they have prioritized and why they chose to do so.

Q1: Sometimes you have to pick the problem to focus on that is right in front of you. One of my children (HA and CI) has no friends in school so our focus there is on the social part. My other child has multiple disabilities, one of which is hearing impairment, so we decided not to start learning sign language, since there are other areas to work on. On the other hand we do use every possible way to express ourselves that we already know to communicate and we have our own signs that we use together.

Having problems with interacting socially with peers is a recurring subject in social media sites where parents discuss implications of their children’s hearing impairment. Stating something about your child having no friends often elicits supportive responses. These are in the form of expressions of knowing what it feels like to see your child having difficulty in maintaining meaningful or close relationships with others. By contributing this relational aspect in the discussion, this commenter displaces a language choice with an overriding, primary consideration: social participation.

## The alternative understanding rests on identification with disability

The construction of parents' ideas about language and sign language emerge from criticism towards clinical staff who views sign language negatively. A negative view of signing for these parents seems also to be representing a negative view towards the group deaf or hard of hearing, which creates a dilemma for a parent who both appreciates the medical expertise but cannot reconcile how the practice would hope to eliminate deafness. An assumption of the negative view towards signing is tied in with a medical model of impairment which can be understood to be a negative view of disability and deafness. The goal is to use procedures so people do not have to use signing and the use of signing in this view would mean undermining the goal of the medical care.

When a parent maintains on open-ended 'both/and' strategy, spoken and signed communication, in the event that the child would need or want to sign, it is partly constructed in the overt and covert resistance in encounters with professionals that led to their adopting or strengthening this view. This in turn means that an alternative understanding resolves a dilemma through understandings of disability which allow co-existence of three elements: pride of being part of the sign language community, engagement in medical practices of alleviating impairment and shared aims in a more encompassing assemblage including families with children with other disabilities.

To claim disability as a 'parent of' is to claim marginality by association in one's identity. Because of the liminal position of supporting but not being DHH the alternative understanding underpinning an allyship with the group requires continual sensitivity and negotiation. This is possibly how the alternative understanding remains unconventional and agonistic. For a parent to adopt this understanding they have to accept the possibility of associating with others holding a contested view, either in the in-group of parents or in another group, i.e., the deaf community. A mixed 'hearing-deaf' support group of parents unites through the utilization of a disability understanding as a type of pact to support one another. This is done through keeping the climate open to differing views through welcoming the sharing of personal stories.

## A source of softening the edges between communication orientations

This is where the nuancing effect reached through ‘network of networks’ comes in and the way boundary areas between Communities of Practice are permeable (Wenger, 1999 pp.103-121). Parents are interacting on SMSs in multiple groups which are loosely linked through their networked individualism (Rainie & Wellman, 2012). The alternative understanding exhibited in these composite conversations requires this type of space for ongoing meaning exchange. It results in a loosening of bands to attitudes of right or wrong in reference to communication choices made by parents. It also serves as offering glimpses into others’ lives and the many ways to be deaf or hearing.

This finding, that parents are more likely than before to be exposed and connected to examples of experience with other parents who are similar to them in one respect but different in others, is reached through networked individualism motivated by a significant life event like a health issue. This presents an example of a unique cultural organization of meaning in constellations of micro groups related to sensorial differentness and technology use. Frustrations with ‘right path’ thinking and silent antagonism are more easily solved through personal combinations of support systems through CMC.

Another finding has to do with the ‘both/and’ as opposed to ‘either/or’ approaches in reference to two areas. You can use spoken and/or signed language is the one. The significant point expressed at the end of this composite conversation (Q1) is that there is room for different viewpoints towards signing. It softens the edges by disarming the conflict. Secondly and most importantly, this comment presents a new viewpoint in the discussion and a new representation of a ‘both/and’ approach. It builds on an argument to respect parents’ reasoning about needs in disability contexts as well as deaf, hard of hearing and disability cultural ideals. It is an alternative understanding that dis/ability (disability, ability and function variation) overrides as an interpretative system of what to do as a parent when it comes to communicating and fostering language skills for all family members. Placing the priority on a level of factuality, as the parent in Q1 does, connects to how individuals can become knowledgeable in dis/ability through the alternative understanding.

## Participation ideal replaces linguistic ideals

There is a shift from linguistic ideals to participation through an accessibility ideal that is constructed through the tolerance of different viewpoints in interactions between hearing and deaf parents. The tolerance is a product of loosely connected groups of individuals seeking support and information for their situations. CMC affords a contact between hearing culture and deaf culture through social media which was not earlier possible. This type of intercultural contact helps parents share particularities in order to find common ground. That common ground is accessibility and participation for their families who resemble each other but perhaps through a reversed order. The deaf parent with a child who uses a CI will perhaps experience a new space of sensorial differentness when the child begins to use sound which requires similar perceptual work as the work in apprehending and practicalizing in their lived parenting. In other words, these ideas new parents are coming into contact with through their participation are grounded in lived experiences of disability through children. The resulting interaction in parenting contexts, where the primary interests are interactions between children and families, transcends linguistic ideals in online environments.

An additional aspect that is made clear is that there are personal claims of impairment shared in these conversations. This pattern of narrativizing in OSGs and SMSs provides the examples of ‘many ways to be deaf.’ Speaking coexists with being deaf or hard of hearing and sign language coexists with hearing and ‘something else’ disability. The dispersal of examples of individuality of disability is made possible through networked individualism in this alternative understanding. This is exhibited in how parents in discussing disability moments deepen the complexity of the online discussion. It is possible to discern that there is extra caution being exhibited when disability makes an entrance. Typically to explain opinions or exceptions from ideals, a parent offers the other readers both more detail about their family’s situation and a relatively rare motivation for action, for example not learning sign language as in Q1. The message in this comment is that there are larger problems for the family that make it impractical or impossible. The compounded element of ‘no friends’ for one child and the other child’s ‘multiple disabilities’ results in nuancing the conversation. The mention of what does get used, home signing and alternative communication brings forward the thought of what works in a home environment. The individual with the most need determines where this parent decides to place their effort. Also the example of parents of children with language or intellectual disabilities ‘who hear perfectly fine’ but want to use sign language bring attention to participation rather and nuance the different struggles to be able to use signing which offer a perspective which deepens

parents' knowledge of language rights, modality and problematic views expressed in "deaf not disabled".

## Possibilities through sustained social media conversations

Subjects about medical encounters and language choices are often sought out by newcomers to the group. A typical example of how a new parent would go about posing a question would begin with an introduction of themselves via a presentation of their child which typically includes the child's age, sex and technology use and then a question would be asked. Another group member would offer an answer and give the advice to enter key words in the search function on the group site to find out what has been discussed previously. By using this function earlier conversations appear which contain the search word used in the exchange and present them together on the parent's screen. The way CMC reaches beyond immediate time and space shows that the accumulation of digital material underlying constructing alternative understanding remains accessible to other parents. How meaning is organized through being able to have access to other parents' experiences and the possibility of being able to contact them, sustains the alternative understanding. It is strengthened by making available the specific social and cultural understandings founded in this network of networks.

## CI use cannot change the accessibility of all environments

The last comment ends the composite conversation in a fashion that is characteristic for discussions on 'thoughts about language'. Last comment patterns in social media exchanges tend to signal the end of a discussion either by summing up, hitting on the main point again or in back and forth exchanges between an ever-decreasing amount of commenters sometimes ending in agreeing to disagree. A frequent thematic ending in these social media sites about hearing impairment in children is implied; i.e., if you are doing what is best for your child then you are doing it right.

The commenter in Q2 returns to directly remarking on the original post about why Anna felt discouraged from using signing and why there are so many different attitudes in the services that are directed towards the group of families who have children who are deaf or hard of hearing.

Q2: The message I'm getting is that the CI team wants to focus on speech which is all good. I have no problem with that and he seems to be doing fine, actually even better than other kids his age. What I am missing is that I want

my child to be able to understand supportive signing and sign language WHEN HE CAN'T HEAR! No therapy in the world is going to make loud environments, bad acoustics and failing technology go away.

Communicating through speech is the goal of cochlear implantation. This parent agrees with this general objective. Their child knows how to speak and 'seems to be doing fine' is a common statement about CI using children because of the potential problems that parents are made to either expect or become aware of through other parents' experience as time passes. At the same time this indicates that the parent has seen that the therapy and early interventions after receiving a cochlear implant have had an effect by comparing their child's progress with the children in the same age group.

What other parents read into the statement 'even better than other kids his age' also serves as a representation of being a parent of an '*A' CI child*' as it is colloquially expressed in conversations between Swedish parents. This means that the child after cochlear implantation excels in language skills or school subjects beyond expectations. Other parents who read this will know the child does not have 'something else' disability. This is noteworthy because the motivation for learning sign language by this parent has to do with sound environments as the main argument and not coexisting problems or other diagnoses.

The parent in Q2 wants their child to be able to use signing in a particular way, to be able to 'read' signing to ensure that when sound conditions are poor the communication can continue. The last sentence implies that there is an understanding about how learning to speak using a cochlear implant occurs in controlled environments whereas everyday surroundings are not controllable. That the child can't hear refers then to not being able to hear language messages. Spoken communication *can* be accessible. The problem is due to all the other sounds which compete in hearing spaces. Also, therapy refers to what gets done by the team. 'What I am missing' refers to an uneven balance between developing speech and listening skills, and sign language. This parent is advocating for their child to be able to learn signs and sign language elsewhere like in a school run program and separates language therapy from learning a second language. This pair of language objectives corresponds to separating communication goals inherit in early intervention from a language goal in a lifelong perspective. This is motivated with the shortcomings of technology which is the theme of the next composite conversation.

## Technology (in)dependence: a composite conversation

This second composite conversation from the same netnographic material begins with a parent's thread starter containing a repost which was not written by a parent, but by a young adult CI user. A common practice in these thematically adjoining SMSs is that parents will post a link to another site or blog. They may quote directly from other non-group members' posts and conversations. This is done to partially bypass the criteria for group membership when a parent feels it would be of interest to at least some of the other parents to share views from an outsider. Sharing in this way is an example of a practice in the network of networks which broadens the content of what users of the site see. Also tips about other groups contained within the current group are posted. Examples of these are other OSGs for certain diagnoses and SMSs about children and youth groups, sign language groups and deaf culture groups.

When the parent states they have read a blog by a person outside of the group, a CI user, it signals it is of special interest to parents whose children use CI technology. This intended audience in a mixed group may want to click on the link to read further. Once the parents have read, the majority of the comments are direct responses sharing their opinions on the post or how the post affected them. Users of a parent SMS like the fictive one composed here will only see responses on the page and not the actual blog post. That post they would have had to click on a separate link to be able to see. This composite conversation is ordered alphabetically from R to U, where each letter signals extraction from separate conversations in social media groups.

Post: I just read a blog post from a 20 year old CI user. [name of person and link to post]

This post described a series of unfortunate incidents related to CI use by a young adult. The blog post takes on a narrative quality of what can happen, when a chain of consequences connected to relying on people and bureaucracy for one's ability to hear occurs at inopportune times. All in all it is a concentrated narrative of the realities of his life as a CI user. The main point made throughout is that he used sign language with his family and others while all of these problems came up and emphasized how important this was for him to be able to do this even though he normally lived a large part of his life in hearing contexts. Additional details about feeling at home with people who are hearing impaired who learned signing as adults provides a belonging theme parents have begun to imagine but few have had direct contact with through a CI user. The comments share the quality of reacting positively to the blog post.

R1: This was excellent. He explained it so well. Our daughter is very young but I can't help thinking about how we are contributing to the situation he wrote about. We are depending on the devices and the batteries to always be working and being used.

R2: What I realized was that my child's ability to hear is going to be steered by other people. We've experienced unanswered emails when you report a malfunction (since you can't use the phone), technicians overloaded with work, under-staffed clinics, cochlear implant companies, even the postal services! If one person is sick one day, there is a domino effect collapsing on a person's ability to hear.

S1: The most interesting perspective to gain for a parent of a CI-user is... yes... the one from a CI user!

T1: So well put by a bona fide CI user!

U1: Thanks for "coming out" to parents of deaf kids as a CI user who uses sign language. CI+SSL= <3 TRUE! [CI + Swedish Sign Language = HEART TRUE!]

U2: I'm so glad a CI user has written this! The languages benefit each other and do not interfere either way. Not like so many specialists try to make parents believe. We've had to repair our son's CI on numerous occasions and each time it took from 4 days to 2 and a half weeks. "Technology is fantastic... when it works" as the saying goes. We've always been able to sign in these situations and new insights [about signing] in our family are gained each time it happened. Malfunction has its advantages.

U3: This should be a part of a parent education package. It's a way to take part in your CI using child's future reality. The CI clinics would gain even more credibility if they included this early implanted/adult/signing/bilingual perspective in their programs.

The message in the blog, to learn sign language even if your child uses a CI, can be understood to be unique due to the reactions and possibly having been linked into the site from an outside source. There is also an indication represented that there weren't any parents negative to discussing a personal account by an individual telling parents they should be learning sign language. The conflictive atmosphere isn't overtly demonstrated because it appears to close off the possibility of stating a differing opinion about sign language in this case. The pro-sign language message is coupled with the witnessing of this person's experience and presents a situation where you can't or shouldn't engage in offering a differing opinion. The atmosphere is likely polarized and uncomfortable for some non-signing parents of CI users at the same time as the story is credible and complex.

A future version of the CI using child is embodied by this text. The parents combine this account with their own expressions of realization or hardships

with technology. The focus shifts in the exchange and takes on the form of an insistence upon change so there is better access for parents and children to learn about how many different people use sign language, not just the culturally deaf, which is a highly recurrent theme in the groups studied.

R1, R2 and U3 offer reflections on the disadvantages of the CI technology. The first comment expresses a goal as to not be overly dependent on the complex of interconnected system of services, organizations and individuals. This is a reiteration of the major theme in the blog post they are commenting on. The parent that linked to this young person's blog post adds the role of the parent to the combination of circumstances which creates this dependency. They point to their own role and are self-critical.

This composite offers two main interpretations of technology (in)dependence. First, the CI is the example of a system that is fragile due to its complexity and the number of links in the chain required to be able to access sound. This is made even more fragile by not having a back-up system. Secondly the composite presents a construction of resistance to the idea that signing is not desirable for hearing-using individuals.

This 'technology (in)dependence' theme is an example of how life circumstances of a person exhibiting situational and relational disability contributes to both a nuancing of a discussion in a parent forum through resisting solidified views of a hearing and deaf divide. What is interesting here is that changing this view of who should be able to use sign language and why sign language is desirable shifts the divide towards one modality (spoken) or two modalities (bimodal) in interpersonal, physical, face-to-face communication. This demonstrates how an alternative view materializes.

The comments have the structure of 'realizations' which build on their individual circumstances that support or change their personal understanding. Once shared in the conversation varying versions on the same theme congeal into a shared understanding of what the future holds for their children. The last comment in the composite, U3, summarizes the theme of dependency and transforms it into an objective for improving practice and care. It functions as an example of how this exchange results in proposing cooperation between groups outside the forum, the CI clinic and the lived experience of CI use by an adult. Through this proposal this parent commenter incorporates a view from outside parent groups which is mutual to some parents on this site, represented in this positive exchange about sign language by a CI user and in so doing incorporates it into an emerging hearing parent perspective.

The merging of viewpoints like this is what Hannerz calls the perspectivization of meaning (Hannerz, 1992 pp. 65-67). In the interactions between parents, there is a creation of diversity in respect to hearing and deaf culture within the complex structure of networked society. The alternative understanding, a type of micro culture expression is produced through the interaction of perspectives. The parents commenting and the much larger group of parents 'legitimately lurking' are all managing the meaning of attitudes, values and beliefs. They take part in these 'perspectivization of meaning' situations online. This making of meaning occurs from their individual standpoint at that time in life where one of their roles, the role as parent, is prominent. We also can assume that there is a cumulative build up, as Hannerz puts it, of how perspective as a type of understanding is generated. As the parent becomes more experienced through their engagement with a growing child and technology use for instance, their shifting perspective will also shift how they see the meaning of practices. Their viewpoint widens through this experience based shift. The more interaction in situations of sensorial differentness, the more it will be a part of their way of seeing and how they interpret the world.

The perspective is the device which organizes the attention and interpretation which an individual gives to externally carried meaning, as well as his production of such meaning, whether deliberate or spontaneous (Hannerz, 1992 p. 65).

'Externally carried meaning' through the usage of SMSs affords a way for parents to go beyond 'communities of place' like family, school, work, neighborhood and town. Today their worlds are intersected by many more families like theirs than were available to others before widespread social media use. This makes this generating space of alternative understanding knowable through recognizing themselves in others and engaging in new practices like joining OSGs. The similar life conditions in one respect and the diversity of deafness in another are permitted to intersect. Being active, involved and interested in lives lived by others in online environments is not fundamentally different from face-to-face interaction in this respect but is different in how a parent can access experience and at what intensity. It is likely that the biographical element Hannerz includes in the cumulative process of perspective-gaining takes place at a faster pace because of these communities beyond time and place. In that way, the parents being able to reach further spatio-temporally, to other parents like them, influences the organization of meaning and the complexity of culture. In these parent forums there are elements of socially shared ideas, a way of thinking of what is local on the Internet, as well as cultural content influenced by the global reach of Internet structure.

## Complimentary systems

The composite conversation on technology (in)dependence shows how these parents see two systems as complimentary and as requirements for equalizing access for their deaf CI using children. ‘Malfunction has its advantages’ as commenter in U2 expressed it. This means the negative impact of dependency can be revealed and be vicariously experienced by parents as an opportunity to be reminded of how two systems, the CI and sign language, cover two different mediums. This conversation contributes to new knowledge for parents who have yet to meet adult CI users as well as other parents who have experienced malfunctions of their children’s technology. In the blog writer’s case his family was able to sign which forms their possibilities to interact through the use of different modalities. The U2’s comment expresses the same thing. The temporary conditions enacted through going in and out of spaces of sensorial differentness reveal new knowledge for a family. The other families’ experiences of communication and unequal distributions of power provide a way for others to see what possibilities they have because of sign language. The enmeshed social and cultural practices secure a realness others can observe through parenting role perspectives.

## The early implanted, young adult CI user opinion as guidance

What signals a difference to parents in these online groups is the age of when a CI user was implanted and how they describe that experience. The CI users who were implanted after detection of deafness from a universal hearing screening program represent a special category for the parents of CI users. They are informed that their children belong to the group who is expected to be able to utilize the technology to the highest extent (Fieldwork protocol no. 36). This is why parents through these comments welcome the opinion differently than if the blog had come from a HA user or from an individual implanted later in childhood or adulthood. They are interested to know the opinion of this specific group as a form of guidance in their advocacy for their children because of how they have been informed through cochlear implant practitioners and manufacturers (Netnographic fieldwork protocol no.10).

In other parts of the netnographic material there are examples of how parents resist being influenced by those who are not parents and make their way into the online support forums (Netnographic fieldwork protocol no.11). Their posts can have a similar message to the one in this composite or are engaging in deaf group activism. When this happens these individuals are

usually reminded of the description of the forum and asked to respect the criteria for participation. In other words they are asked to either leave the group or are blocked from the group. Legitimate parent members become conscientious gatekeepers which refers to how they decide whether a given message will be distributed keeping in mind the interests and security of other parents. Parents who grew up with hearing impairment or deafness themselves are the most prominent voices in these groups. In this written exchange form hearing status is inconsequential. The DHH parents are utilizing their two positions: parent and deaf or hard of hearing person, to facilitate a continued discussion between perspectives on the issues most important to families with DHH children. The blog post has the intention of getting parents to engage in self-reflection on their part in making their child technology dependent. Looking at examples of the implications in this blog, the parent is told the answer of how to safeguard against the worst drawbacks of becoming overly dependent on technology.

## Alternative understanding through a community of practice

In my overall analysis of the netnographic material presented in the form of composite conversations I first discovered the critical discussion of the dominant understanding of the CI child's best opportunities for developing language as the construction of an alternative understanding. My basic interpretation is that the Internet based conversations provided the participants with a forum where alternative understandings of the language development of a child with a CI implant were presented and supported. In fact, one of the main activities of the participants of the presented composite conversations seems to have been to establish an alternative understanding of the relation between speech and hearing based language development and signing language development. As mentioned in this chapter's introduction, social media use of parents of CI users offers an illustration of the significance of the social dimension of becoming in sensorial differentness. Learning through personal experience together with social learning through others' experiences in this type of differentness means that lived parenting is shared. To a certain extent, the presentation of this alternative understanding can be said to start with a problem that some of the parents participating in the social media conversations experienced. The problem in relation to parenting a CI user can be said to start with one parent's thoughts in the form of a post about feeling passively discouraged to pursue the use of signing with her child. She also adds a question in her post about why the message being sent about sign language is so different from one geographical area to

another. Her question is based on observations through reading other posts in these groups which provide evidence of the idea of regional differences in professional opinions about signing. The netnographic material from which the composite conversations are constructed shows that this is how parents experience becoming aware of ‘thoughts about signing’ held by others.

## Construction of understanding through a ‘school in disability’

Parents accessing other parents’ knowledge can be likened to a ‘school in disability parenting’. Anderson Gustavsson, building on Goffman, writes about how an alternative social world is built up by a collective of individuals who share life circumstances (Gustavsson, 2001 p. 227). This alternative social world answers to the stigmatizing world they experience in their new role as parent. Choosing to inhabit worlds to avoid stigma may involve choosing to identify through having a disability. Being in this alternative social context does not mean that the values concerning this particular disability are absent, unimportant or not debilitating in their life. The point Gustavsson makes is that they are able to discover others’ prejudices about a disability which exaggerates its consequences. These individuals who identify as disabled have a lived experience which provides them with the possibility to develop a more nuanced perspective of what this particular disability is, because of living it and belonging to an alternative social world where belonging requires this disability experience. This leads to being drawn to others who share this social world with others.

As I have previously pointed out, Goffman’s analysis and my own propose an entirely different implication in the relations between the disabled on the one hand and relatives and professionals on the other, than the conflict theories which emphasize these groups’ disagreements. Behind all the conflicts of interest and conflicts which may develop between people in these categories, there also appears to be important alliances and mutual understandings. And these alliances contribute to the possibility of maintaining alternative views of reality even though they conflict with other established views and ideals (Gustavsson, 2001 p. 229).

Gustavsson emphasizes the connection between groups as alliances which stand on mutual as well as alternative understandings. Alliances are best understood here as a relationship between committed groups to support each other’s goals while allyship describes the dominant hearing group’s commitment to the DHH group inhabiting identity positions where the main trait of stigma is not shared. These two relationships, alliance and allyship enable the alternative understanding because of how it involves cooperation which crosses over borders between communities where there is an unequal distribution of power between majority and minority positions. Members of

the majority hearing group aid in upholding the alternative reality through personal orientating processes of their own where they realize they inhabit the world differently. This is crucial in how meaning is constructed through a relationship of the becoming process of a parent. The category first seen as only illness or disability transforms into an acceptable and defensible way for humans to exist. The role of allyship will be further explored in the next chapter.

## Uncertainty made visible through a Community of Practice of parenting

A community of practice (CoP) framework (Lave & Wenger, 1991) adds an extra dimension to the analysis in the following ways: It aids in understanding what determines boundaries in belonging to numerous groups defined by what is shared and how it is shared. Social media group conversations are artefacts of a way of participating in a CoP. The nature of the site is designed for being able to return to these discussions when they are needed in individual lives. The imagined group of other parents materializes through online interaction which is how OSGs and SMSs operate as communities. Parents of CI users can observe how ideas transform and then transfer online to new members in an observable process of legitimate peripheral participation (LPP) (Lave & Wenger, 1991) through 'legitimate lurking' reading and taking part in practices online without being directly identified. Commitment to ideas of the group is visualized online through practices, styles and a use of repertoires about parenting a DHH child. In this terminology, commitment to ideas can be related to the alternative understanding in the type of parenting presented above. Online support groups as CoPs have been studied to show what values are necessary to adhere to in order to enlist support (Drentea & Moren-Cross, 2005; Stommel & Koole, 2010).

Community of practice as a social theory of learning illuminates a substantial part of lived parenting in sensorial differentness in society today. Many times Internet use and social media are the only way to access information and establish contact with others who are either entrusted with supporting parents, officially or are parents of or members of the DHH group. How individuals learn particular parenting skills from a group of parents is a prime example of the type of situated learning which is being discussed in this netnographic material.

Parents seeking out other parents, is an auxiliary activity to enlisting health care services through websites. Social media sites like Facebook are where

some parents will first learn how to and how not to refer to problems, name disabilities, refer to other individuals, overshare, keep to the topic of the group, and what content can be reposted in a group. All of this is learned socially through engaging in a CoP. What makes this group different from other support groups is that it is an intersection between deaf culture, sign language, technology and disability support. This can be explained and understood with how boundaries overlap between CoPs and are involved in how the members bring in new ways of expressing and understanding the core issues or goals of the different communities. An example is when a parent of a deaf child receives an additional diagnosis. A post asking for tips of other similar support groups is quickly answered with suggestions from other parents. This is possible because of the overlap.

What is most interesting from a CoP perspective is how opposing views of an activist or lobbying like nature are able to coexist. This spilling over of rhetoric from close lying groups because of deaf-disability crossings create an atmosphere where parents can safely begin to understand controversies and learn ‘community appropriate’ behavior to respond to them. A parent may feel most at home or anchored in one OSG which makes it easy to ‘practice’ there. They do however have access to closely situated groups where they may enter more easily because of the effect of other community members’ participation. When a parent finds material or information pertaining to DHH issues, it may be shared into the different close lying groups creating a pathway for others. In this way the ‘home group’ practice is permeated by digital material which belongs or fits more centrally in another group’s interests and goals. In an event like this presented in the second composite conversation, a parent understands other parents to potentially be as interested as they are and contact between close lying groups enables members to intermingle. Whether the post gets accepted or shunned may not be obvious but if it isn’t ‘liked’ or doesn’t elicit comments, the disinterest of the community’s core understanding will be communicated to members. The initial individual act of linking and sharing communicates approval of at least one parent which can be seen by the whole group. This statement by the individual reaches the wider network they are connected with through other social media sites. A direct notification to the blogger, often in the form of asking permission to share a post in another forum, can spread through the blogger’s network. The permeation of boundaries is often multidirectional in these overlapping sites that have been studied. Because of the nature of sustained access of previous conversations, the pathways stay open and the circulation of information and experience can continue. The spread and distribution of content that is peripheral to the point of being contradictory to legitimate practice of one CoP, covertly ‘instructs’ parents about the shared debate climate. It will at any rate still be visible as a post and may lead to a shifting in the core of the practice of this parenting OSG

community. Posts like it will follow in its path until a moderator judges the content to be inappropriate. An example of this is when a non-parent's post is allowed to remain visible on the SMS but other attempts of direct participation of non-parents are repeatedly discouraged.

A CoP of parents in sensorial differentness should not be confused with particular OSGs though each group in a social media context can also be viewed as a CoP. This is demonstrated in how an overarching goal of inclusion is enacted when the members of the networked group 'parents of DHH children' allow for a combination of 'signing' and 'technologizing'. There is discouragement of categorical denouncements of HA and CI use as well as opinions speaking negatively of wanting to learn to sign. If such opinions are expressed they are met with responses that communicate a defining feature of this community, this type of parenting requires 'communication care' of others. The message discernible here is that the need of the child, often portrayed through 'a parent knows their child's needs best', is modified. Instead, what is best for the child, according to this CoP includes acknowledging others' expertise based on personal experience, of both other parents and other DHH individuals, which in this material often is embodied by the same person. The parenting ideal is also modified through acknowledging that children who are hard of hearing are similar to children who are deaf. They have commonality in their position in hearing society as marginal. This is an indication that identity ground work is being laid through a parenting CoP. What is gained in being a part of this community, namely belonging, a parent gives up in autonomy. This indirect message contests that a child's parents should make decisions without some degree of involvement of a DHH community. In this chapter it was demonstrated that this involvement is reached through networked parenting. Until the child can express their desires, there is an online source of stand-in expression by former DHH children which is acknowledged in the network of CoPs in sensorial differentness. It is in this way that the tension between differing views can be seen as producing resistance, the beginning of advocacy of parents and the seeds of activism. The tension between ideological standpoints leads to resistance to practices which exclude access to the many ways to be deaf. One such practice is revealed through attitudes towards signing and how clinics and centers facilitate contact with members of DHH communities. To ensure openness and disclosure in this wider community, the practice of facilitating contact has to be guarded or managed, a practice which constructs alliances and allyship through coalitions between groups. 'What is right is what is right for the child' is the counter and alternative understanding that has been demonstrated in the composite conversations as a core mission of these communities of parenting.

In this chapter, a social source of parental uncertainty can be characterized as being sought out and engaged in by parents, which introduces a deeper understanding of why parents with conflicting views wish to encounter one another's arguments. Embracing and facing uncertainty appears to be motivated by a struggle worthy of effort and done in a spirit of humility. What I find most telling from the findings here is that parents continue to navigate – about communication, disability and technology – they either can't avoid it or they seek it out. In either case there is a climate of uncertainty which can be linked to acknowledging that what is 'right for the DHH child' involves not knowing what is right and requires trust in others. In addition to this, especially in disability contexts regarding language development, parents continue to live with past decisions and actions. This involves dwelling on if you have done enough or done 'the right thing', answers which are mostly unknowable.

A conflict in how to raise deaf or hard of hearing children, as it is portrayed in society through mass media, remains a part of what the parents share in these online settings. Rejection of portrayals as well as willingness to consider what other parents do brings parents together to continue to revise what this parenting means. Willingness to consider unites the parent group. What they do while navigating, orientating and considering requires resting in uncertainty. Even though they may feel diametrically opposed and choose accordingly in issues of schooling and language, they are able to express the views from the same facticity of having implanted their children and engage in the ways others have gone forward. The meetings with other parents online, in clinics and at activities and events leads to experiencing opposition and controversy and is how these parents are destined to or allowed to remain in uncertainty. Uncertainty comes also in the form of knowledge of multiple possibilities which was to a large extent made available in interaction with other parents in the same situation as well as parents with children older than their own.

# Chapter 9 Dis/ability literacy

## Introduction

In this chapter a situation of social learning which continues in parenting a child who uses a cochlear implant will be described. This task involves answering the question of how the lifeworld becomes shared through having been parented and brought up in a similar type of differentness. Departing from one parent's case, lived accumulation of understandings about disability will be presented. This exemplifies how experiences occur, sometimes before and sometimes after becoming a parent in this particular social situation of sensorial differentness. I call this lived accumulation of understandings and social skills *dis/ability literacy*, where literacy is a type of development in relationships through a social learning process where a person is actively engaged in continuous and life-long commitment to challenging systems which result in exclusion of social groups (DiAngelo, 2012 pp. 290-306; Sensoy & DiAngelo, 2012 pp. 145-164). In this work, these groups are the deaf, hard of hearing and individuals with disabilities in language and communication. This becoming literate process impacts both the parent's communication orientation and affective outlook toward disability. I will then identify characteristics through parent accounts of encounters with others which could indicate allyship (McDonald-Morken, 2014; Minges, 2016). Dis/ability in allyship includes going in and out of ways of being focused on another person's way of existing in terms of ability, what has been discussed as apprehending in the previous chapters. This begins for many parents with their child in the ways that relate to what the child perceives and the way the child uses senses (Harmon, 2010 p. 38). Below an example of how social learning progresses when the person grew up in a family context like this, a native to a disability microculture, is presented. This is later extended to include others' developing perspectives on disability and ability instances in everyday life. Becoming *dis/ability literate*, a tacit type of social awareness, emanates from parents' understandings of the child's body where the presences or absence of disability are processual and are situated in a sociocultural exchange.

## Transcending antagonism through dis/ability literacy

First I will present a case study of a parent, John, who exhibits having acquired experience with disability earlier in life. He came to Sweden from an English speaking country and learned Swedish as an adult. He and his partner were raising their children as bilingual. When analyzing John's interviews in terms of communication orientations the accounts differ in a major respect related to previous experiential knowledge. I began to see John as having qualities that differed from spoken and bimodal orientation characteristics in that he was markedly unaffected by the conflictive atmosphere. I probed the material with the question of how John was transcending the antagonism which led to discovering behaviors exhibited in others' parenting processes, for example in Chapter 7, in Eva's retrospective parent story presented for new parents.

One of the objectives in this chapter is to identify how one parent's experiences can be related to appropriating characteristics before becoming a parent. Appropriating in this sense would mean that a parent acquires ways of thinking which enables them to bridge different perspectives between a majority 'abled' group and a minority excluded from this group in dealing with a situation related to parenting. Literacy, in a social sense, is acquired in how a person becomes conscious of disability as a status or a source of identity and thus adopts interactional patterns and skills. Dis/ability literacy is used here to introduce the idea that there is a way that individuals who are socially literate in this regard are able to elude interpersonal controversy on an individual level through awareness of structural relationships between groups.

Through previous contact via email and informal meetings, John and I began an extended conversation about parenting and disabilities in general. Through this he had come to see me as a person who would understand him in the way parents can understand each other in support groups. John felt that to be able to share what he did, the other person needed a certain type of prerequisite knowledge and experience to be able to understand his viewpoint about disability. This generated a rich descriptive material akin to confiding in another person. John was able to disclose what he knew and was explaining from an impression he had of me sharing an 'inside disability' perspective which comes through in the excerpts.

John's account quickly takes on the form of narrativizing about how he had been able to learn and know what he did about disability. I began to think of this type of 'coming to know about' process building upon experience with living with people with disabilities, as a type of social literacy of disability

and ability a person can hold. For the sake of this analysis of a case study this was thought of as a type of proficiency about differentness and came to be termed as dis/ability literacy.

This case study builds on multi-sited ethnographic methods aimed at providing a description of situated learning. It draws on going between family experiences in John's childhood as well as his current encounters with others through his child's cochlear implant use. John was the one person in the interview material who had extensive experience in living with people who were disabled, were guardians of disabled family members and working in disability contexts. John grew up with two siblings who are disabled. His past experiences provide accounts of understandings about body and disability and differ from the others. It is provided here to exemplify how a parent is best understood to be orientating between the two types of communication orientation, in a type of transition. John's experience as a becoming parent of a cochlear implant user differs in that the division between spoken and bimodal approaches is not a strong characteristic of how he gives his account. In contrast, it is best understood as a type of maturity emanating from lived experience and ways of knowing he has developed in situ. He grew up seeing adults (parents, grandparents, aunts and uncles) in relationships with children and adults with disabilities. Examining John's accounts will allow us to see displays of dis/ability literacy involving experiential knowledge. Orientation has another much earlier starting point which is experience of living with or alongside disability as part of everyday life from a young age. In many regards, John did not have to unlearn or reorientate as others engage in which has to do with attitudes, beliefs and values about disabled lives.

John had a parent and a grandparent I would describe for purposes here as being 'self-taught' in dis/ability literacy. They were both guardians and caregivers of children with disabilities and had other relatives and friends who became disabled in accidents, in combat, through illnesses and old age as reported in John's interviews. They passed on what they knew to John in a manner similar to how a small child learns a native language. They handed down an attitude and an approach towards people with disabilities that becomes noticeable in skills that John presents in his examples. This transferal of knowing appears to have been done by showing how parenting is practiced where there were different ability statuses among intimate family members.

From the beginning of the interview with John there were indications of how his previous contact with children with disabilities framed his story about the detection of hearing problems in his newborn son.

Liz: And did you pay attention to that first failed test?

John: Uh, in as much as it was a yes no that there was something wrong. I guess there was already 'If there is, there is. I don't want it to be'. I always clinged to hope but I think I'd already got to that stage where, my brain had kicked into 'You've already been here, you've already got the jacket and the little star.' So, I think 10 – 15 per cent of my brain had gone 'Yeah, ok, we'll roll with it.'

Here John comes to know that there is a chance of his child having a disability and is aware from past experience what that may entail. That he reports to have so quickly moved from the shock of finding out about an indication of a problem to what he will do is one sign of dis/ability literacy. Along with this, John does not refer to this detection experience as many other parents in the material have; first that there must be some mistake, then that it was like a black hole, a trauma, a black cloud or dark and physical weight. The nature of his reaction to the initial shock is explained as knowing what failing a test means. He is disappointed and not in denial. There is even an inclination to suspecting the worst which involves knowing what that means for a family. In this way John's narrativizing differs from all the other parents.

Liz: So you had Hannes. 'Ok, this child might not hear.'

John: Yeah, I was a bit bummed because quite often that's an indication of other disabilities.

Liz: That's what you were thinking?

John: Yeah it was like 'Aw crap! I didn't want to do this!' But I mean that lasted for about 24 hours and it's like, 'You've got the skill for it! So what? Just go on with it as if it were anything else.' [...] and because it wasn't uncommitted territory once we got over the initial shock, 'Yeah, yeah. Just go with it, there's not a lot we can do. There's no point in getting stressed over everything. The technology exists. Let's leave it to the people who know what they are doing.'

John's practicalizing can start almost immediately. He knew what a cochlear implant was beforehand. This is the foundation he builds on through his previous experience which serves as a type of short cut through the shock, stress and anomie. In a sense he can place himself outside of encounters with a perspective of getting information, knowing what needs to be dealt with, and enlists help quickly through consolidation of the news about a hearing impairment together with his life experience. Even though the same thoughts about the future other parents have are actualized, he can partly compartmentalize them and focus on practicalizing a present situation more than his partner could.

As a young boy John had attended open lectures on medical advancements because they were patrons of the research hospital. This is why he knew about the technology of cochlear implantation, prosthetic devices for

physical impairment and advances in treatment of premature newborns which he listed as examples. He summarized this as part of why he knew about disabilities. He 'had always been around it' not only at home but by attending outreach programs intended to educate, inform and enlist donations from the community where he grew up.

In the last line of the excerpt above, John exhibits faith in professionals and technology in a matter of fact way. There does not seem to be any need to have an opinion or a viewpoint for or against procedures nor be in a difficult decision making position. John is neutral in the way he presents needing this expertise for his son. He continues to tell me about his knowledge of 'other disabilities.' This account is characterized by how John told that he and his wife so quickly practicalized their situation. He was able to go directly to action unlike parents who need time and other's support for explanations about what it means to not hear and what can be done. John is able to read the situation through a disability perspective whereas other parents were occupied with apprehending. John's process of apprehending differs due to how he was socialized through having close personal contact which included a particular way of understanding differentness. Consolidating was, in an apparent sense, already initiated because of John being literate in dis/ability and therefore is exhibiting a different initial orientation point than can be expected from the general population.

Liz: Did your thoughts about other disabilities kick in then too?

John: It always is [there]. As soon as they start failing something like that I automatically, because I've done [lived and worked] such a lot with it [disability], it's just like uhhh. [hesitating] Ok. The thing is because quite often it's a lot of neural problems. Um, with deafness and stuff like that.

Automatically for John means how he thinks about the body and disability. He can't *not* think about disability in this manner. John knows that developmental problems might transpire later and not be detectable early in life. This was due to having grown up with siblings whose disabilities became more pronounced as they advanced in age. This was how John utilized a lifespan frame and how he was contemplating possible futures for his child. In this sense John's thoughts about the future build on knowing something, perhaps too much, rather than not knowing what the future will bring which characterizes his becoming processes in a different manner than the other parents.

John relates his childhood, growing up with siblings with disabilities, working with children and adults like them, to how he presented his way of understanding what was necessary in raising any child. Hannes was John's second child so he had already experienced first-hand the routines of

examinations of a newborn. He also told and showed how he ‘checked out that everything was working’ by picking up, inspecting, counting limbs, fingers and toes which was delivered in a humorous tone but also to demonstrate his very hands-on approach to becoming a parent. He said this manner he had adopted was especially important with a child who you may suspect could exhibit developmental difficulties later on. These could be as John says, ‘neural’ as sensory or ‘affecting animate nerve organs’, something the child was born with related to not hearing. Another instance John provided was that due to the consequence of ‘simply’ not hearing, development can be affected by a child missing out on linguistic input and falling behind because of that, a gradually acquired consequence of a disability through language deprivation which can be avoided or lessened.

John: [It's because of] my gran and mother and the way they've brought up kids. They've always said, unless you've got a child's attention, then you may as well speak to a brick wall. Even with [my first child] she was ahead of her age in all her speech as well. It was because I never speak to the back of a child's head. The child looks at me. I'll say 'Look at me and then we'll have a discussion'. And if half way through, their eyes wonder, I'll stop the sentence and we'll start it from the start when I get their attention back. And I've always done that. And Hannes, probably because he couldn't hear so well he was, even from a baby, very focused on the face which made it even easier for him! So, teaching him has been a dream! So, and [also] I speak clearly.

This was the first time in John’s interview where he makes reference to the strength of his son’s visual ability. An interpretation of this is that he discovered that his child fit his fostering style because of what he knew about disabilities. This lived quality of knowing about disabilities results in a habit-like way of relating to the needs of another developing person. What is different in this situation is that John talks about how attention, regardless of ability, is vital for communicating. It isn’t special or adjusted for a child with a disability. Rather, it is just more obvious to John that this is the case for all children. The way he treats his son with a disability is not different from how he had treated his daughter but he did point out the child’s inclination towards a visual modality as an ability.

## **Signing and auditory verbal therapy (AVT)**

John chooses parts of the two communication orientations with which he sees possible benefit. He approaches it as a set of tools and is less affected by the ideological tensions that exist. John is not willing to eliminate any of the tools on the table, an outlook he shares with many other parents in the study. The difference lies in how he portrays using both in order to combine them in just the right way for his child. This is an example of being

pragmatic in the sense that there is no need for him to take a position for or against a communication orientation. John is concerned with how to make sign language and AVT work together at the right times in language development based on what he knows to be at risk.

John: And he goes both ways [uses both signed and spoken words] because when they are younger, when they first get the CI and stuff like that. I think it's very, very important to concentrate on the speech. Concentrate on the speech in a way that you at least sit down and you take time to really concentrate on pronunciation like um what was it called? [beats table, sighs]

Liz: AVT?

John: Yeah, the AVT. That should be done with all of them like that because they need that. Because just like in speech taking over [as they grow older] sign language would take over first because it is a lot easier for a kid to have motor skills for sign than to speak. So I think you've got to be careful. I think you've got to play that knife-edge balancing game of making certain speech is coming along. But also make certain sign is there and what we did is we signed and spoke at the same time. So for Hannes because he can hear it's a lot easier. He gets both the sign and the verbal as well. So that's how we've done it.

'That knife-edge balancing game' transcends the conflict in that the issue for the individual is in focus and not a right path in either direction. In a previous chapter, Anneli explained that in her view speaking is much easier than signing for children CI users in hearing families. Anneli's family felt that signing was where they needed the most help. Here John provides an example of the opposite where signing is seen as easiest so they need help with speech even though before his child's birth, John did not have any practical knowledge of sign language. He uses his experience on getting attention, eye-contact with children before talking to them and direct visual messages being easier to comprehend for children as an indication that this is the case. This presents the idea that signing is easier for children in general so you must be cautious. This is an example of where dis/ability literacy is exhibited in a display of heightened awareness of risk because you cannot know in advance which child will need extra support. The risk is that speech won't come along so added effort and cautiousness are necessary. This shows that a parent's previous knowledge of what may go wrong can be the prominent interpretation and not the professional expertise of potential problems. Signing was already being used with Hannes and since he is a child like any other child in this sense they were secure with that. Hearing was new for him so the need to work hard at it is because of the way John understood his son's disability as seen through the light of other children's disability, namely his siblings.

A significant point to note here is that John exhibits a heightened awareness by stressing that you need to be observant to indications of problems a child

may have. This expression of dis/ability literacy comes in the form of reminders like ‘You’ve got to be careful’ and ‘Make sure speech is coming along’. The reason for caution in John’s case is to be prepared for the onset of development delay, not that there would be any type of linguistic interference between languages or modalities. He simply knows a great deal from experience about what may be a possible risk associated with hearing problems, the co-occurrence of other disabilities and that catching other possible problems is important.

### Tolerance of ‘illiteracy’

What can be said of John in particular, which is likely because of his dis/ability literacy is that he has found a way to manage his own intolerance of ‘illiteracy’ in other parents and personnel. This came up jokingly a number of times but points to how John understood that people can’t be expected to know or behave without the knowledge and experience. He compared other parents’ inability to navigate between two communication ideals to his own difficulties learning to sign. For instance, adjusting to how close you should stand, how you touch others and how you have to constantly keep your gaze on another person’s face and body were difficult skills. It went against John’s learned behavior. He understood that all parents have learned behavior like this which makes it hard to master new skills. This is a detail which clearly differs from most of the material. John felt that he was able to be tolerant of others’ illiteracy because he knew his experiences were exceptional as well as knowing that new skills require practice. He related practical skills to attitudinal skills. This was mentioned and demonstrated in how he dealt with professionals in disability services. If they gave advice he didn’t agree with he was respectful and thanked them for their opinion even if he saw them as lacking in expertise. On the other hand he readily admitted having to exert effort to be patient with them and had to adjust to being in a parent advocate role. He saw this as a small drawback of knowing as much as he did and related it to his ‘being on the side of the disabled.’

### Starting points in dis/ability literacy development

There is a difference in dis/ability literacy development related to what point in life it begins and what aspects of disability have been experienced. This could have to do with childhood experiences, current profession or any other life experience. Parents who from the start know about disability as a positive aspect of identity will have a different starting point. John exhibits this when he places emphasis on being proud of what he knows. A large part

of his identity, how he does not resemble other parents, has to do with knowledge about disability. John feels that his family environment taught him to help others, that it is a natural response and does not feel strange or intimidating to him. He also knew previously that being part of a deaf community is for many of those members a vital source of identity. This can be related to parts of the material where taking pride in difference can also be seen in how the parents who had contact with sign language before they had children tended to be very positive to learning and using signing for whatever reason. An interpretation is that when parents know that dis/ability is a positive aspect of people's identities, these types of parenting beginnings enable them to see multiple openings and make them more apt to change than others' re-orientation to sensorial differentness.

## Bypassing antagonism by being pragmatic

During the interview John and I were discussing languages and that he was observing how well Hannes, his CI using child, was developing his use of Swedish, Swedish Sign Language and English. He explained that he patiently listened to the professionals' advice which was to concentrate on one spoken language only, Swedish in this case. He could understand why they would advise that but had his own experience and ideas of what to expect of a child and what you could teach them. He described it as being opposed to what the professionals thought he was hoping for, a normal bilingual development in his child. He was also opposed to their own 'expecting him to jump through hoops right away' to establish a strong base in verbal communication. John appears to demonstrate an attitude that language learning is a lifelong process.

John: So, and because of working with the disabled when I was younger you see the signs, what they are. So I was fairly certain there wasn't any major ones that I knew of like I know there is no such thing as mainstream [commonly occurring disabilities] but you know the ones you see more, types. It's all the neural ones you can't see until they got older and stuff like that though. So I was a little bit worried about that. So.

Liz: Ok. Then we know what happened basically. He got his CI.

John: Yeah.

Liz: And then, you know right now I'm interested in choices about language, schools, preschools and I know you have experience with preschools and meeting professionals about language, multilingualism, and those types of things.

John: Yeah

Liz: Can you give me your thoughts on that?

John: Yeah. Let me think. Um. Well language wise I just ignored what the professionals said and went with my own, uh my own thing anyway. Cause

they were all telling me that um that we should be lucky if he learned one language.

Liz: Really? [John shakes his head] Did you shake your head at them like that?

John: I went ‘Yeah good view, I appreciate your opinion but I am not listening to it.’ So they found out very early that both [wife’s name] and I are very opinionated... and we will listen to them and *consider* what they say but we won’t necessarily run with it. Um so I said to them I said ‘That’s fair enough’ I said. They were looking for him to jump through hoops straight away and I went ‘No. He’s got his whole life to learn language.’ And at that stage we weren’t quite certain how deep it was all gonna go and how much everything was gonna help and whether the CI was going to be a massive change or what it was. And I said ‘He’ll learn both languages [English and Swedish]. End of it. End of story. I said ‘Because he *is* Scottish and he *is* Swedish.’ So I said ‘He will be learning both languages.’ Um so I ‘Really, thank you for your opinion and your input but *no*.’ We’ve proved them wrong.

Liz: Definitely.

John: So he’s, he was tested. The last couple of tests he was tested [...] He’s age group equivalent in *two* languages. Which he shouldn’t even be able, according to his, historically speaking, with his level of hearing loss, he shouldn’t be able to test age appropriate *yet* in one language.

A perspective on learning language throughout life can be seen as a way for John to balance the intense focus of early intervention strategies on language learning that are the main concern of professionals in the habilitation center. Most importantly, John described himself as not likely to be intimidated by experts. He interpreted their recommendations as being isolated from the life span as a whole likely connected to his own experience of learning a second and third language as an adult. This is different from generally held ideas of knowing Swedish and thinking about the future in terms of language use and groups of belonging as involving only one national context. This shows that John has a lifelong understanding of using linguistic systems of communication that change with the child. John *expected* people to advise him to concentrate on one language for the reason of learning to read, succeeding in school and not falling behind. He assumed he had a different skill set than they did, that it made sense that they wouldn’t be able to advise him in this matter. They hadn’t lived with children with disabilities when they were children, while they were growing up or spent an equivalent amount of time in day to day living with people who were different developmentally and intellectually. Also John assumed most of the professionals he met advised families to focus on one language because of ideas about interference from foreign languages in the home on Swedish language acquisition.

John is exhibiting how he is prepared for his child to need time to show signs of developing. He is not the typical parent that the professionals are used to meeting who are thought to be more anxious about deviating patterns like

when a child starts to speak after receiving the implant. He has experience that displaces typical issues of what a parent would worry about (speech) with the possibilities of other neural problems. He believes he knows what to expect in bilingual language development due to his own experience in learning Swedish late in life and experiential knowledge of children developing at different rates when they have other challenges. This can be seen in how he handles the professional's expectations that he is already worried because their work involves advising worried parents. John is not only more relaxed about what to expect which is expressed with the viewpoint that Hannes has his whole life to learn languages, he understands why the professionals advise him as they do.

### Being pragmatic about modalities

John expresses an idea of balancing acquisition of sign language with developing speech as previously demonstrated. This is based on his understanding of an infant's body being more apt to signing than speech because of the different motor skills it takes to execute them. The way John demonstrates neutrality in preference of communication mode is simultaneously a demonstration of his focus on abilities of children. This is a pragmatic stance on communication and practices for children who may have a need to be met. He is aware that the visual-gestural based system of signing is easier than the verbal based system of spoken language for very small children and children with 'neural' disabilities (sensory, cognitive, and intellectual) who do not develop the fine motor skills for speech production. John incorporates his experiential knowledge of the difficulties of certain groups of people to speak with what one can expect from children of different ages, which is a manifestation of dis/ability literacy.

Relating this to the fieldwork, parents who sign with their children, including deaf parents, report how well their child does with verbal language and scoring high on the battery of tests given to map the progress in children who use cochlear implants. This is often in the form countering low expectations from health care and rehabilitative professionals in cases where more than one language are used in the home and when sign language is used alongside spoken language. As pointed out, there are warnings from professionals about not getting enough auditory stimulation if signing is used and have expectations that the rehabilitative advice to practice listening at every available opportunity is complied with. That both hearing and deaf parents in the ethnographic material chose not to comply fully with these guidelines and still achieve results is gratifying to them but more importantly become part of resisting what they see as falsely informing other families. Likewise, parents don't comply fully with the 'don't mix sign language with

spoken language' advice they receive from sign language teachers. A finding in the material as a whole is that parents are using alternatives, mixing therapies, and using their own judgment about how much time they spend on working towards goals of interventions and language practice. They also report feeling indirectly judged from the advice givers and from parents who argue strongly to do things in specific ways.

John doesn't need to distance himself from a spoken communication orientation idea that proposes that a child benefits the most from focusing solely on one language. The detached manner in which he related this to me is a sign of not having a need or wish to contest this advice. The dis/ability literacy John possesses disarms the antagonism that exists between a bimodal and a spoken communication orientation.

On both occasions I interviewed John he spoke about meeting a teenager who was a CI user and how he took the opportunity to ask him about school and learning foreign languages.

John: I asked him 'So how's your English?' He answered 'Pretty much like my friends', I play a lot of computer games. I would say it's my favorite subject.' And he said he took Spanish and French and wanted to learn German!

This is a way for John to relay his own beliefs and hopes about what is possible when it comes to language acquisition and people who use cochlear implants. This young man in his late teens said he was like his friends in this respect, that the gaming interest motivated the learning and use of English and he studied languages in school. This was John's way to dismiss that it was problematic, difficult or a reason to be cautious about expecting your CI using child to learn languages. He wasn't so much arguing for a bimodal approach as he was refuting the idea there should be a mono-linguistic norm for CI users. Meeting this individual who was nearing adulthood gave John an opportunity to imagine a future version of his own child.

We continued to discuss language and development, mainly his negative opinion of using a limited number of signs initially until the child learned to speak to then eliminate using signs altogether. There are a number of systems where signs are used to support speech. John said they recommended that this sign use be used less and less and then discontinued when the child starts speaking. His main point was to criticize the use of signs in signed speech or simultaneous communication where the signs are disconnected from the syntactic structure they are used with in a signed modality of language. This also is an expression of what is a good vs bad signing for kids who might have developmental challenges, teaching them a

small number of ‘signs not as language’ would be unnatural and confusing in John’s opinion. Again, John’s viewpoint exhibits ideas about natural language, not a therapeutic strategy, being more beneficial for any child and absolutely necessary if a child has the potential of developing disability in speech production. I interpret this idea about signing to be an example of languages as lifelong assets, not therapy connected to a technical device or a cultural affiliation with deaf people. John’s view emanates from the needs of a child as the child currently exists embedded in a lifelong language learner which is different than many parents’ reasoning characterized by a bimodal communication orientation.

John’s idea about language and communication was to be methodical and diligent because of having a goal for learning signing, like being able to use interpreters. His main experience centers on the practical uses he has discovered and his child’s strengths in communicating visually. That sign language learning is meant to be used with a potential group in the future was a point he stressed later in the interview when he described why they as parents were learning it and wanted to ‘keep it going’ for both their children’s sake to show how they thought it was important and a positive way to communicate.

John: Yes, we definitely want to keep it going [through sign language classes].

That John emphasized continuing to learn SSL as a part of what they want to do as role models for their children demonstrates ideas about being deaf or having a disability as a positive position. Knowing his behavior could benefit his child beyond immediate communication emerges in this way but again is embedded in a larger and longer perspective which resembles a bimodal communication orientation. Unique for John is that he repeatedly brings up the image of a child with influenceable disability.

John: [...] yes, kids can accept languages but they, you’ve got a child who is potentially going to have problems with learning anyway because of environment problems, hearing, everything around about [acoustics]. Why do them a disservice and teach them a form of signing they can’t use [with deaf sign language users and interpreters]?

Liz: Do people ask who is he going to use sign language with?

John: Not so much because he excels so much with (spoken) language. Sign we keep going for the future, if the CI breaks, the hearing aid breaks, pools, beaches, things like that, loud environments.

When discussing the versions of signing meant to be dropped early on and the fact that he is offering his children ‘poor signing’ examples as many hearing parents using sign language do, John realized he may be contradicting himself. This strengthens the point that John’s signing is not

only for communication but for exhibiting acceptance and pride by wanting to learn signing as a second language because it is interesting and useful to him. Setting a good example is more important than getting it right. Giving up his status position is required, an important part of becoming allied with the interests of a group his child could choose to belong to.

John continues to offer examples of benefits of signing with children but with children like his son in particular. He clarified this point by expressing how Hannes picks up on visual messages quicker and more directly and that this can be utilized. This was a way for John to express support for the idea of signing with children based on a comparison between how they process visual and verbal cues. By doing this he again conveys a positive attitude about visual ability.

John: It's also really cool so when you get his attention you don't have to scream like one of these parents who screams across the grocery store 'Get over here you!'

You get his attention. [Signs 'Come and stand here!'] And for some bizarre reason if you sign to him, it's a bit like when your mother uses your full name. You know there's problems. [laughs] But it's so funny. Whenever you sign at him, he stops and comes and does what you've asked him to do. And it's not like we've actually used it in an aggressive way. [...] I don't know. He doesn't have to process the sound to work out what you said. He gets it directly. He gets a direct command, because he knows 'that' means 'that'. [Signs 'Come and stand here' again] He doesn't have to go 'What did they just say?' or 'What was that, that flew by here?' He gets a direct visual cue, and he does it straight away. So it seems to be a more perceptible or, definitely for kids, because they get a direct command without any other influence. Because the visual command is a lot stronger than a verbal.

A visual message is just more naturally discernible by children, is John's point, not just children who are hard of hearing. What is beneficial for children in general is beneficial to children who use a CI. Signing is demonstrated to be a practical communication aid with all children.

A characteristic of dis/ability literacy is being able to have the idea that a person takes on an obligation and an entrusted responsibility to further other's ability. John expressed capitalizing on a childhood trait Hannes embodies which if nurtured could help him communicate better. What he thinks and acts on as a parent increases the child's ability. The same trait can go without being positively reinforced or valued. This natural ability when it is underutilized retreats to the background or may remain on the surface as a peculiarity. A message John repeats is that every ability a child does have needs to be recruited in the larger project of development when challenges in the form of impairment are made known. Among the parents in the material, this is a common sense idea on which early stages of a literacy in dis/ability

appear to be built upon that is most clearly recognizable in parents with a spoken communication orientation. They may be orientating around spoken language in all they do but point out strengths in their child's way of being visual and how these strengths can be maximized in hearing culture.

In a parent's bimodal communication orientation there is also an emphasis on valuing the visual modality because of how it makes environments accessible to deaf individuals. The rights to learn and use sign language and interpreters for social equity are centrally emphasized in its portrayal. This makes it a bit harder to see where personal obligation for an individual's or group's ability is discernible from society's responsibility for rights. A much more obvious dilemma can be found in the opposition to interpret deafness as disability in a bimodal orientation. This results in missing a social or relational understanding of disability since it is a pathological model of disability which deaf communities oppose. Fear of stigmatizing or being stigmatized perpetuates anxiousness about pointing out difference which ends up reproducing stigma. The strengths in acknowledging difference in ability status go unrecognized. The taken for granted able-bodied ideal is perpetuated by deaf culture ideals. John is very secure in his views and knowledge of disability and that what he does in regards to attitudes and practical accommodation makes a huge difference. This assuredness from literacy of a social situation makes it easy to discuss without feeling he will be stigmatized. On the contrary, he presents his skill set as an asset.

## Advocacy, activism and allyship

This type of entry to parenting transcends issues of communication in orientation to include broader aspects of life than how the parent and child will communicate. It includes how the child will live as a member of a group determined by a life condition of differentness. Parents have to negotiate and use the terms that exist in medical, technical, habilitative and educational contexts. They must have knowledge of the terms to navigate these realms and use them to manage advocating for their child in their parenting life. The parent as advocate is a closely related idea to becoming dis/ability literate. Being an advocate is a part of their developing dis/ability literacy but not all of it. The idea of allying with the group DHH involves an understanding of the group's position in social, cultural and political structures and a particular relinquishing of power in personal actions by the parent. This requires that a parent exhibits pride in who the child is *because of* not in spite of how the child differs from others.

Attainment of pride for many parents travels through advocacy for their own child as it intersects with others' struggles. In order to reach a high level of dis/ability literacy which is necessary for allyship of hearing parents, in this respect draws on confronting both the fear and the injustice of how society values able-bodiedness and health. Activism in many forms appears to link individual advocacy by extending it to a social literacy. I attended a lecture organized for parents of DHH children with additional disabilities. During the break one parent offered this narrative of their efforts in accessing resources for their child.

Parent: I figured out early on how I needed to be able to use legal language to access the resources which are intended to support my child who is deaf. If I didn't do this then it was apparent early on that we would most likely be denied what we were entitled to so we could support his learning more. I found a manual online that was written for the appraisal officers for the insurance authority. I gave it to a friend of mine who is a paralegal. Together we applied using the right wording and level of detail and have also helped other parents do the same. Now there are even Facebook groups on how to fill in these forms and other useful strategies. What is interesting is that if you don't know about this or maybe don't even speak Swedish you are at a huge disadvantage and it is the authority's obligation to apply for you. We have yet to hear about anyone who has been helped by them. It's a catch 22. If you need the help you have to [already] know that they are supposed to help you apply but you don't know that. You don't know that that is how it works. (Fieldwork protocol no. 26)

Firstly, this parent exhibits being aware of what type of actions would be required to counteract inequality. The excerpt offers three examples of activism by parents, all of which assume unequal societal structures; extending legal help to other parents, establishment of social media groups to assist and distribute examples of successful applications, and bringing to other parents' attention that the system disadvantages people they have personally met who do not get resources because they are unfamiliar with how Swedish authorities operate. When a parent takes steps like these where they assist another parent in a struggle to access resources they have made a step towards being what is called 'an agent of change' in regards to allying with non-privileged groups.

## The parent-as-ally position

John explains a complicated point about hearing parents of deaf children who see benefits of using signing. They are almost always beginners in sign language. They mix language modalities, spoken and signed due to their 'hearingness'. They use it to support speech especially in the initial stages after implantation. If the child does not hear or grasp the spoken message

used alone first on advice by the therapist, then a sign is added, a common practice described by many parents of CI users. I understand John's main objective of using signing to be to give his child positive feelings about knowing sign language. He says 'We will never be fluent but we try'. It is a project for a future potential belonging for his son in particular but also for his other child who he says loves learning it and picks it up very quickly.

John: If Hannes was deaf then there would be no question. He'd be going to a deaf school with all its sign language. End of story. Hannes is not deaf, but we don't want to do him the disservice as we've heard from a lot of people who are in their 20's 30's now, that we've spoken to, who are deaf or hearing impaired with stuff. They'd wished their parents had kept going because it was so much harder for them [as young adults] to learn when they decided [for themselves]. Now Hannes might decide to be a garbage truck driver. Who knows in the future? But he also might, because historically speaking a lot of people with hearing problems, end up going into the deaf side of things and working on that side of stuff. So if we keep it going for him at least he's got the option and it's just a matter of holding his options open. But we're never going to be fluent. We try.

John's background provided him with knowledge about future careers in working in areas related to hearing impairment or deaf culture. In a matter-of-fact manner John also acknowledges that there are different 'sides'. This recognition of a division between worlds is also an example of a neutral portrayal of the hearing and visual deaf cultures. 'Being fluent' is not a goal because it just isn't possible in John's view. A large part of his background knowledge about disability came from being involved in organizations for the disabled and supporting causes related to his family's situation. John is applying the same type of relationship model to his new parenting situation where he is supportive and open to the group but can't become a group member. This can be described as a parent-as-ally position, where John is relinquishing part of his hearing privilege where hearing is the norm.

John understands his son to be hearing impaired but with the possibility of choosing to become deaf. To 'become deaf' can be interpreted from this excerpt to be a sign language user and in this way to be a part of the deaf community. He also knows that adults for any number of reasons can choose to not use their hearing technology. John understands his role as a parent of a CI user is to keep options open, 'keeping the sign language going'. This is reminiscent of David in chapter six who has taken relatively few courses in signing but felt very strongly about choosing a school which would provide instruction in sign language.

An important aspect to consider in relation to dis/ability literacy is that John and his partner have consulted with young adults in the deaf community as

experts, serving as models of their future child. Being open to the opinions and wishes of individuals like their child is a way to positively acknowledge their experiences. These opinions from adults because of their ability status can be interpreted as how literates in dis/ability recognize and value other's adjacent literacies. In this way dis/ability literacy entails making connections with other groups based on disability as a source of identity.

This passage in the interview about a child's future choices brought John's ideas of be/longing together. Be/longing is demonstrated when a parent is in the position of choosing in the present to enable one's child to belong to a particular imaginary group set in the future. John categorizes his child as not deaf but possibly wanting to be deaf. What John as a parent is doing here is showing that he does not expect to become sign language fluent, but is a sign language supporter. With these statements he has shown that he sees value in seeking the advice of individuals, the people in their 20s and 30s who decided to learn and use sign language, who are like him in the respect that they embrace disability categories as positive. Also by juxtaposing a future in driving a garbage truck and going into the 'deaf side of things and working on that side of stuff', he states an acceptance of his child's possible belongings that he wishes to support. In both instances, the possible choice of profession and the possible 'side of things' are belonging categories for the child. John sums up a goal of his parenting to hold Hannes' options open by enabling the use of sign language through acts of allyship not his own proficiency.

Throughout the interviews, Eva, Ella, John, Mari, Mario, and Olivia were the parents who referred to or illustrated particular qualities of knowing about and having lived with people with disabilities. The fieldwork included countless judgments and attitudes expressed in spoken and written statements about respect for differences in ability, awareness of accommodation needs of care, ability in perspective switching with a child, and humility and curiosity towards people who were different. It is with this backdrop of ways of being in dis/ability that it became evident that these expressions emanate from coming to know about dis/ability through close personal relationships. As has been demonstrated, John especially exhibited a matter-of-fact acknowledgment of the hard work required to make environments accessible for people with physical and intellectual disabilities. Caring about another person's relative vulnerability and being attentive to accessibility was exhibited through what these parents said they were reprioritizing in encounters outside of their parenting. John's interview stood out from the other parents in the matter of already having adopted these types of attitudes and behaviors. Together these differences serve as a way to embark on exploring orientation as the development of dis/ability literacy in a parenting context.

I interpret John's transcendence of communication orientations to be linked to his aptitude in expressing and understanding issues about living with disabilities. This is not an interpretation of a third communication orientation but rather it is an attitude bypassing two alternatives that are in conflict. This attitude is based on personal values and beliefs about disability. It involves knowing that hearing impairment can be related to other problems, being attentive to developmental needs of the individual, that speech cannot be taken for granted because of the fine motor skills it requires for some people, difficulties in communication can be bypassed by knowing sign language and that disability can be a positive category of a person's self-identity. John clearly takes pride in what he knows and how he was raised. I refer to this collection of characteristics as dis/ability literacy because it is a form of an early socialization process leading to proficiency in disability 'culture'. John exhibited a way of being 'fluent' as well by readily showing his level of literacy by giving accounts about disability in his interview. The backslash in dis/ability denotes a fluid and complementary perspective in a duality where ability assumes, refers to and creates disability and vice versa. John was able to talk about how deaf and hard of hearing people are able to do things that he can't. He spoke straightforwardly about hardships as well. He realized that even though they will never be fluent in sign language they can support another person's ability to use signing and value it as a lifelong language resource. Being capable of nurturing ability that does not build on personally possessing that ability is an ethic of care. This ethic appears to require a transitioning between viewing disability as a state to viewing disability as dynamic.

Utilizing a pragmatic facet of a language modality is an example of John's literacy in dis/ability. How language is viewed can be related to the stories about fishing and the sign language using community in Martha's Vineyard which was portrayed in the book *Everybody here spoke sign language* (Groce 1980, 10-19). A relatively large percentage of the people in the small community had hereditary deafness which led to the daily use of signing for all the inhabitants. When on the fishing boats out at sea, the use of signing was not only possible, it was much more practical. What came with the knowledge of sign language was the realization of its strengths over verbal communication in distance and wind in common working environments. This can be compared to a pragmatic approach to the use of languages that John exemplifies. In his sociocultural context and with his past personal experience, he can see strength in using the visual mode because that is what comes naturally to children and is also a way to know if a child is taking in a message. This is an alternative idea to what is valued and reiterate in the two communication orientations which transcends them, emanating from a knowledge of disability.

When summarizing John's case there is a level of progression that he seems to have reached which was not detectable in material from other parent accounts in the study. All the parents besides John are in a process of coming to understand that does not take its point of departure from previous life experiences of disability. He knows this because he has lived with, worked with and met many others with disabilities, in fact this is what constitutes 'normal life' which is how John differs from others. John knows he is in a special category which contributes to how he understands that other parents have to learn and come to terms on their own. Perhaps this is part of this particular specialized literacy, having tried on numerous occasions throughout life to tell others about his experiences and not be understood. Perhaps even trying to educate or enlighten others about disability and often failing especially when others are corrected about misconceptions and their prejudices are pointed out results in a deeper understanding about the dynamics of perspective-changing.

Another parent in the material, Ella, offers a type of snapshot in a social literacy developing process. She expressed being sad that she knew she couldn't come out and tell another parent what to do. She expressed it as seeing the other parent suffer by spending time in a group of parents with children with 'no other problems'. Ella viewed this as the parent hindering her child's development by clinging onto the hope that her child wasn't disabled. Actually this may be showing us the ethical dilemma Ella and other parents in the material can be faced with. If she were to point out a sign of an additional disability this parent would undoubtedly be affected, and may react or misunderstand in a negative way. By not saying anything, the child and family will continue to be in a harmful situation where both the parent and child internalize negative attitudes towards themselves for not measuring up to unrealistic standards of ability. In addition, there is perceived harm in not addressing development problems early.

John and Ella acknowledge that other parents cannot be expected to know or to understand when they aren't ready. However erroneous a 'literate' parent views others' decisions to be, they know you can't *make* someone literate. The question then is what makes a parent able or willing to want to develop in this way? Is there an important milestone of preparedness to identify in order to best serve parents in their new parenting reality? This is one task that could be carried out by reviewing characteristics exhibited by John and the other parents in the material when they demonstrate commitment to others like their child.

A dis/ability literate person would seldom argue for a 'right path' with other parents. This type of knowledge includes awareness of tensions and strategies at work in a group with mixed levels of experience. Taking sides

or defending a standpoint is possible but not a priority. The priority is to the needs of the disadvantaged group. Perhaps reflecting on past experiences and how they came to know what they do serves to identify specific examples in dealings with others when they learned a skill, like when John learned to get a child's attention and visual focus before speaking to them. Or when Ella was told by a parent that her child's ability to communicate in play with a favorite friend showed where they should direct their efforts. Ella then shared this information as an example of when she decided to focus on which forms of play and which friends were her child's favorite, which showed her a way to practicalize a schooling placement.

Skill development detectable in accounts like Ella's are learned aspects of circumstances of living with a person's disability as a parent. John, having grown up immersed in disability as part of his family life can't as easily describe a particular moment. Ella, on the other, hand remembers distinct revelations when she met other parents with deaf children for the first time. She re-oriented her previous goal of getting 'objective information' to finding children her child could play with and be understood through signing. Although John has more experience recognizable as dis/ability literacy, his level of preparedness to take in what others know can be recognized in his meeting members of the deaf community, especially with a certain sign language teacher. This educator shared what it was like to grow up in a hearing family and her personal portrayal had a great impact on John, likely because he had already reached a level of preparedness. He did not need to 'unlearn' regarding disability which impacts how he was being open or receptive. He was less worried in one sense about disability in general because of his skills. Much of the type of concern about disability signifying strangeness and tragedy can be an indicator of undeveloped literacy.

Dis/ability literacy appears to disarm antagonism between opposing communication orientations. Part of knowing you have to let people learn at their own pace is not expecting others to understand the decisions you make regarding your own child. It was evident in the material that parents certainly avoided these types of confrontations with other parents of DHH children. Actually they generally appear to develop ways of finding out 'what type of parent' others are in regard to the question of communication. When a literacy in dis/ability is developed parents become less guarded when conflicting views come up and categorize other parents differently. Instead of 'spoken' or 'bimodal' in orientation or approach, dis/ability literate parents exhibit an overarching quality, and identify others in terms of their understanding about disability.

## Dis/ability literacy and allyship

Washington and Evans have examined the process of becoming an ally from a psycho-social theoretical perspective (1991 pp. 195-240). They define ally as “a person who is a member of the ‘dominant’ or ‘majority’ group, and are often more powerful when the supporter is not a member of the oppressed population” (Washington & Evans, 1991 p. 195). The levels in development in this model are ascending from awareness, knowledge/education, skills and ultimately in action. The concept of being an ally, coming from a social justice perspective in education, includes focus on examining attitude change with the goal of working towards standards of equality, particularly through cultivating coalitions (Adams & Bell, L.A. & Griffin, P., 2007 p. 14; Ayers, Quinn, & Stovall, 2009 p. xiv).

When attitude change is in focus in allyship work it can be concluded that an understanding for how meaning is constructed in sociocultural contexts is based on individuals' experiences. The question of which parent encounters with others benefit allyship development can be illuminated by examining the process of change these parents of cochlear implant users undergo. A closer examination of social justice issues with research in everyday life engaging deafness and disability show an opening to interpret the findings thus far as illustrations of how parenting is involved in more encompassing social change. For instance, in *New forms of transformative education: Pedagogy for the privileged*, education in social justice can be seen to have three pillars: equity, activism and social literacy (Curry-Stevens, 2007). A social literacy brings to mind the development of skills in awareness of one's own identity and how it is connected with others in structural power relations. Some have come to identify trends in teaching and developing these skills as pedagogy for the privileged or pedagogy of the oppressor (Curry-Stevens, 2007; Kimmel & Sykley, 2010). In both cases there is a goal to educate which relies on processes of moral development in individuals.

Through reviewing literature specifically on being a disability ally and how it has been studied works also to identify what has yet to be investigated in respect to parenting and the process of transformation involved in parallel processes of advocating, activism and allyship in the lives of parents. Reviewing research about disability concepts and becoming an ally show that actions, awareness and accurate learning led to people becoming allies in disability (Evans, Assadi, & Herriott, 2005p. 72). Ways to be supportive to disabled people were identified through actions such as being helpful and encouraging, and these actions increase people's awareness and accurate learning about disability which also results in dispelling misconceptions about having a condition or impairment. Literacy of social situations is seen

to be accomplished through cognitively linking different forms of oppression, such as racism, ableism and autism to the ideas upon which they rest with the oppression under which different lives are put at risk when excluded from participating in society. Evans, Assadi and Herriott also write of “living in accordance with belief” which they call direct action (Evans, Assadi, & Herriott, 2005 pp. 75-77).

Relevant for the analysis of this study is that there are positive and negative reactions involved in a process of developing allyship when parents advocate for their children and the group they belong to. For instance, what John has accomplished through the help of his family is to have made his way through what can be a painful part of the process of becoming an ally. This has to do with an individual’s own identity development in relation to disability and being in a dominant position as able-bodied. John knew about the attitudes towards disability because of how he has lived and reflected on what others have said about members of the groups his siblings belonged to. This is important in understanding how John seems to transcend conflicts, which is arguably related to how he has processed the anger towards others and the attitudes they hold over a long period of time together with others who understand him. Also John did not have to acknowledge feelings of guilt and shame to the same extent as others concerning belonging to the dominant group and having a child with a disability. These emotions are usually associated with being passive or not actively supportive of the oppressed or stigmatized group resulting in worsening conditions for people with disabilities or in a minority group position. This is in addition to guilt people usually feel for being members of groups who hold negative views. Also John is well aware that his life has been easier in comparison to his siblings and continues to be because of the position he holds as a dominant group member. In this ally development framework, acknowledging privilege is a conscious act at which most adults must put forth great effort. John seems to have internalized values of justice related to differentness in ability.

## Qualities of dis/ability literacy through parenting

The following collection of qualities has been compiled from examining the empirical material combined with following a social justice education framework on privilege studies, social literacies and allyship (Adams & Bell, L.A. & Griffin, P., 2007; DiAngelo, 2012; Evans & Wall, 1991; Evans, Assadi, & Herriott, 2005; Kimmel & Ferber, 2014; Ong-Dean, 2009; Sensoy & DiAngelo, 2012). Specific for this analysis is that it departs from the intersection between deaf and disability issues in parenting. For the sake of brevity this chapter concludes with a collection of descriptive qualities in a literacy of dis/ability of parents in contexts of sensorial differentness. These qualities were compiled based on characteristics described in this chapter together with the ethnographic work in its entirety through participant observation. The resulting descriptions of characteristics were first put into thematic categories. Each heading in this list is a particular quality which also represents one of those categories.

- Practical action and a social model of disability including awareness of disability being a product of the environment
- Awareness of inequalities and necessity of advocacy
- Pragmatic approach to communication based on what works for the child
- Parenting over time can increase literacy
- Personal commitment through intimate relations to child leads to other longer term relationships to others in similar contexts (sharing in sign language learning or alternative communication models in groups)
- Personal engagement in authentic relations with members of the target group of DHH
- Knowledge seeking and according adjustment in behavior
- Literacy based knowledge sharing at levels that others can handle
- Identity and pride in associating with disability groups
- Deaf culture knowledge and engagement in deaf community

These qualities are modeled on other compilations and checklists of privilege awareness, ally characteristics and social literacy development (McIntosh 1988; Evans, Assadi, & Herriott, 2005; Adams, Bell and Griffin 2007). In addition to the above and based on literature in privilege studies (Kimmel & Sykley 2010; Kimmel & Ferber2014) an allyship with deaf and hard of hearing groups would also include additional awareness of how privilege operates in universal systems involving dominance and subordination. These include acknowledgement that all people are privileged in relation to some aspect of identity and location and that identities are

intersecting in this regard as well. As one progresses through life from early childhood, school age and through adult phases of life, privileges are also affected (Kimmel & Ferber, 2014 p. 36). That parenting in differentness encompasses relationships with children throughout the lifespan is a significant aspect of becoming and orientation.



# Chapter 10 Uncertainty in lived parenting

## Introduction

This discussion chapter serves two purposes. The first is to provide the summarizing analyses of the empirical results as it pertains to the becoming process of parents of children who use cochlear implants in the study. This results in the general summarizing interpretation through the presentation of the subject of *parental uncertainty* at the beginning of the section “Aspects of parental uncertainty”. The second purpose is to explore aspects of parental uncertainty by discussing it with previous research. A central example of how I do this is in the idea of a pedagogy of the ‘not yet’ borrowing from Ahmed as a description used to describe embodied differentness in this certain process of parenting (2006a). This description of lived parenting as something incomplete and ongoing emphasizes the potential in the becoming process of parents as it relates to uncertainty and struggle.

## Rupture and material affectivity

As is shown in Chapter 5, an encounter with the choice of colors of a child’s hearing aids illustrates the overwhelming uncertainty associated with becoming a parent of a child with a cochlear implant. The *rupture*, described as *material* and *affective*, revealed how two parents experienced their new world. Two main aspects beginning in their new parenting were explored. The first is the loss of earlier taken-for-granted ways of being a parent based on what they had known before and expected in relation to parenting. The second aspect was the blurring of the boundaries between the child and the technological device that the parents come to learn would be necessary for their child to be able to communicate with other hearing people. This blurring involves a basic existential circumstance of sense use which emanated from the disappearance of the taken-for-granted view of how their child would live, relying on technology involving a particular dependency on institutions. At the core of these accounts were the contemplations of what a human being is with disability, with technology and how such a human being with technology is viewed by society. This theme of human/technology hybridity represents how understandings about technological advancements and use of technology in the future are largely

unknown. Hybrid is a useful term to follow in how uncertainty continues to be explored. As a mix between two entities that shape the parents' new reality, the human feature and the technological object illustrate a crossing between ways of feeling and acting. In the same way as the implant becomes a part of the child, so can we think of how it becomes a part of the parent who will exist in uncertainty in the ways they become entangled in both the social practices of cochlear implantation and their contemplation of how they and their child will exist together.

### Apprehending, practicalizing and narrativizing

In order to address issues of uncertainty in Chapter 6, an initial reorientation is described through instances of *apprehending*, *practicalizing*, *narrativizing*, and their *consolidation*. Experiences involving the child are both bodily observable and conceptually ungraspable. A description of how parents contemplate senses leads to a description of how parents understand disability in their lives. They were trying to grasp an unexpected situation at the same time as they were practically engaged in parenting. This gives these parents a new orientation point which was reflected in how parents narrativize their experiences. This technique of the telling of lives reorganizes instances of what they had experienced, in order to become orientated and achieve a cohesive story. Narrativizing also involves a special kind of relation to uncertainty in that they had to produce the telling of an account with an experience they could present that made sense to them and to others. In essence this reordering of events was necessary in order to do this type of parenting as was shown in the analysis. Their own experience of having been parented didn't serve as a model, nor did the normal parenting of others, as they understand it. Narrativizing was shown to be processual because their accounts moved back and forth between different themes. It was fruitful to use this subtle shift between apprehending and practicalizing to examine how this uncertainty in sensorial differentness became a way of how they exist.

### Be/longing and communication orientations

The issue which is the most prominent theme in the material as a whole is the one of language use together with technology use where the visual-gestural modality is in tension with spoken communication. In Chapter 7, communication choices and environments are shown to be crucial for future life conditions and interpersonal relations. This can be seen in how they either report on the conflict they happen upon, or show concern or doubt as to what is feasible in their hearing world for the child. How much they

should accommodate the child becomes a question of how much of their previous life they should abandon. The analysis indicates that once decisions have been made about how a child will be taught to communicate, the parent remains in uncertainty in regards to both past and future actions about the child's needs, the family's needs and the parent's own needs.

*Be/longing*, longing for a future for the child involves ambivalence in that it involves balancing what is considered positive for the child and what is desirable for the parent. Directed towards the future, orientation through be/longing has a direction in time at the same time as it is a way for the parent to be anchored in the present. A communication orientation develops in the family in contact with experts with goals of utilizing sound for a future. The combination of present and future is what demonstrates a way to exist as a parent who is be/longing. The enactment of a communication orientation, spoken or bimodal, illustrates this. The perception of one's own needs with the perceived needs of the child is partially formed by others and changes as the parents come into contact with experiential knowledge alongside expert knowledge in different networks.

In the context of sensorial differentness, parents are provided with suggestions, answers and solutions from many institutional sources. Where difference is suggested to impede a good life, advice and plans are provided at every turn, communicating shared socio-cultural values and beliefs, perhaps with different emphases depending on the practices each expert is situated in. What was found was that parents remained to be in a state of be/longing even though they had practicalized the situation. This came through as concern about friends, what the child heard and missed in school, how well the technology actually worked outside the home and what all this meant for the child's development and social possibilities in the future. Parents were also consistently presented and confronted with others' answers to questions that had barely begun to solidify as concrete problems in their own lives. Each time that a problem materialized, from within the parent or from outside, a reorientation was needed. The overall impression is one of recurring concern and how the present situation the child is in will impact the future. Parental be/longing involves the child's identity and belonging as well as their own. The kind of parent they are seen to be by other parents appears to be an expression of the conflict between language and modality approaches. Specifying what type of communication orientation a parent develops can be understood as a type of process best understood as an expression of belonging interconnected with be/longing. This is more a way of understanding where they and their children belong in social relationships as a family first, and then in the future when the child becomes independent and the time spent with the family lessens. Orientation of parents is extended through the communication modes which directs where they belong as

‘parents of’ in the intersecting networks they become a part of. In many senses the communication orientation serves as a stabilizing function in day to day practices.

## An alternative social understanding

In Chapter 8, social meaning-making in parenting a DHH child was shown to first focus on how the child’s speech will develop but then continues in what relations and constellations will be possible and in what types of environment. We have seen that the new social perspectives of the hearing parents derive from an *alternative understanding* from sharing reality with others. These others include hearing, hard of hearing and deaf parents of children who are hard of hearing, deaf or have language disabilities.

The netnographic study shows how extremely important online social interaction with parents in similar situations seems to be for these parents. They are compelled to try to find a valid reorientation in the uncertainty associated with the sensorial differentness. This was explained in the way parents used narrativizing techniques online. The feeling of being like others in certain ways increases at the same time as feelings of being different appear. They are also being made aware of problems yet to come or problems revisited. The polarized field is inhabited by the roles of professionals and lay people having or not having personal experiences of being deaf or having hearing impairment and remains perplexing for parents. In this way the two dominating social perspectives, spoken and bimodal, can be identified as constructing the polarized field and is made visible in how mixed groups of parents who are hearing, deaf and hard of hearing, discuss their concerns about communication and technology use when a child has a cochlear implant. These perspectives have ideological centers that advocate for language approaches which contradict each other. Taking one or the other perspective appears to be resisted and leads towards alternative understandings nuanced through lived situations blurring the division. The polarization creates a force which requires a decision between two possible choices in the way social institutions regard schools for deaf and hard of hearing children. A type of mutual dedication by parents to allow ‘not choosing’ comes through by focusing on what plays out in everyday situations. The polarization and the resistance to it appear to be constructed through a ‘once and for all’ impression about choice which makes little sense to individual families in their day to day lives. Also the mix of newcomers and parents of older children demonstrate realities of CI users. They exhibit their experiences of needing to be flexible, combining strategies which borrow from both perspectives to adapt to unique situations. Engaging in online support groups is a way of practicalizing the situation

through a shared alternative understanding. It makes clear what a communication orientation serves to alleviate: what to do about school, language and communication and what it cannot do, which is to provide certainty about their child's future.

## Dis/ability literacy

An interpretation of the descriptions in the empirical chapters is presented as a collection of qualities of a social literacy in dis/ability. These include awareness, actions and commitment to goals of more inclusive and equal conditions for the child and others like the child. Engaging in deaf or hard of hearing communities provides opportunity for the development of certain characteristics which are necessary for interpersonal interaction. Often developing these social literacy qualities building on those characteristics is a way parents exhibited perspective-changing through 'unlearning' and can be summarized as being interested, concerned, obligated, aware of needs, and willing to accommodate. The motivation to do so lies in the betterment of social relations between individuals and groups in sensorial differentness, building on a care ethic.

In Chapter 9 there seems to be a way of embracing uncertainty through becoming literate in dis/ability. John finds temporary trust in solutions found for the child which is combined with accepting that there are no guarantees aside from his own actions carried out in the present. He knows, through having lived with a basic type of uncertainty regarding how children with disabilities develop, that what they need along the way changes. He has a type of inbuilt map which means his disorientation started differently. He has learned through observing his own parents that there are things a parent can do when they anticipate problems a child may have in development. The 'may have' is the uncertainty regarding to what extent these potential problems may materialize.

An expression of dis/ability literacy in the material is characterized by being able to identify with others who have similar experiences in other types of differentness leading to insight about disability in their relationships. In John's case his experience with disabilities in childhood prepared him for being able to 'read' deafness in his child. In addition, this is how having experience in a type of differentness may bring realization to valuing experiential knowledge of other groups like one the parents' child belongs to. John showed this in how he spoke of what he learned from a person who grew up with deafness. A related manifestation of dis/ability literacy is found in how parents, worried about issues which are not common concerns of ordinary families, seek out experienced parents. Turning to others who

have similar experiences is based on a shared uncertainty which unites them. ‘Not knowing together’ with other families is combined with contact with adult lives in differentness, individuals who are deaf, hard of hearing or with disabilities. This combination of levels and kinds of social literacies comes together in a shared type of parenting. Interaction with hard of hearing and deaf lives together with ‘parents of’ lives constitutes the parents’ map towards literacy. This map appears to guide some parents into further engagement in the groups, undoubtedly leading to chances for them to reevaluate their ideas about others, their viewpoints, and thus developing their own literacy of differentness by examining inequalities which privilege them. In this way, direct engagement with deaf or hard of hearing adults serves as a substitute encounter with their future adult child. Seeking out guidance through these types of relationships is a necessary enactment of embracing uncertainty to reach social literacy.

Juxtaposed with the ethnographic study, the entire material can be seen to be circulating in these literacy potentials of uncertainty. When discussing how parents beside John could be seen to exhibit characteristics of dis/ability literacy, Ella’s thoughts about other parents illuminate a struggle of how to exist with others who make up the world around them situated in deaf and disability contexts. This was demonstrated through relaying how she was faced with a dilemma of whether or not to point out to another parent that their child needed more help than they would be able to access in a mainstream school setting. The tension was created in what was best for that child, what was best for that child’s parent, what Ella was willing to risk socially and what she wanted to disclose having a child with an additional disability in that particular setting. There were a number of similar examples presenting ethical dilemmas for parents in how to interact with other parents. It appears that dilemmas like this are unavoidable which means that there is ample opportunity for considering and developing a way to treat others which takes into consideration what they have lived through and what has not happened yet. Was it better to tell another parent what you knew, withhold information because you may cause harm or withhold because they wouldn’t be able to take it in anyway? Questions like these are morally complex for parents, which I interpret to be uncertainty shown through a struggle between negative notions about disability and a positive relationship through parental obligation to a child with a disability. Ella and other parents in the study embody affectively charged ideas. They simultaneously hold or recognize prejudices towards disabled people and have the new lived experience of disability they had gained since they had come into this new world. The way parents in the material expressed dilemmas like this illustrates the conceptual struggle in what to think and what to do. Instances in parenting where dis/ability literacy is being developed through these interactions shows a relationship of uncertainty related to moral life.

## Aspects of parental uncertainty

A study of lived parenting in differentness offers the possibility of understanding how diverse experiences of belonging are the fertile soil of embracing ways of being towards others that do not dehumanize or exclude. In different ways the parents in this study showed how they were confronted with new experiences which challenged their own ideas and others' about deafness and disability and how these ideas change. This led to an investigation of how and what parents learn from others, especially those parents who are in similar situations. An interpretation about this process where parents learn from 'like others', illuminates how this is not akin to instrumental learning where something can be mastered and achieved. Instead this parenting entails ongoingness; the process as developing literacy implies more accurately that ability to communicate and interact can be enhanced and has to be maintained. The combined understandings from this study of how parents make sense of their situation and are involved in social processes of learning provides an image of becoming literate in a social sense through practice and interaction.

Parenting in sensorial differentness for the individuals in the study begins intensely in the rupture of earlier taken-for-granted expectations of what it means to become a parent. Sensorial differentness characterizes their new "parentscape" and basic questions of where they and their children belong are actualized. Parents begin to struggle with how their need to be able to provide a good life for the family will be reconciled with constraints of normality when they no longer are considered an ordinary family. The way communication is viewed as both a problem and a possibility extends this new situation beyond the child and parent in the family to include the rest of society where they live their lives. Hearing parents of deaf children in this study become intertwined with early intervention and education practices which create the circumstances for future participation through language(s). This focus on language offers a way to see how groups in society who have unique experiences in reference to senses are like other groups who differ from their parents.

The empirical chapters offered summaries of experiences and descriptions of networks of parents of children who use cochlear implants. A general synthesis interpretation of this study is presented as a particular type of parenting in an everyday world. Stepping back from this collection of understandings of parents' lives from their points of view, as individuals and in groups, a picture painted with many layers of sense-making in everyday contexts appears. This is a picture of an exploration of the processes of parenting involving cochlear implant technology where becoming transpires

through contact and over time leading to new ways individuals inhabit the world. This type of pedagogical process can be described as a pedagogy of the ‘not yet’, the unfinished, where parents are being shaped. The ‘not-yet’ subject is directed and turning and the ‘not’ says more than what it qualifies (Ahmed, 2006b; Ahmed, 2012 p. 184). Ahmed has focused on the not-yet adult in families and following family lines. This dissertation does the same with the ‘not-yet’ involved in parenting and parenting involved in the ‘not-yet’ (Ahmed, 2006a pp. 556-557). In focus has been how these parents come to know and be through change. However, this social learning process does not end in complete knowledge but rather as a way of becoming which can increase and recede because of how it involves the minds and lives of others. Parents continue arriving as they continue ‘reading their child’.

As parents deal with practical issues, tests, treatment, health care encounters they develop an intra-personal orientation. The stream of advice from professionals, the conflict they discover, and the practices they become entangled in are additional problems which give opportunity to reconsider, defend and question. Realization of the societal structures impacting conditions for the group deaf and hard of hearing begins with advocating for one’s child as a patient. Conflict between dominating views and navigating the regulations in social services requires transcending outside forces and influences to some extent, as well as negotiating needs of family members. By dwelling in uncertainty, parents work to search for new ways of parenting that they feel suits their child and family in the present and for the future. Often parents showed how communication, language and identity actually play out in homes and lives. Here we were able to see examples of what actually happens in caring for a child who uses a CI which replaced the constant focus on “what you should do” coming from outside the home. Instead a different type of imperative, formed through lived experience, takes form in these close relationships which is perhaps easier to see when so many others appear to be invested in shaping the child or shaping environments. Parenting practices surrounded by power struggles show what actually happens and what is operating and departs from the ambition to take into account who the child is in all their social contexts. When parents found other families who share in this same type of differentness they were able to confirm their view of the world.

The parents of children who use cochlear implants are submerged in contradicting information, not lack of information. In the parent’s experience and relationship to their child this produces situations of feeling conflicted, on top of the initial disorientation of their new life circumstances. This can be described as a combination of two main forces. The first is being in a state of having to choose, choosing or having chosen who to listen to and what to go looking for in respect to care and communication with the hard of

hearing/deaf child. The second force is the cycle of disorientation and reorientation in differentness when there are hearing and deaf members in the family. These co-existing forces create possibilities of transformation through parent-child relationships. What needs discussing is how different types of uncertainty may be interacting in how advocacy, activism and allyship emerge in parenting practices when transcending a societal conflict. This becoming process in lived parenting can be seen as a process of acquiring a social literacy of dis/ability.

As long as a parent is engaged they are becoming. As long as the child evolves, so does the engaged parent. An appropriate term for parents who often speak of their experience as a journey is ‘arriving’. Becoming is a social and relational process of coming to know but remains unfinished. Past choices parents have made continue to impact their lives and their children’s lives and in this way the process of becoming has no end. This pedagogical idea can be summarized as always arriving while one continues to be engaged in the lives of others, either through one’s thoughts or through actions. In this sense, parenting can tell us something about social literacy development and vice versa. The uncertainty involved in orientation and becoming builds on close personal engagement, as does perspective-gaining in social literacy. The work in this project brings together these two processes, becoming parent and becoming literate, in how an intimate relationship and relationships in differentness, when they intersect, produce a pedagogy of the “not yet”.

The summarizing analysis from each chapter in the last section speaks to this phenomenon of becoming and “the unfinished” as *parental uncertainty*. This concept will serve as a canvas on which the parts of the interpretation will come together. It begins with themes of being overwhelmed in discovering deafness which changes the parents’ lives. Taken for granted ways of living are upended by the entrance of the realization that they cannot manage this situation alone. This adds the important dimension of the encounters with others in a shared reality. Becoming a parent of a child who uses a cochlear implant is a type of recurring disorientation on different levels. What disorientation adds to uncertainty concerns the aspect of direction in respect to feeling at home in the world. Ahmed describes this as a migrant orientation where an individual faces, in two directions, the lost ‘home’ and a place not yet ‘home’ (2006b p. 10). Uncertainty as a state and a response demands finding a direction to go in, either in thought, as in apprehending, or action as in practicalizing. This is how (re)orientation is related to uncertainty. How parents also come to realize that their own lives have changed in a permanent way is how the existential condition and the social situation are related in parental uncertainty. In this way it makes sense to see a process of becoming as resting in uncertainty as a way of learning to

“read” and bit by bit be able to do a new kind of parenting from the early years and into the child’s adulthood. Things will be different as time passes, as one acts and is enacted, as one moves from one point to another, a fundamental aspect of human existence. Parenting comprises an orientation towards something; the future for another person but also for oneself with that person as far as life is sustained for both. All this can be named *parental uncertainty*.

Uncertainty calls forth ideas about how to proceed or move forward where paths are unclear and the future is unpredictable. How parenting implies thinking about the future actualizes the changeability of the state of things through one’s own actions as well as being influenced by social circumstances and conditions. Simone de Beauvoir’s theory of the ambiguity of the self has been vital in my analysis in understanding how this aspect of subjectivity, where a person is both an acting subject and an acted upon object, illuminates parents’ relationality (1948). A related term to ambiguity is ambivalence which is Sarah LaChance Adams’ contribution to how parental subjectivity involves a particular ethical relationship to others through caring (2014). Ambivalence in experiencing uncertainty as a parent involves acknowledgement of how we exist in a type of a dilemma. In this sense, being uncertain is to experience a struggle between how much to give to a child for them to exist and how much to keep to continue existing as a recognizable self and nurturing adult. Important for what has been found in this dissertation is that attunement to this dilemma is what makes the parenting relationship possible. Parents direct themselves towards the child with questions. Are you alright, am I understanding you, am I fulfilling your needs? At the same time parents are addressing these questions to themselves. The questions to the other represent parental uncertainty on multiple levels of making sense of need, one’s own and the child’s. A question is the signpost of uncertainty. Here, for the parent, uncertainty is an involvement with change and adaptation to new circumstances. How ambivalence characterizes an individual parent’s involvement will help to explain this.

Overall, the theme of uncertainty as a synthesis of individual and social processes is describable with help of these understandings of ambiguity and ambivalence. Parents require and reach for conditions which support their situation of not being able to know what the future holds. This is a primary and often implicit need in parenting in disability contexts. Support for adapting to uncertainty about the child’s future is a desired response from others in choosing for the child in the present. What follows now is a discussion of different aspects of parental uncertainty.

## A fundamental dilemma

When parents relayed being expected to understand test results they also had to figure out to what extent they needed new knowledge about deafness. As parents, in being repeatedly informed by experts, the struggle to understand is what I began to link to uncertainty in a more far reaching respect, namely the impact of repeatedly being given advice. When testing situations become more routinized, there is room for doubting what the testing practices and medical solutions would mean in a longer perspective. This was an expression of managing uncertainty through having faith in the practices. Entrusting in this way made room for considering how to continue. The focus of a parent's efforts then turns to get ahead of the next problem they were either now able to anticipate or as a result of new discoveries. 'What more can I do or should I do?' This appeared to be a process parents were in which was cyclical and continuous: being given advice, taking advice, making decisions and getting space to consider the next step where the cycle begins rotating again. What others think about what the parent should do appeared to be much more pervasive than in ordinary parenting. The opinions from both experts and non-experts, add to the uncertainty in different ways, as Stuart Blume teaches us (2009). The question turned to what this type of experience was leading to when 'uncertainty by way of advice' on many levels has to be accepted. Blume explains an important point for understanding parental uncertainty in hearing parent/deaf child relationships. Based on his study of parental decision making in light of the development of cochlear implants, the ethicist's dilemma of balancing free choice against the best interests of the child was not problematic in practical terms for parents. Knowing what those best interests are, in the present and how they will change in the future, were expressed as a real challenge to some parents. This dilemma is difficult enough and even more so when put in relation to what another person actually wants (Blume, 2009 p. 153). This is the issue which involves the fundamental dilemma between 'should' and 'want' that lies at the center of parental uncertainty which involves decision making about another person's life. For a parent in differentness, negotiating choice is done in the light of uncertainty about needs and wishes of another person in the future. The diversity of options has to do with the countless ways a human being could reason as an individual parent about how the child should develop or could want to develop in social interaction in collectives. When a parent has no traditions of conduct to follow, which for a hearing parent of a deaf child is one of many examples, parenting in sensorial differentness presents a perpetual dilemma.

## Leaps of faith

To better understand experiences of uncertainty in everyday life of these parents in the study, a distinction made by Alaszewski & Coxon is important to raise, namely that one can adopt two basic approaches in managing uncertainty: one where risk is calculated and one which involves trust as an act or leap of faith (2009). In daily life, risk is described as broad, general and in the form of worry or concern. The strategies to manage this are inherently social. These involve social skills, judgments of others, heuristics like common sense and educated guesses, intuition and shared experiences. What this can tell us about the present study is that parental uncertainty leads to employing strategies which are not only social but multiple and contextually complex.

In managing uncertainty, parents turned to other sources, such as friends, neighbors, and most of all other parents who had contact with people who were deaf or hard of hearing. Alaszewski & Coxon call this an everyday life “low cost strategy” because it draws on resources in interpersonal relations and the individuals’ own feelings and intuitions addressing a perceived threat posed by uncertainty (2009). Institutions operate by managing risk through rationalization involving “high cost” strategies operating through formal risk approaches, i.e., analyses of costs and benefits, in an attempt to make uncertainty visible and measurable.

While formal risk analysis and management seeks to make uncertainty visible and measurable through cognitive rationality, trust renders uncertainty invisible through an act of faith. The structured approach to risk turns specific events into abstract numbers to measure probability. Trust in contrast is embedded in personal relations and communications, so that when individuals encounter abstract expert systems such as medicine they judge them in terms of the person who is the representative of that system (Alaszewski & Coxon, 2009 p. 204).

These two types of strategies demonstrate that uncertainty and risk are not synonymous and that there is little evidence of being able to manage worries or concerns through the use of formal risk management techniques (Alaszewski & Coxon, 2009 p. 206). This partially explains why parents feel uninformed and professionals express not wanting to add to their burden or cause feelings of guilt. Alaszewski & Coxon’s analysis of the two different strategies, the one addressing everyday life concerns and the other equipped to control certain aspects of the world can aid in revealing how the antagonism between communication approaches is constructed. In the journal *Health, Risk & Society*, Alaszewski writes in the editorial of this special issue *Uncertainty and Risk in Everyday Life* that approaches to

communicating health risk assumes that individuals review evidence in the same manner as experts do: with comparison, calculation and intentions to maximize benefits of medical care (2003). On the contrary, individuals tend to reject messages which do not accord with their own experiences. For example when told sign language will compromise a child's speaking and hearing ability in spoken language and subsequently their intelligence, they compare this information with their own experience of knowing that individuals and families use sign language successfully and for different reasons. Parents in the study were made aware of this discrepancy either through cumulative experience as they meet others in their situation or through the Internet when they started to do their own research. Also the life stories of deaf and hard of hearing individuals present a diametrically different view on sign language, namely that it safeguards against isolation and language deprivation. When parents are told they will *most likely* manage well with only verbal communication with their child they are already aware of the possibilities of different scenarios. In addition to this, parents in the study began to think about the quality of education and entered into discourse about learning problems associated with hearing impairment either due to school environment, limited resources or lack of training of educators.

The medical context that frames hearing and deafness exemplifies a lack of understanding of the mismatch of styles of communicating information, as well as the content parent advocates of patients want to communicate about. Alaszewski summarizes the mismatch in communicating health care messages by citing a study of drug campaigns in Australia (Alaszewski, 2003 p. 239; Duff, 2003). If communication from experts and authorities "is to have any effect it must take into account and be grounded in current perceptions and strategies" used by individuals. Mistrust between groups will be sustained if these two ways of thinking about risk are conflated and misunderstood. Scientific determination of risk does not take into consideration that individual parents are influenced by social contexts, how they view information and advice as relevant to their life situations reaching across the life span of their children, and how much they trust the source of information (Alaszewski, 2003 p. 238). Parental uncertainty requires a 'social management of risk'. Parents in the study are developing their knowledge about deafness outside of what professionals are willing to communicate about: the quality of life of a CI-user over time. In line with Brownlie and Howson, the current study's ethnographic and interpretive approach of the perspectives of the parents shows how relations which require trust are varied and interrelated (2005). Themes of trust, parental anxiety and risk must be understood in relation to parents' interpretations through interactions, and institutions situated in particular socio-political

contexts (Brownlie & Howson, 2005 p. 225). Parental uncertainty has qualities that are personal, relational and involved in organizational systems.

## Ontological (in)security and parents' moral thinking

Anthony Giddens provides a sociological analysis of the self and institutions of modern society. To begin in the situation of medical encounters we can *continue with Giddens' concept 'the sequestration of experience'* (Giddens, 1991 pp. 145-180). This is a theoretical explanation of how everyday experience of engaging in practices in societal institutions, and the knowledge ideals upon which they are built, produces relationships with actors loyal to their place in these institutions. The moral sequestration in institutions involves keeping apart experiences of existential or moral dilemmas from formalized social practices. It is described by Giddens to be characterized by reflexivity and disembedding mechanisms where expert systems are based on trust in strangers and their position in those systems. Together with later modernity's emphasis on the roles of institutions, social relations involving mutual trust and co-presence are lifted out of the contexts of interaction between individuals in encounters with institutions and the trust in abstract systems on which they build (Giddens, 1991 pp. 8-9).

In discussing the findings to understand uncertainty in the daily life of parents of CI users, Giddens work on the self and society can help explain their experiences. The concept of ontological security refers to a state of being human characterized by a sense of continuity in a life (Giddens, 1991 pp. 35-69). Each individual has a narrative of self-identity which provides them with a sense of continuity in their lives. Uncertainty would mean a lack of this sense or a split in continuity for the parent and is a 'dilemma of the self'. The following quote will help link an element of ontological security to parental uncertainty as such a dilemma. As Giddens notes "The expansion of internally referential systems [of institutions] reaches its outer limits; on a collective level and in day-to-day life moral/existential questions thrust themselves back to centre-stage" (1991 p. 208). With this he means that the sequestration of experience is a sequestration of morality in institutions where individuals are often faced with issues of their own and others' existence. When individuals concern themselves with moral issues – madness, sexuality, death, nature, responsibility and so on – that challenges us to find an existential anchor and a sense of human relatedness to inform our being in the world. This is what Giddens means is 'the remoralizing of social life'. Moral and existential issues threaten ontological security. Parents' accounts in this study are an example of a demand for a renewed sensitivity to questions that the institutions of modernity systematically dissolve. When parents in the study engage in this remoralizing they engage

themselves in a struggle because of a dilemma or a fateful moment. It involves a struggle, a level of intimacy, a long term commitment or some type of agency demanding a moral decision (Giddens, 1991 pp. 142-143). Remoralizing further illuminates the role of parental uncertainty in experiences in everyday life in this material. This is how parents advocate and act in the interest of others which began with their child but commonly is extended to other children's needs. Parents, in this way, showed how they often can check one or all of these remoralizing boxes. Existential issues are actualized in their everyday lives. These issues appear and disappear with contemplation connected to sensorial differentness through apprehending and practicalizing. Most clearly these ideas come through in criticism of the medicalization of how to best give a deaf child the means by which to be socially included.

Giddens holds that doubt is pervasive when the individual and the social come together in everyday life. When apprehending and practicalizing, a parent is intently focused on the present but becomes intertwined with how the future is drawn into their contemplation through concerns about social implications. The social of belonging, is viewed through the individual child by the parent. In these moments, thoughts about existence enter. If we see apprehending and practicalizing as a type of dialectical interplay it would be here where "the body is becoming a phenomenon of choices and options" (Giddens, 1991 p. 8). When parents meet the abstract systems and the sequestration of experience they become existentially isolated and separated from moral resources. The lack of ontological security would then be a starting point for their parenting in a type of struggle. More concretely these are dilemmas to be resolved which involve maintaining continuity of self, i.e., of who the parent is. Nearly all the parents in the study exhibit how they make a 'leap of faith' in accepting quite readily what the medical professionals recommended for their child as an individual. Once this leap was taken they directed themselves to other things more related to the future and family life in social contexts. Parental uncertainty, especially where abstract systems dominate, is a manifestation of moral existential questions which the parents experience in daily life.

In my study it was shown that parents learned that they weren't being presented with a complete picture of what life with deafness could be. Often it was expressed as lack of objective information which overall can be interpreted to mean everything the institutional practices and logic of medical technology and health care do not address, among these being identity issues, accessible environments and how the two can be related. It is because of the resulting complexity involving human and non-human factors that antagonism exists between experts of biomedicine and the deaf community. There are "many ways to be deaf" which is evidenced by

research in linguistics, anthropology and sociology on the commonalities and differences in deaf communities and in the diverse ways in which they are in transition (Monaghan, 2003). The major theme of critique presented by parents in this regard was that while they experienced that everyone was well-meaning and regarded the medical expertise as very high, the advice they do receive tries to eliminate their concerns rather than address them. An avoidance of causing parents additional worry and or feelings of guilt was seen to result in neglecting to focus on their child's lifelong situation.

## Trust and uncertainty

In the sociology of trust in health care, the distinction between dependency and trust illuminates the situation of parents in this study and the nature of parental uncertainty. When parents find out their child is deaf beginning with hearing screenings in neonatal units in hospitals, they can be seen as exhibiting dependency upon medical advice in the earlier stages of the child's life as it contrasts with trust in professionals and practitioners over time. This is due partly to the message of time being crucial or that there is a risk of 'losing time' related to language stimulation as was demonstrated in the interview material. This neurological issue is a significant factor figuring in the controversy between communication strategies and modalities. Conveying the situation as a language *emergency*, delivered as an urgent message and a medical situation, underpins the parents' initial dependence in these settings. Meyer & Wand have shown that the more urgency there is to a situation the more likely an individual will feel dependent on doctors as opposed to trusting them, which usually involves either a long term relationship or a long term commitment (2013). This illustrates the complex relationship parents of CI users have to doctors and medical experts. They just had a child which in itself changed how they relate to the world so they are both dependent and involved in a long term relationship with biomedical and technological practices. A view of the coexistence of dependency and mistrust in medical encounters is offered in this study of parents.

There is a complex combination of risk, familiarity, relationality and time due to circumstances early on when deafness is detected through the hearing screening of infants. Parents in encounters with doctors feel dependent on them because of urgency to stimulate the hearing nerve. As they become more familiar with the medical team the levels of trust and control gradually change. Here the relationship with the clinic will continue for these parents over the course of the child's life until they reach adulthood. The accounts given by parents in this study indicate that there can be relations of trust alongside relations of dependency. The relationship to doctors and clinics builds up over time beginning in feelings of gratitude and include an

increasing level of familiarity. Alongside this bond, there is a growing mistrust of the doctor's biomedical and technological expertise when making knowledge claims in other areas, both scientific and lived. This annexation of how to live life as a deaf person becomes a contested area in regards to other aspects of children and adults living as deaf *and* hard of hearing, as a CI user does. Critiques of medicalization are involved in how initial dependency circumstances change but remain emotionally a part of who the parent and child have become involving matters of identity for the family. One parent's concern exemplifies this: "If I send him to a school with others like him, he might be influenced to stop using his CI." The question of why this isn't addressed as an ethical dilemma can be raised. The successful use of the CI, in medical terms, requires eliminating influences that would jeopardize CI use. Being with other (former) CI users is considered risky. This is a way to understand how trust and dependency are differentiated in specific, separate and parallel social relations of trust and mistrust in medical encounters, and demonstrates what we can learn about the role of uncertainty in the becoming process of parents of CI users.

Parents' relationships to the experts in clinics were shown to be a significant source of frustration. This parallels other relationships where they are immersed in rehabilitative and educational settings which contribute with additional sources of information. Parents become concerned with new issues and new, often opposing, expert advice. Additional relationship situations emerge in being privately connected with communities online with other parents and deaf and hard of hearing individuals and in real life activities in organizations directed towards their children. These parents offer examples of alternative ways of establishing trust. This involves affective qualities especially in the online support groups and social media sites in the study as well as in the mixed hearing/deaf communities of families. This returns us to how disorientation is related to finding one's footing through complex relations of intersubjective trust. In the study it appears that the more conflicting advice, the more opportunity there is to reflect on issues of morality and existence, summarized in the contradictory positions of 'passing as hearing' and 'pride'.

The extensiveness of interacting daily with a child provides ample opportunity to be reminded of uncertainty about the workings of technical devices for hearing. This is related to how parents were observed to use strategies like asking questions in forums ranging from a concern about the handling of technical practicalities to direct questions to users about what it is like to use and experience the devices. This is a heuristic technique where a parent comes to the conclusion that the person who would best be able to describe this would be a cochlear implant user. This strategy is broadened to include the other concerns besides the device use, namely, what the future

may hold for a deaf CI user. Social relationships are established through text online and through physical meetings which makes it possible for parents to access experiences of deaf and hard of hearing individuals.

When parents are engaged in relationships which change over time through the shifting of their levels of dependency on a medical clinic, some experience an intertwined problem. The medical practice includes evading other sources of knowledge by default by utilizing an ‘advancement of health care’ perspective. This institutional goal may even limit parents’ access to social and emotional support sources for strategies to manage uncertainty. When parents realize this divisiveness it adds a dimension of mistrust in regards to how the overall practice is experienced. Parents in the study experience an unease which they link to indirect messages that speaking with adults like one’s child would be negative. This may be a point of contention between views on best practice or it may be unintentional consequences of not encouraging contact with DHH adults. At any rate it sets in motion the process of a parent engaging in the ‘trust approach’ to socially manage uncertainty alongside a ‘risk approach’ in certain regards to their parenting a CI user. A balance of two types of approaches materializes in lived parenting. They turn outwards and away from experts and assumptions of certainty in expert knowledge because of a personal feeling that their child is indirectly devalued, which is a result of experiencing the animosity between people who hold different views of deafness.

### Reorientation: becoming in sensorial differentness

A parent of a CI user has sensorial contact with two ways their child exists. This makes them aware that they also have two ways of being: with and without technology. Understood in Sara Ahmed’s terms the path in front of these parents is mapped out in the practices of clinics. Being put on this path also often served to put out of reach how DHH adults live with deafness. It appears that the child’s body as well as the child’s visual way of being reminded parents that there were other ways they could engage in their practicalizing. The professionals were often understood to see these other ways, including signing, taking classes to learn to sign and spending time in activities where signing is used, as less popular, more complicated and too taxing for parents. For parents these paths are discernible but not always reachable. To apply the idea of orientation as taking one path and not the other would in this study be how the parents know that their own orientation away from something is also a way to become aware that it exists especially since they have a child who is both hearing and deaf throughout the day.

Other researchers of parents in cochlear implantation contexts have described how the medical context is separated from the deaf community context in the respect that hearing parents seldom have early contact with adults with hearing impairment. This appears to be due to the early decision-making about communication approaches before a family has understood their child's abilities and the options available (Blume, 2009; Christiansen & Leigh, 2002; Meadow-Orlans, Sass-Lehrer, & Mertens, 2003 p. 20). It can be argued that in a parenting position, the self-questioning of providing and advocating for a child provides access to ways to see other paths. The conflict between whether or not to take different paths is not completely from the outside in the form of societal structures but is how a parent exists in ambivalence in relation to a child (LaChance Adams, 2014). A parent has to constantly choose to continue to care for the other. In the situation of sensorial differentness, the maps provided by biotechnology do not mark out the surrounding territory of society which makes it difficult to orientate. This is a way to understand how parents begin to experience uncertainty. For many parents, as long as the map provides one path with a clear destination for the moment, then they will experience knowing where they are in this particular sense of what to do about communication. As parents become more familiar with their child they become aware of many issues that either were not presented to them or that they weren't able to fathom at the time. It appears that the parents early on have two images of their child: one is of the child as they are in the present and the other as an adult. This can be further understood as a parent holding two ideas about the child at once: the child as being and the child as project (Halldén, 1991). The developing deaf child isn't as easily conceivable but is revealed as time passes bringing with it questions about why they feel that they weren't informed objectively or were expected to ask about needs they never knew they would have. These sources of uncertainty enter in retrospect.

Parental uncertainty is not a solvable dilemma; rather it seems to be a necessity in a continual becoming with a child in the world where sensorial differentness emerges. One pattern that illustrates this is how often parents express wishing they had been given more information about living life as a DHH person which is a consistent theme over time for parents of DHH children (Marschark, 2007; Traci & Koester, 2003; Young, 2003; Young, Greally, & Nugent, 2003). It is possible that there is unprocessed advice which is not graspable early on in a parenting context. The dilemma lies in that parents are hoping to feel more certain through being informed which often results in the opposite. What is needed then is guidance in how to live in uncertainty.

Parenting in sensorial differentness provides an empirical foundation to see that when lines are followed, i.e. communication orientations, certain objects

and experiences, and not others are made available to parents and children. It is in this way sensorial differentness emerges for a parent of a child who is deaf. A phenomenological perspective of the lived body and of the lifeworld is a part of exploring a field of disability following other disability researchers who argue for this initial departure point (Campbell, 2009; Paterson & Hughes, 1999). Ahmed's use of phenomenological ideas in orientation tells us that social relations are embodied experiences (Ahmed, 2006b; Merleau-Ponty, 2002). Sensorial differentness, in this study, is centered on hearing and sight, and is encased in understandings of deafness as disability. The situations of becoming oriented, disoriented and reoriented utilize Merleau-Ponty and Ahmed's unifying idea of the body and experiences of disorder, being at a slant or angle (Ahmed, 2006b p. 4). "Orientations, then, are about the intimacy of bodies and their dwelling places" and "Bodies may become orientated in this responsiveness to the world around them, given this capacity to be affected" (Ahmed, 2006b pp. 8-9). Following Ahmed, uncertainty as it has been discussed thus far is due to social differences and is initiated through the body. Inhabiting space with others produces effects (2006b p. 4). When a parent has a child who is deaf, the effect comes from existing social differences. Beginning with how bodies dwell together, a parent's uncertainty can be described as a process of these effects.

How the individuals in the study become parents, in respect to how they see themselves, is a becoming process which draws on this understanding of one's own body. Phenomenologists focusing on practice claim that we must obtain the experience level of how phenomena are lived by exploring and collecting material that is experiential and pre-reflective (Van Manen, 2014). Here patterns are discernible in the parents' accounts and in the participant observation unveiling the uncertainty of how one exists as the mother or father with the child. Being able to hear was previously taken for granted but the experience of 'being hearing' emerges in their becoming through apprehending.

'Becoming hearing' involves realizing that there are different perspectives to being able to use the senses. Seeing deafness as a lack of something is a hearing perspective and coming into contact with deaf people who do not see deafness in this way, but rather as a their most defining trait in identity, is new for many parents. Bauman describes when he first came into contact with a school for the deaf and sign language and describes similar phenomena as they emerge in contact with deaf ways of existing (Bauman, 2015; Bauman, 2008). Ladd also describes how parents come to know about what it means to be hearing when coming into contact with Deaf culture and 'Deaf culture becoming' of individuals (Ladd, 2010). A cultural analysis of Deaf collectives includes how individuals come to understand themselves as

how they exist which is what Ladd calls Deafhood. The insights this can bring to how a parent becomes hearing are linked with what they similarly identify in the opposing direction, i.e., what they are not and how they differ from their child. Ladd developed the term in 1990 to begin to define a becoming process in existential terms to denote a state of Deaf ‘being-in-the-world’ (Ladd, 2010 p. xviii). This existential state is not definitive or static but processual where a Deaf individual actualizes their own Deaf identity through a collective together with other categories and circumstances. One of these circumstances for a becoming Deaf individual through a process of Deafhood is the parents’ becoming hearing process. If a parent realizes and considers how their identity shapes one possible perspective and that certain perspectives are privileged because they are more typical than others, their relationship to their children is impacted. The dialectical relationship between hearing parents and deaf children results in a becoming of both. Ladd’s ethnography of Deaf Culture teaches us how learning about one’s own (hearing) culture through meaningful contact with another (Deaf) culture is possible. Observations about the ‘other’ can offer double evidence of the party doing the observing. He would call this work an example of majority-cultural study in the Deaf-hearing interface (Ladd, 2010 p. 452).

A great deal of my focus has been to access how certain parents in the study have seen or sensed both the body of the child and the testing practices they have worked to consolidate. In following Ahmed’s way of employing phenomenological tools, an explanation of how going in and out of ways of being in sensorial differentness as a new experience is used to described the process of becoming. Here I am particularly considering parents’ accumulation of bodily “lived-through” experiences in understanding the ‘other’, these parents’ children. This arrival or ‘coming to be’ would center on sense-using by an infant who is deaf. The parent comes to know more about self and other through realizing things they did not incorporate in their perception earlier, e.g. ‘sense’ as reflected, as well as ‘the technology of testing on senses’ as reflected. The parents’ learning to ‘see’ senses is, to some extent, their own awareness through their body as it changes with the new use of their body to think about these things. Their body as hearing appears through the new cluster of meanings about senses. It is thematized, where previously it had been unreflected. This would mean that they become ‘hearing’ parents only when the child is not because that is when it first presents itself as a problem. The idea of hearing and not hearing comes out of the shadows, comes into view and changes how they exist (Ahmed, 2006; Ahmed, 2012 p. 127). The embodied experiences are taking the parent onto new paths. Ahmed by positing a queer phenomenology later writes that “Becoming confirms nonbeing through how it extends the very surface of being toward that which is not it” (Ahmed, 2006b p. 128). This is an idea Ahmed shares with Fanon (1967) and de Beauvoir (De Beauvoir, 1997) and

what Ahmed calls a phenomenology of being stopped (Ahmed, 2006b p. 139). That these parents are contemplating otherness, what I call differentness, is the aspect which drives the way parents are learning to see senses in the meeting with the child as other. They have to do this repeatedly through addressing what defines the child, and divides them from who the parent is and how the parent exists. These parents exhibit becoming what they are not yet, but I would include here that their becoming is directed also through what they never will be in two additional ways: they will not return to a previous non-parent self and they will not use the senses like the child who was born or was found to be deaf early in life. In this case we can see the parent ‘being stopped’ which is to enter a new world where they are stopped from being what they were, stopped in proceeding as unmarked able-bodied, and stopped in communicating without having to reflect on if they are heard or seen by the child. At the same time as being stopped, the parent is thrown into ‘being hearing’. To express despair about not being deaf or knowing sign language is another way of experiencing alienation; it isn’t a notion recognizable to their previous selves. These combined experiences of parents’ becoming emerge as uncertainty. How they live by ‘being stopped’ makes them uncertain and is how they will live together with the child. Uncertainty is a probability whenever they consider if the child hears what they have said. In this way becoming through the consolidation of apprehending and practicalizing is how the process of orientation continues to circulate fueled by existing in uncertainty. To further the analysis to understand the material in these terms, it helps to consider orientation, in both Merleau-Ponty and Ahmed’s meaning. It is how the body strives to come back to vertical, back from “slantwise”, to be able to carry out actions by extending into phenomenal space. Contemplating existence characterizes parental uncertainty and is when an existential theme enters into an individual’s thought. Ahmed quotes Merleau-Ponty: “What counts for the orientation of my spectacle is not my body as it in fact is, as a thing in objective space, but as a system of possible actions, a virtual body with its phenomenal ‘place’ defined by its task and situation. My body is wherever there is something to be done” (Merleau-Ponty, 2002 p. 291) (Ahmed, 2006b pp. 65-66). Parents contemplate that they hear and the child doesn’t which lies at the center of how they are embarking on new paths of being ‘where there is something to be done’. Becoming, in this combined phenomenological sense of body and orientation is a system of possible practicalizing actions, apprehending in a phenomenal place of sensorial differentness and the relationality of parenting. To explain this as uncertainty leads to a way to understand lived parenting as the life of the relationship between a parent and a child through actions in differentness. This contributes to the description of parental uncertainty as coming from balancing one’s own needs and an individual’s needs in a relationship to their child together with their future relationship with the child as an adult.

Ahmed's concept of orientation devices are exemplified by how the whiteness of the body is confirmed through bodies that are marked by difference (2006b p. 128). What it means for a parent to hear turns into how the parent becomes hearing through sensorial differentness. Remembering that for Ahmed, becoming is an embodied 'not yet' state, the parent is not yet hearing in the sense that they are not yet aware of what it means to be a parent of a deaf child. This can come about in the realization of what the intersubjective meaning of sensorial differentness will take on in how life together will be lived, now and in the future. Orientation refers to this directedness to others and objects. Becoming encompasses disorientation at intervals. Disorientation is related to uncertainty in how it describes the phenomenon of striving which involves directionality towards one's own body, the body of another and a sensorial landscape or space. A queer phenomenology would function as a disorientation device. This means that not bringing objects back in line opens up other angles on the world (Ahmed, 2006b p. 172). It would appear that being disoriented, living with disorientation is required in order to be unconventional where a family does not follow the expected scripts. For Ahmed, orientation requires others and objects that are not me (2006b p. 115). Ahmed makes no moral arguments but this is akin to how ambivalence characterizes a care ethic. In this way othering is not a simple negation but an extension and direction that incorporates the 'not me' into the body. Another aspect important for understanding parents' becoming is that parents in these chapters have children who cannot 'follow' family lines of identity. Following involves passing down through family lines and what is able to be passed down follows 'good lines'. The parent's becoming is a display of the struggle to unite the idea of ailment (deafness) to a category of identity (hard of hearing or deaf). Relationality in differentness involving social identity categories is the source of the parents becoming. This is what we learn in Andrew Solomon's work *Far from the Tree: Parents, children and the search for identity* (2012). Sexuality, deafness, disability, neuropsychiatric diagnoses, illness and sometimes race (adoption, skin pigmentation) are described as 'horizontal identities' which do not get passed vertically from a parent to a child. In Ahmed's terms these are instances of deviations from the good family line (Ahmed, 2006b pp. 12-21, 74). This relationship with their child serves as a pathway for their own becoming through orientation.

## Agonappearance

In reorientation, the parent uses both the points of their own body and the child's which creates the sensorial differentness. This can be illuminated through describing what gets noticed that was previously always taken for granted, in this case, the sense of hearing. In *The Absent Body*, Drew Leder

presents the principle of dys-appearance (Leder, 1990 pp. 69-99). When the body is functioning according to plan then it disappears from consciousness. When we experience pain, for example, the body then dys-appears, a dysfunctional state. This means that the body appears as thematic focus in a state that is negative, bad or not working according to plan. In *A phenomenological analysis of bodily self-awareness in the experience of pain and pleasure: on dys-appearance and eu-appearance*, Kristin Zeiler has done work to further the use of this principle to include what she calls eu-appearance, when the body comes into focus through pleasure and positively associated sensations (Zeiler, 2010). In working on the suffering experiences of women who menstruate I drew on these works to describe experiences of pain and suffering as positive signs of a fertile body which were valued and guarded as important for a woman's understandings of self (Adams Lyngbäck, 2010). The woman's body can *dysappear* and *euappear* in the same embodied moment.

In the situation of parents of infants of cochlear implant users I see a use in drawing on Leder's and Zeiler's work to develop a deeper understanding of what becoming means in this lived parenting situation. The sense of hearing becomes the focus of a problem in the body of their infant where the parent uses their own way of existing to understand a sensorially different way of existing. Their hearing becomes thematized, where they are made aware of it because it works but is both positive and negative, as they come to know over time. It is negative in the sense that deaf parents have abilities the hearing parent doesn't and language development for deaf children is contingent upon a parent's ability to communicate. Being able to hear in this case is problematic. If they had been deaf they would be more likely to be able to communicate with their deaf child. This utilizes Leder's notion of disappearance and Zeiler's notion of euappearance in an intersubjective contemplation by the parent. The ability to hear is previously taken for granted when it does not work it *dys-appears* for the individual. In the case of the hearing parent, *eu-appearance* represents bringing their own ability to hear to the forefront of intentionality. What is particularly important is how *eu-appearance* of the sense of hearing, that the parent 'becomes hearing' is how sensorial differentness becomes experienced. *Eu-appearance* of a visceral sense is involved in the emotional dilemma of knowing that this same sense, this very ability when they hear sound, is problematic in relation to a deaf child.

In the case of the parent of a deaf child, realizing they are hearing when confronted with the presences of deafness, is not *dysappearance* or *euappearance* but what I would describe as an earnest endeavor or striving in terms of apprehending in sensorial differentness. *Agonappearance*, drawing on phenomenological ideas of embodiment, would be a way to understand this type of striving to make sense and how a sense is both subjectively lived

and in focus as an object in a child's body. This also relates to intersubjective ambiguity, where the parent is both a subject who experiences and an object upon which the forces of the world act (De Beauvoir, 1948). In this case one of the forces is the child's way of being in the world, as is the framing of technological thinking in modern institutions.

*Agon*, an ancient Greek word, generally refers to a struggle or contest. It is commonly used to mean to try to understand a thought or to pay attention to detail as in when someone agonizes over something which is uncertain. *Agon* as it denotes an earnest endeavor would be to strive to enter a state, or strive to resolve a perceptual dilemma. This type of striving is a conflict of differing forces, the first of which attends to senses in a process of becoming for a parent. If the parent had been deaf (and signing) the sensorial differentness, as it is experienced retrieves to the background of intentionality. This is due to its insignificance in the relation between a deaf parent and a deaf child but likely to be thematized in interaction with others who are hearing. As for the hearing parent, being a part of normal society where hearing is the norm becomes problematic and perhaps a source of suffering. It is through circumstances that pose problems in communication in the future that start the beginning of becoming a parent who does not use senses in the same way as one's child.

This is only a part of the uncertainty experienced by parents of cochlear implant users. Later, as an exterior source, others' subjective experiences aid in collectively putting practices into question and provide multiple '*agon*' appearances, i.e. experiences of how parents have understood and practicalized their situations. The antagonistic atmosphere shifts to parents trying to understand the conflict and in so doing becomes *agonistic* in dealing with uncertainty together. Social media and the Internet allow for meeting points in order to 'listen in' on negotiations and ways to understand what this lived parenting is all about. Community offers a safe way to do this, a way to handle uncertainty together in day to day living.

## Narrativizing to handle uncertainty

Arthur Frank's *The Wounded Storyteller* presents a theory of how we need to tell stories in order to understand ourselves (1995). Frank is especially interested in the ways storytelling figures in episodes of illness throughout life. As I have shown in Chapter 6, narrativizing allows the parent to reorientate by pulling together distinct instances. These moments transpired in accounts about the senses, their child's as well as their own. Events are reordered and emphasized, usually involving when they encounter new ideas about their parenting situations. These patterns of narrativizing showed a

parent's sense-making of different events, putting them together in ways that both they and others could understand.

Points of disorientation were found in the focus on the moment of detection of deafness in parents' narrativizing. Re-making sense through putting events in the past into new situations, doubling-back was used to describe how parents would bring their own life narrative, the story of the self, back in an order they could present. This exemplifies the effort put into making sense through ordering events in a new way. How they narrativize about deafness as permanent *and* permeable again points to living with sources of uncertainty side by side. Added to this is how parents cannot return to a previous way of existing, and the before and after of certain realizations about deafness need a type of biographical anchor.

Rather than understanding parts of a narrative, narrativizing points to how parents are reorienting through constructing a coherent story. Frank likens this storytelling to constructing new maps when relationships to the world change a person's destination. When parents shared accounts with me it appeared that they also were learning to think through their story which Frank also develops (1995 p. 23). This is how reorientation through narrativizing could transpire in social interaction, both in an interview and in online forms. On social media sites one of the main forms of interaction is presentation through stories but in ways where the parent could read others' accounts of apprehending and practicalizing instances to understand their own situation. A parent sitting alone engages in thinking through stories others provide, an encouraged 'legitimate lurking', and can continue to piece their own narrative together.

Orientation through sense-making about deafness, where one becomes a wounded storyteller is a way to understand narrativizing and lived parenting in sensorial differentness together. Understanding how individual parents' realities become shared is illuminated by how Frank departs from theorizing about the body and what he calls other-relatedness and the dyadic body, where the other 'has to do with me, as I with it' (1995 p. 35). Through a dyadic body, being a body for others contrasts with the monadic body of medicine. The difference, expressed through these two ideal types, the dyadic and the monadic is that when sharing narratives, the dyadic body represents an ethical choice to place oneself in a different relationship to others. Narrativizing, as exhibited by the parents offers other parents their embodied experiences, their selves and bodies within a "community of pain" (Frank, 1995 p. 37). That this is seen as an ethical choice is related to the ideal types where dyadic bodies exist for each other and fill the need to learn about what this new world in their parenting is like: an uncertainty experienced together in everyday life. I have likewise wanted to show how

the parenting relationships, in applying lived parenting as a ‘non-conceptual’ example of practiced ethics is what contributes to the desire to seek outside of the expert contexts where parents are given information. Frank presents ethics as qualities of the body, draws on relatedness and how one’s own suffering can be seen in others. The relationship through the body is one where there is a desire to relieve the other person’s suffering. It is communicated through the body in a way that prepares one for being sensitive to the needs of others and is how humanity is constructed in relation to other bodies (Frank, 1995 p. 49).

To see the parents in this study as wounded or suffering in a “community of pain” must be contextualized as a way of longing and be/longing grounded in their struggle to comprehend and to manage a new situation living with disability. The way that parents, Tess, William and Josef as examples, turned outward to other groups involves wanting the best for a child but also wanting the best for others. The link through affectivity, a link which be/longing inhabits, connects the individual parent to other parents through narrativizing. In line with Frank, connectedness through telling certain stories is an enactment of an ethical choice made by parents. This aids in clarifying how Communities of Practice through caring and support opened up the possibilities for an alternative understanding (Wenger 1999; 2000). This ethics in practice represented by the dyadic body will be revisited in how care ethics is the foundation of relationships in differentness.

One example of a theme of narrativizing in the accounts of parents was how they understood senses before and after implantation. How this relates to the parent’s experience of how the child exists can be understood better with work done on parental biographical disruption. Departing from a description of how parents go from their former way of existing to a life as a parent of a disabled child, Todd & Jones set out to describe experience across both the child’s and adult’s life-span (2005). They have described how the middle years of a parent’s life coincide with the adolescent’s development, and using life course research with a biographical approach have found that parents experience the uncertainty of a ‘biographical time bomb’. Todd & Jones refer to Giddens’ work on the self in everyday life and how identity continuously comes into question through parents’ reflexively reordering of their self-narratives (1991 p. 244). Biographical disruption is not fixed in time or reach of significance. The full experience of events of disruption is more accurately described as being distributed in ongoing life. Why and how this comes about as reinforcement or as discontinuity of a self-identity is the more interesting question to pose. This shows us a way to view parental uncertainty which can be supported by how Todd & Jones include elements of ongoingness in how life events are experienced. The full meaning of what it means to be a parent of a deaf child who uses a CI cannot be grasped

without taking part in other peoples' life stories, particularly the parts which reveal 'distributed disruption' transcending parents' life stages far into their children's adulthood. When parents include reflection on past decisions which have impacted family life they exhibit a distribution of experience. The struggle to comprehend is very central to these parents' way of living even long after events. Sharing stories of either being in the same situation or having figured something out are readily shared which is a way to be unified through uncertain circumstances as well as being able to have a glimpse into how others experience reinforcement of or loss of self-identity.

What I have found is that even within accounts given in single interviews, narrativizing reveals how parents exist in uncertainty about past events as well as what will perhaps happen in the future. 'Doubling-back' appears to be an example of how parents of cochlear implant users make sense through reinforcing their narratives by recalling the conditions at the time of detection and then implantation. These conditions need to be remembered in order to continue because it was the best they could do under those circumstances. As parents come to know more about their lives with their children in sensorial differentness, certain parts and events may become harder to fit together and a doubling-back and reordering is necessary again. Because of how children develop and also choose as they become older, what a parent has done comes into new light as well.

## An alternative understanding through the generation of perspectives

In Chapter 8 it was demonstrated how individual parents sharing information and experiences in social media groups have access to a collection of ideas that come from others' medical and rehabilitative encounters. This collection also contains other alternatives to mainstream perspectives. This concentrated content in this computerized and virtual space aids in the construction of new and alternative understandings of a different parenting reality shared by a minority of people in a society. Hannerz offers a description of a social composition of such alternative perspectives. Perspective describes a basic, socially shared way of perceiving and understanding shared experiences. In *Cultural Complexity* Hannerz writes how perspectives are generated in situations in social life focusing on activities and experiences (Hannerz, 1992 pp. 65-66). Activities by parents of CI users can exemplify perspective generation. Part of the parenting role involves directing communication efforts towards a way to use language with one's child when they begin and continue to use a CI. Each parent engages in this activity, as well as the activity to make sense of the available

information about it, which are two major parts of the situation they share with other parents of deaf children. As individuals they try to make sense of the information about deafness, technological devices and language approaches. This is partially done with other people, usually the other parent or family members, as well as with professionals. Hannerz's point is that people sometimes find that their experiences differ from what others know and believe. If parents with unusual experiences have the opportunity to meet and recognize similarities then sharing these alternative perspectives make it possible for them to construct new realities. This is what is meant by generation of new perspectives in micro-cultures. The activities of social interaction through computer mediated messages are also partly a positioning of a parent within a group member role wanting to access alternative opinions about issues in communicating with a deaf or hard of hearing child together with others parents. The collection of activity and experience accounts offer a backdrop for how to carry out both these roles, one in lived parenting and the other as a role of how to participate in a parent forum.

Hannerz argues that peoples' lives produce experiences from a number of situations. Meaning constructed in micro-cultures, even one-on-one encounters, is one of the keys to understanding cultural complexity and the construction of alternative ways of understanding in the becoming of a parent of a CI user. In these situations parents take on different roles that regulate which type of experiences they gain.

To contrast what individuals gain in experience because of their parent role we can look at the professional role. Professionals in their role gain experience about how families and their children best learn language from a particular vantage point where they meet many families and adhere to ways of knowing in line with forms of knowledge in health care organizations. This role will impact what they come away with from such interaction in terms of understanding, whereas parents, because of their role, will have other experiences combining interpretations from other knowledge forms. The perspectives gained through activities, medical treatment and health care services vis-à-vis parenting responsibilities, lay the groundwork for a different collection of meaning depending on roles. The roles a person holds lead to accumulating and organizing experiences in a certain way. The roles parents hold construct a way of seeing and knowing things about language and deafness through their parenting activities. It is important though to note that roles held are always multiple and interacting and, as I have argued are conflicting in both social and existential manners (LaChance Adams 2014; de Beauvoir 1976). Cultural complexity then would imply more opportunity for engaging with uncertainty depending on how parents inhabit their

various roles, only one of which is parenting, in respects to time, effort, commitment and emotions.

Social media use is an example of a highly complex society offering multiple ways of creating alternative socially adopted perspectives. Hannerz teaches us that in complex society, specialization of knowledge leads to tension between different ways of understanding. In small-scale societies with less differentiation the tension is less than in a complex society.

The perspective is the device which organizes the attention and interpretation which an individual gives to externally carried meaning, as well as his production of such meaning, whether deliberate or spontaneous. As I understand it, the perspective exists in a tension zone between culture and social structure, insofar as there is no assured congruency between situational experiences and demands on the one hand and available, ready-made meanings on the other. But the tension can be resolved when there is such a close fit. The small-scale society, insofar as it has an undifferentiated social structure and a continuous, nearly all-inclusive flow, is more likely to minimize this tension than complex societies are (Hannerz, 1992 p. 65).

The communities on the Internet in this study bring together spontaneous production of meaning in a ‘close fit’ of parents. The different approaches and ideologies meet in the network which allows a dialog or flow between them in these groups. The knowledge specialization of medical technological treatment of deafness is an example of a tension zone between culture and social structure. How each individual links to other individuals’ networks particularly through computer mediated communication can be a way to understand how alternative perspectives exist under a type of pull or strain. This is done through interpreting how ‘networks of networks’ around a particular interest of hearing, deafness and language, as a tension zone, allows us to imagine how alternative understandings are constructed in the permeable boundaries of groups and positions. The parent in a role organizes their attention and interpretation, according to Hannerz. They engage in, new for them, digital society which is loosely structured and interconnected with other social groups. The tension is partly minimized through undifferentiated membership, the criteria being ‘parent’ and ‘child with hearing impairment’. Assumptions of how to behave and interact are based on ideas of ‘good parenting’ and netiquette. Also the style of the online support group seen as a social group, meeting needs of people differing from others in mainstream culture, allows differing views to meet and coalesce by sharing mutual defining characteristics. When a variety of experiences are portrayed and represented in a semi ‘all-inclusive flow’ based on the important characteristics of parenting in differentness as an inhabitable subject position, then the conditions are met for construction of an alternative perspective.

This is what we see happening in the composite conversations of parents in social media interaction. The understanding constructed here is that of parents in sensorial differentness and disability. This group has enough in common, through either intent to follow the groups posted rules or the factuality of the situation they are in, as parents that the tensions between hearing and deaf culture are minimized to a point where they can be socially productive. This is one prerequisite for the generation of an alternative understanding. Another harnessing of a tension element is how parents recognize themselves in others in the online groups embedded in parenting culture which results in a way of feeling familiarity and security in one respect. Differentiation is minimized when you only see the words and profile pictures increasing how parents experience ‘like’ others. An alternative understanding in this case is created in a space partially closing out the antagonistic atmosphere of competing views and specialized perspectives, but retaining the agonistic striving towards effective results for each of their children.

The organization of attention understood as perspective in Hannerz view is a way a parent orientates towards what they are able to see as possibilities. What is played out in the composite conversations is change in parent understanding. The alternative understanding involves discussing daily language interaction as well as future school and work settings and social relationships.

### Ambivalence and ambiguity in parental uncertainty

It is through parents’ first-person experiences surrounding their child and cochlear implant which offer the empirical richness of how others are objects of parents’ consciousness and become part of how they exist. This is an additional aspect of what it means to be uncertain, that our way of existing is ambivalent in regards to what we should do as well as ambiguous in terms of intersubjectivity in being both subject and object (De Beauvoir, 1948; LaChance Adams, 2014). The idea of ambivalence in the experience of mothering, not as mothers but in the act of what the human relational nurturing of children entails, is central to the discussion of a lived ethics (LaChance Adams, 2014 p. 7). To understand experiences of basic uncertainty in the becoming process of parents who have children who use a CI, this study of contradictions in mothering from a first-person perspective and the examination of care ethics where it falls short in addressing these contradictions will be helpful. LaChance Adams explores the phenomenon of maternal ambivalence where there is a separation between the desire to nurture the child and wanting to be independent. This is a division in the self which emerges in caring relationships. LaChance Adams’ interest in the

existential and the social aspects of mothering sheds light on the current study on how existential issues are actualized in everyday practices of parenting a child in sensorial differentness. Maternal ambivalence and the ambiguity of the self in this particular parenting context can help us understand the role of uncertainty in the lives of the parents in the study. Parenthood, a sense of self and other and how an individual exists as both a subject and an object opens up for a way of using feminist phenomenology to explore sources of uncertainty exhibited by parents as both internal and external.

Ambivalence is exemplified in how parents in the material, entering with their initial belonging and self-identity are presented with circumstances which transform them as they meet the child's needs, particular in respect to how they no longer can take language for granted and matters of disability enter. There is a tension between what parents do for themselves and do for their child which is expressed in having both positive and negative feelings about technology and sign language. In following LaChance Adams, descriptions of feeling ambivalent come from experiences of being motivated, compelled and inspired which clash with feelings of being forced in their relationship to their child.

In my material this comes out in practices and social exchanges, in how parents air their frustration, worry and impatience while simultaneously gaining a type of positive energetic movement from this sharing to act and influence their situation in an earnest struggle.

Drawing on both Merleau-Ponty's and Simone de Beauvoir's work, LaChance Adams describes how ambiguity of self as subject and object is involved in ambivalent experiences (2014 p. 8). In my material I have utilized these connections to understand how the hearing parent/deaf child relationship makes possible a certain type of uncertainty, especially when the child is seen to be socially divergent from her parents. This is a description of the structure of the self which extracts the relationship between existing as both subject and object. It emerges in interpretations about how a person can see oneself as an individual (experiencing subject) as well as a parent (object of social circumstances and relations).

In terms of parental uncertainty it would seem that the relationship to the child brings out this division in actions to ensure that the child thrives but in order to do so the parent has to thrive just the same. The example the empirical material provides of how parents are choosing not only for the child in respect to what language to choose, but they also make a more defining decision which is personal in nature about who the child will become and how they will belong. The acts where parents exhibit being

‘most like themselves’ conflict with how they feel they should be for the child. This plays out in embodied ways. Accommodating in the form of being more visible for the child is one example. Having to turn to face the child, to articulate or read cues the child gives of having heard or not heard are additional examples.

LaChance Adams’ theorizes about an ethics of ambivalence where it plays out in actions in caring practices because of inherent tensions and limitations (2014 p. 193). The above examples are some of the ways parents of CI users can be seen to be making ethical decisions where their way of existing is impacted. The significant question in the chapter on be/longing and communication orientation is constituted through these embodied moments of struggle about who the parents themselves are to become. Parents are first called upon to answer the question if they will use a language they will have to struggle to adopt. If they are to do so, they will change their status in a sociolinguistic respect which has repercussions in all of their existing relationships where they and their child are present. What is a significant part of these parents’ experiences is that even if they do not use a signed language, their status is impacted based on this decision as it is socially and culturally understood. It continues to be made over and over again in each interaction regarding what to do next in parenting a deaf child. This is the persistent connection between decision making, choice and uncertainty for parents. As long as the child is at a sensorial disadvantage in social situations, the issue for a parent is repeatedly actualized in respect to how the child wants to communicate, what the parent is willing and capable of accommodating and, most importantly for this discussion of parental uncertainty, how they understand their involvement to be an ethical dilemma. The relationship between these ideas is summarized in LaChance Adams’ thoughts on ethics, ambiguity and ambivalence.

The ambiguity of our intersubjective relations, as described both by Merleau-Ponty and in maternal accounts, results in an ambivalent ethical orientation, contingent as it is on negotiating the interrelated yet discrete interests of the self and the other. Although Merleau-Ponty never wrote on ethics, he describes a life world that comprehends intersubjective ambiguity, provokes the question “What should I do?” and indicates that the answer will often be conflicted and founded in ambivalence (LaChance Adams, 2014 p. 110).

Parents’ communication orientations extracted from their accounts in the material magnifies their ethical life as it is experienced as a struggle. Language choices are ethical choices which lay bare the interests of the self and the other.

## Manufactured uncertainty and life politics

Individuals in the present study live a reality of ‘manufactured uncertainty’ in making themselves into parents of CI users (Giddens, 1994 p. 4). Cochlear implantation is a result of human intervention which constructs conditions of social life. Giddens names these types of interventions ‘new uncertainties’. Life is changed for the family but it continues to be a theme in their thought of what it might have been like if they had not implanted their child. At the same time parents must ‘choose correctly’ on any number of matters which becomes a question of selecting between ‘possible worlds’ (Giddens, 1991 p. 29). What remains available to parents to consider are the deaf body *and* the hard of hearing body of their child in daily life as well as the diversity in the population of people who are deaf or hard of hearing with or without devices. In addition to this, hypothetically, their child may at any moment stop using a CI and be ‘just deaf’. This is a specific case of an experience of the subjunctive, ‘what would have been if.’ They contemplate what they make available and inaccessible through cochlear implantation.

Giddens’ concept of life politics can further explain the nature of situations related to parental uncertainty. Life politics is a transformation within modern society where individuals live out in action a production of political goals. It is in many ways like an individual staging a play about their personal narrative including commitments and convictions departing from their individual action.

The parent-child relationship demonstrates the life political issue and how parents act when new to differentness. These individuals become parents involving unfamiliar worlds and do not depart from a collective form of identification. Initially, any connection between emancipatory goals and the parenting situation at hand is loose when compared with their individual engagement connected to their child. As Giddens says “virtually all questions of life politics also raise problems of an emancipatory sort” and that emancipatory politics is a possible outcome connected to life politics (Giddens, 1991 p. 228). This is demonstrated in the study where awareness of social injustices and rights based disputes in language and disability arenas increases as the parent learns about their new world. Life politics permeates social life and is “concerned with settling debates or conflicts where opposing interests or values clash” (Giddens, 1991 p. 226). Examples in the fieldwork show how emancipatory politics led by parents of children who are deaf and hard of hearing became and stayed engaged because of how many viewed that the impact of their work had reached a broader range of life political issues which Giddens’s understanding supports (Giddens, 1991 p. 230).

Zygmunt Bauman contributes to this discussion about parental uncertainty and politics in *Community: Seeking safety in an insecure world* (2003). Belonging provides an effect of reassurance: that you are not alone in dealing with living with risk, that not knowing together is better than not knowing alone. Bauman connects this idea to the dream of community and what we have in common through like-mindedness (2003 pp. 58-73). Of the two authorities left in modernity, the authority of experts, (by definition not testable by lay people) and authority of numbers (where the larger the number of people, the less likely this authority is going to be wrong) are where we reach for community. Bauman points out that this situation requires that identity must stay flexible, ‘until further notice’ in the numbers communities and uses the example of ‘authority of celebrities’ to demonstrate this loose bond individuals have through thinking, feeling and being like people through celebrities’ popularity. What are not found in these identity constructing ‘numbers communities’ are ethical responsibility, long-term commitment and binding relationships. These are located in day-to-day life and routines. Parents in the study, when finding themselves in a new situation of parenting a deaf child have the possibility of seeking community on these enduring grounds rather than ‘until further notice’. What is possible today through social media and hand held devices is that there are ways of connecting and reordering lives to be connected in communities of this kind. If not prior to finding others who are struggling to do the right thing, parents will in networked ways through CMC be exposed to other individuals seeking ethical community. Bauman argues that community today is what individuals seek as ‘a warrant of certainty, security and safety.’ Being in parental uncertainty may lead to ethical community with others that builds on belongingness in that it is mutual, binding and based on moral commitment. How these two phenomena are interrelated will be discussed as individuals gaining a literacy of dis/ability.

### The necessity of uncertainty in being ethically engaged

Ways of answering or living with uncertainty, a broad and general worry or concern rather than a measured risk, include heuristics like intuition as well as formalization or reliance on institutions. Carole Smith in reviewing morality in modern society brings attention to how “rights talk constitutes the sequestration of morality in late modernity” (Smith, 2002 p. 43). This article offers a look at how we might understand a rights approach to the issues of parenthood, much like the formalizing involved in social intuitions which puts moral and legal rights into ethical codes and law. Smith writes about the hijacking of moral issues “ – abortion, death, reproduction, intimate relationships, poverty, oppression, parenting – and translated them into ethical codes that are not designed for moral debate but for public

consumption” and expressions of resistance to such intrusions in family relationships and therapeutic encounters (2002 p. 60). Examining “rights talk” brings up an issue that illuminates parental uncertainty by pointing out that reaching certainty, a stabilizing at a level of ontological security, even in issues of morality, is problematic. Following this argument shows how uncertainty is necessary in a parenting relationship. Regulating morality not only hijacks the issues but also hijacks the basic uncertainty necessary to being ethically engaged. This is what LaChance Adams tells us in her message of the ethics of ambivalence, where an ambiguous subject, usually a mother, is caught in the bind of providing for the other, the child. Dependency relationships make up the core of a realistic and practical ethical engagement and ought to be reconciled with traditional rights-based ethical theory (2014 pp. 1-25). Furthermore, Smith helps us understand the way parents in the material exhibit the ‘excruciating difficulty of being moral’ using Zygmunt Bauman’s words, where being morally responsible is related to having to choose (2002 pp. 60-61). As parents who are given so much conflicting advice, even when they want to rely on a type of ethical code or law in the form of allocated funds and available services they can’t feel absolved from the moral responsibility of choosing. They are reminded of this in their day to day lives when making decisions of how to care and interact with their children. The research literature presented in this discussion shows that there is a reason to study what people actually do, spontaneously and intuitively that lead to moral acts. Issues of trust in relationships and uncertainty in situations, is what comes through in the accounts in parents’ experiences.

Parents of CI users realize relatively quickly that rights afforded their deaf children are not guaranteeable. One of the strongest legislations existing for the protection of sign language rights is not enforceable for the reasons Smith points out: interpersonal responsibility and care require personal moral behavior (Language Act. Swedish Code of Statutes no: 2009:600). In the study parents are dealing with deciding in which areas they will act intuitively alone, act together or go along with depending on the regulations of rights. Trusting in regulations like these, that a system is fair and just since this is what has been produced in the social institutions in a rational, formal and impartial way does not require a struggle. It is when they see how their child is accommodated that they point out inequalities in the agencies and institutions which are meant to abide by them. The area of language rights and rights to education are two examples. It is when the codes do not work that parents report resisting and/or becoming resigned which often appear to work interchangeably. The two paths, rights’ talk and personal action are intertwined in everyday situations. The more complex (and uncertain) the situation, which it is for deaf device users, the more likely a personal and intuitive moral approach will be employed. Parents are

presented with ample opportunity to remain in a moral struggle when it becomes clear how they can influence environments to be more inclusive, or they can choose not to do so. This is evident in the material when thoughts are expressed as concerns: that there are many ways to be deaf. How should their child be deaf or how deaf should their child be?

## Social literacy and uncertainty

In a critical social justice perspective, to be dis/ability literate would be one type of social literacy where one has lived and acquired a way to exist which acknowledges and works towards breaking down the systematic oppression of ableism and audism. This idea of literacy involves becoming an ally from a privileged position in a system of unequal power (Washington & Evans, 1991). Allyship builds on the need for constant maintenance which is found in the nature of a parenting relationship over time. Many of these parents in the study are either put in or put themselves in challenging situations, like interacting with DHH adults, learning a new language, interrogating views of hearing professionals or asking questions as a beginner in how to communicate with a child in sensorial differentness. This insecurity in these types of situations is necessary in order to be able to do their parenting of a child unlike them in sensory use but also may serve as gaining perspective of operating in a modality unfamiliar or difficult to use. There is a type of motivation made available through parenting which comes from doing, acting and engaging for another person and minimizes the fear of potential failure. Social literacy in this way can be seen as requiring engagement already existing in parent/child relationships. Increasing dis/ability literacy relies on an aspect that goes beyond individual and personal levels of experiencing inequality inside familial relationships. When individuals connect these experiences and resulting actions to a larger struggle on a societal level, according to this social justice education framework, a critical dis/ability literacy is being developed. The parents strive to see how the social and structural nature of a system creates that inequality (Kimmel & Ferber, 2014 p. 3).

In the material, parents exhibit agency as advocates for their child. The development of their dis/ability literacy begins with examining their hearingness. The cycle can begin in seeing the violation of values, for example, the rights of a child to an equal education which calls forth emotions. The parent takes action through practicalizing the situation through interacting with others, in the institutions and in the social groups who share their distress. Through the personal interaction new knowledge and awareness is gained about how others view and prioritize the needs of others and on what grounds. Allyship comes about in the performance which can be placed in an existential domain where the ethic of caring is lived out (Kimmel & Ferber, 2014 p. 262). Allyship is enacted through aligning with the path made visible by the child. Dis/ability literacy, first of others and then one's own, enables a reading of the new map about how to live life in differentness with one's child.

Interpreting the findings from the study as potential for the development of literacy of dis/ability captures the way parents experience be/longing for futures for their children. It can also be how their ‘reading of the child’ and their ‘reading of the map of margins and centers’ in sensorial differentness provide the necessary conditions for developing skills needed to interrupt ableism and audism. This can begin through acknowledging that there are multiple epistemologies which begin in the body. By attempting to comprehend deaf epistemology, i.e., what it is like to navigate the world as visually oriented, hearing members of society can enact social change (Hauser, O’Hearn, McKee, Steider, & Thew, 2010). This is the initial and embodied struggle parents in the material, in one way or another and to some degree, engage in. They have begun to connect personal situations, actions and emotions to social issues which impact their children.

To summarize, becoming, described as a process in parenting in this study, is a description of arrival through instances of disorientation and reorientation. Seen as a circular orientation process displayed in different ways in the empirical chapters, a quality of uncertainty appears to explain how a non-static, non-secure state in parenting amounts to existence with others in differentness. This relationality leads to other processes the parent is involved in, namely how they and their children will exist with others in society, in the immediate present and in their futures.

I have demonstrated how I extracted the notion of parental uncertainty from the joint analysis of the findings. The line of argument in the discussion of this concept showed how experiences in differentness involve uncertainty and its role in a process of becoming a parent of a child who uses a cochlear implant. These five chapters are conjoined by viewing how parental uncertainty can be found in the apprehending, practicalizing, narrativizing, be/longing and shared connectedness where parents have been able to engage in others’ ways of existing. This describes the process of understanding the child, a perspective they are compelled to gain in order to care for them which begins the experience of struggle by the parent. A type of social learning is described as dis/ability literacy which is contingent upon experiential knowledge and remaining in multiple uncertainties. The argument can be summarized as showing how a willingness to accept a degree of parental uncertainty in cooperation with others can lead to the development of dis/ability literacy. Reorientation is how this social unlearning and relearning is realized. It illuminates social differentness and privilege within familial relationships. A parent’s sense of belonging in respect to social categories (hearing/deaf, able/disabled) is complimented by their ‘parent of’ position defined through a state of longing for a social future for the child: be/longing. The types of community parents turn to offer a way to continue in uncertainty together.

## Closing comments

I began this project by delving into the world as it is experienced by parents of cochlear implant users. It presented an opportunity to study encounters with multiple societal organizations and cultural understandings of deafness and disability. An ethnographic work on parenting led to discovering the understandings which develop in the intersection of hearing, deaf and hard of hearing groups. I found that uncertainty is involved in the becoming process which makes a social literacy of dis/ability possible.

The continued challenge for future research is to investigate how to share knowledge for the betterment of DHH groups in society through cultivating actions in practice informed by these parenting experiences in differentness. More studies from parent perspectives and embodied methodologies are needed to guide the educational, medical, technological and supporting practices which families become a part of through their children. There is no lack of advice for parents rather, there is a lack of understanding of how presumptions about what advice they need are based on medical events or isolated life stages and not the life spans of the child and parent. The strength of this pedagogical research examines societal norms and power relationships together with the analyses of processes of becoming and social learning which take place in everyday life. To study experience gained through parenting in differentness is only the first step, and practices and further research informed by this knowledge is inevitably the next. This can ensure a shift towards including the lives of deaf and hard of hearing people, their families and communities.

It is my conviction that the predicament created by societal inequalities calls for more opportunity, not less, to engage in understanding opposing views. I have tried to point out that the issue of understanding the controversy of language approaches for inclusion of groups in society is exemplary of the struggle to comprehend how others exist. All of our lives are lived in differentness in many respects. Adopting goals towards social literacy about dis/ability in deaf and hard of hearing contexts can be used to productively engage in discussions in all sectors of diversity. Experiences of uncertainty are potentially perspective-changing. What is gained by remaining in a struggle, the willingness to continue to try, shows how commitment to cooperation goes beyond tolerance of others to becoming more human through others. How can we afford to not continue pursuing this?

# Svensk sammanfattning- Erfarenhet, nätverk och ovissitet: Att vara förälder till ett barn som använder cochleaimplantat

## Avhandlingens syfte

Syftet med denna avhandling är att utforska och beskriva erfarenheter hos föräldrar som har barn som använder cochleaimplantat. Fenomenologiska /hermeneutiska, etnografiska och netnografiska metoder används för att studera hur föräldrars livsvärld är förkroppsligad i deras förstapersonsperspektiv men också hur livsvärlden delas med andra personer som föräldrarna och barnet kommer i kontakt med och påverkas av. Ett viktigt fynd i det övergripande tolkningsarbetet av olika typer av empiriskt material är att vissa föräldrar tycks utveckla vad jag kallar en social litteracitet, dvs. en social kunnighet som innefattar både medvetenhet och förmåga i att förstå barnet och andra som är likt barnet. Detta görs genom att interagera med och inta olika perspektiv hos individer och grupper som har ingående kännedom om det samspelet mellan språk, sinnen, funktion, funktionshinder och teknologi som aktualiseras för föräldrarna till barn som använder cochleaimplantat. Ett viktigt syfte i avhandlingen blir härmed att undersöka hur individer, när de som föräldrar möter en väsentlig olikhet i förhållande till sina barn, kan utveckla en sådan social litteracitet och vad som kan försvåra den utvecklingen. Den sammanfattande tolkning görs för att bidra till kunskap om föräldraprocesser som sträcker sig över både barnets och förälderns livslopp.

## Motiv och sammanhang

*Sensorisk olikhet* är ett begrepp som utvecklats för att peka på vad som karakteriseras föräldrarnas erfarenheter i mötet med den oväntade nya världen de träder in i när barnets dövhets upptäckts. Studien tar avstamp i just sådana situationer som föräldrar möter tillsammans med sitt barn: på sjukhus, på kliniker och i grupper med andra personer i liknande situationer. De första mötena med andra föräldrar och deras berättelser sker via Internet och i

synnerhet via sociala medier. Genom att följa erfarenheter och handlingar i föräldrars vardagsverklighet som återberättats i intervjuerna undersöks båda fysiska och virtuella miljöer. I syfte att ytterligare berika fältarbetet samlade jag också in kontrasterande material i en region i sydöstra USA. Härigenom fick jag möjligheter att jämföra föreställningar om språk, teknologi, dövhets-, funktionsnedsättning och aktivism.

## Metod och teoretiskt ramverk

Mitt teoretiska perspektiv utgörs av *critical disability studies*. Den övergripande metodologiska ansatsen är fenomenologisk/hermeneutisk. Min utgångspunkt i studien var att ingående analysera föräldrars förstapersonsperspektiv på förkroppsligade erfarenheter av att bli förälder till ett barn som är dövt. Dessa analyser ledde mig emellertid till att successivt vidga mitt perspektiv och även studera föräldrars upplevelser i interaktion med teknik, objekt och barnets kropp. På samma sätt kom studien att omfatta samspelet mellan föräldrar med likartade erfarenheter och mellan föräldrar och professionella. I detta syfte genomförde jag etnografiska observationer och analyser och netnografi användes för att studera samspel mellan föräldrar i sociala medier. *Critical disability studies*-perspektivet tar sig bland annat uttryck i ett kritisk feministisk fokus på *ableism*, diskriminering och förtynck på grund av funktionsvariationer. Här utgår jag ifrån föräldrarnas egena erfarenheter och granskar kritiskt hur de påverkas av dominerande sätt att förstå barn som är döva och hörselskadade, samt maktförhållandet mellan de olika synsätten.

## De empiriska kapitlen

I de fem empiriska kapitlen har föräldrabilvandeprocessen hos mammor och pappor till CI-barn undersökts på olika sätt. För att understryka processens aktiva karaktär skriver jag om ”lived parenting”, på svenska översatt till *levt föräldrande*. Huvudsakligt fokus i analysen av denna process ligger på hur föräldrar *orienterar* sig utifrån sitt barn och den nya världen de inträder i genom sitt barn. Kapitel 5 utforskar föräldrars första möten med den nya världen, och aspekterna *affekt och materialitet* utifrån intervjuer med två föräldrar. Det illustreras hur affekt spelar roll när det gäller hur föräldrar träder in i den annorlunda världen genom interaktion med teknologi kopplad till cochleimplantat och datamedierade kommunikation. Hur föräldrar upplever sina första möten genom *sensorisk olikhet* undersöks i kapitel 6. Här analyseras i första hand intervjuer med tre föräldrar mot bakgrund av

min analys av hela intervjuaterialet med särskilt fokus på det föräldrarna berättar om tester och upptäckten av dövheten hos det nyfödda barnet. Viktiga resultat är att föräldrarna ägnar sig åt att *fånga* och få ihop (apprehending) hur barnet existerar och hur detta sedan *praktikaliseras* (practicalizing) utifrån sin nyvunna erfarenhet av det de upplever. Kapitel 7 handlar om föräldrars *kommunikationsorienteringar* så som de växer fram ur den sociokulturella kontexten som barnet och föräldrarna befinner sig i. Föräldrar uttrycker en stark längtan efter att barnet ska känna tillhörighet till framtida gemenskaper och denna längtan vägleder dem i deras sätt att försöka orientera mot fruktbara sätt för barnet, och dem själva, att kommunicera. Detta sker, i sin tur, mot bakgrund av ett spänningsfält som innefattar olika mer eller mindre uttalade förslag som föräldrarna möter från professionella och andra föräldrar om fruktbar användning av olika språk och språkmodaliteter. Detta diskuteras i min analys i termer av föräldrars längtan och deras och barnets tillhörighet: *till-längtan* (be/longing). I kapitel 8 utforskas de tematiker som är mest framträdande i föräldrars utbyten med varandra via inlägg i sociala medier. Hur föräldrar diskuterar och upptäcker andras tankar om språk, teknologi och funktionsnedsättning presenteras med hjälp av metoder för netnografisk fiktion som kallas *sammansatta samtal* (composite conversations). Det avslutande empiriska kapitlet handlar i första hand om en förälder som tycks överskrida konflikten mellan de dominerande orienteringarna mot tal respektive bimodal kommunikation som många föräldrar upplever. Föräldern, John, har ett rikt, eget erfarenhetsbaserat förhållningssätt till personer med funktionsnedsättningar som tycks ha varit viktigt för utvecklingen av den sociala litteracitet som han uppnått. Karakteristiska drag i hans historia och litteracitet har sedan använts i jämförelser med andra föräldrar i materialet. Kärnan i dessa karakteristika är medvetenhet, agerande och engagemang för att bidra till mera inkluderande och rättvisa villkor för barnet och andra som liknar barnet. Slutligen presenteras en samling av kvalitéer som kan antas känneteckna *social litteracitet* med speciell relevans för dövhet, hörselnedsättning och funktionsvariation/funktionsskillnad (dis/ability). Diskussionskapitlet tar avstamp i den sammanfattande tolkningen av studien och tar upp olika aspekter av ovissitet i föräldrars livsvärld.

## Sammanfattning av forskningsresultaten

Analysen av de dominerande kommunikationsorienteringar som föräldrarna möter i sitt *föräldrande* i sensorisk olikhet visar att de brottas med dilemman gällande språk, kommunikation och cochleaimplantat. Resultaten talar för att föräldrarna fortsätter att vara engagerade i och påverkade av dessa dilemman förmodligen genom hela sitt liv efter att barnet fått sitt/sina

cochleaimplantat. Dessa dilemman omfattar frågor som när man bör operera, användning av olika modaliteter i kommunikation, interventionsmetoder och val av skolmiljöer. Ett viktigt resultat rör hur föräldrars orienteringar tar form i dessa dilemman där merparten av föräldrarna upplever antagonistiska konflikter. Processen mot *social litteracitet* tycks börja med egen levd erfarenhet av ovissitet i språk- och funktionshinderkontexter, i att kunna ”läsa av” sitt barn, de miljöer som delas med barnet och villkoren som gäller de grupper barnet kan tillhöra. Resultaten visar att anammandet av den grundläggande ovissheten präglar *föräldrandet* som slutligen möjliggör för vissa föräldrar att överskrida konflikten mellan kommunikationsorienteringarna genom en relation bland annat till olika grupper av teckenspråkiga, döva och hörselskadade vuxna som liknar ens barn. Här kan man tala om ett *socialt kunnande om varierande funktionsförmåga* (dis/ability literacy). Den annorlundahet som oväntat trär in i föräldrarnas liv genom barnet och de begränsade kommunikationsförutsättningarna dem emellan, tvingar således fram en mångfacetterad reorientering hos föräldrarna. Diskussionskapitlet tar avstamp i den sammanfattande tolkningen av den sociala litteraciteten (dis/ability literacy) och tar upp olika aspekter av hur föräldrarna lär sig hantera den oundvikliga ovissheten i sin nya livsvärld.

## Slutsatser och rekommendationer

Jag har skrivit avhandlingen i dialog med en rad aktuella samhällsproblem som blivit synliga genom föräldrarnas erfarenheter av ovissitet, undran och ängslan i mötet med andra individer och verksamheter relaterade till cochleaimplantat och hur det är att leva med sådana implantat i vardagen. Jag har identifierat tre områden studien kan bidra till. Det första är forskningen om föräldrar till barn som använder cochleaimplantat och hur deras vardag gestaltar sig. Det andra området rör samspelet mellan föräldrar och de viktiga personer de möter och vilken betydelse det kan ha för föräldrars utveckling av alternativa perspektiv, exempelvis via sociala medier. Betydelsen av dessa medier understryks av att föräldrar med barn som är döva eller har en hörselskada sällan träffas, beroende på deras unika situation. Ett tredje område studien bidrar till är pedagogisk forskning och utbildningsfrågor om social rättvisa genom att belysa hur föräldra-barn-relationer i olihet kan leda till komplexitet i deras sociala interaktion. Processer hos de här grupperna kan utforskas för att bättre förstå vad som krävs för att uppnå ett samhälle som är mer jämlikt. Till exempel hur föräldrar lär av andra föräldrar som de tänker sig liknar deras barn i vuxen ålder innehåller viktiga grundläggande steg mot social medvetenhet. Genom sådana möten och strävan att förstå fogas personliga relationer samman med

faktiska ojämliga förhållanden för individer som påverkar delaktighet. Att nå förståelse och lösningar mellan grupper i samhället med olika perspektiv och villkor kan studeras genom hur föräldrar lär sig genom sitt barn som kommer att leva under andra omständigheter än vad de själva gör.

Fortsatta studier av samspelet mellan mänskliga och teknik i vardagen är viktiga för att följa och förstå hur teknologiska förändringar ändrar villkoren för mänsklig. En sådan fortsatt studie kan vara att följa hur det som händer tidigt i livet i en familj med barn som använder cochleaimplantat vad gäller språkutveckling kan påverka individuella utvecklingsprocesser och relationer mellan mänsklig som sträcker sig över hela livsloppet. Ett specifikt exempel är skillnaden mellan hur föräldrar upplever behov respektive stöd som de möter i nuet och de behov de tror sig ana att barnet kommer att ha när barnet blir äldre och sedan vuxen. Till detta kan läggas hur de som ger stöd och hjälpa förstår barn och föräldrars behov utifrån sina olika roller.

När föräldrar vill hitta svar på sina frågor om den sensoriska olikhet som de lever med vänder de sig ofta till dem som befinner sig i liknande situationer. I den här avhandlingen har det emellertid också visats att en speciell gemenskap med andra, som är olika dem själva i väsentliga avseenden men har betydande likheter med deras barn, kan öppna möjligheter för föräldrar till barn som använder cochleaimplantat. Även dessa gemenskaper tycks ha ett stort värde för föräldrarna. En intressant fråga är hur föräldrakontakter kan överbrygga olikhetsklyftorna mellan döva, hörselskadade och hörande personer. Tillsammans kan de nå större kunskap om vad språk betyder i familjerelationer men också i förskoleåldern, skolåldern och i arbetslivet.

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# References

- Adams Lyngbäck, E. (2010). *I don't feel like myself: Women's accounts of normality and authenticity in the field of menstruation* (Thesis). Retrieved from DIVA <http://su.diva-portal.org/smash/get/diva2:601939/FULLTEXT03.pdf>
- Adams, E. B. (2011). *Hearing mothers' resolution of the identification of child hearing loss: An exploration of the reaction to diagnosis interviews*. Ann Arbor, MI: Gallaudet University.
- Adams, M., & Bell, L.A. & Griffin, P. (Eds.). (2007). *Teaching for diversity and social justice*. (2nd ed.). New York, NY: Routledge.
- Adler, P. A., Adler, P., & Fontana, A. (1987). Everyday life sociology. *Annual Review of Sociology*, 217-235.
- Ahlgren, I. & Bergman, B. (2006). Det svenska teckenspråket. In: *Teckenspråk och teckenspråkiga*. Kunskaps och forskningsöversikt: Betänkande av utredningen Översyn av teckenspråkets ställning. 11-70.
- Ahlström, M. (2000). *Hörselskadade barn i kommunikation och samspel*. Stockholm, Sweden: Psykologiska institutionen.
- Ahmed, S. (2004). Affective economies. *Social Text*, 22(2), 117-139.
- Ahmed, S. (2006a). Orientations: Toward a queer phenomenology. *GLQ: A Journal of Lesbian and Gay Studies*, 12(4), 543-574.
- Ahmed, S. (2006b). *Queer phenomenology: Orientations, objects, others*. Durham, NC: Duke University Press.
- Ahmed, S. (2012). *On being included: Racism and diversity in institutional life*. Durham, NC: Duke University Press.
- Ahmed, S. (2013). *The cultural politics of emotion*. New York, NY: Routledge.
- Åkerström, M. (2004). *Föräldraskap och expertis– Motsättningar kring handikappade barn*. Lund, Sweden: Liber.
- Åkerström, M., Eriksson, K., & Höglund, B. (1995). *Dövvärlden i förändring: Om döva och hörselskadades omgivning*. Lund, Sweden: Department of Sociology, Lund University.

Alaszewski, A. (2003). Risk, trust and health. In *Health, risk & society*, 5:3, 235-239, Retrieved from doi10.1080/13698570310001606941 or <http://dx.doi.org/10.1080/13698570310001606941>

Alaszewski, A., & Coxon, K. (2009). Uncertainty in everyday life: Risk, worry and trust. In *Health, risk & society*, 11:3, 201-207, Retrieved from doi 10.1080/13698570902906454 or <http://dx.doi.org/10.1080/13698570902906454>

Alftberg, Å., Apelmo, E., & Hansson, K. (2016). Inledning. In Å. Alftberg, Apelmo, E & K. Hansson (Eds.), *Ljud Tar Plats*, (pp. 1-9). Lund, Sweden: Lund Studies in Art and Cultural Sciences II.

Ambert, A., Adler, P. A., Adler, P., & Detzner, D. F. (1995). Understanding and evaluating qualitative research. *Journal of Marriage and the Family*, 879-893.

American Speech-Language-Hearing Association. (1994). Joint committee on infant hearing 1994 position statement. *Asha*, 36, 38-41.

Anderson, L. (2006). Möjligheter och hinder för elever med stora kommunikationssvårigheter. In C. Roos & S. Fischbein (eds.), *Dövhet Och Hörselnedsättning-Specialpedagogiska Perspektiv* (117-141). Lund, Sweden: Studentlitteratur.

Anmyr, L. (2014). Life circumstances of children and adolescents after cochlear implantation. (Doctoral dissertation). Stockholm, Sweden: Karolinka institutet.

Anspach, R. R. (1997). *Deciding who lives: Fateful choices in the intensive-care nursery*. Berkley, CA: University of California Press.

Anspach, R. R., & Mizrachi, N. (2006). The field worker's fields: Ethics, ethnography and medical sociology. *Sociology of Health & Illness*, 28(6), 713-731.

Archbold, S. M., Lutman, M. E., Gregory, S., O'Neill, C., & Nikolopoulos, T. P. (2002). Parents and their deaf child: Their perceptions three years after cochlear implantation. *Deafness & Education International*, 4(1), 12-40.

Archbold, S., Sach, T., O'Neill, C., Lutman, M., & Gregory, S. (2008). Outcomes from cochlear implantation for child and family: Parental perspectives. *Deafness & Education International*, 10(3), 120-142.

Asker-Árnason, L. (2011). *Narration and reading comprehension in Swedish children and adolescents with hearing impairment*. (Doctoral dissertation). Retrieved from Lund University Publications <http://lup.lub.lu.se/record/1852055>

Ayers, W., Quinn, T. M., & Stovall, D. (2009). *Handbook of social justice in education*. New York, NY: Routledge.

Bagga-Gupta, S. (2004). *Literacies and deaf education: A theoretical analysis of international and Swedish literature*. Stockholm, Sweden: Myndigheten för skolutveckling.

Bagga-Gupta, S., & Holmström, I. (2016). Language, identity and technologies in classrooms for the differently-abled. *Journal of Communication Disorders, Deaf Studies & Hearing Aids*, 2015.

Barnplantorna. (2015). *Statistik CI på barn under 18 år 1 januari 2015*. Retrieved from <http://www.barnplantorna.se/UserFiles/file/rapporter/StatistikBARN2015webb.pdf>

Bat-Chava, Y., Martin, D., & Imperatore, L. (2014). Long-term improvements in oral communication skills and quality of peer relations in children with cochlear implants: Parental testimony. *Child: Care, Health and Development*, 40(6), 870-881.

Bat-Chava, Y., Martin, D., & Kosciw, J. G. (2005). Longitudinal improvements in communication and socialization of deaf children with cochlear implants and hearing aids: Evidence from parental reports. *Journal of Child Psychology and Psychiatry*, 46(12), 1287-1296.

TEDxGallaudet (Producer), & Bauman, H. (Director). (2015, 20150306). *On becoming hearing: Lessons in limitations, loss, and respect*. [Video/DVD] <https://www.youtube.com/watch?v=yCuNYGk3oj8>.

Bauman, H. (2004). Audism: Exploring the metaphysics of oppression. *Journal of Deaf Studies and Deaf Education*, 9(2), 239-246.

Bauman, H. (Ed.). (2008). *Open your eyes: Deaf studies talking*. Minneapolis, MN: University of Minnesota Press.

Bauman, H., Simser, S., & Hannan, G. (2010). Beyond ableism and audism: Achieving human rights for deaf and hard of hearing citizens. *The Canadian Hearing Society-Barrier-Free Education Initiatives*. Retrieved from [https://www.chs.ca/sites/default/files/uploads/beyond\\_ableism\\_and\\_audism\\_2013july.pdf](https://www.chs.ca/sites/default/files/uploads/beyond_ableism_and_audism_2013july.pdf)

Bauman, Z. (1992). *Hermeneutics and social science approaches to understanding*. Hampshire, UK: Gregg Revivals.

Bauman, Z. (2003). *Community: Seeking safety in an insecure world*. Cambridge, UK: Polity.

Blume, S. (2013). Medical innovations: Their diffusion, adoption, and critical interrogation. *Sociology Compass*, 7(9), 72-737.

Blume, S. (2009). *The artificial ear: Cochlear implants and the culture of deafness*. New Brunswick, NJ: Rutgers University Press.

Bohman, J. (2015). Critical theory. In *The Stanford encyclopedia of philosophy*. Retrieved from <http://plato.stanford.edu/archives/win2015/entries/critical-theory>.

- Bosteels, S., Van Hove, G., & Vandenbroeck, M. (2012). The roller-coaster of experiences: Becoming the parent of a deaf child. *Disability & Society*, 27(7), 983-996.
- Bourdieu, P. (2003). Participant objectivation. *Journal of the Royal Anthropological Institute*, 9(2), 281-294.
- Bridges, D. (2001). The ethics of outsider research. *Journal of Philosophy of Education*, 35(3), 371-386.
- Brownlie, J., & Howson, A. (2005). 'Leaps of faith' and MMR: An empirical study of trust. *Sociology*, 39(2), 221-239.
- Buchanan, E., & Markham, A. (2012). Ethical decision-making and Internet research. Recommendations from the AoIR ethics working committee. (2.0). Retrieved from <http://www.aoir.org/reports/ethics2.pdf>
- Burch, S., & Kafer, A. (Eds.). (2010). *Deaf and disability studies: Interdisciplinary perspectives*. Washington, DC: Gallaudet University Press.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.
- Campbell, F. K. (2008). Exploring internalized ableism using critical race theory. *Disability & Society*, 23(2), 151-162.
- Campbell, F. K. (2009). *Contours of ableism*. New York, NY: Palgrave Macmillan Basingstoke.
- Castaneda, R., & Peters, M. (2000). Ableism. In Adams, M., Blumenfeld, W.J., Castañeda, R., Hackman, H.W., Peters, M.L. & Zúñiga, X. *Readings for Diversity and Social Justice* (319-323). New York, NY: Routledge.
- Christiansen, J. B., & Leigh, I. (2002). *Cochlear implants in children: Ethics and choices*. Washington, DC: Gallaudet University Press.
- Curry-Stevens, A. (2007). New forms of transformative education pedagogy for the privileged. *Journal of Transformative Education*, 5(1), 33-58.
- Czarniawska, B. (2004). On time, space, and action nets. *Organization*, 11(6), 773-791.
- Czarniawska-Joerges, B. (2007). *Shadowing: And other techniques for doing fieldwork in modern societies*. Copenhagen, Denmark: Copenhagen Business School Press DK.
- Davidson, D., & Letherby, G. (2014). Griefwork online: Perinatal loss, lifecourse disruption and online support. *Human Fertility*, 17(3), 214-217.
- De Beauvoir, S. (1948). *The ethics of ambiguity*. New York, NY: Citadel Press.

- De Beauvoir, S. (1949). Introduction. In *The second sex*. Retrieved from <https://www.marxists.org/reference/subject/ethics/de-beauvoir/2nd-sex/introduction.htm>
- Denzin, N. K. (1980). A phenomenology of emotion and deviance. *Zeitschrift Für Soziologie*, 251-261.
- Denzin, N. K. (1997). Interpretive ethnography: Ethnographic practices for the 21st century Sage.
- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 89-93.
- DiAngelo, R. (2012). *What does it mean to be white? Developing White racial literacy*. New York, NY: Peter Lang.
- Drentea, P., & Moren-Cross, J. L. (2005). Social capital and social support on the web: The case of an internet mother site. *Sociology of Health & Illness*, 27(7), 920-943.
- Duff, C. (2003). The importance of culture and context: Rethinking risk and risk management in young drug using populations. *Health, Risk & Society*, 5(3), 285-299.
- Duquette, C., Durieux-Smith, A., Olds, J., Fitzpatrick, E., Eriks-Brophy, A., & Whittingham, J. (2002). Parents' perspectives on their roles in facilitating the inclusion of their children with hearing impairment. *Exceptionality Education Canada*, 12(1), 19-36.
- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.
- Eckert, R. C., & Rowley, A. J. (2013). Audism A theory and practice of audiocentric privilege. *Humanity & Society*, 37(2), 101-130.
- Eckert, R. C. (2010). Toward a theory of deaf ethnos: Deafnicity ≈ D/deaf (hómaemon • homóglosson • homóthreskon). *Journal of Deaf Studies and Deaf Education*, 15(4), 317-333. doi:10.1093/deafed/enq022
- Eisen, M. (2009). The history of cochlear implants. In J. K. Niparko (Ed.), *Cochlear Implants: Principles and Practices* (89-93). Philadelphia, PA: Lippincott Williams & Wilkins.
- Eriksson, K. (1993). *Dövsamhällets avvikare och avhoppare: Den social problematiken kring cochleaimplantat*. (FoU rapport 25). Lund, Sweden: Research program in medical sociology. Department of Sociology, Lund University.
- Evans, N. J., Assadi, J. L., & Herriott, T. K. (2005). Encouraging the development of disability allies. *New Directions for Student Services*, 2005(110), 67-79.

- Evans, N. J., & Wall, V. A. (1991). Beyond tolerance: Gays, lesbians and bisexuals on campus. ERIC.
- Fanon, F. (1967). Black skin, white masks [1952]. New York, NY: Grove.
- FDA. (2016). *Cochlear implants*. Retrieved August 24, 2016 <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/>:
- FDA. (2014) Cochlear implants. Retrieved October 28, 2015. *Cochlear implants*. Retrieved October 28, 2015  
<http://www.fda.gov/medicaldevices/productsandmedicalprocedures/implantsandprosthetics/cochlearimplants/ucm062823.htm#a>
- Fisher, P., & Goodley, D. (2007). The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness*, 29(1), 66-81.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: The University of Chicago Press.
- Gale, E. (2011). Exploring perspectives on cochlear implants and language acquisition within the deaf community. *Journal of deaf studies and deaf education*, 16(1), 121-139.
- Gallaudet Research Institute. (2011). *Regional and national summary report of data from the 2009-10 annual survey of deaf and hard of hearing children and youth*. Washington, DC: GRI Gallaudet University.
- Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Paolo Alto, CA: Stanford University Press.
- Giddens, A. (1994). *Beyond left and right: The future of radical politics*. Paolo Alto, CA: Stanford University Press.
- Ginsburg, F., & Rapp, R. (2013). Entangled ethnography: Imagining a future for young adults with learning disabilities. *Social Science & Medicine*, 99, 187-193.
- Goffman, E. (1963, 2009). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.
- Groce, N. (1980). Everyone here spoke sign language. *Natural History*, 89(6), 10-19.
- Gustafsson, B., Hermerén, G., & Petterson, B. (2011). *Good reserach practice*. (No.3). Stockholm, Sweden: Swedish Research Council.
- Gustavsson, A., & Bergström, H. (2005). Pendlingen mellan olika tolkningsintressen. In S. Selander, & P. Ödman (Eds.), *Text och existens: Hermeneutik möter samhällsvetenskap* (pp. 199-220). Riga, Lettland: Daidalos.

- Gustavsson, A. (2001a). *Inifrån utanförskapet: Om att vara annorlunda och delaktig*. Stockholm, Sweden: Johansson & Skyttmo förlag.
- Gustavsson, A. (2001b). Studying personal experiences of disability-What happened to verstehen when einfühlung disappeared? *Scandinavian Journal of Disability Research*, 3(2), 29-40.
- Gustavsson, A., & Tøssebro, J. & Traustadóttir, R. (2005). Introduction. Approaches and perspectives in Nordic disability research (23-44). In Gustavsson A., Sandvin J., Traustadóttir R. and Tøssebro J. (Eds.), *Resistance, reflection and change: Nordic disability research*. Lund, Sweden: Studentlitteratur.
- Halldén, G. (1991). The child as project and the child as being: Parents' ideas as frames of reference. *Children & Society*, 5(4), 334-346.
- Hannerz, U. (1992). *Cultural complexity: Studies in the social organization of meaning*. New York, NY: Columbia University Press.
- Hardiman, R., Jackson, B., & Griffin, P. (2007). Conceptual foundations for social justice education. In Adams, M., Bell, L. & Griffin, P. (Eds.), *Teaching for diversity and social justice*, 2nd ed. (35-66). New York, NY: Routledge Taylor & Francis.
- Harmon, K. (2010). Deaf matters, compulsory hearing, and ability trouble. *Deaf and disability studies: Interdisciplinary perspectives*. In S. Burch, & A. Kafer (Eds.), *Deaf and disability studies: Interdisciplinary perspectives* (31-47). Washington, DC Gallaudet University Press.
- Hassanzadeh, S. (2012). Outcomes of cochlear implantation in deaf children of deaf parents: Comparative study. *Journal of Laryngology and Otology*, 126(10), 989.
- Hauser, P. C., O'Hearn, A., McKee, M., Steider, A., & Thew, D. (2010). Deaf epistemology: Deafhood and deafness. *American Annals of the Deaf*, 154(5), 486-492.
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, 11(4), 493-513. doi:enl005
- Hintermair, M., & Albertini, J. A. (2005). Ethics, deafness, and new medical technologies. *Journal of Deaf Studies and Deaf Education*. (184-192).
- Hintermair, M. (2004). Sense of coherence: A relevant resource in the coping process of mothers of deaf and hard-of-hearing children? *Journal of Deaf Studies and Deaf Education*, 9(1), 15-26. doi:10.1093/deafed/enh005
- Holmström, I., Bagga-Gupta, S., & Jonsson, R. (2015). Communicating and hand (ling) technologies. Everyday life in educational settings where pupils with cochlear implants are mainstreamed. *Journal of Linguistic Anthropology*, 25(3), 256-284.

Holmström, I., & Schönström, K. (Forthcoming). Number of students in Swedish special schools 1992-2016.

Holmström, I. (2013). *Learning by hearing? Technological framings for participation*. (Doctoral dissertation). Örebro, Sweden: Örebro universitet.

Horsch, U., Weber, C., Bertram, B., & Detrois, P. (1997). Stress experienced by parents of children with cochlear implants compared with parents of deaf children and hearing children. *Otology & Neurotology*, 18(6), (161-163).

HRF. (2007). *Årsrapport. Äh, det var inget viktigt... Om hörselskadades situation i Sverige*. Retrieved from <https://hrf.se/wp-content/uploads/2016/06/rapport07.pdf>

HRF. (2014). *Myternas marknad: Svensk hörselvård – från behov till business*. doi:1652-8387 or [https://hrf.se/wp-content/uploads/2016/06/myternas\\_marknad\\_rapport2014.pdf](https://hrf.se/wp-content/uploads/2016/06/myternas_marknad_rapport2014.pdf)

Hyde, M., & Punch, R. (2011). The modes of communication used by children with cochlear implants and role of sign in their lives. *American Annals of the Deaf*, 155(5), 535-549.

Hyde, M., Punch, R., & Komesaroff, L. (2010a). A comparison of the anticipated benefits and received outcomes of pediatric cochlear implantation: Parental perspectives. *American Annals of the Deaf*. 155(3), 322-338.

Hyde, M., Punch, R., & Komesaroff, L. (2010b). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education*, 15(2), 162-178. doi:10.1093/deafed/enq004

Hydén, L. C., & Olin Lauritzen, S. (2007). Medical technologies and the life world: The social construction of normality. *Critical studies in health and society*. Hoboken: Taylor & Francis.

Ibertsson, T. (2009). *Cognition and communication in children/adolescents with cochlear implant* (Doctoral dissertation). Lund, Sweden: Lund University.

Incesulu, A., Vural, M., & Erkam, U. (2003). Children with cochlear implants: Parental perspectives. *Otology & Neurotology*, 24(4), 605-611.

Inckle, K. (2010). Telling tales? Using ethnographic fictions to speak embodied ‘truth’. *Qualitative Research*, 10(1), 27-47.

Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication Disorders Quarterly*, 29(2), 82-98.

Jacobsson, K. (2000). *Retoriska strider: Konkurrerande sanningar i dövvärlden* (Doctoral dissertation). Lund, Sweden: Lund University.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.

- Karlsson, E. (2013). Congenital CMV infection and connexin 26 mutations in childhood deafness: Intervention with early cochlear implantation. (Doctoral dissertation). Stockholm, Sweden: Karolinska institutet.
- Karolinska universitetssjukhus. (2016). Cochleamottagningen. Retrieved from <http://www.karolinska.se/for-patienter/alla-mottagningar-och-avdelningar-a/o/oron--nas--och-halskliniken-behallare/cochleamottagningen/>
- Kemp, D. T., & Ryan, S. (1993). The use of transient evoked otoacoustic emissions in neonatal hearing screening programs. *Seminars in Hearing*, 14(01), 30-44.
- Kennedy, B. L. (1988). Adult versus child L2 acquisition: An Information-processing approach. *Language Learning*, 38(4), 477-495.
- Kermitt, P. (2009). Deaf or deaf? Questioning alleged antinomies in the bioethical discourses on cochlear implantation and suggesting an alternative approach to D/deafness. *Scandinavian Journal of Disability Research*, 11(2), 159-174.
- Kermitt, P. (2010a). *Etikk etter cochleaimplantering av døe barn: En undersøkelse med fokus på anerkjennelse, identitet og språk* (Doctoral dissertation). Norges teknisk-naturvitenskapelige universitet, Fakultet for samfunnsvitenskap og teknologiledelse, Institutt for sosialt arbeid og helsevitenskap.
- Kermitt, P. (2010b). ‘Hearing’ or ‘Deaf’? Discussing epistemological and methodological issues related to the bioethical discourse on paediatric cochlear implantation. *Scandinavian Journal of Disability Research*, 12(2), 91-107.
- Kermitt, P. (2010c). Choosing for the child with cochlear implants: A note of precaution. *Medicine, Health Care and Philosophy*, 13(2), 157-167.
- Kermitt, P. (2012). Enhancement technology and outcomes: What professionals and researchers can learn from those skeptical about cochlear implants. *Health Care Analysis*, 20(4), 367-384.
- Kimmel, M. S., & Sykley, J. (2010). *Privilege: A reader*. Retrieved from ReadHowYouWant.com.
- Kimmel, S., & Ferber, A. (2014). *Privilege: A reader* (3rd ed.). Boulder, Colorado: Westview Press.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books.
- Klima, E., & Bellugi, U. (1979). *The sign of language*. Cambridge, MA: Harvard University Pres.
- Kluwin, T. N., & Stewart, D. A. (2000). Cochlear implants for younger children: A preliminary description of the parental decision process and outcomes. *American Annals of the Deaf*, 145(1), 26-32.

- Knoors, H. (2007). Educational responses to varying objectives of parents of deaf children: A Dutch perspective. *Journal of Deaf Studies and Deaf Education*, 12(2), 243-253. doi:enl029 [pii]
- Komesaroff, L. R., & McLean, M. A. (2006). Being there is not enough: Inclusion is both deaf and hearing. *Deafness & Education International*, 8(2), 88-100.
- Kozinets, R. V. (2010). *Netnography: Doing ethnographic research online*. Los Angeles, CA: Sage.
- Kozinets, R. V. (2015). *Netnography: Redefined* Sage. Los Angeles, CA: Sage.
- Kral, A., Kroneberger, W., Pisoni, D., & O'Donoghue, G. (2016). Neurocognitive factors in sensory restoration of early deafness: A connectome model. *Lancet Neurol*, 15(6), 610. doi: 10.1016/S1474-4422(16)00034-X. Epub 2016 Mar 12
- Kyle, J. G., & Woll, B. (1985). Sign language. *The study of deaf people and their language*. Cambridge, MA: Cambridge University Press.
- LaChance Adams, S. (2014). *Mad mothers, bad mothers, and what a "good" mother would do: The ethics of ambivalence*. New York, NY: Columbia University Press.
- Ladd, P. (2010). *Understanding deaf culture: In search of deafhood*. Clevedon, UK: Multilingual Matters.
- Lane, H. (1989). *When the mind hears: A history of the deaf*. New York, NY: Vintage.
- Lane, H. (1992). *The mask of benevolence: Disabling the deaf community*. New York, NY: Alfred a Knopf.
- Lane, H., Hoffmeister, R., & Bahan, B. J. (1996). *A journey into the deaf-world* San Diego, CA.: DawnSignPress.
- Lange, A., & Westin, C. (1985). *The generative mode of explanation in social psychological theories of race and ethnic relations*. Retrieved from DIVA. <http://www.diva-portal.org/smash/get/diva2:462530/FULLTEXT01.pdf>
- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge, MA: Cambridge University Press.
- Leder, D. (1990). *The absent body*. Chicago, IL: University of Chicago Press.
- Lederberg, A. R., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, 7(4), 330-345. doi:10.1093/deafed/7.4.330
- Leigh, G., & Marschark, M. (2005). Ethics and deafness: A matter of perspective? *Journal of Deaf Studies and Deaf Education*, 10(2), 109-110.
- Leigh, I. (2009). *A lens on deaf identities*. New York, NY: Oxford University Press.

- Lind, J. (2013). Föräldrastöd on-line: En analys av ett digitalt diskussionsforum för föräldrar. Research report on Childhood and the study of children (2013,1) Retreived from [http://www.diva-portal.org/smash/get/diva2:642305/  
FULLTEXT01.pdf](http://www.diva-portal.org/smash/get/diva2:642305/FULLTEXT01.pdf)
- Lindberg, L. (2016). *Svensk forskning om funktionshinder: Forskning som hältar.* Stockholm: Hörselskadades Riksförbund. The Swedish Association of Hard of Hearing People (HRF).
- Linikko, J. (2009). *"Det gäller att hitta nyckeln...": Lärares syn på undervisning och dilemman för inkludering av elever i behov av särskilt stöd i specialskolan.* (Doctoral dissertation). Retrieved from [http://www.diva-portal.org/smash/get/  
diva2:200384/FULLTEXT01.pdf](http://www.diva-portal.org/smash/get/diva2:200384/FULLTEXT01.pdf)
- Löfkvist, U. (2014). *Lexical and semantic development in children with cochlear implants.* (Doctoral dissertation). Retrieved from Karolinska institutet <https://openarchive.ki.se/xmlui/handle/10616/42040>
- Luckner, J. L., & Velaski, A. (2005). Healthy families of children who are deaf. *American Annals of the Deaf*, 149(4), 324-335.
- Lyxell, T. (2014). *Se språket. Barns tillgång till svenska teckenspråket.* (3). Stockholm, Sweden: Institutet för språk och folkminnen. Språkrådet.
- Magnuson, M. (2000). *Hearing screening of infants and the importance of early language acquisition.* (Doctoral dissertation). Linkoping studies in education and psychology. 72. ERIC.
- Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology*, 95-117.
- Markham, A. N. (1998). *Life online: Researching real experience in virtual space.* Lanham, MD: Altamira Press.
- Markham, A. N. (2005). The methods, politics, and ethics of representation in online ethnography. *The Sage Handbook of Qualitative Research.* Thousand Oaks, CA: Sage.
- Marklund, K., Andershed, A., & Andershed, H. (2012). *Nordic children—Early intervention for children and families.* Stockholm, Sweden: Nordic Centre for Welfare and Social Issues.
- Marschark, M. (2007). Raising and educating a deaf child: A comprehensive guide to the choices, controversies and decisions faced by parents and educators. Oxford, UK: Oxford University Press.
- Marschark, M., & Spencer, P. (Eds.). (2003). *Oxford handbook of deaf studies, language and education.* Oxford, UK: Oxford University Press.
- Marschark, M., Rhoten, C., & Fabich, M. (2007). On ethics and deafness: Research, pedagogy and politics. *Deafness & Education International*, 9(1), 45-61.

- Mauldin, L. (2012). Parents of deaf children with cochlear implants: A study of technology and community. *Sociology of Health & Illness*, 34(4), 529-543.
- McDonald-Morken, C. A. (2014). *Mainstreaming Critical Disability Studies: Towards Undoing the Last Prejudice* (Doctoral dissertation). Retrieved from <http://gradworks.proquest.com/3620330.pdf>
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.
- Meadow-Orlans, K. P., Sass-Lehrer, M., & Mertens, D. M. (2003). *Parents and their deaf children: The early years*. Washington, DC: Gallaudet University Press.
- Mellan, N. K., Niparko, J. K., Rathmann, C., Mathur, G., Humphries, T., Napoli, D. J., & Lantos, J. D. (2015). Should all deaf children learn sign language? *Pediatrics*, 136(1), 170-176. doi:10.1542/peds.2014-1632
- Meristo, M. (2007). *Mental representation and language access: Evidence from deaf children with different language backgrounds*. (Doctoral Dissertation). Retrieved from GUPEA [https://gupea.ub.gu.se/bitstream/2077/9901/2/M\\_Meristo\\_Dissertation.pdf](https://gupea.ub.gu.se/bitstream/2077/9901/2/M_Meristo_Dissertation.pdf)
- Merleau-Ponty, M. (2002). *Phenomenology of perception*. London, UK: Routledge.
- Mertens, D. M. (2010). Transformative mixed methods research. *Qualitative Inquiry*. doi:10.1177/1077800410364612 or <http://qix.sagepub.com>
- Mertens, D. M., Sass-Lehrer, M., & Scott-Olson, K. (2000). Sensitivity in the family-professional relationship: Parental experiences in families with young deaf and hard-of-hearing children. In P. E. Spencer, C. J. Erting & M. Marschark (Eds.), *The Deaf Child in the Family and School: Essays in Honor of Kathryn P. Meadow-Orlans* (pp. 133-150). Mahwah, NJ: Lawrence Erlbaum Associates.
- Mertens, D. M. (2012). Transformative mixed methods: Addressing inequities. *American Behavioral Scientist*, 56(6), 802.
- Meyer, S. B., & Ward, P. R. (2013). Differentiating between trust and dependence of patients with coronary heart disease: Furthering the sociology of trust. *Health, Risk & Society*, 15(3), 279-293.
- Midbøe, M. (2011). *Upplevelse av delaktighet i det sociala samspelet hos ungdomar med cochleaimplantat*. Retrieved from DIVA <https://scholar.google.se/scholar?hl=sv&q=Midb%C3%B8e%2C+M.+%282011%29.+Upplevelse+av+delaktighet+i+det+sociala+samspelet+hos+ungdomar+med+cochleaimplantat&btnG=>
- Minges, J. (2016). *Moving toward allyship: A current climate of agent skill sets of hearing ASL-english interpreters*. (Doctoral dissertation). Retrieved from <http://digitalcommons.wou.edu/cgi/viewcontent.cgi?article=1033&context=theses>

- Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4(2), 138-163.
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*, 106(3), E43.
- Mol, A. (2002). *The body multiple: Ontology in medical practice*. Durham, NC: Duke University Press.
- Monaghan, L. F. (2003). *Many ways to be deaf: International variation in deaf communities*. Washington, DC: Gallaudet University Press.
- Moores, D. F., & Miller, M. S. (2009). *Deaf people around the world: Educational and social perspectives*. Washington, DC: Gallaudet University Press.
- Murthy, D. (2008). Digital ethnography: An examination of the use of new technologies for social research. *Sociology*, 42(5), 837-855.
- Najarian, C. (2006). *Between worlds: Deaf women, work and intersections of gender and ability*. New York, NY: Routledge.
- Narr, R. F., & Kemmery, M. (2015). The nature of parent support provided by parent mentors for families with deaf/hard-of-hearing children: Voices from the start. *Journal of Deaf Studies and Deaf Education*, 20(1), 67-74. doi:10.1093/deafed/enu029
- Nelfelt, K., & Palviainen, Å N. (2004). "Det hörs!": Från visuell till auditiv kommunikation hos små döva barn med cochleaimplantat. *Slutrapport från projektet: Språkutveckling hos barn med CI-språkliga konsekvenser av ny medicinsk teknik*. Gothenburg, Sweden: Gothenburg papers in theoretical linguistics. 31.
- Neria, C. M. (2011). *Emerging adults with cochlear implants: Their experiences and lifeworlds*. Retrieved from <http://www.deaf.elemedu.upatras.gr/images/Proceedings/EMERGING%20ADULTS%20WITH%20COCHLEAR%20IMPLANTS.pdf>
- Neuss, D. (2006). The ecological transition to auditory-verbal therapy: Experiences of parents whose children use cochlear implants. *The Volta Review*, 106(2), 195.
- Newport, E. L. (1991). Contrasting conceptions of the critical period for language. *The Epigenesis of Mind: Essays on Biology and Cognition*, 111-130.
- Ohna, S. E. (2004). Deaf in my own way: Identity, learning and narratives. *Deafness & Education International*, 6(1), 20-38.
- Ong-Dean, C. (2009). Distinguishing disability: Parents, privilege, and special education. Chicago, IL: University of Chicago Press.
- Padden, C. & Humphries, T. (2005, 2009). *Inside deaf culture*. Cambridge, MA: Harvard University Press.

- Paludneviciene, R., & Leigh, I. (2011). *Cochlear implants: Evolving perspectives*. Washington, DC: Gallaudet University Press.
- Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society*, 14(5), 597-610.
- Peñaranda, A., Suárez M, R., Niño M, N., Aparicio, M. L., García, J. M., & Barón, C. (2011). Parents' narratives on cochlear implantation: Reconstructing the experience of having a child with cochlear implant. *Cochlear Implants International*, 12(3), 147-156.
- Perold, J. L. (2001). An investigation into the expectations of mothers of children with cochlear implants. *Cochlear Implants International*, 2(1), 39-58.
- Pisoni, D. B., Conway, C. M., Kronenberger, W. G., Horn, D. L., Karpicke, J., Henning, S. C., & Hauser, P. (2008). Efficacy and effectiveness of cochlear implants in deaf children. *Deaf Cognition: Foundations and Outcomes*. 52-101.
- Preisler, G. (2009). The situation for the deaf in Sweden. In D. Moores & M. Miller (Eds.), *Deaf people around the world: Educational, developmental, and social perspectives*. Washington, DC: Gallaudet University Press.
- Preisler, G., Tvingstedt, A., & Ahlström, M. (2002). A psychosocial follow-up study of deaf preschool children using cochlear implants. *Child: Care, Health and Development*, 28(5), 403-418.
- Preisler, G., Tvingstedt, A., & Ahlström, M. (1999). *Cochlea implantat på barn: En psykosocial uppfölningsstudie. mötet mellan föräldrar och CI-team samt mötet mellan förskolepersonal och CI-team*. Malmö, Sweden: Institutionen för pedagogik, Lärarutbildningen, Malmö högskola.
- Preisler, G., Tvingstedt, A. L., & Ahlström, M. (2003). Skolsituationen för barn med cochlea implantat-ur föräldrars, lärares och assistenters perspektiv.(The school situation of children with cochlear implants—from the perspective of parents, teachers and assistants). Stockholm, Sweden: Stockholm University: Department of Psychology. 116.
- Punch, R., & Hyde, M. (2011). Social participation of children and adolescents with cochlear implants: A qualitative analysis of parent, teacher, and child interviews. *Journal of Deaf Studies and Deaf Education*, 16(4), 474-493. doi:10.1093/deafed/enr001
- Quittner, A. L., Steck, J. T., & Rouiller, R. L. (1991). Cochlear implants in children: A study of parental stress and adjustment. *Otology & Neurotology*, 12, 95-104.
- Rainie, H., & Wellman, B. (2012). *Networked: The new social operating system*. Cambridge, MA: MIT Press.
- Ramcharan, P., & Cutcliffe, J. R. (2001). Judging the ethics of qualitative research: Considering the 'ethics as process' model. *Health & Social Care in the Community*, 9(6), 358-366.

- Rauscher, L., & McClintock, M. (1997). Ableism curriculum design. In *Teaching for Diversity and Social Justice*. 198-229.
- Robinson, K. M. (2001). Unsolicited narratives from the internet: A rich source of qualitative data. *Qualitative Health Research*, 11(5), 706-714.
- Roos, C. (2009). Fakta om döva barn. *En Förstudie Om Döva Små Barn [Facts about Deaf Children.]* Retrieved from <http://www.pinfo.se/pages/sdr-forstudie.pdf>
- Sach, T. H., & Whynes, D. K. (2005). Paediatric cochlear implantation: The views of parents: [Implantación coclear pediátrica: Los punto de vista de los progenitores]. *International Journal of Audiology*, 44(7), 400-407.
- Sacks, O. (2009). *Seeing voices: A journey into the world of the deaf*. Los Angeles, CA: University of California Press.
- Samp, C. (2010). Cochlear implants in the deaf community: Current circumstances of cochlear implant users among the deaf youth in Sweden's educational system. (Thesis). Retrieved from <http://scholarworks.rit.edu/cgi/viewcontent.cgi?article=8296&context=theses>
- SBU Statens beredning för medicinsk utvärdering. (2006). Bilateral cochleaimplantat (CI) hos barn. (2006). Alert-rapport 2006-01. ISSN 1652-7151). Stockholm, Sweden.
- Scambler, S. (2013). Cochlear implants and identity politics: A parent's perspective. *Medical Sociology Online*, 7(1), 34.
- Scheetz, N. (2012). *Deaf education in the 21<sup>st</sup> century: Topics and trends* (1st ed.). Boston, MA: Pearson.
- Schönström, K. (2010). Tvåspråkighet hos döva skolelever: Processbarhet i svenska och narrativ struktur i svenska och svenska teckenspråk. (Dissertation). Retrieved from <http://www.diva-portal.org/smash/get/diva2:347371/FULLTEXT01.pdf>
- Scott, D., & Usher, R. (2010). Researching education: Data, methods and theory in educational enquiry Bloomsbury Publishing.
- Sensoy, Ö, & DiAngelo, R. (2012). *Is everyone really equal? An introduction to key concepts in social justice education*. New York, NY: Teachers College Press.
- Smith, C. (2002). The sequestration of experience: Rights talk and moral thinking in Late modernity. *Sociology*, 36(1), 43-66.
- Smith, D. (2002). Institutional ethnography. *Qualitative Research in Action*, 17-52.
- Smith, D. (1987). *The everyday world as problematic: A feminist sociology* Toronto, Canada: University of Toronto Press.

Snoddon, K., & Underwood, K. (2014). Toward a social relational model of deaf childhood. *Disability & Society*, 29(4), 530-542.

Socialstyrelsen (2009). Vård vid nedsatt hörsel: utveckling inom valda områden. In *Hälso- o sjukvårdsrapport* (294-304) (*Hearing impairment health care*). Retrieved from <http://www.socialstyrelsen.se/publikationer2009/2009-126-72/Documents/Utveckling%20V%C3%A5rd%20vid%20nedsatt%20h%C3%B6rse1.pdf>

Solomon, A. (2012). *Far from the tree: Parents, children and the search for identity* New York, NY: Simon and Schuster.

Solorzano, D. G., & Yosso, T. J. (2002). Critical race methodology: Counter-storytelling as an analytical framework for education research. *Qualitative Inquiry*, 8(1), 23-44.

Solvang, P. K., & Haualand, H. (2014). Accessibility and diversity: Deaf space in action. *Scandinavian Journal of Disability Research*, 16(1), 1-13.

Sparrow, R. (2005). Defending deaf culture: The case of cochlear implants. *Journal of Political Philosophy*, 13(2), 135-152.

Spradley, J. P. (1979). The ethnographic interview. New York, NY: Holt, Rinehart and Winston.

Specialpedagogiska skolmyndigheten. (2014). *Årsredovisning 2013*. Retrieved from <https://webbshop.spsm.se/globalassets/publikationer/specialpedagogiska-skolmyndighetens-arsredovisning-2013-pdf/>

Stokoe, W. C. (1978). Sign language structure [Abstract]. Retrieved from <http://eric.ed.gov/?id=ED189874>

Stommel, W., & Koole, T. (2010). The online support group as a community: A micro-analysis of the interaction with a new member. *Discourse Studies*, 12(3), 357-378.

Sveriges dövas riksförbund. (2014). *Dövkultur*. Retrieved from <http://sdr.org/dova/dovkultur>

Swedish language act. (2009) Swedish Code of Statutes no: 2009:600Cong. doi:[http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/spraklag-2009600\\_sfs-2009-600](http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/spraklag-2009600_sfs-2009-600)

Szagun, G. (2008). Proceedings from CLS2007: *Child Language Seminar 2007*. The younger the better? Variability in language development of young German-speaking children with cochlear implants. Retreived from [http://wap.rdg.ac.uk/web/FILES/cls/CLS\\_Proceedings2.pdf#page=177](http://wap.rdg.ac.uk/web/FILES/cls/CLS_Proceedings2.pdf#page=177)

Thouttenhoofd, E. D., Archbold, S. M., Gregory, S., Lutman, M. E., Nikolopoulos, T. P., & Sach, T. H. (2005). *Paediatric cochlear implantation: Evaluating outcomes*. Hoboken, NJ: Wiley Blackwell.

- Todd, S., & Jones, S. (2005). Looking at the future and seeing the past: The challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research*, 49(6), 389-404.
- Traci, M., & Koester, L. S. (2003). Parent-infant interactions: A transactional approach to understanding the development of deaf infants. *Oxford Handbook of Deaf Studies, Language, and Education*, 190-202.
- Trevisan, F., & Reilly, P. (2014). Ethical dilemmas in researching sensitive issues online: Lessons from the study of British disability dissent networks. *Information, Communication & Society*, 17(9), 1131-1146.
- Tvingstedt, A., Preisler, G., & Ahlström, M. (2003). *Skolplacering av barn med cochlea implantat*. Stockholm, Sweden: Stockholms Universitet, Psykologiska Institutionen.
- Utbildningsdepartementet. (1997). *Förordning (1997:1158) om statsbidrag för teckenspråksutbildning för vissa föräldrar*. Regulation for national grant for sign language instruction for certain parents TUFF. (1997). Stockholm, Sweden.
- Valente, J. M., Bahan, B., Bauman, H., Petitto, L., & Hall, E. T. (2011). Sensory politics and the cochlear implant debates. *Cochlear Implants: Evolving Perspectives*, 245-258.
- Van Dijck, J. (2013). *The culture of connectivity: A critical history of social media*. Oxford, UK: Oxford University Press.
- Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek, CA: Left Coast Press.
- Wacquant, L. (2015). For a sociology of flesh and blood. *Qualitative Sociology*, 38(1), 1-11.
- Washington, J., & Evans, N. J. (1991). Becoming an ally. In N. J. Evans & V. A. Wall (Eds.), *Beyond Tolerance: Gays, Lesbians, and Bisexuals on Campus* (195-204). Alexandria, VA: American College Personnel Association.
- Watson, L. M., Hardie, T., Archbold, S. M., & Wheeler, A. (2008). Parents' views on changing communication after cochlear implantation. *Journal of Deaf Studies and Deaf Education*, 13(1), 104-116. doi:enm036 [pii]
- Wellman, B., & Rainie, L. (2012). *Networked: The new social operating system*. Cambridge, MA: MIT Press.
- Wenger, E. (1999). *Communities of practice: Learning, meaning, and identity*. Cambridge, UK: Cambridge University Press.
- Wenger, E. (2000). Communities of practice and social learning systems. *Organization*, 7(2), 225-246.

- Wennergren, A. (2007). Dialogkompetens i skolans vardag: En aktionsforskningsstudie i hörselklassmiljö. (Doctoral dissertation). Retrieved from Luleå tekniska universitet <http://pure.ltu.se/portal/files/1013023/ltu-dt-0734-se.pdf>
- Westin, C. (1994). Från registrering av uppgifter till tolkning av texter. In B. E. Eriksson och E. Nässman (Eds.) *Samhällsvetenskap Och Vardagserfarenhet: Teori, praktik, etik* (149-170). Stockholm, Sweden: Liber Utbildning.
- Wetherell, M. (2012). *Affect and emotion: A new social science understanding*. London, UK: SAGE.
- Wheeler, A., Archbold, S. M., Hardie, T., & Watson, L. M. (2009). Children with cochlear implants: The communication journey. *Cochlear Implants International*, 10(1), 41-62.
- World Health Organization. (2015) Deafness and hearing loss. Retrieved from <http://www.who.int/mediacentre/factsheets/fs300/en/>
- World Health Organization. (2016). *Grades of hearing impairment* Retrieved from [http://www.who.int/pbd/deafness/hearing\\_impairment\\_grades/en/](http://www.who.int/pbd/deafness/hearing_impairment_grades/en/):
- Yoshinaga-Itano, C. (2003). Early intervention after universal neonatal hearing screening: Impact on outcomes. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(4), 252-266.
- Yoshinaga-Itano, C., Coulter, D., & Thomson, V. (2001). Developmental outcomes of children with hearing loss born in Colorado hospitals with and without universal newborn hearing screening programs. *Seminars in Neonatology*, 6(6) 521-529.
- Yoshinaga-Itano, C., Sedey, A. L., Coulter, D. K., & Mehl, A. L. (1998). Language of early-and later-identified children with hearing loss. *Pediatrics*, 102(5), 1161-1171.
- Yoshinaga-Itano, C., Baca, R. L., & Sedey, A. L. (2010). Describing the trajectory of language development in the presence of severe-to-profound hearing loss: A closer look at children with cochlear implants versus hearing aids. *Otolaryngology: Official Publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology*, 31(8), 1268-1274. doi:10.1097/MAO.0b013e3181f1ce07
- Young, A. (2003). *Parenting and deaf children: A psycho-social literature-based framework*. London, UK: National Deaf Children's Society. Retrieved from <http://www.worldcat.org/title/parenting-and-deaf-children-a-psycho-social-literature-based-framework/oclc/61480776>
- Young, A. (1999). Hearing parents' adjustment to a deaf child- The impact of a cultural-linguistic model of deafness. *Journal of Social Work Practice*, 13(2), 157-176.

- Young, A., Greally A., & Nugent, J. (2003). Parenting and deaf children: Report of the needs assessment study undertaken as part one of the NDCS parents' toolkit development project. London, UK: NDCS.
- Young, A., & Tattersall, H. (2005). Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. *Journal of Deaf Studies and Deaf Education*, 134-145.
- Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, 12(2), 209-220. doi:enl033
- Young, A., & Temple, B. (2014). *Approaches to social research: The case of deaf studies*. Oxford, UK: Oxford University Press.
- Zaidman-Zait, A. (2008). Everyday problems and stress faced by parents of children with cochlear implants. *Rehabilitation Psychology*, 53(2), 139.
- Zaidman-Zait, A., & Young, R. A. (2008). Parental involvement in the habilitation process following children's cochlear implantation: An action theory perspective. *Journal of Deaf Studies and Deaf Education*, 13(2), 193-214. doi:enm051
- Zeiler, K. (2010). A phenomenological analysis of bodily self-awareness in the experience of pain and pleasure: On dys-appearance and eu-appearance. *Medicine, Health Care and Philosophy*, 13(4), 333-342.
- Zeiler, K., & Käll, L. F. (2014). *Feminist phenomenology and medicine*. Albany, NY: SUNY Press.

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*Appendix I*

Department of Education  
Stockholms University

**A research project-  
The everyday experiences of parents of children with  
cochlear implants**

**Hello!**

**Would you be interested in being interviewed about what it is like to have a child who has a cochlear implant?**

Today there is limited knowledge about parents' experiences in living with a child who hears differently or is deaf. What is it like to be a parent in a situation that differs from most others? What help or information should our society provide for families? You have received this letter because your child either attends a school, you are a member of an organization or you have contact with social services or a hearing clinic. I am going to conduct interviews with parents about their thoughts about hearing and everyday life. The aim is to find out how parents experience having a child who uses a CI. Both mothers and fathers are encouraged to participate.

**How does it work?**

The interviews will take place wherever we decide, either in your home or at my office at the university or via Skype. I am flexible and will adjust to your schedule. In this interview you will be asked questions about your situation and given ample opportunity to talk about issues you feel are important. The conversation takes about an hour and is digitally recorded. Participation in this study is voluntary and the material that is produced will be handled confidentially so that no individuals can be identified. You can also choose to discontinue your participation at any time during the study.

**I hope you think this sounds interesting and you choose to participate.**  
Please contact me by email [liz.adams.lyngback@edu.su.se](mailto:liz.adams.lyngback@edu.su.se) or mobile phone 070-887 50 80 if you choose to take part in this opportunity. If you have any questions about this study you can contact me at any time.

Sincerely,

Liz Adams Lyngbäck BA, MS  
PhD Candidate in Education

Professor Anders Gustavsson  
Supervisor

En studie om hur föräldrar till barn med cochleaimplantat upplever sin vardag

## **Hej!**

Vill du/ni delta i ett intervjustal om hur det är att ha ett barn som har CI?

Idag finns det begränsad kunskap om föräldrars erfarenheter av att leva med hörselskadade barn och ungdomar. Hur är det att vara förälder till ett barn som inte hör som andra? Vilken hjälp och information efterfrågar föräldrar från samhället? Du får det här brevet för att ditt barn antingen går i skolan, du är medlem i en intresseförening eller har kontakt med hörselhabiliteringen eller vården. Jag kommer nu att genomföra intervjuer med föräldrar om tankar kring hörsel och vardagen. Syftet är att ta reda på hur föräldrar upplever situationen att ha ett barn som använder CI. Både barnets mamma och pappa är välkomna att delta.

## **Hur går det till?**

Intervjuer kommer att genomföras på en plats som vi kommer överens om, antingen i ditt hem, på min arbetsplats på universitetet eller via Skype. Jag anpassar mig till en tid som passar dig/er. Det är en intervju där du kommer att få frågor om din situation och får möjlighet att ta upp sådant som du själv tycker är viktigt. Samtalen beräknas ta cirka 1 ½ timme och spelas in digitalt. Deltagandet i studien är frivilligt och materialet från samtalen kommer att behandlas konfidentiellt så att inga enskilda personer kan identifieras. Man kan naturligtvis avbryta sitt deltagande närsomhelst under studien.

## **Jag hoppas att du tycker detta är intressant och du vill medverka.**

Vänligen meddela mig genom att besvara via mail liz.adams.lyngbäck@edu.su.se eller mobil 070-887 50 80 om du kan tänka dig att delta. Om du har några funderingar om studien får du gärna höra av dig till mig.

Bästa hälsningar,

Liz Adams Lyngbäck  
Doktorand

Professor Anders Gustafsson  
Handledare

## *Appendix 2*

Hello, 2014  
My name is Liz Adams Lyngbäck and I am hoping to contact someone to request a study visit at your clinic. I am working on a research project at Stockholm University in Sweden where I have lived for the past 25 years. I am a native of Kentucky and have family in the area.

The reason I am contacting you is to ask some questions and visit your clinic as part of collecting contrasting material about lived experiences of cochlear implantation. I am in the social science research in health and illness group here at the Department of Education. My main focus is on parents and how they experience the technology, what is important to them, what they think about.

I will be in the area between April 5 and April 16 this spring. I know what workloads are like for you so even a half hour would be very helpful.

I am also interested in coming into contact with parents for interviews in the near future and would like to post information about this in your waiting areas.

I look forward to hearing from you.

Sincerely,  
Liz Adams Lyngbäck  
PhD candidate  
Department of Education  
Stockholm University

Jag heter Liz Adams Lyngbäck och är forskarstuderande vid Institutionen för pedagogik och didaktik inom området Pedagogik och Hälsa. Jag studerar vardagsupplevelser hos föräldrar till barn med cochleaimplantat. Under 2014 planerar jag att göra fältarbete på CI sektionen på Karolinska sjukhuset i Huddinge. Jag kommer att finnas i klinikens lokaler och delta vid konsultationer och samtal mellan klinikens anställda och familjer där föräldrar närvarar. Mitt syfte med fältarbetet är att lära mig om hörselvård, cochleaimplantat och lärande. Allt deltagande är frivilligt och konfidentiellt. När som helst kan personalen eller patienter och medföljande föräldrar be att jag avstår utan förklaring.

I den här delen av mitt avhandlingsprojekt gör jag fältarbete på medicinska kliniker och i olika sammanhang där familjer träffas för att utbyta erfarenheter. I den andra delen av projektet gör jag intervjuer med föräldrar om deras upplevelser av barnens cochleaimplantat. Resultaten kommer att användas för att förbättra vården och ge föräldrar förbättrade förutsättningar att stödja sina barn och leva ett gott liv.

Är du intresserad av att veta mera om projektet eller vill träffa mig vid ett annat tillfälle kan du nå mig via mejl eller mobiltelefon. Annars ses vi kanske under ett av dina besök på kliniken.

Med vänliga hälsningar

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## *Appendix 4*

### Interview guide 1

What is it like being a parent of a deaf/hard of hearing child?  
What has changed in how you communicate?  
Do you consider your child to be deaf if s/he uses a CI?  
What does it mean to be deaf?  
How do you behave differently in speaking with your child?  
What do you think about when you think of your child's future?  
How do you think your child's way of experiencing the world impacts you?  
Do you know other children in a similar situation?  
Do you spend time with them?  
How do you talk about deafness in your family?  
Do you feel like you live in two worlds?  
How have you changed?  
Can you describe a situation that you think would be different if your child could hear like you do?  
What concrete examples can you give of day to day living that takes into account your hearing difference?  
Do you interact or communicate differently with others because of different hearing status in your family?  
What do you think about sign language? (attitudes, beliefs, the CI debate's effect)  
Do you want your child to be part of a community that has members with different hearing status?  
Do you think about hearing differently now?  
What thoughts do you have about being dependent on technology to communicate with each other?  
What are the practical situations that you worry about?

## Interview guide 2

Meeting deafness story?

Meeting other children and adults in the same situation?

What have you learned?

How did you learn that?

What do you do that is different than before?

What do you think that is different than before?

What type of relationship with deaf person/child?

Challenges?

Closeness?

Focused on?

Hindered?

How do you communicate best with each other?

Do you have a role model when it comes to this?

Do you have a teacher figure that you think is a great role model?

What do they do?

What do they have that you have learned from?

Do you relate to others in new ways because of what you know about deafness?

Do you relate/communicate better or differently because of how you communicate with your child?

How do you feel different?

How do you feel about being different?

Do you see your child as different still?

Good, bad or different experience?

How can you describe your identity, your child's your families when it comes to hearingness... differentness?

How has your life changed? Concrete examples.

Home environment.

Preschool/day care

Schools

Biographical information

*Appendix 5*

Informerat samtycke / Informed consent

Undertecknad

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Har tagit del av information om studiens syfte genom inbjudan och fått  
möjlighet att ställa frågor angående studiens utformning och användning.  
Undertecknad samtycker till att delta i studien.

I have read the information about the aim of the study through the letter to  
informants and have been given the opportunity to ask questions about the  
design and use of the study. I hereby consent to participate in the study.

---

Datum, Plats och Namn  
Date, City and Signature

(Presented with copy of 'Call for informants' letter and attached and archived  
with Interview Record)

## **Interview Record**

**Date:**

**Name:**

**Child(ren)'s age:**

**Age at time of operation:**

**First CI:**

**Second CI:**

**E-mail:**

**Mobile:**

**Other contact info:**

## Appendix 7

### Transcription conventions

I have chosen to present the excerpts from interviews in a revised form using fewer transcription markers. The transcribed data were made using the following transcription conventions:

-	interrupted word
,	short pause with no intonation of conclusion
.	intonation of conclusion followed by a pause
#	unintelligible
(?)	inconclusive transcription
<i>italics</i>	marked speech either by volume or utterance or emphasis
(laughter)	laughter without speech or other non-verbal sounds
<u>underlined</u>	simultaneous speech
(L: “mm”)	utterances during speech indicating listening
[comment]	comment on the transcription content
[...]	sequence left out of the transcription or excerpt

## *Appendix 8*

List of fieldwork sites and contexts where field notes were generated

The physical fieldwork consists of three main arenas: medical contexts, the educational contexts, cultural historical contexts of deafness and disability. The digital fieldwork includes material from these arenas as well but is organized as social media use materials and online information materials (not primarily interactive)

## **Physical fieldwork**

### **Educational contexts (253 hours)**

- TUFF (Swedish Sign Language instruction for parents/ Teckenspråksutbildning för föräldrar) outings for families, week long camps, thematic weekend courses ( 2007-2015 200 hours)
- 2 terms of university level classroom observation of deaf lecturers and first year college students learning Swedish Sign Language Introductory level L2 instruction (shadowing adults who either were hard of hearing or had interpersonal connection to sign language users and CI users) (2012-2013 40 hours)
- Visits at two hearing centers and adjoining preschool programs in southeastern United States (2014 6 hours)
- Presentation of study plan and recruitment at evening sign classes (2013 4 hours)
- Special Education Department of a university in southeastern United (2014 1 hour)
- Introduction day to new parents at preschool States, parent presents himself, 'What we have to offer'(2014 2 hours)

### **Medical contexts (60 hours)**

- Hearing clinic at hospital (observation of hearing tests primarily how audiologists explain audiograms to parents) (2013 2 hours)
- Hearing Rehabilitation Clinic (shadowing parents, shadowing different professions, attending staff meetings (2013 25 hours)
- Waiting rooms in hospitals and clinics (2013 8 hours)
- CI clinic personnel meetings (2013 2 hours)
- Parent council advisory meetings at hearing rehabilitation clinic 2013- 2015 12 hours)
- Cochlear implant parent organization -Barnplantorna's 2 day Nordic conferences 2012 and 2014 (4 days)

- “Cochlear implantation in Sweden 30 years anniversary” symposium (2014 3 hours)
- Conversations with five new parents on neonatal hearing screening experiences with normal readings (2012-2015) (2 hours)
- Hearing technology and communication fairs (2014-2015 6 hours)
- Interview with speech pathologist (2014 3 hours)
- All day meeting with research team on DHH disability(audiology and cognitive science) (2013 6 hours)
- Following dissertational work in connected fields of cochlear implantation (medical, audiological, clinical counseling) (2013-2015 6 hours)
- CI 30 years in Sweden lecture and program (CI 30 år 5 hours)

### **Cultural historical contexts (191 hours)**

- Parent and family activities in organizations for children with hearing impairment and/or other communication related disabilities(climbing, camping, boating, fishing, skiing, museums visits, theater performances, swimming lessons, skiing trips, painting workshops and art exhibits, lectures, zoos and zoo schools, technology fairs) (2013-2015 20 hours)
- Winter activity camps for families (2013 and 2014 4 days)
- Weekend courses for parents of DHH children with multiple disabilities (2014-2015 5 days)
- Two summer family camps 2013 and 2015 (10 days)
- Parent organization board meetings (2014-2015 30 hours)
- Meeting with coordinator of deaf parent groups and networks (2013 2 hours)
- Döv för en kväll (Deaf for an Evening): monthly outreach sign language practice activities run by an organization for the deaf during (2013- 2014 6 evenings 12 hours)
- SDR’s Swedish Deaf Studies (Dövstudier för alla) course, 2 day introduction and 8x2 hour online class meetings (2014 40 hours)
- Deaf Studies conference ( 2015 6 hours)
- Sign language interpretation department study visits (2014 3 hours)
- Nordic conference ‘Why bilingualism?’ Gothenburg, September 15-16 2015 (16 hours)
- Following dissertational work in connected fields of cochlear implantation (linguistics education) (2013-2015 8 hours)
- Interview with university research employee (1 hour)
- University Deaf Studies classroom observation (2014 2 hours)
- University American Sign Language classroom observation (2014 2 hours)
- Swedish Sign Language theme days for families (2013-2014 6 hours)

- Interview about Swedish Language institute and Swedish Language Act 2015 interview (1 hour)
- Child care activities of CODA care worker and signing children 2013-2014 (short intervals amounting to 2 hours)
- Child care activities with signing, hard of hearing care worker and signing children (2014-2015 short intervals amounting to 3 hours)
- Child care activities with beginner signer hearing care worker and signing children (2015-2016 short intervals amounting to 6 hours)
- Proceedings from Multimodal Multilingual Outcomes in Deaf and Hard-of-Hearing Children. June 13-15, 2016.

## **Digital fieldwork**

### **Social media (approx. 100 hours throughout 2013-2014)**

- Facebook (10 closed groups and 5 open groups)
- Facebook groups for parent organizations
- Twitter (when linked with Facebook groups)
- Pinterest (visual material when linked with Facebook groups)
- Blog and vlog materials
- Instant messages

### **Online information materials**

- Web pages linked to OSGs and SMSs above
- Web pages of and linked parent organizations
- Email correspondence including fieldwork contacts, parents, parent organization board members, personal communication via email cited in text