

Parents' Experiences on Follow-up of Children's Language Learning after Cochlear Implantation

By

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In loving memory of my parents

Abstract

This study explores parents' experiences on follow-up of children's language learning after cochlear implantation (CI). A cochlear implant is a surgically implanted hearing device that provides access to sound for a person diagnosed with profound hearing loss. In Norway, more than 90 % of children diagnosed with profound hearing loss receive a cochlear implant, often before their first birthday. Research states that the parents' involvement is significant for outcomes after CI, which is why professional support for parents is considered crucial; however, the parents' experiences with follow-up have received little scrutiny in research. The study's overarching research question is *what are parents' experiences on follow-up supporting language learning after cochlear implantation, and how may these experiences be understood?*

The study has a qualitative, explorative design and its empirical material consists of two data sets: 1) 27 written parental responses to an online questionnaire with open-ended questions, and 2) 14 verbatim transcripts of individual, semi-structured interviews with 14 of those parents. The study draws on analytical resources anchored in Foucauldian power/knowledge structures, conceptualizations of learning, as well as narrative methodological approaches. The study consists of four sub-studies, which together address the overarching research question.

The purpose of the study is twofold. Firstly, the study aims to contribute to the knowledge field concerning professional support for parents of children using a cochlear implant. Secondly, the study of parents' experiences on follow-up after CI is situated within larger contexts of scientific and public discourse that address professional support for parents and parental involvement in general educational contexts. The answers to the overarching research question will provide grounds for discussing how the specific case of follow-up after CI may play into current discourses about parental involvement and support for parents in educational contexts on a more general level.

Abstract

Main findings show that follow-up of children's language learning after CI is generally constructed as a process of rehabilitation. The study brings to the fore that the parents' experiences with follow-up are characterised by living with and responding to uncertainties. It is argued that the parents' experiences may be understood as impressions of a performative, instrumental reasoning in follow-up, reflecting normalising practices, causing parents to become caught up in the current of a rehabilitation stream. The study discusses possible consequences for the parents and children involved and emphasises that professional support may reduce the pressure of the language of instrumentality and its inherent focus on performativity, leaving room for parents to be parents, not teachers.

List of papers

The following papers are incorporated in the thesis:

Bruin, M. (2015). Research on language development: Discourses on learning and messages to family support after CI. In H. Knoors & M. Marschark (Eds.), *Educating Deaf Learners: Creating a Global Evidence Base* (pp. 93-113). New York, NY: Oxford University Press.

Bruin, M., & Nevøy, A. (2014). Exploring the Discourse on Communication Modality after Cochlear Implantation - A Foucauldian Analysis of Parents' Narratives. *Journal of Deaf Studies and Deaf Education*, 19(3), 385-399.

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PART 1

An introductory note on researcher subjectivity

Every story has a beginning.

The impetus for the topic of this research traces back to the year 2003 when our youngest daughter was diagnosed with profound hearing loss, at thirteen months of age. From then onward, we – her parents – were involved in a professional support system guiding us. From the day our daughter received her bilateral cochlear implants in the fall of 2004, and onward, our family has been, and will continue to be, part of the same professional support system as described by the participants in this study.

On the one hand, being a parent to a child who uses a cochlear implant has provided me with experiences similar to those of the research participants. On the other hand, back in 2003, there were not as many parent programs in Norway. The parent program available to us was ‘Se mitt språk’ [See my language], which is the Norwegian parent program on sign language in which we participated. In addition, I took a university course of 30 ECTs in *Norwegian sign language and Deaf culture*. Being a Dutch family living in Norway, we used two spoken languages, Dutch and Norwegian. Choices had to be made regarding communication in everyday family life. Parent programs concerning spoken language learning, which are readily available to contemporary parents, were not available at the time. In summary, due to quickly changing contexts in which the professional support options have increased, my experience with professional support as a parent has been slightly different from the participants in the study.

Being a parent to a child who uses a cochlear implant has been a driving force in the research process. This double role as parent and as researcher points to matters concerning researcher subjectivity. However, following Ricoeur, personal prejudice on part of the researcher – threatening research validity and trustworthiness – may be prevented not by *denying* the role of “personal commitment in understanding human phenomena”, but by *qualifying* it (Ricoeur, 1981, p. 220). Therefore, a core issue throughout the research process has been to qualify my personal commitment. This I have tried to do by

An introductory note on researcher subjectivity

providing rigorous descriptions of theoretical foundations through broad and thorough reviews of the literatures, as well as the provision of transparency concerning specific choices of theoretical perspectives selected for analysis. I have tried to clarify and explicate choices of research design, to provide coherence and multi-angled argumentation, as well as to explain choices of ethical stance. This process qualifies my subjectivity as a researcher. Therefore, my personal engagement as parent to a child who uses a cochlear implant may provide additional strength helping to understand “the meaningful patterns which a depth interpretation wants to grasp” (Ricoeur, 1981, p. 220).

1 Introduction – Researching parents’ experiences on follow-up of children’s language learning after cochlear implantation

1.1 Background, purpose and overarching research question

The topic for the study concerns an interest in parents’ experiences on follow-up of their children’s language learning after cochlear implantation (CI)¹. Follow-up in the form of parental involvement is considered significant for children’s language learning after CI²; it rests on the general premise that parental care, support and guidance are important for children’s learning and academic achievement. Within the context of CI, parents are particularly important regarding issues that concern the child’s language learning; yet, the majority of children with profound hearing loss are born into families with no prior knowledge about hearing loss, CI and issues of language learning. Therefore, professional guidance and expert knowledge are matters considered significant in supporting parents. From this follows that the research interest in parents’ experiences encompasses two interconnected aspects in follow-up, namely 1) the parents’ involvement in the child’s language learning, and 2) the professional support guiding them.

¹ A cochlear implant is a surgically implanted hearing device that provides access to sound, and thus to spoken language, to a person diagnosed with profound hearing loss. About 90-95 % of children in Norway who are deaf are offered cochlear implants (Kirkehei, Myrhaug, Garm, Simonsen, & Wie, 2011), often before ten months of age (source: Rikshospitalet Oslo [Oslo University Hospital]).

² Being sensitive to the fact that parents in follow-up may communicate through multiple modalities with their child, the extended abstract uses the generic term ‘language learning’, referring to language as both spoken and signed, acknowledging that various options are possible. Nevertheless, studies on follow-up of language learning after CI mainly address language learning as *spoken* language learning.

Notwithstanding the importance of parents for children's language learning after CI, the experiences of parents on follow-up have received little scrutinising attention in research. Exploring parents' experiences may provide relevant information about how parents engage in children's language learning after CI, as well as how parents experience the professional support. Research states that how parents are affected by professional support is to a great extent subject to its *reception* by families, rather than by its provision (Young, Gascon-Ramos, Campbell, & Bamford, 2009). How parents make sense of, and construct meaning of, professional advice will affect how they engage in children's language learning. Hence, the research interest in this study has focussed on parents' personal narratives on their experiences on follow-up. More precisely, the study explores what parents convey about their experiences with 1) the professional support guiding them after CI, and 2) their involvement in the child's language learning. Thus, the focus is not on language learning from a linguistic point of view.

The research topic encompasses the expression 'language learning', and not 'language development'. Focussing on 'learning' rather than 'development' is motivated by the research interest of the study. The parents' involvement in the child's language learning is viewed from a perspective that involves the situated nature of parent-child interaction in everyday family life, more than a psychological perspective on development. This notwithstanding, whenever the dominant contextual understanding in research forming a background for the topics incorporated in this thesis has been focussed on language *development*, the expression 'language development' has been used in the thesis.

Anchored in the study's topic of language learning, a specific interest has been on *language*. The issue of language in the term "follow-up of children's language learning after CI" is complex and a source of debate in both research and professional support. The debate is centred on opposing views concerning language modalities and their supposed effect on spoken language learning. The modalities form a spectre ranging from approaches based on spoken language to sign/bilingual approaches. Caught at the challenging core of these scientific and professional debates, parents have to choose between varying options. Since the issue of language modality and its accompanying choice will influence the parents' involvement in the child's language, a central

point of interest in exploring parents' experiences on follow-up has been to investigate the parents' experiences with the professional debates.

From this follows a second topic of research interest. Similar to the issue of *language* being part of language learning after CI, is the concept of *learning*. An important source of inspiration for this study stems from writings addressing learning as a concept that can be understood in multiple ways; the concept of learning is not straight forward but a rather complex, and by no means unambiguous, phenomenon (Alexander, Schallert, & Reynolds, 2009; Deleuze & Guatarri, 1987; Illeris, 2009; Jarvis, 2006; Sfard, 1998; Säljö, 2009, 2016). More precisely, and relevant for follow-up of children's language learning after CI: the way in which learning is understood will influence how *support* for learning is designed (Säljö, 2016; Wenger, 1998). Therefore, an additional point of interest has been to view the parents' accounts on their experiences on follow-up of language learning after CI in the light of various conceptualisations of learning.

Summarised, the study's general interest is focussed on what parents express about their experiences on being involved in their child's language after CI, as well as their experiences with the professional support guiding them. Subsequently, the aim is to explore the following overarching research question: *What are parents' experiences on follow-up of children's language learning after CI, and how may these experiences be understood?*

Follow-up of the child's language learning after cochlear implantation rests on the premise that parents are important for children's learning (Harris & Goodall, 2008). What parents do is considered to have a strong influence on the child's learning and academic achievements (Vincent, 2012). An extensive body of research addresses the significance of these issues; parents' actions regarding how they support the child's learning are suggested to greatly affect children's educational accomplishments (Harris & Goodall, 2008; Sheldon & Epstein, 2005). The particular group of parents having a child who uses a cochlear implant is part of a wider, universal group of parents who encounter issues of parental involvement and professional support in educational settings in various ways. Part of these encounters concern discussions about the parents' role in educational contexts. In Western, post-industrial countries, parenting is at the centre of public and scientific attention, fuelled by concern about children's educational future and expressed through an extensive supply of

professional advice (Nelson, 2010). A substantial part of the research addressing the significance of the parents' role in educational contexts reports on the importance of parental involvement for children who are categorised with specific needs or diagnoses. This concerns a myriad of diverging topics. To name a few, it concerns matters on language intervention for children who are described as having "developmental delays" (Ronski et al., 2011, p. 111). Another topic concerns children diagnosed with "autism and related behavioural difficulties" (Preece, 2014; p. 136). Further, research addresses the involvement of parents in facilitating learning of children who are considered otherwise 'at risk', due to socioeconomic reasons (Heydon & Reilly, 2007). The common focus in this research is on the significance of providing knowledge and skills to parents that may help to support their child's learning. The examples presented here draw a picture that illuminates how the case of CI is a particular example within a broader context that focusses on parental involvement in children's learning. The research emphasising parents' importance for children's learning constitutes a background against which the scrutiny of parents' experiences on follow-up of language learning after CI is set.

1.2 One study - four sub-studies

The study consists of four sub-studies, which together address the overarching research question. The thesis consists of two parts. Part 1 is an extended abstract stating the research problem, reporting on the research process, discussing the findings and answering the overarching research question. Part 2 consists of four papers that report on the individual sub-studies that conjointly answer the study's overarching research question. Each sub-study has its individual research question, purpose and analytical focus. As will be explained in chapter 4, the study takes on an exploratory, data-driven approach. The following section presents a short overview of the research process, explicating how four sub-studies constitute the main study reported on in the extended abstract. The sub-studies consist of a conceptual literature review and three empirical studies.

The first sub-study is a conceptual literature review. The aim of a conceptual review is to clarify how core concepts are understood in the research domain (Jesson, Matheson, & Lacey, 2011). The study's particular interest in

understandings of learning, and how these may influence the design of support for language learning in follow-up after CI, generates a concern about how the research domain informing professional support conceptualises learning. This may affect how learning is conceptualised in professional support and may consequently influence how parents are guided in their support for the child's language learning. Therefore, by means of a conceptual review, the first sub-study explores how learning is conceptualised in research on language development after CI. The conceptual scrutiny roughly distinguishes between individual and social perspectives on learning as an analytical lens for identifying different understandings of learning. The analytical category of learning understood as an individual process is based on perspectives that view learning as transmission of knowledge. These perspectives draw on cognitive theories (Piaget, 1952). The analytical category of learning understood as a social process is based on perspectives that view learning as situated in social practice (Rogoff, 2003; Wenger, 1998). The contrasting categories were chosen based on the "cognitive versus situated learning debate" (Hodkinson, Biesta, & James, 2008, p. 29), a major debate about contrasting ways of understanding learning, raging at the end of the 1990s and still existent (Hodkinson et al., 2008).

The conceptual review generates knowledge about research underpinning professional support, concerning conceptualisations of learning and their implications for designing parent support. The sub-study hence provides a lead, a triggering interest in the phenomenon *learning*, providing "sensitizing concepts" suggesting "directions along which to look" (Blumer, 1969, p. 148) in the empirical sub-studies. Therefore, apart from being interesting in its own right, the conceptual review provides insights relevant for the subsequent empirical pursuit of the parents' experiences on follow-up.

In pursuing the parents' experiences on follow-up of children's language learning after CI, the study explores empirical material consisting of two data sets: 1) 27 written parental accounts in response to an online questionnaire with open-ended questions, and 2) 14 verbatim transcripts of interviews with parents who answered the questionnaire. The data construction focusses on issues such as parents' experiences on their involvement in follow-up and on supporting the child's language learning. Further, it focusses on parents' experiences on debates and controversies concerning language modalities. Moreover, data

construction focusses on parents' experiences on professional support, what they consider of importance, and why. Through a careful reading of the empirical data, possible topics of interest emerged, suitable for further research. Of those, with the insights from the conceptual review in mind, three topics were chosen for this study, considered suitable to address the study's overarching research question. These topics are 1) debates on communication modality, 2) parent insecurity and professional support, and 3) parental involvement in the child's language. These topics provide the research interests for the empirical sub-studies.

Based on the questionnaire data, one of the sub-studies investigates parents' written accounts on their experiences with the debates concerning language modality after CI, which is a major issue in follow-up (Archbold & Wheeler, 2010; Knoors & Marschark, 2012). The purpose of the sub-study is to explore the discourse on communication modality in follow-up of language learning after CI and to bring into conversation how the discourse might affect the parents and their involvement in the child's language. Another sub-study is based on the interview data and investigates how parents handle the insecurity of not knowing whether the implant will be of benefit to the child's language learning. Further, the study investigates the meaning parents ascribe to the professional support in this regard. The sub-study provides insight into how the parents' view their own roles in follow-up. The final sub-study is based on both the questionnaire data and the interview data. The study explores what parents express about their involvement in follow-up of the child's language learning after CI. It explores how their involvement might be shaped and how it might be motivated, in order to discuss possible consequences for the parents and children involved. It is argued that the three research topics, inductively generated from the two data sets, provide versatile grounds for answering the overarching research question from multiple angles.

The relatively new situation of technological advancement of cochlear implantation raises general issues of relationships between children, education and parents. It raises issues of expectations on children with reference to learning, as well as expectations on parents and professional support, and is therefore worth exploring. The purpose of the study is twofold. Firstly, the study aims to contribute to the knowledge field concerning professional support for parents of children using a cochlear implant. Secondly, the study of parents'

experiences on follow-up after CI is situated within larger contexts of scientific and public discourse that address professional support for parents and parental involvement in general educational contexts. The answers to the overarching research question will provide grounds for discussing how the specific case of follow-up after CI may play into current discourses about parental involvement and support for parents in educational contexts on a more general level.

1.3 General outline of the structure of the thesis

The thesis is divided into two main parts, 1) an extended abstract reporting on the research and answering the overarching research question, as well as appendices, and 2) four papers that report on the sub-studies. Part 1 of the thesis outlines the research problem and points out its significance for professional support guiding parents in facilitating their children's language learning after CI. Further, it describes the theoretical and methodological foundations for investigating the parents' experiences on follow-up. Cochlear implantation and associated follow-up in the Norwegian context is presented in Chapter 2. After a short introduction of the implant, the chapter elaborates on the concept of follow-up and how it is applied in the study. The chapter continues with a description of professional support after CI in Norway, presenting the medical and the educational/pedagogical context. With the aim to provide a knowledge field location for the study, chapter 3 traces how questions concerning follow-up after CI, the role of parents and support for parents, as well as language learning have been approached in prior research. The intention of this review is to provide a contextual backdrop and to provide a framework for the study's overarching research question, data construction and analysis. Chapter 4 describes the research process, specifically by presenting the sample and how it is recruited, as well as describing data construction, theoretical approaches and interpretation analyses. The chapter includes ethical considerations that have been carefully addressed throughout the entire research process. The four sub-studies that jointly constitute this study are summarised in chapter 5. Part 1 of the thesis is subsequently concluded in chapter 6, with a discussion about the parents' experiences on follow-up of children's language learning after CI and how these may be understood. The second part of the thesis contains the four papers in full text, as well as the appendices.

2 CI in the Norwegian context

This chapter will start with a description of the cochlear implant as a technological artefact, followed by constructing the concept of *follow-up* as it is understood in the study. The chapter concludes with a description of how professional support after CI is organised in Norway. In this description, a picture is drawn from two perspectives: 1) the medical context and 2) the educational and pedagogical context.

2.1 What is a cochlear implant?

A cochlear implant is a surgically implanted electronic device that provides access to sound to a person diagnosed with profound hearing loss, due to damage to the sensory hair cells in the cochlea. A cochlear implant is different from a conventional hearing aid. A conventional hearing aid amplifies the sound, whereas a cochlear implant electronically stimulates the hair cells in the cochlea, bypassing the damaged cells that cause the hearing loss, allowing the brain to perceive sound³. The sound quality coming from a CI is different from natural hearing, due to less sound information received and processed by the brain. The auditory system has to learn to interpret the information conveyed to it by the implant (Peterson, Pisoni, & Miyamoto, 2010). Even with optimal benefit of the implant, users will still be considered to have moderate hearing loss (Wie, 2005). Notwithstanding the rapid technological advancement of cochlear implant technology, the users of a cochlear implant may continue to experience challenges similar to those of users of conventional hearing aids, such as difficulties to understand speech in noisy environments (Kermit, 2010b).

The following figure illustrates the cochlear implant's internal and external components:

³ Retrieved from <http://cochlear.com> on December 1st 2016

Figure 1. The cochlear implant ⁴



In Norway, more than 90 % of children diagnosed with profound hearing loss receive a cochlear implant (Sæbø, Wie, & Wold, 2016) and all children who have the possibility from a medical perspective, have, since 2004, been offered bilateral implantation⁵. The international research domain concerning outcomes after CI is equivocal. On the one hand, studies state that children who use a cochlear implant may develop a high degree of accuracy in speech perception, developing spoken language skills categorised as “near-normal” (Peterson et al., 2010, p. 237). On the other hand, it is indicated that children using a cochlear implant are “delayed in language acquisition” (Nittrouer, Lowenstein, & Holloman, 2016, p. 143). Either way, the research acknowledges huge variations in outcomes following children’s cochlear implantation, whilst at present the causes are only partially understood (Niparko et al., 2010; Peterson et al., 2010). Potential predictors for outcomes, besides for instance early auditory stimulation and early bilateral implantation, as well as daily use time and non-verbal intelligence (Boons et al., 2012; Klein & Wie, 2014; Wie, 2010; Wie, Falkenberg, Tvette, & Tomblin, 2007), are factors concerning family environment (Boons et al., 2012; Quittner et al., 2013). This is why follow-up after implantation is considered highly significant, concerning parental

⁴ The picture on the left is printed with permission from Cochlear Nordic AB, Mölnlycke, and the picture on the right with permission of the person in the photograph.

⁵ CI – Hva så? Rapport fra tverrfaglig utvalg for en samordnet pedagogisk oppfølging av barn med cochleaimplantat [CI – and now what? Interdisciplinary report for a coordinated pedagogical follow-up of children who have cochlear implants] (2014). Retrieved on March 1st 2017 from: <http://www.statped.no/fagomrader-og-laringsressurser/finn-laringsressurs/horsel/CI---og-hva-sa/>

involvement as well as professional support guiding parents (Holt, Beer, Kronenberger, Pisoni, & Lalonde, 2012).

2.2 Professional support after cochlear implantation in Norway

In Norway, after a child has received a cochlear implant, professional institutions provide support services directed towards the child, towards schools and preschools, and towards parents, in the form of counselling, speech and language therapy, as well as parent course programmes. Norwegian educational policy states that parents “will need support and guidance from professionals with audiological experience” in connection with their child’s cochlear implantation (Norwegian Directorate for Education and Training, 2010, p. 16). The range of parent programmes and counselling available in Norway is presented in the following section; a distinction is made between two different contexts, indicated as the medical context and the educational/pedagogical context.⁶

2.2.1 The medical context

CI is a surgical procedure and is therefore, at least initially, situated within a medical context. In Norway, the surgical procedure of CI is free of charge, including the actual technological device, subsequent after-care and a wide range of professional support for parents and their children. In 2004, bilateral implantation has been introduced in Norway, and since 2008 universal newborn hearing screening has been standard procedure. Due to neonatal hearing screening many children may receive their implants as early as between the age of 5 and 10 months. By March 1st 2017, 681 children had received their implant, all at the same hospital (source: Oslo University Hospital, personal communication). In Norway, the Oslo University Hospital is the medical institute responsible for children’s cochlear implantation on a national basis, as well as for sound activation, regular technological check-ups, audiological

⁶ The overview describes the situation as it was at the time of data construction. Since then, a number of changes have taken place.

testing and outcome monitoring. The hospital conducts clinical testing of speech perception and production on a regular basis.⁷

2.2.2 The educational and pedagogical context

After cochlear implantation, the responsibility of coordinating pedagogical and educational follow-up of the child lies with the Educational-Pedagogical Service (EPS)⁸ in the family's residential municipality. The municipality may apply for support from Statped, the national centre of expertise within the field of special needs education⁹. Statped provides individual counselling and/or courses for (pre)school pedagogical personnel, building and maintaining expertise within specialised areas. The organisation provides special education support to professionals in schools and preschools in local and regional communities. In particular, they contribute with knowledge and competency relevant to the educational follow-up of children categorised as having special educational needs (Ministry of Education and Research, 2010-2011). Statped is managed by the Norwegian Directorate for Education and Training, which is the executive agency for the Ministry of Education and Research¹⁰. Schools, preschools and municipal EPS services may also receive support from Oslo University Hospital, either via telephone, or they are welcome to join the regular check-ups¹¹.

⁷ CI – Hva så? Rapport fra tverrfaglig utvalg for en samordnet pedagogisk oppfølging av barn med cochleaimplantat [*CI – and now what? Interdisciplinary report for a coordinated pedagogical follow-up of children who have cochlear implants*] (2014).

Retrieved on March 1st 2017 from: <http://www.statped.no/fagomrader-og-laringsressurser/finn-laringsressurs/horsel/CI---og-hva-sa/>

⁸ Translated from Norwegian: Pedagogisk psykologisk tjeneste (PPT)

⁹ Source: <http://www.statped.no/Spraksider/In-English/statpeds-mission-statement-2017-2022/about-statped/>, retrieved on March 2nd 2017.

¹⁰ Source: <http://www.statped.no/Spraksider/In-English/>, retrieved on March 17th 2014.

¹¹ CI – Hva så? Rapport fra tverrfaglig utvalg for en samordnet pedagogisk oppfølging av barn med cochleaimplantat [*CI – and now what? Interdisciplinary report for a coordinated pedagogical follow-up of children who have cochlear implants*] (2014).

Retrieved on March 1st 2017 from: <http://www.statped.no/fagomrader-og-laringsressurser/finn-laringsressurs/horsel/CI---og-hva-sa/>

The Norwegian Day Care Institutions Act Chapter V A §19a on special needs education and sign language tuition¹² establishes the parents' legislative right to professional support, emphasising that the special needs provisions must offer provisions of professional support for parents. Further strengthening the parents' position, the White Paper no. 18 (2010-2011) *Learning Together* points to the legislative rights of parents who have children with a statutory right to special education and the expectations parents may have of the educational system (Ministry of Education and Research, 2010-2011).

Statped is the main government agency responsible for parent support after children's cochlear implantation. Statped organises a variety of different course programs for parents, from which parents may choose, based on different language modalities (sign language and/or spoken language) and approaches. In 1997, based on the recognition of deaf people as a linguistic minority, Norwegian educational policy strengthened the rights of users of Norwegian Sign Language (NSL) by recognizing "functional bilingualism in NSL and Norwegian" as a "major educational goal" (Vonen, 2006, p. 221). The new legislation ensured children who have NSL as their first language a legal right to compulsory education *in* NSL, as well as studying NSL as a central part of the curriculum, at their local school. Section 2-6 of the Norwegian Act of Education describes this as an individual right (Vonen, 2006). Conducted by Statped, this has led to the development of a support program for parents, in the recognition that parents were in need of opportunities to learn NSL in order to facilitate parent/child communication, emphasizing "the importance of parental skills in communication as a significant predictor of positive language and academic development" (Arnesen et al., 2008, p. 67).

The parent course program *Se mitt språk* ("See my language") started in 1996 and was developed to give parents the opportunity to learn NSL and to gain information about having a child who is deaf or hard of hearing. The course consists of 1000 hours in total, divided over 40 modules of 1 week each, for parents with children aged 0-16 years. The course plan is divided into two main parts: NSL and thematic topics. The sign language tuition consists of 858 hours, tailored to the child's age. The thematic part of the course consists of 142 hours

¹² Retrieved on March 6th 2017 from <https://lovdata.no/dokument/NL/lov/2005-06-17-64>

covering 6 main themes that include parent counselling and deaf history and culture. Here as well, information is tailored to the child's age. Evaluation of the course program in 2011¹³ indicated that parents found the program useful, because it helped parents improve daily communication with the child, it provided useful insights in deaf culture and it created a platform where parents could meet other parents in a similar situation. All courses are free of charge. On an international level, parents who have children with a disability generally face exceedingly higher expenses than parents with children who do not have a disability (e.g., see Russell, 2003). In Norway, the government mostly covers expenses concerning implantation, travel expenses and follow-up; this includes a financial compensation for lost time at work due to courses and regular check-ups taking place during office hours.

With the rise of cochlear implantation in the beginning of the new millennium, the focus on developing spoken language increased, as well as the parents' role in the child's language learning. In the first decade of the new millennium, studies on outcomes started to emphasise the impact of family factors for children's language learning after CI (Thoutenhoofd et al., 2005). The information expressed by the research about the importance of family background and parental involvement for the child's language learning became distributed by professionals to parents. Vonen (2006, p. 221) quotes an information leaflet for parents, provided by the Oslo University Hospital in 2005:

The child should be stimulated with sound as much as possible. Parents' daily effort is important, and it is essential and crucial for the result that the voice is used in the daily communication with the child.

The sentence "Parents' daily effort is important" hints at a parental responsibility for the child's language learning after implantation. In 2015, information for parents on CI on Statped's website stated parents to be in need

¹³ Statped (2011). Evaluering av opplæringsprogram for foreldre til døve og hørselshemmede barn [Evaluation of course program for parents of deaf and hard of hearing children]. Retrieved on February 16th 2017 from: <http://www.statped.no/globalassets/fagomrader/horsel/dokumenter/sluttrapport-evaluering-sms-endig.pdf>

of counselling, referring that one particular factor influencing outcomes after implantation may be influenced by “the parents’ motivation and efforts”¹⁴.

Over the years, parents and user organisations have showed a growing interest in education based on a monolingual spoken language approach. This increased the focus on a need for course programs and counselling based on oral forms of communication, anchored in the same right as the sign language tuition for parents. At the time of data construction for the study, Statped provided various options, based on different approaches and communication modalities. Apart from the sign language approach, there were programmes based on spoken language such as “Hør mitt språk!” [“Hear my language!”] and counselling through Audio-Verbal Therapy (Estabrooks, 2006). However, a complication arose because of the various different alternatives. Having a variety of options available for parents to choose from is not without problems. A report to the Ministry of Health and Care Services and the Ministry of Education and Research (2014)¹⁵ expresses that because of the variety of options available to parents, it has become a challenge to guide parents in their choice of direction. “Both parents and the educational-pedagogical service (EPS) have expressed that this is a difficult issue that has led to frustrations for the involved parties” (p. 21, translated from Norwegian). In addition to having to make a choice that is ‘right’, the factor ‘time’ is perceived as critical, by parents and professionals, adding to the pressure (Hardonk et al., 2011; Young & Tattersall, 2007).

¹⁴ Retrieved in November 2015, from: <http://www.statped.no/Tema/Horsel/Cochleaimplantat/>
Currently, the link is no longer operative.

¹⁵ CI – og hva så? Rapport fra tverrfaglig utvalg for en samordnet pedagogisk oppfølging av barn med cochleaimplantat [*CI – and now what? Interdisciplinary report for a coordinated pedagogical follow-up of children who have cochlear implants*] (2014) Retrieved on March 1st 2017 from: <http://www.statped.no/fagomrader-og-laringsressurser/finn-laringsressurs/horsel/CI---og-hva-sa/>

3 Research on follow-up of children's language learning after CI

As pointed out in the introduction, the research interest pursued in this thesis concerns parents' experiences on follow-up of their children's language learning after CI. This chapter presents a scoping review of research on follow-up of children's language learning after CI, providing a background for, and being relevant to, the topic of interest for the study. In accordance with Jesson et al. (2011), the aim of this scoping review is to set the scene for researching parents' experiences on follow-up of children's language learning after CI. The following sections review research on language after CI, follow-up of children's language learning and parents' experiences on follow-up. The purpose is to identify gaps in the knowledge with the aim to frame the overarching research question and provide an informed foundation for data construction and analysis.

The international body of research concerning language after CI is exhaustive, forming a vast and diversified research domain representing a myriad of topics. Spoken language and communication, the use of sign language and bimodal approaches to communication, literacy, interaction and peer relations, social competence and participation in communities communicating in spoken language are all issues addressed in the research, tapping educational and social challenges for children who use a cochlear implant. The review is structured according to core concepts in the overarching research question, *what are parents' experiences on follow-up of children's language learning after CI and how may their experiences be understood?* First, the chapter documents research that reports on language learning after CI. Although the study applies the term 'language learning', it is noted that the literatures on follow-up after CI apply the term 'language development'. The review is meant to provide a description of the research; therefore, the first section will reflect the dominating mode of expression 'language development'. It carries a corresponding title, providing an overview of key issues and perspectives addressed in the research. The subsequent section focusses on research explicitly addressing the topic of *follow-up* of children's language learning after CI, i.e. both related to parental involvement and to professional

support for parents. The third section presents an overview of research addressing *parents' experiences* on follow-up. The chapter concludes with a section summing up predominant issues and absent perspectives in the research, thus framing the research questions for the study.

On the one hand, the scoping review provides a backdrop for understanding the contexts in which the research participants take part. On the other hand, besides providing a validation for the conceptual review, the scoping review provides a rationale for investigating *parents' experiences* on follow-up. More precisely, this chapter provides a rationale for investigating parents' experiences on their involvement in the child's language, as well as their experiences with the professional support guiding them.

3.1 Language development after CI

As with 'hearing' children, children's language learning after CI is crucial for their learning in general; from a Vygotskian perspective, people think through applying conceptual tools (Säljö, 2016). The importance of language for children's learning might in part be why questions addressed in the research on language development after CI are directed primarily at issues concerning results of spoken language after CI. The dominating mode of expression in the research on spoken language after CI focusses on the term *language development*, rather than *learning*. A common denominator across studies, and a universal, recurring term, is the designated use of the word 'outcomes', indicating results of speech perception and production. Cochlear implantation starts as a surgical procedure and is hence – at least initially – rooted in a medical context. Therefore, research on language development after CI has inevitably been influenced by research traditions belonging to the medical realm, characterised by acknowledged levels of evidence. Moreover, in the early years after CI was introduced, the research was meant to prove the implant's efficacy and therefore to justify its implementation (Thoutenhoofd et al., 2005). The medical discourse views being deaf as "a condition to be cured" (Dillehay, 2011, p. 28). In general, research into issues of deafness is dominated by a medical discourse (Hardonk et al., 2013), characterised by a means to an end rationality in terms of causal links between interventions and outcomes of spoken language, focussed on rehabilitation. This is reflected in research

focussing on language development after CI, which carries the rehabilitation perspective up front. On the one hand, this is noticeable in the key issues addressed in the studies, such as 'outcomes' and 'predictors for outcomes'; on the other hand, as the following paragraphs will illustrate, the linguistic expressions used in the research indicate an instrumentalist rehabilitation perspective, focussed on measurable results that are the effects of causal links between interventions and outcomes.

Research on spoken language after CI indicates that there are wide variations in individual outcomes following cochlear implantation (Humphries et al., 2012; Peterson et al., 2010). Numerous children who use a cochlear implant are suggested to develop "near normal language skills" (Peterson et al., 2010, p. 237). However, "some CI recipients never develop useable speech and oral language skills" (p. 237). Compared with their peers¹⁶, children using a cochlear implant are said to be "delayed in language acquisition [...] Mean performance is reliably found to be one standard deviation below that of peers with normal hearing" (Nittrouer et al., 2016, p. 143; see also Caselli, Rinaldi, Onofrio, & Tomasuolo, 2015 and Tobey et al., 2013). It means that a cochlear implant does not automatically "offer accessible language" to children who are diagnosed with profound hearing loss (Humphries et al., 2012, p. 1), and the causes of this huge variation are only partly understood (Nittrouer et al., 2016; Peterson et al., 2010). Outcomes are measured through for example word recognition skills and expressive language and vocabulary (Fagan & Pisoni, 2010; Geers, Moog, Biedenstein, Brenner, & Hayes, 2009; Holt & Svirsky, 2008; Wie, 2010). A substantial part of the research focusses on factors that may *predict* outcomes after implantation, in order to better gain understanding for what causes the wide range of outcomes. Findings, which "may help improve the identification of children at risk of poor progress after implantation" (Edwards & Anderson, 2014). There is consensus in the research that predictors for outcomes after implantation consist of multiple variables that contribute collectively (Peterson et al., 2010). The differences in language outcomes are suggested to be related to variables concerning child characteristics - such as experience with the implant, residual hearing, additional disabilities and cognitive skills – as well as variables concerning

¹⁶ Children not diagnosed with hearing loss

parental involvement, early implantation and intervention programs (for an overview, see Han, Storkel, Lee, & Yoshinaga-Itano, 2015).

A large number of studies indicate that early implantation predicts better language outcomes. It is suggested that age of implantation is an important predictor regarding possible benefits from CI (Boons et al., 2012; Geers et al., 2009; Geers & Nicholas, 2013; Klein & Wie, 2014; May-Mederake, 2012). A metastudy conducted by Bruijnzeel et al. (Bruijnzeel, Ziylan, Stegeman, Topsakal, & Grolman, 2016) investigated 203 studies and confirmed that children who received the implant early (<12 months) showed better results regarding speech production and auditory performance, as well as in part speech reception, compared to their peers who received an implant past the age of twelve months.

The role of parents in follow-up is indicated by the research as an important factor for spoken language after CI (Boons et al., 2012; Cruz, Quittner, Marker, & Desjardin, 2013; Holt, 2010; Klein & Wie, 2014; Niparko et al., 2010; Quittner et al., 2013; Sarant, Harris, & Bennet, 2015). The parents' actions in supporting the child's language learning in everyday life is suggested to influence language learning in a significant manner. Related to this, the research indicates that early intervention in the form of professional support is essential (Yoshinaga-Itano, 2003, 2006, 2014). The medical discourse is the dominating perspective in the literatures on early intervention practices, addressing spoken language development outcomes as its key incentive, establishing causal links between interventions and outcomes. It promotes early professional intervention as prerequisite for successful spoken language outcomes after implantation (Dettman, Wall, Constantinescu, & Dowell, 2013; Holzinger, Fellingner, & Beitel, 2011; Yoshinaga-Itano, 2014).

Closely connected to discussions about prerequisites for spoken language outcomes are issues concerning the role of sign language and bilingual education for deaf children, which have been at the core of forceful debate for quite some time (Knoors & Marschark, 2012). The issue is in particular relevant for this study, since the debates affect parents in the sense that the responsibility of making the decision lies with them, causing stress and insecurity (Archbold & Wheeler, 2010).

3.1.1 Debates on language choice after CI

The parents' choice of language modality after implantation is a controversial issue that has been the subject of heated debate for quite a number of years (Archbold & Wheeler, 2010; Kushalnagar et al., 2010). At the heart of the debate are opposing views concerning communication modalities and their effect on spoken language development (Geers, 2006). These modalities form a spectre ranging from approaches based on spoken language to sign/bilingual approaches. Kermit (2010a) describes the choice between language modalities as an ethical dilemma for parents, stretching between "two mutually exclusive interventions" (p. 157). Within the Norwegian context, two opposing standpoints reside. On the one hand, it is argued that a spoken language environment will provide the necessary conditions for what is defined as maximum benefit of the implant (e.g., see Wie, 2005; Wie et al., 2007). On the other hand, a bilingual approach is promoted, where both spoken language and Norwegian sign language (NSL) and/or signed supported speech (SSS) are used (e.g., see Kermit, 2008; Kermit, Mjøen, & Holm, 2010). This discord is not without problems; at the policy level, the White Paper 18 (2010-2011) *Learning together*, states that parents of children using a cochlear implant in Norway are affected by the disagreements within the professional debate:

Parents of children with cochlear implants experience receiving different advice concerning language development with or without the use of signed support and/or sign language from pedagogical, psychological and medical professions [...] Parents experience pressure and become part of a certain ideological discussion about what promotes early communication, bilingualism and cognitive development. Conflicting advice inflicts disturbances and worries on parents (Ministry of Education and Research, 2010-2011, p. 86, author's translation).

The Norwegian controversy reflects the ongoing international debate; divergent views on communication modality have been a central issue for debate in the international research on CI for a long period of time (Kushalnagar et al., 2010), without being able to provide empirical evidence in favour of any modality (Knoors & Marschark, 2012). Even though some recent studies have

indicated the use of sign language as beneficial for spoken language outcomes (Davidson, Lillo-Martin, & Chen Pichler, 2014; Rinaldi & Caselli, 2014), there is currently not enough evidence to draw final conclusions (Caselli et al., 2015; Knoors & Marschark, 2012). Parents are placed at the centre of these debates, which affects their decision making (Archbold & Wheeler, 2010).

In summary, the literatures on language after CI focus to a large degree on outcomes, measured in speech perception and production. It is stated that parental involvement is of major significance for language development after implantation. Therefore, professional support for parents after CI is considered essential. Part of the research on language development after CI focusses on debates concerning the effects that the use of different language modalities may have on spoken language outcomes. These are issues affecting parents, since the responsibility of making the decision lies with them. The following section takes a closer look at the issues addressed in the research concerning *follow-up* of children's language learning, i.e. the parents' involvement in the child's language, as well as the professional support guiding them.

3.2 Follow-up of children's language learning

3.2.1 Parental involvement in children's language learning

As with normally hearing children, parental involvement is suggested to be a significant factor for language learning for children who are deaf or hard of hearing (Calderon, 2000; Moeller, 2000; Quittner et al., 2013). Likewise, the research on language learning after CI emphasises the role of parents as particularly significant (Boons et al., 2012; DesJardin & Eisenberg, 2007; Desjardin, Eisenberg, & Hodapp, 2006; Holt et al., 2012; Sarant et al., 2015). It is suggested that parents play a central role in the child's language development, especially the first few years post-implantation, for instance through providing high quality parent-child linguistic interactions (Cruz et al., 2013; Lam-Cassettari, Wadnerkar-Kamble, & James, 2015; Szagun & Stumper, 2012). Parents' use of certain language techniques, such as open-ended question, will optimise children's communicative competencies (DesJardin & Eisenberg, 2007), as well as children's literacy skills (DesJardin,

Ambrose, & Eisenberg, 2009). It is suggested that the way in which parents manage to scaffold the child's environment to facilitate language learning may influence the opportunities for learning available (Cruz et al., 2013; DesJardin & Eisenberg, 2007; Quittner et al., 2010; Spencer, Erting, & Marschark, 2000). According to Sarant (2014), relatively small changes in parents' actions may support children's language learning in significant ways, whilst Boons et al. (2012, p. 638) conclude that "insufficient parental involvement in the rehabilitation process" is related to lesser quality in language outcomes. Numerous studies indicate that the way in which parents manage to be involved is an important element for language learning after CI. "In order for oral language to occur [...], parents need to be fully involved in their children's early-intervention program" (Desjardin et al., 2006, p. 179). As mentioned earlier, in order to guide parents in their involvement, professional support for parents is considered essential. The following section will take a closer look at research on follow-up concerning professional support. The research on parent support suggests multiple reasons for the importance of professional support. Apart from positively influencing the child's language learning, professional guidance is considered beneficial because of grounds related to parents' stress relief and support in decision-making processes.

3.2.2 Professional support for parents

As mentioned in chapter 3.2.1, there is consensus in the research that professional interventions should include parents to enable maximum support for children's language (Archbold & Wheeler, 2010; Cruz et al., 2013; DesJardin & Eisenberg, 2007). In order to be meaningful, the interventions will have to provide high quality guidance and collaboration (Holt et al., 2012; Reichmuth, Embacher, Matulat, am Zehnhoff-Dinnesen, & Glanemann, 2013). It is proposed that

Equipping parents with the knowledge of how to best support their child's language development and use of CI may help bring effective language and listening strategies into the home to be integrated into the child's life. (Klein & Wie, 2014, p. 14)

The notion is supported by Knoors (2007), who emphasizes that in follow-up, focus should be on the conditions in the child's environment necessary to provide maximum support for language learning. Therefore, professional support is essential; professionals can support families "to create robust language-learning environments that can maximise their child's potential with a cochlear implant" (Holt et al., 2012, p. 848). Following Yoshinaga-Itano (2014), to fully support language learning, it is recommended that individualised intervention is "implemented promptly, utilizing service providers with optimal knowledge and skill levels and providing services on the basis of research, best practices and proven models" (p. 143). This will support the development of "skills that are consistent with children's cognitive abilities and chronological age" (Yoshinaga-Itano, 2014, p. 144). It is suggested that parents should be encouraged to stimulate delayed vocabulary knowledge of children with cochlear implants via intervention strategies (Lund, 2016). Inherent in this perspective is that ensuring the process of language learning depends on what is described as "consistent monitoring of child and family outcomes" (Yoshinaga-Itano, 2014, p. 163).

Meanwhile, the research indicates additional reasons why professional support for parents is considered essential; as mentioned in section 3.2.1, these reasons concern issues of stress relief and parental decision-making. A cochlear implant is a technological artefact that allows people to hear; however, it also intervenes in people's lives, having individual, existential and social implications, potentially changing life conditions of children diagnosed with profound hearing loss and their families (Leigh & Paludneviene, 2011). This brings with it challenges for parents and for professional support, especially because it involves making complex decisions. "Raising and parenting a deaf child is about having choices and making decisions" (Marschark & Spencer, 2006, p. 17). Following from this, a considerable amount of studies have been dedicated to parents' decision-making processes (Matthijs et al., 2012). Making complicated choices concerning controversial issues that will affect the child's life on a fundamental level is stressful for many parents. Because most parents will have no prior knowledge of deafness, they will need information and support concerning the decision-making about medical, linguistic and educational issues (Kushalnagar et al., 2010). The significance of the parents' role in follow-up indicates great relevance of parent support that provides

parents with knowledge that is both enabling and empowering, and which can provide a fundamental platform that is helpful in making informed choices (Knoors, 2007).

Research conveys that being a parent to a child who is deaf or hard of hearing, or who uses a cochlear implant, may be stressful (Hintermair, 2004, 2006; Zaidman-Zait, 2008; Zaidman-Zait & Young, 2008); therefore, professional support may help parents in ways that reduce stress (Quittner, 2010). Teaching parents facilitative language techniques that are predictive of increased language development (DesJardin & Eisenberg, 2007) could reduce the stress associated with being both a parent and a language teacher, as well as facilitate optimal use of the auditory information provided by the implant (Quittner et al., 2010). Early interventionists and other professionals who work with children and their parents following CI can provide parental language strategies that promote spoken language development: this would ultimately increase communicative competence in young children who receive cochlear implants (Cruz et al., 2013). For professionals, parental involvement and self-efficacy are critical aspects to consider in supporting language learning in families of young children who use cochlear implants; parents may feel empowered by early intervention programmes that capitalize on their sense of knowledge and competence in facilitating their children's language learning (Desjardin et al., 2006).

However, the professional support services that are considered crucial for parents' involvement in children's language learning after CI may in some cases become sources of distress. This is related to the debates raging about choices of language modality and their supposed effects on spoken language development. The topic of CI in children is filled with controversy and debate, rendering decision-making a complex and stressful enterprise for parents (Hyde, Punch, & Komesaroff, 2010). In Norway, parents of children who use a cochlear implant encounter different service providers who may represent diverging views on communication modality (Ministry of Education and Research, 2010-2011; Strand, 2003). Service providers are rooted in varying professional disciplines, such as for example medicine, audiology, speech-language pathology, psychology and education. These institutions represent alternate and opposing views concerning follow-up, communicating opposing views on possible options (Ministry of Education and Research, 2010-2011;

Strand, 2003). Kermit (2010b) points to Norwegian parents' vulnerability in being confronted with a divided field of expertise. Parents of a child who has recently been diagnosed with hearing loss will find themselves negotiating a world previously unknown to them (Hyde et al., 2010). They encounter hegemonic views suggesting that on condition of the 'right' initiatives, positive outcomes in terms of speech development are anticipated, implying a "promise of normalization" (Matthijs et al., 2012, p. 387). For these parents, being caught up in the ongoing controversies is challenging (Archbold & Wheeler, 2010).

Even though considered significant in follow-up after implantation, parents experience their involvement in the child's language learning after CI as challenging and intense (Most & Zaidman-Zait, 2003, p. 100). Several studies report on the strain that extensive focus on follow-up can cause on family life (Bosteels, Van Hove, & Vandebroek, 2012; Hardonk et al., 2011; Thoutenhoofd et al., 2005). These issues will be elaborated on in the next section, to give voice to *parents' experiences* on follow-up of children's language learning after CI, as they are addressed in the research domain.

3.3 Parents' experiences on follow-up

Notwithstanding the substantial research addressing the significance of parental involvement for children using an implant, studies exploring parents' experiences on follow-up of children's language learning after CI are relatively few. The following section will present an overview of central perspectives and core topics addressed by the research exploring parental perspectives.

In 2005, the major review study on outcomes after CI by Thoutenhoofd and colleagues stated that the parental and family perspectives were "under-researched and [...] worthy of further consideration" (p. 267). At the start of this doctoral project, Archbold and Wheeler (2010) still held that the areas of family perspectives on follow-up after cochlear implantation in the literatures were "comparatively sparse" (p. 227). A few years later, Hardonk et al. (2013) stated it to be "surprising that parents' perspectives have received little attention in research" (p. 14), given parents' important role as decision makers and partners in follow-up. Even though there has been quite an increase in studies featuring parental perspectives in the past few years, the majority of these

studies focus on the significance of parents and their involvement for the child's language learning and on expectations parents may have concerning CI. They focus less on parents' personal narratives on their *experiences* in follow-up. In studies published in roughly the past five years, an example of a topic discussed is for instance the influence of family environment for speech and language outcomes (Glanemann, Reichmuth, Matulat, & am Zehnhoff-Dinnesen, 2013; Holt et al., 2012; Reichmuth et al., 2013).

Huttunen and Välimaa (2012) researched parental perspectives on “the effects of paediatric cochlear implantation and habilitation” (p. 184). The study explored the parents' perspectives on the effectiveness of CI and the quality of professional support. Findings indicated that parents were satisfied by the improvement in communication and social interaction in the family; however, some parents conveyed that their child did not get enough speech and language therapy, whilst others were dissatisfied with the quality of professional support. Other topics addressed in the research on parents' experiences from the past 5-7 years are parental impressions of their child's spoken language development and quality of peer relations (Bat-Chava, Martin, & Imperatore, 2014), as well as for instance parental stress (Quittner et al., 2010).

The first decade of the new millennium saw a handful of studies exploring parents' experiences with follow-up after CI. The few studies that have explored parents' experiences report on parental experiences with debates about language modality, experiences with professional support, expectations of the implant, feelings of insecurity, as well as follow-up being a strain on family life. Sach and Whynes (2005) interviewed 217 families between 2001 and 2002. The parents were asked about the process of choosing the implant, about the impact of CI on the family, and about their reflections on outcomes and quality of life. The study found that parents report extensive adjustments within family life, using words such as ‘normal’ and ‘fight’ frequently. The former expression expressed the hope for a ‘normal’ life, and the latter addressed the parents' perceived continuous battle with educational authorities (Sach & Whynes, 2005). Another study, conducted by Christiansen and Leigh (2002) reported on parents relating about constantly facilitating their child's language development and ways of communication in everyday life. A major adjustment on part of the parents was the time commitment parents needed to make so their child may benefit as much as possible from the implant. “Every

moment with our daughter is a language opportunity” (p. 147). The parents spoke about modelling language for their child and generating a variety of ways to support language learning, enhancing listening skills and the perception of speech (Christiansen & Leigh, 2002). This is one of very few studies presenting parents' narratives relating about their involvement in the child's language learning after CI.

Another issue addressed by research focusing on parents' experiences on follow-up is parents' uncertainty and frustration concerning the choices they make in follow-up. Mitchiner and Sass-Lehrer (2011) interviewed three deaf mothers about choosing CI for their child. The mothers were asked about their support for their children's language development, as well as their educational choices and decisions for their children. The study's findings indicate that the mothers encountered challenges similar to hearing parents, with reference to opposition about the choices they made. The mothers expressed frustrations with what they described as lack of understanding in both deaf and hearing communities about their choice of language modality (Mitchiner & Sass-Lehrer, 2011). Parental engagement in similar issues of debate is likewise indicated in a recent study by Adams Lyngbäck (2016). The study focussed on parents' experiences on follow-up after CI from a critical disability perspective. The study investigated parents' meaning-making in interaction with other parents living under similar circumstances. Findings indicated that, among other things, parents were engaged in issues of debate such as choice of communication modalities and intervention approaches. The study brings into view how being a parent to a child who uses a cochlear implant induces issues of parental uncertainty. This is connected to the notion of “lived parenting in differentness” in which parents find themselves confronted with “the rupture of earlier taken-for-granted expectations of what it means to become a parent” (Adams Lyngbäck, 2016, p. 271).

Research on parents' experiences on follow-up of children's language learning after CI conveys that intense focus on follow-up may cause pressure on families. Citing Thoutenhoofd et al. (2005), “intensive rehabilitation can be a strain on family resources” (p. 254). This was confirmed by Hardonk and colleagues (2011) who emphasise “the burden of therapy” (p. 319). Being a parent of a child using a cochlear implant may, through following a path of intensive rehabilitation, be in danger of becoming a process reduced to

language development (Bosteels et al., 2012). The Belgian study concluded that parents were expected to do whatever they could to support their child's language learning, whilst encountering "heroic discourse of progress and technological advances that included promises of cure on condition of parents' hard work" (Bosteels et al., 2012, p. 993). Further uncertainty and strain is described as being related to finding a way through a jungle of alternative options. This is challenging for parents. "Some of the decisions are time sensitive and irreversible and come at a moment of emotional turmoil and vulnerability (when some parents grieve the loss of a normally hearing child)" (Kushalnagar et al., 2010, p. 143). The issue of time adds to the parents' stress, as described by Young and Tattersall (2007). The authors interviewed 45 parents/caregivers, representing 27 families and found that parents perceived themselves "to be on a timetable and under pressure to perform within that, otherwise somehow their child would lose ground" (p. 217). The authors explain this to be a distinct source of pressure and distress and refer to "a potent promise of normalization (or at least parents' interpretation of such a promise)" as inducing the feeling that "the best possible outcome will only be realized if action occurs quickly and on time" (Young & Tattersall, 2007, p. 217).

In summary, relatively few studies explicitly explore parents' personal narratives on their experiences on follow-up after CI. Moreover, the small number of studies presented here emphasise that parents may experience follow-up as challenging and stressful, in particular because they understand the child's language learning to depend on their own involvement.

3.4 *Predominant issues and absent perspectives*

The body of research on follow-up of children's language learning after CI is extensive. Reviewing the research brings to the fore that the research is steered by various perspectives, such as the way that learning is understood, as well as perspectives on language and language learning. Predominant issues in the research are foci on outcomes of spoken language development after CI, measured in speech perception and production. These issues reflect a discursive orientation focussed on rehabilitation. The studies in the review establish consensus about the significance of parents' involvement for the child's language learning, which is why professional support for parents is emphasised

as crucial. Notwithstanding the importance of parental involvement for children's language learning, parental narratives concerning experiences on follow-up are relatively absent.

As mentioned in the introduction on page 3, the study holds specific interest in the concept of learning. With reference to this interest, the review of the literature on follow-up of children's language learning after CI portrays language learning as the individual – and measurable - acquisition of language, with less focus on language learning from other perspectives, for instance situated approaches. A few recent Norwegian studies address issues of children's language learning and communication after CI through situated perspectives on learning, focussing on the child's participation in social interaction (Eilertsen, 2016; Hillesøy, 2016; Sæbø et al., 2016). However, of international studies that focus on participation in social interaction after CI, the majority do not focus on learning but on children's challenges with psychosocial factors, socioemotional well-being and peer relations (see for instance Punch & Hyde, 2011). As explained in the introduction on page 11, learning can be conceptualised in multiple ways. Considering that perspectives on learning determine how support for learning is designed (Säljö, 2016; Wenger, 1998), the understandings of learning in the research informing follow-up will be of consequence for the way in which follow-up becomes designed.

This supposition validates an investigation of *how* learning comes forward in research that informs follow-up. What perspectives on learning are predominant, and are there studies taking divergent approaches towards learning? If so, what is their focus? How might predominant perspectives on learning affect professional support for parents and what might be possible implications for the parents and children involved? Therefore, one of the sub-studies will be carried out as a conceptual review; the unit of analysis will be the conceptualisation of learning in the research on follow-up of children's language after CI and in research on the broader category of children who are deaf and hard of hearing. In addition to gaining knowledge about understandings of learning in the research, the insights that are generated – including reflections about possible implications for the parents and children involved – will generate information relevant for the subsequent empirical

pursuit of the parents' experiences on follow-up. Because of the comparatively little attention in the research for parents' personal narratives on their experiences with follow-up, the three empirical sub-studies in the study will focus on investigating the parents' personal experiences.

The scoping review indicates that the small number of studies that focus on parental narratives emphasise the strain involved with follow-up. Other issues addressed by these studies are experiences with professional support and parental uncertainty, in particular because of insecurity about outcomes of CI, as well as professional debates on language modality. The issue validates further investigation of the discourse on language modality: exploring the discourse on language modality, and how it affects the parents and professionals involved, may contribute to the development of helpful, constructive professional support.

Due to the relatively small number of studies conveying parents' experiences on follow-up, relatively little is known about how parents perceive the uncertainty of outcomes after CI, and the meaning parents ascribe to professional support within this context. More precisely, how do parents experience the insecurity concerning their child's learning after CI, and the professional support available to them? Results after CI are uncertain; the long-term consequences for many of the choices that parents have to make are unknown (Archbold & Wheeler, 2010). The technological advance provided by CI changes the needs for support that families have in comparison to earlier. In order to be able to meet those needs, more research on family perspectives is required to ensure that support services can adjust accordingly (Archbold & Wheeler, 2010). As mentioned on page 2, the result of parent support is suggested to depend largely on its *reception* by families, on the parents' meaning-making, rather than the provision. That reception needs to be interpreted in terms of what is meaningful to families; it is essential that the provision tunes into the families' values and strengths (Young et al., 2009). Gascon-Ramos et al. state that

[...] seeking to understand how child and family variables mediate the very nature of the intervention is crucial – how it is received, the meaning attributed to it, the trust put in it, the motivation it provokes, the extent of perceived fit and

so forth' (Gascon-Ramos, Campbell, Bamford, & Young, 2010).

In order to create insight in what is meaningful for parents, research is needed exploring parents' experiences. Investigating how parents deal with uncertainty and the meaning of professional support will provide insights that may enable construction of professional support services matching parents' expectations and needs.

In a similar manner, relatively little is known about the nature of parents' *involvement* due to the small number of studies conveying parents' experiences on follow-up. Parents are considered important for children's language learning, but an interesting question arises concerning what involvement means? In concrete terms, what is it that the parents do? It would be interesting to know how parents talk about learning; what perspectives and metaphoric constructions underpin their conceptualisations of learning and thus shape their support for the child's language learning? What do parents convey about their actions and how do they reflect on their role in follow-up? These questions argue for further exploration of parents' experiences on their involvement in the child's language, how parental involvement might be shaped and how it might be motivated.

Researching parents' experiences on follow-up of children's language learning after CI provides an opportunity to develop new knowledge that may contribute to the domain of professional support for parents; it will shed light on how professional support affects parents through ongoing controversies and debate, and through perspectives on learning. Therefore, in the three empirical sub-studies, the unit of analysis will be the parents' experiences on follow-up of children's language learning after CI. Moreover, researching parents' experiences on follow-up after CI provides a case, enabling reflections about general settings of professional support for parents in educational contexts.

4 The research process

4.1 Introduction

The study's overarching research question is what are parents' experiences on follow-up of children's language learning after CI, and how may these experiences be understood? Four sub-studies address the overarching research question through their particular research interests. The findings of the sub-studies are discussed in chapter 6; these jointly contribute to answering the study's overarching research question. The study contributes to the knowledge field of professional support and parental involvement concerning language learning after CI, as well as the knowledge field of professional support and parental involvement concerning children's learning on a more general level.

The study is a qualitative study, involving an interpretive approach that attempts to make sense of phenomena in terms of the meanings that people bring to them. Its approach is hermeneutic, viewing analysis from a position that "stresses how prior understandings and prejudices shape the interpretive processes" (Denzin & Lincoln, 2011, p. 16). The study takes on an exploratory, data-driven approach, with the aim to develop insight into, and understanding of, parents' experiences on follow-up. Hence, the study draws on a social constructionist perspective (Berger & Luckmann, 1966), viewing the parents' narrations on their experiences as socially constructed and not as objective blueprints of reality. The parents' expressions on their experiences on follow-up of children's language learning after CI are thus regarded as inhabiting "the socially constructed character of lived realities" (Holstein & Gubrium, 2011, p. 341).

As will be described in section 4.3, the parents' experiences are documented in two data sets, through two types of data construction. Four sub-studies address the overarching research question through their particular research interests. As will be explained in section 4.3, these research topics are derived from the empirical material, guided by an interest in the concept of learning (as described in chapter 1, section 1.1).

Section 4.2 continues with a description of two literature reviews incorporated in the thesis (chapter 3 and Paper I), each with their individual purpose. Subsequently, the empirical study is presented, introducing the sample and recruitment of participants, data construction, as well as analyses and reporting on the research. Lastly, the chapter concludes with a section presenting ethical considerations that have been central throughout the research process, as well as a section outlining reflections about challenges experienced during the empirical study.

4.2 Literature review

Reviewing the literature on follow-up of children's language learning after CI has been a continuous process since the start of this study. Because the field of CI is in constant change, electronic searches have been ongoing. Two literature reviews are incorporated in this study (chapter 3 and Paper I), both with their specific purpose, consisting of a *scoping* review and a *conceptual* review. Whereas a scoping review is about documenting what is known and identifying gaps in the knowledge using a critical analysis, the conceptual review is meant to clarify how core concepts are used and understood in the research (Jesson et al., 2011).

In this study, chapter 3 provides a *scoping review*; its purpose is to identify the knowledge gaps in the field, to frame the study's research questions and to provide an informed foundation for data construction and analysis. Further, the review provides a context for the study's knowledge contribution. The literature search for this review started in 2011, at the time when the study commenced. The aim of the search was to document in a broad manner what was known about the field of CI, in combination with certain key words relevant to the overarching research question, tapping on issues involving language learning after CI and the role of parents and family, as well as professional support. Electronic searches were conducted in the following data bases: *Academic Search Elite*, *Eric*, *PsychINFO*, *Journal of Deaf Studies and Deaf Education*, *Journal of Speech, Language and Hearing Research*, and *Wiley Online Library* (at the time, Wiley contained several journals relevant for deaf education, such as *Deafness & Education International* and *Cochlear Implants International*). To focus on the most recent research, the searches

were directed at peer-reviewed publications between 2008 and 2011. Related to the topics formulated in the study's overarching research question, the search combined the term "cochlear implant" with key words such as "family" (or related terms such as "parent", "mother", "siblings", "parental perspectives"). Further, it combined "cochlear implant" with "learning" (or related terms such as, "participation" and "social interaction"), "spoken language" (or related terms such as "language", "language development", "communication", "communicative practice"). The search resulted in a total amount of 644 articles after elimination of duplicates. Because they were not relevant to the study's research interest, 458 articles were subsequently removed. These were articles based in disciplines such as medicine, audiology, non-relevant age groups, articles concerning children with additional disabilities and sign language teacher training programs. In total, the initial literature search conducted in July 2011 resulted in 186 articles; these were kept in a designated EndNote Library to be analysed through reading the abstracts. 37 references were subsequently deleted from the EndNote Library, since after critical reading of the abstracts they either did not match the study's research interest, they turned out to be book reviews or there were no abstracts available. Subsequently, 149 abstracts were imported into an NVivo database. From these, articles particularly relevant with reference to the study's overarching research question were marked to be read in full text. In NVivo, all 149 abstracts were sorted in categories based on the search terms used in the initial search. This provided a detailed overview of themes in the research.

Through the years, as the study evolved, regular searches have been repeated to expand on the initial literature search. The scoping review presented in chapter 3 is based on this ongoing literature search that lasted throughout the project period.

The conceptual literature review that was conducted had a different purpose than the scoping review. Based on the search results of the scoping review, the conceptual review was conducted in order to "synthesise areas of conceptual knowledge that contribute to a better understanding" (Jesson et al., 2011, p. 15). In this study, the conceptual review investigates how the concept of learning is expressed in the research on language development after CI. Additional electronic searches were conducted in the aforementioned databases, with the aim to check whether there were studies that had not come

up in earlier searches that were relevant for the conceptual review, especially more recent studies. To limit the amount of results, the search was filtered to peer-reviewed articles in the period from 2007 to 2013. In addition to the searches done in the scoping review, new search combinations were used, such as for instance “cochlear implant” * “language development” * “participation” / “cochlear implant” * “language learning” * “therapy” / “cochlear implant” * “mother” * “practice”. This was done to double check whether there would be additional results to the previous searches. A few articles were added to the main EndNote Library that were relevant and had not come up earlier, probably because they were quite recent. Of all search results collected in the EndNote Library, 41 were selected for conceptual scrutiny. These were selected because of their focus on spoken language development after CI, in particular those that focussed on parental perspectives, and all of which explicitly involved CI. To facilitate a structured overview in the investigation of how the concept of learning is expressed in the research on language development after CI, the 41 articles were imported in NVivo software for qualitative data analysis.

During the initial reading of the materials selected for conceptual scrutiny, it became clear that the focus needed to be extended, not only covering studies in the area of CI, but also studies focussing on children who are deaf and hard of hearing. Because the category of CI is part of this realm, these studies had previously come up in the literature search and had been included in the EndNote Library. A manual selection of articles from the EndNote Library, addressing the extended category of children who are deaf and hard of hearing, gained an additional 33 articles. In final, the entire collection of texts intended for conceptual scrutiny contained 74 peer reviewed articles and one book chapter, dated between 2004 and 2013.

4.3 The empirical study

The empirical study is constituted by three sub-studies. The section describes the sample, the process of participant recruitment and constructing the two data sets: development of questionnaire and interview guide, conducting the interviews, description of the data and assessing data quality. Subsequently, the section reports on data analysis, both concerning the individual sub-studies, as well as analysis across the sub-studies in order to provide answers to the

overarching research question of the main study. The section on analysis also discusses issues of credibility and trustworthiness. Lastly, this section addresses research ethics central to the study, discussing respect for individuals as described by the Norwegian Centre for Research Data (NSD) and the National Committee for Research Ethics in the social Sciences and the Humanities (NESH). It further presents issues specific to this study concerning researcher subjectivity, as well as issues concerning the use of language that may cause danger of labelling groups.

4.3.1 Sample and recruitment

Answering the overarching research question about parents' experiences on follow-up of children's language learning after CI requires asking parents about their first-hand experiences. The use of parental accounts on their experiences with follow-up provides important perspectives that, as stated by McCracken & Turner (2012), may build a holistic view of child and family needs.

The study was subject to notification to the Norwegian Data Protection Official for Research at the Norwegian Centre for Research Data (NSD) and the application was submitted on 05.10.2011. The license to conduct the project was received 06.01.2012, confirming the date for finalizing the project as no later than 31.12.2015¹⁷. On 11.01.2017 NSD agreed to extending the final date for completion to 31.12.2017, on condition of informing the interview participants about the delay.¹⁸

Establishing contact with parents was done via different ways, via institutions that are central in the field of hearing loss and follow-up after CI. Invitations to participate¹⁹ in the study were sent out in the spring of 2012 via: 1) a parent organisation for families with children who use a cochlear implant (Cochleaklubben), 2) a national association of the deaf and hard-of-hearing (Hørselshemmedes landsforbund), and 3) five different Resource Centres spread across the country – all part of Statped. The invitations were sent to

¹⁷ The confirmation by NSD is enclosed as Appendix VII

¹⁸ Both the confirmation of NSD, as well as the information letter distributed to the interview participants, are enclosed as Appendix VII

¹⁹ The invitation is enclosed as Appendix II

parents by email including a link to the questionnaire, but also via a direct link to the questionnaire on the parents' organisation's web site. In addition, a flyer was electronically distributed by the Resource Centres, as well as in print²⁰. As described in Paper II, approximately 500 emails have been sent out, but it is not possible to give an estimate of how many parents have been reached by the questionnaire. In addition to the emails, parents may have learnt about the project through other channels, whilst some parents may have received more than one invitation.

Twenty-seven families with children who use a cochlear implant have responded to the online questionnaire. The sample consists of 20 mothers, 4 couples who filled out the form together, and 3 fathers. The children range from 1-14 years of age. All families speak Norwegian at home; four of them also use Norwegian Sign Language. See Paper II for a detailed overview on children's age at time of survey, age at sound activation, gender, bilateral or unilateral cochlear implant, educational setting and use of signed supported speech. A few children had concomitant diagnoses in addition to being deaf. In the questionnaire, parents could indicate whether they would like to participate in the interview study. Of the 27 families that responded to the questionnaire, 14 accepted the invitation. At the time of the interviews, the children's age ranged from 3 to 11 years, and they were all born after the year 2000, eight boys and six girls.

The sample of parents participating in the study is a sample of convenience, invited randomly, with the aim to create as large a sample as possible. The impossibility to make such a sample representative contributes to the exploratory nature of the study. There are natural restrictions in terms of statistical generalizability; the group of parents participating in the study do not represent the statistical characteristics of the group of children who use a cochlear implant. However, due to the substantial first-hand accounts that the participants have provided on their experiences on follow-up, the sample provides a satisfying case in terms of conceptual generalizability. Therefore,

²⁰ The flyer is enclosed as Appendix II

the sample is considered to provide a satisfactory foundation, suitable for answering the overarching research question.

4.3.2 Data construction

In line with Alvesson and Skjöldberg (2009), the exploratory nature of this study entails a method of data construction that is open to adjustment in the course of the research process, with the possibility to be “successively revised”, for example, as a result of the research process (Alvesson & Skjöldberg, 2009, p. 55). As mentioned in chapter 1.2, the exploration of parents’ experiences on follow-up of children’s language learning after CI builds on two types of data that have been constructed in two phases through two different methods. These phases of data construction are autonomous in character, while at the same time the second phase builds on the first, elaborating on issues that come up in the first data set.

Aimed at creating a broad and general impression of parents’ experiences on follow-up, data construction is initiated with a qualitative questionnaire, anchored in the study’s overarching research question. Parents were invited to write about their experiences, which had two purposes. The first purpose was to provide a general overview concerning issues such as demographic information about the family and the child, information about the child’s and family’s languages and communication in everyday life, as well as parents’ experiences with their involvement in the follow-up. The second purpose of the questionnaire was to gain information based on a broad platform of as many participants as possible, which – functioning as a preliminary study - could provide a point of departure for developing the interview guide intended for a smaller sample. The aim was for the questionnaire to inform the development of the interview guide, through generating core topics in the parents’ accounts relevant for further exploration. This inspired both the development of the interview guide, as well as the interview itself: each interview always built on the participant’s response to the questionnaire.

The development of the interview guide was based on a preliminary analysis of the questionnaire data, based on a process of meaning coding and meaning condensation (Kvale & Brinkmann, 2009). This provided an empirical overview of topics that were central to the participants, that were either

recurrent or absent in the material, or generating new questions, a process helpful in developing the interview study. Apart from being an autonomous empirical part of the research, the data from the questionnaire thus served as a platform that helped develop the focus for the interviews. Whereas the questionnaire aimed at mapping out the field so questions had a largely descriptive focus, the interview questions were of a more reflective character. The following sections subsequently describe the contents of the parent questionnaire and the interview guide.

The parent questionnaire. Motivated by the sparsely represented parental perspectives in the research on follow-up after CI (Archbold & Wheeler, 2010; Thoutenhoofd et al., 2005), the questionnaire was developed in order to gain rich descriptions on the parents' experiences with follow-up supporting the child's language learning in everyday life²¹. As described in Chapter 1, the concept of follow-up encompassed both the parents' involvement as well as the professional support. The questionnaire consisted of 23 open-ended questions and was accessed through a link on the university's web site. Parents answered anonymously. Questions that were asked tapped on communication modality, the parents' involvement in supporting the child's participation in the family's everyday communication, and the professional support services the family had been in contact with. Parents were asked about their experiences encountering these institutions, including their own involvement in follow-up. Parents provided information about the parent program(s) they participated in, as well as what they experienced as the main focus for the follow-up. Lastly, parents were asked about their experiences concerning the debates on communication modality, and how the debate has affected them. The questionnaire was formulated in Norwegian; the option was provided to answer in Norwegian, as well as English, German or Dutch, but all parents answered in Norwegian. Because of the open-ended nature of the questions, the parents had received information that they could decide how detailed they wished their answers to be.

Twenty-seven replies is considered a satisfactory number; filling out the form may have been a time-consuming activity, due to the open-ended nature

²¹ A copy of the questionnaire is provided in Appendix I

of the questions. Furthermore, the families differ in size, in form, in their geographic location and in their life situations. The twenty-seven replies thus represent a rich material consisting of multi-faceted personal descriptions of the parents' experiences on follow-up of children's language learning after CI.

The parent interviews. In the questionnaire, parents could indicate whether they wanted to take part in the interview study. Fourteen families accepted the invitation to participate in the interview study, taking place one year later. When trying to understand the world from the subject's points of view, the qualitative interview is useful in unfolding meaning in research participants' experiences (Kvale and Brinkmann 2009). The interviews built partly on information gathered from the questionnaire; by way of introduction, the interviews started with a conversation about core topics in the parents' answers to the questionnaire. Keeping in mind a deliberate aim for flexibility (Kvale & Brinkmann, 2009) to ensure parents the opportunity to elaborate on what was important to them, an interview guide was produced with an outline of topics to be covered²². Part of these topics were based on questionnaire data, such as communication in the family and subsequent challenges, as well as how parents' experienced the advice from the professional support. Other topics were for instance of a more reflective nature, such as parents' experiences with expectations on their role in follow-up and how this related to follow-up. Parents were asked about the meaning of professional support, and their hopes and fears for the future. The study's interest in learning as described in the introduction on page 3 provided inspiration for the questions. Parents were asked about their ideas about learning, what kind of challenges they saw as connected to this, and how they thought about their own role. Parents were also asked whether they experienced these issues as different from their other children, if they had any. With the conceptual paper in mind, parents were asked what it takes to be a parent of a child who uses a cochlear implant, and how they viewed their own learning in the process of follow-up.

The interviews were characterized by mutual conversation, where the interviewer followed the lead of the participants. This meant that each interview had its own distinct character. In the study, the interview data is seen as

²² A copy of the interview guide is provided in Appendix III

constructed through mutual interaction (Holstein & Gubrium, 2004; Kvale & Brinkmann, 2009). Acknowledging that “the environments of storytelling shape the content and internal organization of accounts” (Holstein & Gubrium, 2011, p. 350), it was crucial to inform the participants about the interviewer being parent to a child who uses a cochlear implant.

The interviews were conducted in the spring of 2013, and all but two interviews were conducted face-to-face. All interviews were conducted in Norwegian, by the author of this thesis. The duration ranged from 55 to 115 minutes. Due to practical difficulties to meet in person, two of the interviews were conducted on the telephone. The other twelve families were visited in the place they lived. Nine families were visited in their homes and three interviews were conducted at the participant’s work place. In four of the interviews, both of the parents were present; the remaining interviews were with the mothers. The couples supported each other in their accounts and both parents were equally engaged in the conversation. The interviews were audiotaped and transcribed verbatim in NVivo, software for qualitative data analysis. The process of transcribing was experienced as a way of getting familiar with the data, providing an opportunity to create a primary overview of main themes and patterns. The parents were active participants in the interviews, conveying much information on their experiences on follow-up of children’s language learning after CI.

The parents’ descriptions of their experiences - written and oral combined - thus make up rich testimonies that form a relevant case for analysing parents’ experiences on follow-up supporting the child’s language learning after cochlear implantation in Norway.

4.3.3 Data analyses and reporting

As mentioned in the previous chapter, the study’s empirical material consists of two data sets: 1) 27 written parental responses to an online questionnaire with open-ended questions, and 2) 14 verbatim transcripts of individual, semi-structured interviews with parents who answered the questionnaire, based on approximately 20 hours of audio recording. As explained in chapter 4.3.2, a preliminary, data-driven, thematic analysis (Kvale & Brinkmann, 2009) of the

questionnaire data²³ was conducted, based on a process of open coding. A similar preliminary analysis was subsequently conducted of the interview data. Each time a new analytical category was developed, all previously coded texts were read anew, coded with the new category. Coding every single document started by an initial reading of the text as a whole, whilst coding spontaneously. Thereafter, the coding process was systematic and methodical, analysing all documents meticulously with one category at a time. This resulted in a rigorous process consisting of reading each document multiple times so that the material became very familiar. The preliminary thematic analysis of the questionnaire data and the interview data combined, generated multiple topics of interest that were suitable for further research. Of those, with the insights from the conceptual review in mind, three research topics were chosen for this study. The topics were chosen, because 1) they emerged as the most poignant and recurring in the empirical material, and 2) they were considered suitable to address the study's overarching research question. These topics are debates on communication modality, parent insecurity and meaning of professional support, and parental involvement in the child's language. The topics provide the research interests for the empirical sub-studies. One of the analyses is based on the questionnaire data, another on the interview data, and a third on the questionnaire and interview data combined. The following sections will present their subsequent analytical frameworks.

Analysis of questionnaire data

The research question of the sub-study analysing the questionnaire data directs its focus towards the debates on choice of communication modality, and asks *How is the discourse on communication modality in follow-up after paediatric CI constructed, how does it operate, and how does it govern people's thinking and acting?* The 27 written parental responses to the questionnaire data were analysed following a qualitative discourse analytical approach, anchored in Foucauldian perspectives (Alvesson & Skjöldberg, 2009; Potter & Wetherell, 1987; Wetherell, Taylor, & Yates, 2001). Following Alvesson and Skjöldberg (2009), discourse can be seen as a social text where talk and text both represent,

²³ An overview of analytical categories used in the preliminary analysis of the questionnaire data is provided in Appendix VIII. The analytical categories used in the preliminary analysis of the interview data enter into analysis phase 2, and an overview is provided in Appendix IX.

as well as constitute, social practice. The way in which people engage in discourse by means of using language reflects the way they are involved in everyday social life, but also how they construct their realities (Potter & Wetherell, 1987).

The analytical framework for exploring the discourses on communication modality and their ingrained power structures was chosen in cooperation with the co-author and draws on the work of Foucault (1966, 1972, 1975, 1980, 1981, 1982). A central notion is Foucault's power/knowledge synthesis, representing the perspective that discourses exert knowledge and power: Through knowledge, they "form the objects of which they speak" (Foucault, 1972, p. 49), governing the way people think and act. The Foucauldian reading of the questionnaire data applied three interconnected notions (Foucault, 1966, 1972, 1975, 1980, 1981, 1982) – *Discourses of Truth, The power of the Norm, and Subjugated knowledges* – which constitute the questions asked to the empirical data. The three notions enable gaining an understanding of how the discursive power dimensions are constructed, how they operate, and how they govern thinking and acting. The findings of the analysis are discussed and reported in Paper II, and a short summary of the sub-study is provided in chapter 5.2. The paper is published in the research domain of education of the deaf. This specific context was chosen because of the research interest involving cochlear implantation. The paper is published in the *American Journal of Deaf Studies and Deaf Education*.

Analysis of interview data

The analysis of the interview data consists of two phases. Phase 1 was a preliminary data-driven thematic analysis that aimed – together with the preliminary thematic analysis of the questionnaire data – at identifying the research interests for the empirical sub-studies, as described in chapters 4.3.2 and 4.3.3. Analysis Phase 2 of the interview data directs its focus towards the topic of parent insecurity and the meaning of professional support for parents. The research questions asked are *How do parents respond to insecurity concerning their child's learning and development? What significance do parents ascribe to the professional support?* The analytical framework for exploring the parents' experiences was chosen in cooperation with the co-author and draws on a narrative analytical approach to the data (Bruner, 1990,

1991, 1997; Gubrium & Holstein, 2009; Riessman, 2008). In relation to dominant perspectives in learning and education, based on questions concerning effects, benefits, measurement and productivity, narrative approaches to analysis may give a voice to perspectives that otherwise might be hard to maintain (Lang, Lansheim, & Ohlsson, 2012). Narrative inquiry enables broader commentary because it provides a way to access meaning beyond the surface of a text (Riessman, 2008), or in this case, beyond the surface of the parents' narrations of their experiences on follow-up. Following Young and Temple (2014),

Narrative analysis in its various forms is [...] fertile territory from which to understand a vast range of human experience; to explore, document, and appreciate that which is new or hidden; through which to identify factors relevant to specific intents; and as a result of which to challenge, protest and reconstruct. (Young & Temple, 2014, p. 107)

The analysis views the parents' accounts as "the practice of constructing meaningful selves, identities, and realities" with regard to "how narrators make sense of personal experience in relation to cultural discourses" (Chase, 2011, p. 422). The parents' accounts are regarded as holding personal meaning, attributed by the research participants to their experiences. This way, narrative analysis permits accessing underlying narratives (Silverman, 2003), uncovering "a world behind the narrator (that is knowable)" (Riessman, 2008, p. 13).

Human beings use the narrative mode for construing reality; thus, they make sense of the world. Autobiographical accounts are more than just descriptions of one's life (Bruner, 1990); they evolve around experienced trouble or discontinuity in people's lives (Bruner, 1996; Riessman, 2008). People display identities through narrative construction; they tell themselves and others who they are (Riessman, 2008). Therefore, narratives are told with a purpose; they are "multifaceted textual windows on the world [...] dressed up by storytellers for the viewing" (Gubrium & Holstein, 2009, p. xv). Bruner argues that narratives reveal "a strong rhetorical strand, as if justifying why it was necessary (not causally, but morally, socially, psychologically) that the life

had gone in a particular way” (Bruner 1990, p. 121). The notion reflects what Bruner calls the narratives’ *justificatory function*. Therefore, a subsequent question relevant for analysis is what is being justified, for what purposes and for whom?

Building on Riessman (2008), the analysis of the interview data combines aspects of thematic, structural, and dialogic/performance analysis. This enables different approaches; besides focussing on content, there is attention to how stories are told, to whom, and for what purposes. In line with Gubrium and Holstein (2009), the process of re-storying the parents’ experiences on follow-up enables reframing existing ways of thinking. A narrative analysis of parents’ experiences on follow-up of children’s language learning after CI will therefore enable to challenge and reframe current ways of thinking about parent support.²⁴

The findings of the analysis of the interview data are discussed and reported on in Paper III, and a short summary of the sub-study is provided in chapter 5.3. As the main study progressed, it became clear that the case of CI had relevance for research contexts other than deaf education, which is why this sub-study has been written into a wider academic discourse of special needs education. Therefore, Paper III is published in *European Journal of Special Needs Education*.

Analysis of questionnaire data and interview data

The analysis of both questionnaire data and the interview data directs its focus towards the topic of parental involvement in the child’s language. The research questions asked are *What do parents tell about their involvement in the child’s language? How can their narratives be understood within the context of discourses on parent pedagogicalisation?* The analysis is explorative and inductive in character, following a process of data-driven coding (Kvale & Brinkmann, 2009). The preliminary analyses, identifying the research interests for the three empirical sub-studies as described on page 43, indicated a

²⁴ An overview of analytical categories used in the second phase of the analysis of the interview data is provided in Appendix IX

common, core characteristic emerging from the parents' accounts, in line with Gregory et al. (1995): a major concern for the child's spoken language. This concern was prevalent throughout the questionnaire and interview data. Closely connected to concern for the child's language was the parents' conviction that being involved in the child's language is central to being a parent of a child who uses a cochlear implant.

The exploration of the parents' experiences with their involvement in the child's language followed a process of open coding. It identified two main areas in which the parents describe to be involved: 1) the child's language learning, and 2) the child's social-emotional well-being, due to linguistic challenges. These two main areas became analytical categories, nodes in NVivo: 1) *Parental involvement in learning*, and 2) *Parental involvement in well-being*.²⁵ The nodes are understood as activities that parents undertake, aimed at supporting the child's language learning and well-being. The questionnaire data and interview data were coded according these two broad categories. The coding process draws on the notion of "sensitizing concepts" (Blumer, 1969, p. 148), which applies a common sense understanding of the concepts of learning and well-being. The notion represents the idea that, in contrast to *definitive* concepts that provide precise prescriptions and clear identifications of what to see, "sensitizing concepts merely suggest directions along which to look" (Blumer, 1969, p. 148). Following Blumer, concepts such as learning and well-being are not definite: "They lack precise reference and have no bench marks which allow a clean-cut identification of a specific instance, and or its content" (1969, p. 148). During the analysis, within each category *Parental involvement in learning*, and *Parental involvement in well-being*, sub-themes were empirically derived from the data. In the *Parental involvement in learning* three topics emerged as central: 1) Practising skills, 2) Expert knowledge, and 3) Language in use. In the *Parental involvement in well-being* two topics emerged as central: 1) Fearing exclusion, and 2) Facilitating participation. The analysis' open approach, suggesting directions along which to look through the use of the notion of sensitising concepts, is considered

²⁵ An overview of analytical categories used in the analysis of the questionnaire data and interview data combined, is provided in Appendix X

helpful; it enables rich descriptions that leave room to uncover how the parents make meaning of, as well as how the parents shape, their involvement in the child's learning and well-being.

As the study progressed further, it became clear that the case of CI not only had relevance for the research domains of deaf education and special needs education, but also for educational contexts in general. That is why Paper IV is written into the academic discourse of *Scandinavian Journal of Educational Research*. From this follows that each paper in this study is written into a particular educational context, developing from the specific to the more general. Furthermore, the papers contribute to various international domains: Whereas Paper I entered an anthology that takes an explicitly expressed global perspective²⁶, the empirical articles contribute to American, European and Scandinavian research contexts.

The main findings of the three empirical analyses provide grounds for discussion in chapter 6, providing answers to the study's overarching research question about the parents' experiences on follow-up of children's language learning after CI and how these may be understood.

Issues of credibility and trustworthiness

As indicated by the introductory note on researcher subjectivity, doing research within a field that relates to personal aspects of the researcher's life brings along epistemological threats, challenging credibility and trustworthiness due to possible bias on part of the researcher (Lincoln & Guba, 1985). However, based on careful reflexivity on part of the researcher (Kvale & Brinkmann, 2009), as well as providing transparency concerning theoretical stance and analysis, researcher subjectivity may be qualified, increasing opportunities for in-depth understanding (Ricoeur, 1981). Furthermore, a thorough provision of literature reviews has added to the qualification of researcher subjectivity. Potential bias during interpretive processes has been shielded through close cooperation with

²⁶ In H. Knoors & M. Marschark (Eds.), *Educating Deaf Learners: Creating a Global Evidence Base* (pp. 93-113). New York, NY: Oxford University Press.

fellow researchers, as well as through rigorous procedures of peer review, in communication with the journals and the book editors.

As previously mentioned, to acknowledge that “the environments of storytelling shape the content and internal organization of accounts” (Holstein & Gubrium, 2011, p. 350), prior to all interviews participants were informed about the interviewer being a parent to a child who uses a cochlear implant. Following Gubrium and Holstein (2002), sharing a similar background may have contributed to openness and an interview situation characterised by mutual partnership between interviewer and participant, jointly engaged in constructing meaning in conversation. During the interviews, many parents emphasised that participation in parent programs was important because only parents with a child using a cochlear implant could fully understand their experiences. More than the course content, the parents valued the contact with other parents. As such, being researcher and a parent with a child using a cochlear implant may have created a recognition enabling additional openness in the interviews.

A central issue of care throughout all analyses has been the translation from Norwegian into English. Data construction was conducted in the family’s first language, Norwegian. In line with Temple and Young (2004), in the process of seeking conceptual equivalence across languages, potential bias was addressed through conducting all analyses in the language in which data were constructed. This was done to shield the analysis from corruption by translation. Parental quotes were translated in the final phase when quotes were written into the English manuscript. It is argued that, in the study, the quality of translation is protected by the researcher being multilingual, as well as by additional control of fellow researchers.

Apart from being an epistemological issue, credibility and trustworthiness in research are also matters of ethical concern, related to the researcher’s responsibility of scientific integrity. The next section discusses central issues of ethical nature that have been at the core of the research process.

4.4 Research ethics

The study was registered at the Data Protection Official for Research at the Norwegian Centre for Research Data (NSD), in January 2012. It follows the overarching ethical guidelines as presented by The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH, 2016). Issues of informed consent, confidentiality and the responsibility to do no harm have been core principles throughout the study. The study has followed the guidelines provided by the Data Protection Official for Research (NSD) concerning anonymity and storage of data. Kvale and Brinkmann (2009) mention the notion of “moral enterprise” (p. 62). The notion relates to the researcher’s moral responsibility in encountering the participants, as well as the researcher’s moral responsibility for possible consequences of the inquiry, for both the individual participants, as well as the larger group they represent. During the course of the study this has been a guiding principle.

Chapter 4.3.2 described the distribution of invitations to participate in the study to parents. An information letter accompanied the invitation to participate in the first of two phases of data construction, the online questionnaire. The letter contained information about the aim of the study, and explained that participants had the right to withdraw from the research at any point in time. The information letter also explained that approximately 10 parents were needed for the subsequent interview study, and asked parents whether they would be interested in participating in an interview. In consultation with the Data Protection Official for Research (NSD), parents who were interested to participate in the interview study were invited to send an email with a self-composed password that they had written in their survey as well. This way, the data would be guaranteed anonymity, whilst the identity of the parents who offered to participate in the second phase of the study could be traced between the password in the email and the password in the questionnaire data. Thus, data and participant identity were kept entirely separate.

Of the twenty-seven families who participated in the questionnaire, fourteen accepted the invitation to participate in the interview study. These parents were contacted in the beginning of 2013 with a new information letter that described the aim of the interview study. Again, the letter explained that participants had the right to withdraw from the research at any point in time. At

the beginning of the interview, participants were asked to sign a consent statement and they were asked whether they gave their permission for the interview to be audiotaped. It is the researcher's responsibility, at all times, to protect the participants with respect to possible harm as a direct consequence of participating in the study (Kvale & Brinkmann, 2009). This includes matters of anonymity and confidentiality. After the interviews, the audiotapes were copied to a password secured laptop the very same day, and the original audiotapes were deleted from the portable audio recording device immediately.

Following Kvale and Brinkmann, in qualitative inquiry, the researcher's role and integrity in the research process are critical to the quality of the scientific knowledge and the soundness of ethical decisions (Kvale & Brinkmann, 2009). Being researcher in a similar position as the research participants raises ethical issues regarding the role as a researcher, touching upon all stages of the entire research project: from planning, questioning, conducting, analysing, down to the actual writing of the papers and thesis. In this process, it has been a requirement to practise absolute conscientiousness in this regard. "[...]practicing ethically capable research cannot be reduced to following ethical principles and guidelines but must include elements of situated human judgement" (Kvale & Brinkmann, 2009, p. 60).

In the writing processes throughout the project, the use of language with reference to a danger of stereotyping of children who use a cochlear implant has been a topic of continuous and careful consideration. Constructs of labelling may have harmful, stigmatizing side effects; this has been discussed for decades in academic discourse (Brantlinger, 2006); it is, however, still "largely ignored in professional communities" (p. 234). Research on language development after CI has a tendency to objectify children through certain linguistic expressions. A recurring objectifying term is "CI-child". In the article *Language Choices for Deaf Infants: Advice for Parents Regarding Sign Language* the authors use the label *CI-child*, when stating that "the CI-child must undergo long-term extensive training" (Humphries et al., 2015, p. 1). Further, a generally recurring expression in research is the term "cochlear implanted child". How children are constructed raises fundamental and critical questions about the values with which adult-child interactions are constructed (Miller & Sambell, 2003). This is relevant, because it raises issues of how the

child is understood, how children should be treated and how adults define themselves in relation to children. These constructions will affect how parents interpret their parenting role (Miller & Sambell, 2003). The language used to construct a dominating mode of representation has power (Mehan, 1996). As a consequence, constructions of the ‘special’ child risk bestowing an identity on the child (Brantlinger, 2006). A key issue throughout the project has been to try not to add to the construction of the ‘special’ child. However, it must be noted that the flyer, as well as the invitations that were distributed to parents during the time of sample recruitment did carry the term “your cochlear implanted child”.²⁷ It illustrates that taking language into consideration has been a challenging issue that was not learnt overnight.

4.5 Challenges during the research process

The previous section introduces a specific challenge that was experienced during the course of the research process. Taking into account possibly damaging linguistic expressions generated challenges in the writing process, concerning for instance language flow. Other challenges in this regard were having to adapt the writing to the dominant mode of expression of the book chapter (Paper I). To serve uniformity, all contributing authors were to use the expression “DHH”.²⁸ Therefore, the term “DHH” is to be found in Paper I.

Other challenges experienced in the study emerged due to insecurity about where and how to find the parents, whether it would be possible to reach them and recruit enough participants. Central institutions in the field were asked whether they could distribute the invitations to parents, met by gatekeepers. It was not possible to establish contact with parents through the Oslo University Hospital. Therefore, user organisations and Statped were approached.

Another challenge worth mentioning is that the preliminary analyses of the questionnaire data and the interview data, as described in chapter 4.3.2, generated multiple interesting research topics relevant for further exploration. This meant that deliberating on choosing the three topics for the empirical study has been an extensive process. However, the study’s interest in learning has

²⁷ «ditt cochleaimplanterte barn»

²⁸ «DHH» is an abbreviation of «deaf and hard of hearing»

The research process

proven a helpful compass, identifying directions pointing the way. In a research project stretching over several years, it has been challenging to keep track of focus to ensure the study's inner coherence, and not to lose direction when working the individual sub-studies. Finally, growing a type of meta-awareness necessary for writing the extended abstract - developing a clear line of argumentation - has been a challenging but rewarding process.

5 Summary of the research

This chapter provides a summary of each sub-study, with a view to its research questions, main findings and arguments as they come forward in the respective paper. The four papers that report on the sub-studies can be found in full text in Part 2 of the thesis. All papers were written in the project period, between 2013 and 2017.

5.1 Paper I

Bruin, M. (2015). Research on language development: Discourses on learning and messages to family support after CI. In H. Knoors & M. Marschark (Eds.), *Educating Deaf Learners: Creating a Global Evidence Base* (pp. 93-113). New York, NY: Oxford University Press.

This paper reports on an exploration of how various understandings of the concept of learning are expressed in research on language development after CI, and in research on language development regarding the broader, more generic, context of children who are deaf and hard of hearing. In so doing, the purpose is to create awareness that understandings of learning are fundamental to the way that support for learning is designed (Wenger, 1998) and to subsequently discuss how understandings of learning might influence the design of professional support after CI.

The review of the research roughly distinguishes between perspectives viewing learning as an individual, cognitive process, and perspectives viewing learning as a social process, as an analytical lens for identifying different conceptualisations of learning in the body of research. The sub-study finds that research on language development after CI communicates a predominantly individual, cognitive perspective on learning, describing learning as taking place in the mind of the learner, as an instrumental process that is the result of structured training and therapy. Especially the studies on parents' views do yield thought-provoking examples of underlying perspectives on learning, when considering that the perspectives on learning and the way in which parents describe their experiences, are tied to the realm of family support.

In the quest for more social perspectives on learning, the net has to be cast wider, so that it includes studies in the more extensive category of research on children who are deaf and hard of hearing. In this wide-ranging category, more social perspectives on learning are to be found. The sub-study argues that dominant understandings of learning might influence the design of parent support after CI and that problematizing understandings of learning provides opportunities to think differently, opening up new areas of inquiries. Implications of predominantly individual, cognitive perspectives in the research on cochlear implantation might be that it becomes interpreted by practitioners as though the studies were covering the process of learning in its entirety, and lead to an interpretation that language development after CI primarily depends on speech therapy, training, and structured teaching. It will downplay the importance of social dimension for learning and thus the innate power of the family as a community of practice.

The conceptual review discusses several ethical dimensions that illustrate why a hegemonic perception such as this might be problematic, in particular within the family context. It concludes that research on language development after CI must expand its focus to include the family's community of practice as an important arena for the child's language learning. Likewise, family support services must not base their knowledge exclusively on research on language development after CI but extend their focus to studies displaying social perspectives on learning as they are present in the broader category of children who are deaf and hard of hearing. Comprehensive perspectives on learning view learning as an individual *and* a social process. Therefore, in the process of designing support for parents after CI, becoming reflective to how learning is understood is vital.

5.2 Paper II

Bruin, M., & Nevøy, A. (2014). Exploring the Discourse on Communication Modality after Cochlear Implantation - A Foucauldian Analysis of Parents' Narratives. *Journal of Deaf Studies and Deaf Education*, 19(3), 385-399.

The paper reports on a qualitative analysis of the discourse on communication modality in follow-up after CI, drawing on the work of Michel Foucault (1966, 1972, 1975, 1980, 1981, 1982). The discourse centres on different views with

regard to communication modalities and their effect on spoken language development (Geers, 2006). These modalities form a spectre ranging from approaches based on spoken language, to sign/bilingual approaches, being the issue of forceful debate (Knoors & Marschark, 2012). Parents are caught at up in the ongoing controversy, encountering professional support services that represent opposing views (Archbold & Wheeler, 2010; Strand, 2003). Discourses govern the way in which people think and act, “forming the objects of which they speak” (Foucault, 1972, p. 49). Due to limited attention addressed to parental perspectives in the research, little is known about how the discourse on communication modality affects the parents. Therefore, the sub-study explores the following research questions: how is the discourse constructed, how does it operate and how does it govern thinking and acting?

Twenty-seven parents living in Norway responded to an online questionnaire with 23 open-ended questions. The analysis of the empirical data followed a qualitative discourse analytical approach, anchored in Foucauldian perspectives (Alvesson & Skjöldberg, 2009; Potter & Wetherell, 1987; Wetherell, 2001). The analytical concepts are based on three fundamental, interconnected Foucauldian notions on power/knowledge structures: *Discourses of Truth*, *The Power of the Norm* and *Subjugated Knowledges*.

The analysis shows that parents face challenges determining how to provide the most supportive conditions for their child’s language learning; they are confronted with different truths when they encounter professionals who strongly advocate opposing approaches. The findings indicate that the parents experience the discourse on communication modality in follow-up as implying that there is a ‘right’ and a ‘wrong’ choice, inducing values such as ‘normality’ and ‘success’. The discursive power leads parents to think that making the ‘right’ choice on communication modality will lead to normalisation in the sense of ‘success’ in spoken language learning. Encountering different truths leads to insecurity and frustration on the part of the parents. Although the intention of professional support is to empower parents, parents may experience the opposite. However, findings show that some parents actively resist the dominating discursive power by choosing differently than they had been advised; this reflects that families are diverse and have individual needs. It implies that there cannot be a ‘one size fits all’, a universal truth concerning the

‘right’ or ‘wrong’ choice of communication modality. There are only the different families’ divergent needs.

The parents’ choice of communication modality is demanding; it is characterised by insecurity and will continue to be so. Therefore, parents need professional support that can help them to negotiate the various options available. The sub-study brings to the fore how the discourse on communication modality affects the parents’ as well as the professionals’ thinking and acting. In so doing, the study provides these insights as a critical, constructive voice into the ongoing construction and reconstruction of supportive follow-up systems.

5.3 Paper III

Bruin, M., & Ohna, S. E. (2015). Negotiating reassurance: Parents' Narratives on Follow-up after Cochlear Implantation. *European Journal of Special Needs Education, 30*(4), 518-534.

This paper reports on a narrative analysis of parents’ experiences on follow-up of children’s language learning after CI. Anchored in the Western public discourse on parents’ anxiety about children’s educational future (Furedi, 2008; Nelson, 2010; Popkewitz, 2003; Vincent, 2000, 2012), the research questions are: i) how do parents respond to insecurity concerning their child’s learning and development, and (ii) what significance do parents ascribe to professional support? Through narrative inquiry of parental perspectives, the purpose of the sub-study is to develop new knowledge that may contribute to designing support services tailored to match parental needs.

Fourteen semi-structured interviews were carried out with parents of children who use a cochlear implant. In exploring the parents’ experiences on follow-up after CI, the study draws on a narrative analytical framework (Bruner, 1990, 1991, 1997; Riessman, 2008). In response to the research questions, the findings bring into view how the parents respond to insecurity concerning their child’s learning and development, ascribing great significance to professional support.

The analysis identified two narrative presentations of self, each expressing a story in which the narrators place themselves (Silverman, 2011):

the Parent-as-Learner and the Parent-as-Teacher. The construction of these narratives relates to Bruner's notion of narrative of the self (1997). The narratives show how the parents handle the 'trouble' of insecurity, and how they respond by searching for reassurance. The research participants place themselves in stories about working hard so that future educational outcomes may be ensured. The analysis shows that the purpose of the two narratives is to negotiate reassurance: because the parents believe future educational outcomes to depend on gaining knowledge and working hard with the child, the narrative justifies this. Hence, parents take on the identity of responsible parent, holding themselves accountable for future outcomes. The Learner/Teacher narratives express the parents' insecurity about educational outcomes, as well as how parents understand these as conditional. In line with the narrative framework, a world behind the narrators is exposed; beyond the parents' aims and anxieties, a burden of responsibility is revealed.

The analysis shows that the parents' perspectives on learning reflect a "language of instrumentality" (Ramaekers & Suissa, 2012, p. 16). The sub-study problematizes the merging of the instrumental language of rehabilitation with the family context and discusses the question whether support services may be able to meet the parents' search for reassurance with a different language, avoiding inflicting the burden of responsibility. The study emphasises that, while acknowledging the importance of parents' involvement for their child's learning and development, this should not reduce the relationship with their children to a pedagogical and functional one.

5.4 Paper IV

Bruin, M. (2016). Parental Involvement in Children's Learning: The Case of Cochlear Implantation – Parents as Educators? *Scandinavian Journal of Educational Research*, published online 12 January 2017, DOI:10.1080/00313831.2016.1258728

This paper reports on an explorative analysis of parents' talk on their involvement in the child's language after CI. Extensive research emphasises the significance of parental involvement for children's learning (Harris & Goodall, 2008). The meaning of parental involvement as presented in for instance

educational policy²⁹ indicates a parental role that is expected to ensure children's learning and educational achievement (Bloch & Popkewitz, 2000), a process described by Popkewitz (2003) as "pedagogicalisation of parents" (p. 35). Likewise, parental involvement is considered to be of major significance for children's language learning after CI (Boons et al., 2012; Holt et al., 2012; Klein & Wie, 2014). Notwithstanding the significance of parental involvement in follow-up after CI, the topic has received little scrutinizing attention in the research, in particular through parents' personal accounts. The aim of this sub-study is to provide insight in how parental involvement might be shaped and how it might be motivated, exploring the following questions: 1) What do parents tell about their involvement in the child's language, and 2) how can their narratives be understood within the context of discourses on parent pedagogicalisation?

The empirical material consists of two types of qualitative data: 27 written parental responses to an online questionnaire with open-ended questions, and semi-structured follow-up interviews with 14 of the parents who responded. The analysis is explorative and inductive in character, following a process of data-driven coding (Kvale & Brinkmann, 2009). The analysis shows the parents' extensive involvement in the child's language, indicated as a *practice approach* and a *participation approach*. The *practice approach* shows the parents' extensive involvement to ensure the child's language learning, which is understood as structural and decontextualized practice of linguistic skills and speech, reflecting a cognitive understanding of learning. The *participation approach* shows the parents' extensive involvement in the child's wellbeing through continuous removing of barriers for participation in social interaction. To the parents, their involvement reflecting the participation approach means ensuring the child's wellbeing. However, from a sociocultural perspective (Rogoff, 2003; Wenger, 1998), this particular involvement can be understood as facilitating learning. Contrary to the practice approach, the parents do not connect the participation approach to the professional support. In the way that the parents describe the practice approach and the participation approach, the cognitive perspective on learning clearly dominates: the parents

²⁹ Also Norwegian educational policy, see for instance the White paper 2015: 8, «The school of the Future» (Norwegian Ministry of Education and Research (NMER), 2015).

do not recognise the participation approach as support for learning. The sub-study concludes that the practice approach brings about pedagogicalisation, turning parents into educators, increasing their accountability.

The analysis provides insight into how understandings of learning influence the way in which parents support their child's language learning. It further shows that the professional support fails to emphasise the significance of participation for the child's language learning in a sufficient manner, whilst reinforcing a practice approach. It is argued that when discussing the meaning of parental involvement for children's learning, a key issue is *how* learning is understood. The study argues for a debate on how professionals can help parents to be involved in their child's learning, whilst avoiding reducing parenthood to a series of educational tasks. Professional support for parents may emphasise the importance of the participation approach for the child's learning, whilst reducing the dominating pressure of the practice approach. This may ease the parents' burden and stress, yet help parents to support their children's language learning in significant ways.

5.5 Main findings – a brief résumé

The sub-studies show that follow-up of children's language learning after CI is constructed – in research on follow-up after CI and by the parents participating in the study – as a process of rehabilitation. This reflects the discursive orientation on rehabilitation in research on language development after CI, as presented in chapter 3. The analyses of the four sub-studies incorporated in this thesis indicate that the child's language learning is seen in a linear, developmental perspective, reflecting an instrumental view where certain input is expected to generate a related outcome. The experiences of the parents participating in the study reflect that the parents view their involvement in the child's language learning as an indispensable and significant part of rehabilitation, for which they feel highly responsible. The parents convey that they consider the professional support essential in helping them to facilitate the child's language learning. However, a common denominator across all three empirical sub-studies is that parents are worried by various issues, concerning uncertainties about the possibility of living a 'normal' life; it involves uncertainties about the choice of language modality, as well as the provision of

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supportive conditions for the child's language learning. Further, the uncertainties involve worries about doing the 'wrong' thing, or maybe not doing 'enough', in supporting the child's language learning. Lastly, parents worry about the child's social-emotional wellbeing, due to linguistic challenges that may constrain participation in social interaction. The empirical sub-studies describe how the parents respond to these uncertainties; the parents' responses, the contexts in which they are grounded, as well as the implications they may have, will be topics for discussion in the next chapter.

6 What are parents' experiences on follow-up of children's language learning after CI, and how may their experiences be understood?

The empirical sub-studies bring to the fore that follow-up of children's language learning after CI is generally constructed as a process of rehabilitation. This finding is supported by the scoping review in chapter 3.1, as well as the conceptual review. The research on CI portrays children's language learning as a process of rehabilitation, focussing on the treatment of hearing loss and its challenges associated with language learning. Paper I, the conceptual review, indicates a rehabilitative perspective on follow-up endorsed by a predominant perspective on learning as a cognitive, individual process, taking place in the mind of the learner. In the review, it is argued that the predominantly cognitive perspective on learning emphasises structural training and practice of linguistic skills as essential for language learning. Likewise, the empirical analyses of the parents' experiences indicate that the *parents* understand follow-up of children's language learning after CI as a process of rehabilitation. Furthermore, the analyses indicate that the parents consider their role in the process of rehabilitation as significant for the child's language learning. Simultaneously, the analyses indicate that the parents do not recognise their extensive and continuous removal of barriers for participation in social interaction as support for the child's language learning.

The subsequent chapter is divided into three sections. Answering the first part of the research question, section 6.1 presents the parents' experiences as living with and responding to uncertainties. It is argued that the parents' experiences show that follow-up after CI is characterised by instrumentalist thinking that is indicative of Western educational contexts; as such, the group of parents in the study represents a particular case existing within a wider, general discourse on parenthood in Western educational contexts. These contexts are characterised by performative aims (Biesta, 2007, 2009); they emphasise the parents' significance for children's learning and induce a parental need for education (Ramaekers & Suissa, 2012; Smith, 2010).

Subsequently, section 6.2 answers the second part of the research question and argues that the parents' experiences may be understood as impressions of a "language of instrumentality" present in Western contemporary parenthood (Ramaekers & Suissa, 2012, p. 16). The section explains how the parents' experiences may be interpreted as characterised by instrumentalist thinking. It is argued that the language of instrumentality leads the parents to become caught up in the current of a rehabilitation stream. Finally, possible consequences for the parents and children involved are discussed in section 6.3.

6.1 Living with and responding to uncertainties

As mentioned in the previous chapter, across all three empirical sub-studies, the exploration of the parents' experiences centres on various issues worrying parents. These issues concern the possibility of living a 'normal' life, the choice of language modality, and the provision of supportive conditions for the child's language learning. It is known that, when a child is born with a disability, families undergo considerable adjustments (Ferguson, 2001; Ingstad & Sommerschildt, 1984). This is no different for families with children who are diagnosed as deaf or hard of hearing (Grønlie, 1995; Spencer et al., 2000; Tøssebro & Lundeby, 2002; Young & Tattersall, 2007), especially because the vast majority of children who are deaf and hard of hearing are part of families who have no prior experience with deafness (Thoutenhoofd et al., 2005). These families communicate through spoken language (Mitchell & Karchmer, 2004). A cochlear implant will provide an opportunity for the child to learn spoken language, which is why parents may choose CI for their child (Hyde & Punch, 2011; Mitchiner, 2015). Many parents make the choice because they wish for the child a life as 'normal' as possible (Kluwin & Stewart, 2000; Sach & Whyne, 2005), where "normal" means "as if hearing" (Young & Tattersall, 2007, p. 218). However, as explained in chapter 3, the outcomes are uncertain. The analyses of the parents' experiences indicate that the parents consider their involvement in follow-up as crucial for successful outcomes of the child's language learning. Thus, parents consider themselves responsible for these outcomes. Therefore, they express to be anxious about their ability to provide supportive conditions for the child's language learning. The analyses of the empirical sub-studies indicate that parents respond to these worries through

extensive involvement in follow-up, to ensure future chances of ‘success’ with the implant.

The empirical sub-studies indicate that the parents’ extensive involvement in follow-up takes various shapes, for instance through their engagement with questions and debates about the choice of language modality. The parents use a lot of energy to deliberate about the ‘right’ choice for the child’s language learning, due to opposing views in the professional support network. These engagements in the debates generate frustration and insecurity, especially since the ‘right’ choice is connected to ‘success’ with the implant, described by Young and Tattersall (2007) as the implant’s “great promise” of a “normal” life (p. 218).

Another way of responding to uncertainties concerning follow-up of children’s language learning after CI is the parents’ expressed desire to learn as much as they can; parents view insufficient knowledge about providing supportive conditions for the child’s language learning as a possible threat to future outcomes. The child’s future opportunities depend on the parents’ knowledge; not knowing is disconcerting. Parents consider the professional supports’ guidance and provision of expert knowledge crucial in this regard.

A third response to uncertainty is the parents’ extensive ‘working’ with the child. The analyses indicate that to improve future outcomes of implantation, the parents describe the need of working hard through actively using acquired methods that promote the child’s language learning. These methods are based on practising language skills in a structured fashion; they are promoted by the professional support, which the parents regard as indispensable. The parents ascribe the benefits from the implants to depend on hard work with the child, suggesting that the more ‘work’, the better chance of linguistic and educational results.

However, next to the response of ‘working’ with the child, the analysis shows an additional parental response. This response is different because it is not related to uncertainty about future learning outcomes, but about the child’s social-emotional wellbeing, due to linguistic challenges. The parents worry about the child’s participation in social interaction; they are anxious about exclusion from social environments, equal opportunities and from being with

peers. The parents convey that they respond to the worry about exclusion through continuously removing barriers to participation, increasing the child's opportunities to engage in social interaction, ensuring the child's social-emotional wellbeing. However, the parents do not construct this response as support for learning, and they do not connect it to the professional support.

The parents' involvement and their perceived responsibility for the child's learning may be understood in the light of the notion of a "language of instrumentality" in contemporary parenthood (Ramaekers & Suissa, 2012, p. 16). According to the authors, Western contemporary parenthood is characterised by a language of instrumentality that is anchored in developmental psychology. It takes for granted a causal logic, directed at "achievability" on condition of the parents' involvement. It understands learning as a linear-developmental process, "in which certain outcomes are implicitly posited as the desirable – and, ultimately achievable – end-point", depending on the parents' efforts (Ramaekers & Suissa, 2012, p. 14). Based on this notion, the study reveals the follow-up's language of instrumentality and its inherent focus on performativity. The focus on performativity is for instance illustrated by the conceptual review (Paper I), which shows that the research on language development after CI predominantly views the child's language learning from a performative perspective. Säljö (2016) describes this perspective as focussed on results, on reproduction of knowledge and skills as well as "practice through repetition" (p. 168). Anchored in Wenger (1998), Paper I argues that perspectives on learning influence the design of follow-up after CI. From this follows that a performative perspective on language learning will have its concurring influence on professional support and parental involvement. Moreover, the findings of the empirical sub-studies show that the instrumentalist, performative thinking becomes reified through structural training and practice of linguistic skills (Papers III-IV) and the assumption that the 'right' choice of language modality will lead to desirable outcomes, i.e. a 'normal' life (Paper II).

The language of instrumentality, as it comes forward in the analyses, exists within a larger Western context that is characterised by educational theorising based on various instrumentalist solutions. Contemporary fields of educational practices are characterised by constructions of effectiveness and learning outcomes (Biesta, 2013). As argued in Paper IV, based on the

extensive documentation of parents' significance for children's learning, parents are viewed as an important factor influencing educational "performativity" (Smith, 2010, p. 357). The view emphasises improvement of the input-output ratio through instrumental ways of reasoning, focussing on efficiency and effect. According to Smith (2010, p. 362) parenthood hence becomes "a matter of tasks to be confronted, [with] the skills necessary to carry them out, and of course, the experts to consult for advice".

The findings of the empirical sub-studies indicate impressions of the language of instrumentality in follow-up after CI. The following section will discuss how the parents' perceived responsibility for future language skills induces a need for parent education; it reifies processes of providing parents with expert knowledge, and ultimately leads to extensive 'working' with the child, practising language skills. In the following section, these aspects will be discussed against a backdrop of a larger, more general educational context.

6.2 Impressions of a 'language of instrumentality'

The findings of the empirical sub-studies indicate several – interrelated – impressions of the instrumental reasoning in follow-up. The parents perceive themselves to be responsible for 'success' with the implant. Therefore, they consider to be in need of expert knowledge that may help to design supportive conditions for the child's language learning. Parents feel guilty about possibly doing the 'wrong' things or not doing enough. The findings show that the parents believe they are in need of education, having to "professionalise themselves" (Ramaekers & Suissa, 2012, p. 5). Subsequently, the experts will tell parents "what works" (Smith, 2010, p. 361). From this emerges the idea that parents are expected to relate to their children in educational ways, doing things with their children that are specifically goal-oriented; these assumptions put claims on parents and confront them with institutional interpretations and expectations (Ramaekers & Suissa, 2012). As argued in Paper IV, the meaning of parental involvement in children's learning thus becomes pedagogical, turning parenthood into an "educational project", increasing parental responsibilities (Beck & Beck-Gernsheim, 1995; in Vincent, 2000, p. 23). Popkewitz (2003) marks these processes as "pedagogicalization of parents" (p. 35), indicating a parental role that is governed by policy and by professional

support into a pedagogical role, with the aim to ensure the future learning outcomes of children (Bloch & Popkewitz, 2000). These governing tendencies are visible in Western policies. Growing attention is directed towards “the parenting turn” in European welfare states, indicating tendencies in policy that focus on the significance of parents for children’s development towards future citizenship (Geinger, Vandenbroeck, & Roets, 2014 , p. 488). Hence, as described in Papers III and IV, policy and research pedagogicalise parents, emphasising “the successful parent” as a pedagogical parent (Popkewitz, 2003, p. 53). Programs of parent education are meant to “treat the psychological qualities and patterns of communication that prevent children’s achievement” (Popkewitz, 2003, p. 54). On the policy level within the Norwegian context, traces of pedagogicalisation protrude educational policy documents. As mentioned in papers III and IV, the Norwegian Ministry of Education, Research and Church Affairs (1997-1998) emphasises parents’ educational responsibility, indicating parents as “important partners in the learning processes of their children” (NMERCA, 1997-1998, in Bæck, 2010, p. 550). Likewise, the White paper “The School of the Future” (Norwegian Ministry of Education and Research (NMER), 2015, p. 8), stresses the importance of parents for children’s learning, supported by professional guidance from the school or teacher.

On a general level, in Norway, notions of parent pedagogicalisation become increasingly apparent through the expanding amount of educational services offered to families on the private market, for example via advertisements on Facebook.³⁰ Parents can pay for help with their child’s homework in order to increase academic achievement or there are private courses for parents promising necessary information about child rearing, as well as schooling and learning. This way, normative expectations are placed on parents (Nelson, 2010). The tendency of vigilance in parenthood is said to arise from parental anxiety about the child being excluded from educational opportunities and subsequent future citizenship (Carey, 2014; Nelson, 2010). According to Popkewitz (2003), these issues are anchored in cultural

³⁰ See for instance <http://www.mentornorge.no>, <http://www.goldenacademy.no> or <http://www.kanvas.no/foreldrekurs/> Retrieved on January 9th 2017.

distinctions of the child that highlight issues of normalisation and differentiation: distinctions that “qualify and disqualify individuals to act and to participate” (p. 55). The inner characteristics of the child are seen as those that induce processes that may exclude. The excluded child, according to Popkewitz, is the child who is seen to lack certain capabilities; capabilities that are phrased in expressions of being different and therefore in need of “remediation and rescue” (2003, p. 37). From this perspective, the parents in the study are part of a general climate that focusses on educational achievement and normative expectations on how to be a parent. In addition, the parents’ experiences are part of a particular climate that focusses on their role in the child’s language learning after CI. As the analyses of the parents’ experiences show, this climate is endorsed by the professional support, on which the parents heavily rely. Moreover, as explained in chapter 2, parents in Norway who have a child using a cochlear implant are offered a rich variety of professional support from which to choose. The climate, focussing on the parental responsibilities for outcomes of language learning, conveys messages to parents implying “What sort of parent would you be if you didn’t want all that for your child?” (Vincent, 2012, p. 14).

So far, this section has presented three interrelated impressions of the language of instrumentality as they come forward in the study: the parents’ perceived responsibility, the parents’ need for education, and the pedagogicalisation of parents. It is argued that these impressions contribute to another example of instrumentalist, performative reasoning in follow-up. The findings show the parents’ extensive involvement in ‘working’ with the child, through structural practice of language skills. Smith (2010) criticises professional parent support for its focus on performativity; the author problematizes the issues of efficiency and effectiveness, the improving of the input-output ratio and the “exclusively instrumental reasoning” (p. 357) as particularly unfortunate within the context of family life. As indicated by chapter 3.3, various studies point to the strain involved with continuous practice of children’s language learning after CI (Bosteels et al., 2012; Hardonk et al., 2011; Thoutenhoofd et al., 2005). In line with Bosteels et al., it is argued that the continuous ‘working’ with the child on practising language skills risks reducing parenthood to “the establishment of speech and language development following a prescribed path [of] intensive rehabilitation” (Bosteels et al., 2012,

p. 993). Hence, the instrumental ways of thinking in follow-up may turn parents into educators.

In summary, the impressions of the instrumental reasoning as they come forward through the findings of the study represent a parental struggle to provide the 'right' conditions to enable the goal of a 'normal' life. The concluding section discusses possible consequences for the parents and children involved.

6.3 Possible consequences for parents and children

The construction of follow-up as a rehabilitative process may have its origin in the fact that CI starts as a medical procedure, creating ramifications for educational follow-up. The past three decades have witnessed an enormous expansion of the impact of medicine and medical concepts on people's lives; a growing number of medicalised categories, as well as a vast extension of medicalisation has appeared, aiming at the transformation of human conditions into treatable disorders (Conrad, 2007). The cochlear implant as an innovative technological artefact is an example of a "biomedical enhancement", a particular form of medicalisation developed to "[...] improve body and performance", provided through surgery (ibid, p. xi). Following Conrad (2007), "When biomedical enhancements are used with the goal of bringing the body into line with what the physician or patient deems to be the 'normal' or socially expected standard, this type of enhancement can be called 'normalization'" (p. 87). Normalisation occurs, for example, when parents of children diagnosed with profound hearing loss approach the medical system requesting treatment through cochlear implantation, with the goal to restore the child's hearing. The focus on treatment of that which is diagnosed as outside of normalcy is a core characteristic of medicine. "The general mode is to solve the problem in the individual", its focus being rehabilitation (Conrad, 2007, p. 152). Power (2005) blames the medical profession for indicating "successful" outcomes of CI in terms of "normalization (i.e. making the child as 'hearing-like' as possible)" (p. 452), promising parents normalisation on condition of the 'right' initiatives (Matthijs et al., 2012). A consequence, as indicated by Papers III and IV, is that the parents take enormous responsibility for the implants' "promises of cure"

(Bosteels et al., 2012, p. 993), by working very hard to attain that goal. One way to interpret the findings is that the parents become caught up in the current of a rehabilitation stream.

As the findings show, being caught up in the current of the rehabilitation stream affects the parents' view on their role as a parent, taking on a pedagogical role. Furthermore, it may affect the parents' and professionals' view on the child. As described in Paper I and II, Foucault (1977) speaks about *normalizing judgment*. It individualizes people by measuring gaps and fixing what is considered outside of normalcy. As explained in Paper I, measuring will reflect certain "degrees of normality", establishing over individuals "a visibility through which one differentiates them and judges them" (Foucault, 1977, p. 184). Following this line of thought, children might be "perceived as objects" (Foucault, 1977, p. 185), and as argued in Paper I, this might be particularly unfortunate within the parent-child relationship. As pointed out in Paper II, the "normalizing gaze" (Foucault, 1985, p. 184) makes it possible to qualify and classify. It creates distinctions of normality and deviation, ultimately establishing truth (Foucault, 1975). Building on Sford (1998), Paper I argues that describing children largely by the skills they lack, emphasized by the need for therapy and practice, might have negative impacts on the child. As argued in Paper III, in pursuing the implant's promises of cure, caution is required not to reduce the parent-child relationship to a primarily pedagogical and functional one (Suissa, 2006). Furthermore, Paper III presents reasons of ethical nature indicating this reasoning as problematic. Quoting Suissa (2006, p. 72), the problem of parents ensuring children's learning is "not the complexity of this task, nor its terrifying significance for our children's development [...] but the fact that it is conceived as a task at all". The parents who participate in the study convey that they invest considerable time and effort in follow-up. As explained in Paper III, a burden of responsibility is inflicted on parents: if parent base future outcomes on the performance of their task, and hold themselves accountable, what happens when outcomes are not as expected?

Being caught up in the current of a rehabilitation stream is tied to issues of parental insecurity. The findings show that the parents worry continuously about whether they do the 'right' things, or whether they do 'enough'. The instrumental reasoning and its subsequent pedagogicalisation add to the

insecurity. This becomes salient through the Foucauldian analysis indicating how the power structures ingrained in the professional discourse on language modality govern the parents into thinking about ‘right’ and ‘wrong’ choices in follow-up. Further, the insecurity becomes salient through the extensive ways in which the parents engage in structured training and practice of linguistic skills with the child (Papers III-IV). This could hinder the parents in their *role* as parent. Furedi (2008, p. 16) argues that the instrumental ways of reasoning induce a discourse of public anxiety that “denigrates parental competence”, claiming that parents cannot manage without, and are in need of, the help of experts. According to Furedi, these discursive messages are “zealously promoted by a formidable network of professional experts [...] and politicians” (2008, p. 16) (Paper IV). Although the intention may be to empower parents, the findings show that parents rely heavily on the professional support. Miller and Sambell (2003) point towards the need for professional support to consider what the support is hoping to achieve. The authors reflect upon the question whether professional support should focus on guiding parents to “develop as independent reflective practitioners able to find their own understandings of their parenting situations” (Miller & Sambell, 2003). As mentioned in the introduction of this chapter, and in section 6.1, the findings show that the parents do not recognise their extensive and continuous removal of barriers for participation in social interaction as support for the child’s language learning. In line with Miller and Sambell (2003), the question in the case of CI is whether the professional support meets the parents’ needs for facts and information, but may leave insufficient attention to reflection. As indicated by Paper IV, professional support may stress the significance of removing barriers for social participation, as the findings show that parents do so extensively. The support may reduce the pressure of the language of instrumentality and its inherent focus on performativity through offering space for reflection about the parents’ role in follow-up. This may leave room for parents to be parents, and not teachers. Yet it might ensure that parents know they are supporting their child’s language learning in significant ways.

In summary, the follow-up’s language of instrumentality and its inherent focus on performativity may cause parents to become caught up in the current of a rehabilitation stream. This raises a moral conundrum. Even though extensive research on language learning may indicate rehabilitation

characterised by structural practice and therapy to be effective for the child's language skills, following Biesta (2007), it needs to be taken into consideration that what is *effective* has to depend crucially on judgments of what is considered *desirable*. As pointed out by Smith (2010), this counts in particular for the family context. Skjervheim (1996) argues that the pragmatic, instrumental reasoning has its legitimate grounds, also in pedagogy. However, he cautions that it has its limits, referring to "the instrumental mistake" (p. 241). The instrumental mistake, Skjervheim argues, is a crossing of the limit of these legitimate grounds, by giving preferential treatment to one form of theory that has its legitimate rights *only* within certain limits. This means that, according to Skjervheim (1996), in pedagogy, it becomes problematic when pedagogic practice is misinterpreted as a technique. The study shows that the parents' experiences on follow-up of children's language learning after CI may be understood as impressions of the language of instrumentality; as such, they represent examples of giving preferential treatment to one form of theory concerning language learning after CI. As the analyses show, this renders more situated perspectives on language learning invisible. In concert with Gallagher (2014), the study shows that, motivated by a performative, normalising goal, follow-up of children's language learning after CI risks giving primacy to instrumentalist rehabilitation, consigning moral judgment to certain measures that define what is, and what is not, worth doing. As the study indicates, this has consequences for the parents and children involved.

The aim of research in education, as in all social sciences, is "to bring the consequences of our knowledge and practices under more reflective scrutiny and to weigh more deliberatively the consequences of those actions" (Gallagher, 2014, p. 95). With reference to the question of desirability, the study contributes by bringing to the fore the weight of these consequences.

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PART 2

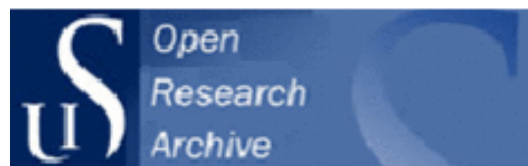
Paper I

Bruin, M. (2015). Research on language development: Discourses on learning and messages to family support after CI. In H. Knoors & M. Marschark (Eds.), *Educating Deaf Learners: Creating a Global Evidence Base* (pp. 93-113). New York, NY: Oxford University Press.



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5

Research on Language Development

Discourses on Learning and Messages to Family Support After Cochlear Implantation

Marieke Bruin

O! this learning, what a thing it is.

—W. Shakespeare, *The Taming of the Shrew*¹

Learning is an everyday concept, but when scrutinizing its content, a myriad of perspectives comes to the fore. The concept is tricky, generating different perspectives and considerable disagreement on how learning is described and where it is situated (Bråten, 2002). Each perspective represents its own particular view on how to facilitate learning. In the field of educational research there are various ways of viewing learning, communicating divergent understandings along with their subsequent recommendations toward different practice fields.

The way that learning is understood is important because it affects how support for learning is designed (Wenger, 1998). Thus, underlying understandings of learning are central to the design of family support after cochlear implantation (CI). According to Wenger, “what we think about learning influences where we recognize learning” (1998, p. 9), and therefore it directs both people’s perspectives and actions. A similar argument is offered by Alexander, Schallert, and Reynolds (2009), who emphasize that understandings of learning, whether expressed or not, shape everyday decisions, thus significantly affecting people’s lives.

The central matter of interest of this chapter is the concept of learning and how different understandings of it are significant for the design of family support after CI. The focus is on different understandings of learning in research on language development after CI,

and in research on language development regarding the broader, more generic, context of children who are deaf and hard of hearing (DHH). The purpose is to explore how various understandings of learning are expressed in this body of research and to bring into conversation how understandings of learning are fundamental to the way that family support after CI is designed. In this context, questions of language modality will not be addressed; therefore, throughout the chapter the general term *language development* will be used. However, all the studies analyzed in this chapter center on spoken language development. It remains an open question whether a focus on sign language development would result in similar answers, but that is not the topic of discussion here.

In the case of children with CIs, the issue of language learning is the primary focus after implantation. Research states that the parents' choice of CI for their child is motivated by their desire to increase the child's opportunities for understanding and developing spoken language, thus enabling interaction based on oral communication (American Speech-Language Hearing Association, 2003; Archbold, Sach, O'Neill, Lutman, & Gregory, 2006; Kluwin & Stewart, 2000). However, how that goal is best achieved is still a matter of debate (Archbold & Wheeler, 2010). Research on language learning after CI shows considerable variability in children's development. Even though efforts to explain differences in development have resulted in the identification of several factors (e.g., see Kronenberger et al., 2013), a significant amount of variance remains unexplained (Pisoni, Conway, Kronenberger, Henning, & Anaya, 2010). However, an extensive literature review on outcomes after CI concludes that the child's family is a specific key factor influencing the child's language learning after implantation (Thoutenhoofd et al., 2005).

ROLE OF THE FAMILY IN THE CHILD'S LANGUAGE LEARNING

The family is essential to a child's development (Knoors & Marschark, 2014). From a sociological perspective, the family is the area for a child's primary socialization, the first stage in which a child learns to become a member of society (Berger & Luckmann, 1966). Here, conditions for learning are situated in the family's everyday life; learning is participation in the family practice. In the family context, through the process of primary socialization, young children learn their first language without formal instruction (Rogoff et al., 2003).

Similarly, family involvement is significant for the language development of children who are deaf and hard of hearing (Calderon, 2000; Moeller, 2000; Quittner, Cruz, Barker, Tobey, Eisenberg, & Niparko, 2013); hence, family support services after CI are essential (Archbold & Wheeler, 2010; DesJardin & Eisenberg, 2007; Hintermair, 2006; Kushalnagar et al., 2007). It is suggested that language development

may be influenced by the challenges parents face in scaffolding their child's environment to facilitate learning and communication (Cruz, Quittner, Marker, & DesJardin, 2013; DesJardin & Eisenberg, 2007; Quittner et al., 2010; Spencer, Erting, & Marschark, 2000). Therefore, interventions should be targeted toward the family to provide maximum support for language development (e.g., see Cruz et al., 2013; DesJardin, Ambrose, & Eisenberg 2009; DesJardin & Eisenberg, 2007). Even though family support after CI is considered crucial, the topic is underresearched and parental views are considered sparse (Archbold & Wheeler, 2010; Thoutenhoofd et al., 2005). Therefore, this chapter directs a particular interest toward research concerning language development where the empirical field includes parents of children with CIs, as well as on studies concerning parental views on family support after CI.

TWO WAYS OF UNDERSTANDING LEARNING

Hodkinson, Biesta, and James (2008) refer to the major debate raging at the end of the 1990s about contrasting ways of understanding learning, which they describe as “the cognitive versus situated learning debate” (p. 29). Since then the debate has continued, although some theorists strive to bridge the cognitive and situated positions (Hodkinson et al., 2008). Contemporary learning theories describe the inherent complexities of learning, indicating various dimensions intrinsic to the process and concurring that a comprehensive understanding involves both individual and social dimensions (Alexander et al., 2009; Bråten, 2002; Illeris, 2009; Jarvis, 2006, 2010; Sfard, 2009). An individual perspective on learning focuses on what happens in the singular mind of the learner, reflecting cognitive learning theories (Piaget, 1952). A social perspective on learning focuses on learning through social interaction and communication, reflecting situated, sociocultural learning theories (Rogoff, 2003; Wenger, 1998). Illeris (2009) holds that the process of learning implies the integration of both individual and social dimensions. Notwithstanding this integration,

Many learning theories deal only with one of these processes, which of course does not mean that they are wrong or worthless, as both processes can be studied separately. However, it does mean that they do not cover the whole field of learning. [...] it seems evident that both processes must be actively involved if any learning is to take place. (Illeris, 2009, p. 9)

As noted by Illeris, both the individual and the social processes can be studied separately. However, when studied on its own, each process alone does not cover the entire process of learning. Moreover, “it must be clear that the situation or process has not been fully covered, and an

open question will remain as to what happens in the areas that are not discussed” (Illeris, 2009, p. 18).

This chapter roughly distinguishes between individual and social perspectives on learning as an analytical lens for identifying different understandings, being sensitive to the fact that such a rough division does not adequately reflect the infinite complexity of the concept of learning. The following section describes how these two perspectives, individual and social, are conceptualized in this chapter.

Learning Understood as an Individual Process

Traditionally in Western society, learning is viewed as an individual process, as “assembly-line instruction” (Rogoff, Paradise, Arauz, Correa-Chávez, & Angelillo, 2003, p. 176). It is based on the idea that learning occurs through transmission of knowledge. As such, the image of learning “immediately conjures up images of classrooms, training sessions, teachers, textbooks, homework and exercises” (Wenger, 1998, p. 8). Individual perspectives on learning are based on cognitive theories (Piaget, 1952), which are centered on the individual learner’s mind and the accumulation of knowledge. “Modern cognitivism holds that individual brains, acting as solitary units from birth, possessed of representational structures and transformation rules, and receiving ‘input’ from the exterior, can account for the way in which we learn” (Winch, 1998, p. 46). In this view learning is decontextualized, separated from ordinary everyday activities; it has a beginning and an end and is the result of teaching in formally structured settings. The process of learning is confined to the individual mind of the learner. As noted by Hodkinson and colleagues (2008), individual understandings of learning that are primarily concerned with cognition run the risk of downplaying the physical, practical, and emotional dimensions of learning and are as such not understood as “embodied and social” (p. 31).

Learning Understood as a Social Process

Wenger (1998) challenges the predominance of individual understandings, stating explicitly that in his efforts to think differently about learning he does not aim to cover the whole field of learning. He makes a case for rethinking learning as a fundamentally social phenomenon, where learning takes place through active participation in the practices of social communities. Participation is viewed as “the transformative potential” (p. 56) of active membership in social communities of practice, where participants shape each other’s experiences of meaning (Wenger, 1998). The family is an example of a social community constituting a community of practice. According to Wenger, communities of practice are quite familiar to all people, because they are an integral part of people’s daily lives (e.g., the local soccer team, a neighborhood, a group of colleagues), although they rarely come into focus explicitly.

Most communities of practice do not have a name and do not issue membership cards, although we tend to know quite well who belongs to our communities of practice and why (Wenger, 1998). In this view learning is contextualized; it involves participation in communities of practice, situated in everyday life contexts. The process of learning is of a social, interactional nature.

WHY DO UNDERSTANDINGS OF LEARNING MATTER?

The processes of learning involve both social and individual dimensions. However, at times one understanding may dominate the other. Following Illeris (2009), whenever learning is viewed as predominantly individual or social, an open question must remain to what happens in the areas that are not discussed. The way we understand learning, says Wenger, requires urgent attention because a key implication for attempts to design support for learning is that “we must become reflective with regard to our own discourses of learning and to their effects on the ways we design for learning” (1998, p. 9). In other words, in designing follow-up systems supporting families in the child’s language learning after CI, it is essential to reflect on how learning is understood, and to reflect on how these understandings may affect the ways in which family support is constructed. In connection to the provision of family support services, the following question becomes relevant: How do understandings of learning come forward in research on language development after CI? The next section will explore how learning is expressed in research focusing on language development after CI. As follows from the text, this body of research views learning to a large degree as a predominantly individual process.

RESEARCH ON LANGUAGE DEVELOPMENT AFTER PEDIATRIC COCHLEAR IMPLANTATION

There is a vast body of studies reporting on language development after CI. In this research, both the social and medical research paradigms come into play, differing in their emphasis (Thoutenhoofd et al., 2005). From a historical perspective, because CI is a surgical procedure, the research on language development after CI is inevitably influenced by values of traditional research set in the medical domain, characterized by recognized levels of evidence. Furthermore, the demands made on the research have been that CI should prove its efficacy and justify its implementation (Thoutenhoofd et al., 2005). This has resulted in “a comparatively large amount of research in a comparatively short space of time” (p. 264). Undoubtedly the fact that CI has had to legitimize its existence has caused many studies to investigate factors related to speech perception and speech production, measuring language

development quantitatively. This might in turn contribute to the predominantly individual perspective on learning in studies on language development after CI. Learning is understood as decontextualized, taking place in structured training sessions, generating keywords such as “spoken language outcomes,” “rehabilitation and treatment of deafness,” and “auditory skills.” For example, one of the topics currently addressed is *word learning processes* (e.g., see Lund & Schuele, 2014; Walker & McGregor, 2013). Walker and McGregor (2013) explored the word learning abilities in children with cochlear implants. They compared the responses of 24 children with CIs, 24 age-matched hearing children, and 23 vocabulary-matched hearing children in a word learning experiment, concluding that “children with CIs demonstrated deficits in word learning” (p. 375), showing “slower vocabulary growth” (p. 386). The underlying assumption is that the learner is the owner of the indicated skills, in this case skills that are lacking. Skills are measured in a clinical test, out of context. The concept of *word learning* reflects a focus on the cognitive processes in the mind of the learner. The approach reflects a perspective on learning as decontextualized and individual.

Likewise, in an article entitled *Effects of a Word-Learning Training on Children with Cochlear Implants* by Lund and Schuele (2013), the individual and decontextualized approach to learning is present in the title: The word *training* emphasizes that learning is a result of structured teaching and practice, and the word *effects* indicates measurements. Learning is conceptualized as accumulating basic units of knowledge (Sfard, 1998). Expressions such as “deficient word-learning abilities” (p. 68) and “receptive and expressive performance” (p. 81) represent a perspective of knowledge and skills as residing in the individual learner. “The language of ‘knowledge acquisition’ and ‘concept development’ makes us think about the human mind as a container to be filled with certain materials and about the learner as becoming an owner of these materials” (Sfard, 1998, p. 5). Lund and Schuele recommend that “Professionals can begin to explore the possibility that systematic training can improve the overall lexical learning process” (2013, p. 80). In this view learning is understood as a predominantly individual process.

An interesting example with regard to different understandings of learning is a study by Holt, Beer, Kronenberger, Pisoni, and Lalonde (2012) that evaluated family environments of children with CIs and examined relationships between the family environment and language development after CI. They concluded that family environment may cause some of the variability in CI outcomes and suggested that families can be helped “to create robust language-learning environments that can maximize their child’s potential with a cochlear implant” (p. 848). On the one hand, the acknowledgment that learning depends

on a relationship between the learner and his or her social environment represents a social perspective. On the other hand, the language used in the text expresses to a large degree a view of learning based on a predominantly individual perspective. The learner is described as a singular individual; no remarks are made toward learning as a result of mutual meaning making in communication or the learner becoming a part of the family's community of practice. The article concludes that

families with higher levels of self-reported control had children with smaller vocabularies. Families reporting a higher emphasis on achievement had children with fewer executive function and working memory problems. Finally, families reporting a higher emphasis on organization had children with fewer problems related to inhibition. (Holt et al., 2012, p. 848)

The quotations express a view of knowledge as something that resides as a measurable amount, in accumulated form, in the mind of the child, as such representing a view of learning as individual. However, this is one of the few studies in the field of CI that emphasize that affordances for the child's spoken language development are to be found within the child's family environment. The article concludes that the study holds exciting promise for its potential application to intervention:

Because family dynamics are fluid and can be changed with explicit communication education and therapy, there is a real possibility that families that function in ways that do not maximize the likelihood of success with a cochlear implant could learn to function in ways more conducive to a child's likely success. (Holt et al., 2012, p. 861)

The use of a word such as *therapy* can be interpreted as reflecting a view of learning as an individual process, where knowledge is transmitted in decontextualized settings.

Notwithstanding the fact that families are important for the child's learning, within the vast body of research on pediatric CI the parental view is hardly ever present (Archbold & Wheeler, 2010). In their review, Archbold and Wheeler (2010) explored research on parental views concerning the decision-making process, outcomes from CI, and educational implications. Since then, only a handful of studies have discussed parental views on family support after CI; three of them are presented in the following section. Understandings of learning influence how learning is facilitated, and as such they have an impact on the construction of family support. Therefore, it is relevant to ask how parents view the support they receive and how they view learning. As follows from the text, the parents' narratives largely reflect perspectives that view learning as a predominantly individual process.

In a qualitative study on parental experiences, Hardonk and colleagues (2011) analyzed the parents' perspectives on "early care

trajectories” (p. 305) after Universal Neonatal Hearing Screening in Flanders (the Dutch-speaking part of Belgium). Sixteen families participated in the study. At the time of the interview the children were between five and seven years of age. In the study the child’s learning is viewed as a predominantly individual process, by both the support system and the researchers. This is reflected in the researchers’ choice of words and in the parents’ descriptions of their encounters with the support system. The child’s development in relation to his or her CI is aligned with “rehabilitation care” and “rehabilitation therapy” (p. 319), understanding learning as a result of structured teaching and training sessions, out of context, where “the intensity of therapy is measured in relation to the functional (developmental) dimension of the care trajectory” (Hardonk et al., p. 319). The authors write that their analysis shows that “therapy is often reduced at the moment when satisfactory oral language development is reached” (p. 319). Through this particular manner of description, oral language development is described as the result of decontextualized training sessions, having a beginning and an end, inherent in the nature of therapy sessions. In relation to CIs, an interesting factor in connection with training sessions is “the perception of the burden of therapy by the child and/or the family” (p. 319). The quotation from Jonas’s mother reflects the family’s encounter with a support system that views learning predominantly as an individual process, with devastating consequences for the child:

After a while my child couldn’t take any more, he really became aggressive because it was too much. They kept demanding intellectual effort from him, but playing and relaxing was never part of the schedule. (Hardonk et al., 2011, p. 319)

In another example, Sien’s father is concerned by the burden that is placed on his daughter by the therapy: “She already spends six hours at school, behind a desk. Three hours in extra therapy plus the extra school support would have been just too much” (Hardonk et al., 2011, p. 319). In the realm of the support system that the family encounters, and through the way the parents describe the encounter, a predominant view of learning as an individual process emerges, with no reference to opportunities for learning that are present in communication through social interaction and informal learning through participation in everyday family life.

Huttunen and Välimaa (2011) explored experiences of Finnish parents of children with CIs and their views on follow-up. The authors state that it is “essential to know parents’ expectations and experiences after paediatric implantation to be able to counsel and support them in obtaining maximal habilitation outcomes” (p. 186). The expressions used are concurrent with an individual perspective on learning. From

the text, it appears that *habilitation* refers to structured training sessions where knowledge is transferred, and *obtaining maximal outcomes* reflects an understanding of knowledge as an accumulative commodity in the mind of the learner. The parental perspectives on follow-up in relation to their child's language learning are connected to "speech and language therapy" (p. 191), and five years after implantation the parents were asked how support services could be improved. In some cases, "the parents hoped for more speech and language therapy services" (Huttunen & Välimaa, 2011, p. 191). The study does not mention support to help parents enhance their child's opportunities for language learning through everyday family interaction and communication, which would represent a more social perspective on learning.

In Bruin (2014, manuscript in progress), Norwegian parents of children with CIs were asked about the support they receive in relation to their child's language learning. The following data are based on 27 written parental responses to an online questionnaire with 23 open-ended questions. The data were constructed as part of a research project on parental perspectives on follow-up after CI. Within the larger project, the aim of the data construction was to gather information to explore the parents' experiences with follow-up after CI (see also Bruin & Nevøy, 2014), with a focus on parental perspectives on the child's learning and participation in the family's community of practice. When asked about the focus of the family support, the parents describe their child's language learning as an individual process:

The focus in the follow-up is on pronunciation, concepts, understanding, grammar, etc., together with a playful way of learning. For our daughter it works well, she works a lot herself and well, in order to become good at speaking. (mother of Rosemary, age 6)

Oscar's parents wrote that they feel secure when preparing effective strategies for "good spoken language development in combination with regular assessment of progression of speech and speech understanding." They said they have become more aware of what to do and are therefore able to "work more goal-oriented"; the "evidence from the assessments that there is a progression happening" gives them a sense of security (parents of Oscar, age 4). Concepts like "training to listen," "assessment," "acquisition of speech," "listening skills," "learning sounds," "speech understanding," "profits," "gains," and "to drill the right pronunciation" all reflect a view of learning as an individual process, a result of decontextualized and structured training sessions. The expressions are used by all 27 parents in a range of contexts.

We are still lacking some repetition of words, the ones he doesn't pronounce rightly (lacking first letters or syllable in certain words) + new words and subjects! (mother of Fredric, age 5)

The parents display ways of thinking about learning as individual acquisition, gaining “basic units that can be accumulated” (Sfard, 1998, p. 6). “The focus in follow-up until now has been language-building, concepts, pronunciation, listening” (mother of Marcus, age 9).

In summary, in the three studies on parental views, language development is described from a predominantly individual perspective on learning. The parents’ perspective on learning is apparent from the way they describe their encounters with the support system. More generally, studies on language development after CI typically take, to a large degree, a predominantly individual perspective on learning. The aforementioned studies describe learning as instrumental, taking place in the singular mind of the learner and being the result of structured training and therapy. No generalizations regarding support services can be made from the limited number of studies available. However, the studies on parents’ views do yield thought-provoking examples of underlying understandings of learning, especially when considering that the understandings of learning and the way parents describe their experiences are tied to the realm of family support after CI. With a few exceptions—in particular the work of DesJardin and colleagues (2005, 2007, 2009, 2011) and Cruz and colleagues (2013), which will be discussed in the next section—research on language development after CI displays a narrow focus, viewing the process of learning from a predominantly individual perspective. In most studies that explicitly cover the area of CI, the actual content and quality of social interaction and communication within the family’s community of practice seem barely addressed as dimensions relevant to the language learning process.

Do any studies take a broader, more social perspective on learning or emphasize social interaction as a central dimension in the child’s language development? To find them, the net has to be cast more widely, covering not only studies in the area of CI but also the broader, more generic field of children who are deaf and hard of hearing.

SOCIAL PERSPECTIVES ON LEARNING IN RESEARCH ON LANGUAGE DEVELOPMENT OF CHILDREN WHO ARE DEAF AND HARD OF HEARING

The current section presents studies on language development regarding children who are deaf and hard of hearing. Although children with CIs may be part of the empirical field in these studies, they are not discussed explicitly, with the exception of the work of DesJardin and colleagues and Cruz and colleagues. As follows from the text, in the quest for social perspectives on learning it becomes apparent that these are to be found in the more extensive category of research on children who are deaf and hard of hearing.

In 2006, Brown and Nott referred to the change in the Western approach of childhood development, which they regarded as particularly useful in understanding and promoting language development in DHH children. The change referred to is the shift toward the influence of the work of Vygotsky, with a main focus on the principle that early development and learning best take place within the context of the child's cultural group, usually the family (Brown & Nott, 2006). According to the authors, a similar trend took place within theories of child language development in the 1970s and 1980s, when emerging views of child language development pointed to the importance of the parents as tutors and to the family and its activities as the primary learning context in early childhood. Interactionist perspectives on children's language learning emphasize that young children learn their language through everyday life experiences and especially in the context of their family (Chapman, 2000), and for both DHH and hearing children, factors related to their parents have been associated with language development (Cruz, Quittner, Marker, & Desjardin, 2013). This orientation toward the child-in-context perspective has led to the philosophy of *family-centered practice* (Brown & Nott, 2006; Dunst, Trivette, & Deal, 1988). From this viewpoint the focus is on promoting an environment that provides an optimal context for the child's learning, rather than direct intervention with the child. The principle of family-centered practice is in concert with a sociocultural perspective, which views learning as situated in social interaction where people interact with mediating, cultural tools (Rogoff, 2003; Säljö, 2000; Vygotsky, 1962).

Reviewing the literature on general language development, Brown and Nott (2006) identified four features of parent-child interaction that promote communication development and that would be important in dyads in which young DHH children are developing spoken language. The first feature the authors identified was *joint attention*, which is said to scaffold the child's early language development (e.g., see Bruner, 1978). The second feature was *responsiveness* (e.g., see Bornstein, Tamis-LeMonda, & Haynes, 1999), defined as a verbal sensitivity where "positive and meaningful changes in the mother's verbal behavior are seen in response to a child's vocal and exploratory behavior" (Brown & Nott, 2006, p. 148). The third feature was *child-directed speech*, described as speech adapted to the language level of the listener (e.g., see Owens, 2001). This includes, for example, using a slower rate of speech, shorter sentences, higher intonation, and so forth. The fourth feature was *everyday life experiences*, which are said to provide a context for language learning (e.g., see Hart & Risley, 1995). Brown and Nott also refer to the work of Dunst and colleagues (Dunst et al., 2001; Dunst, Hamby, Trivette, Raab, & Bruder, 2000), stating that their research has improved the understanding of the learning opportunities afforded by everyday life experiences and how this affects practices for children with

disabilities. Brown and Nott present the four features as facilitative practices for parents interacting with their DHH children, enabling scaffolding of the child's language development. These four features reflect a social understanding of learning.

A 1999 study found evidence of maternal sensitivity predicting language development in children who are deaf and hard-of-hearing (Pressmann, Pipp-Siegel, Yoshinaga-Itano, & Deas, 1999). Since then, however, only a handful of studies on children with CIs have emphasized the impact of maternal facilitative language features on language development (e.g., see DesJardin, 2005; DesJardin, Ambrose, & Eisenberg, 2009, 2011; DesJardin & Eisenberg, 2007). Cruz and colleagues (2013) found that regardless of child and family characteristics, facilitative language features provide an enriched language environment and enhanced improvements in expressive language for children with CIs.

Similarly, a recent German study reports a parent intervention program, the Muenster Parental Programme, designed to teach parents skills in enhancing responsiveness in communication with their DHH child (Reichmuth, Embacher, Matulat, am Zehnhoff-Dinnesen, & Glanemann, 2013). The aim of the program is to empower parents to communicate with their children using a highly responsive style, focusing on everyday parent-child interaction from the child's first year of life. In a connected study, the parent program was shown to enhance parental responsiveness and increase the infants' vocalization after three months (Glanemann, Reichmuth, Matulat, & am Zehnhoff-Dinnesen, 2013).

James, Wadnerkar-Kamble, and Lam-Cassettari (2013) conducted a study designed to test the centrality of parental responsiveness in the scaffolding of early speech and language development. The authors built on work by Goldstein and Schwade (2008) that highlights "the role of parental contingency in the development of pre-linguistic speech skills" (James et al., 2013, p. 667) and on Vygotsky's theories on scaffolding in general child development (Vygotsky, 1978). The study's approach to learning emphasizes informal, unstructured learning in everyday communication. It acknowledges the "social construction of speech-language that we think is built as co-endeavor between parent and child" (p. 677) and recognizes mutual participation in social interaction and meaning making as a central dimension for learning.

These studies emphasize the value of facilitative language features enabling parent-child communication and therefore the child's language learning. They focus on the broad generic category of children who are deaf and hard of hearing, with the exception of the studies by DesJardin and Cruz and their colleagues, who focus explicitly on CI. The studies display perspectives on learning based on social aspects of the learning process, emphasizing social interaction and

communication within the family's community of practice, enhancing opportunities for language learning in the family's everyday life. Learning is viewed as contextualized, situated in the family life in which the child takes part.

In summary, research on language development after CI largely views learning from a predominantly individual perspective, whereas more social understandings are to be found in the wide-ranging category of "deaf and hard of hearing children." The next section will continue with a discussion that problematizes the predominant views on learning present in research that focuses on language development after CI. These views implicitly may convey unintended messages to the areas of family support. According to Foucault, to problematize is "an endeavor to know how and to what extent it might be possible to think differently, instead of legitimizing what is already known" (Foucault, 1985, p. 9). Problematizing understandings of learning may provide opportunities to think differently and open up new areas of inquiries.

IMPLICATIONS OF PREDOMINANTLY INDIVIDUAL PERSPECTIVES ON LEARNING IN THE RESEARCH ON COCHLEAR IMPLANTATION

According to Jackson (2011), within deaf education there seems to be a general turn toward more family-centered support and away from the special education paradigm, where "the historical trend of centered-based, impairment-focused services has gradually shifted to acknowledge the importance of building the capacity of family members and existing support systems within the child and family ecosystem and natural environments" (Jackson, 2011, p. 343). Nonetheless, research on language development after CI largely views learning as a predominantly individual process and echoes as such the child-centered diagnostic values and norms connected with the special education paradigm. It needs to be discussed whether this is a problem. By virtue of its very nature, research is never neutral and as such is free to choose its ontological stances. However, in an implicit manner the research on CI sends out divergent signals about the nature of learning.

A risk develops when the predominantly individual perspective that is present in research on language development after CI were interpreted by practitioners as though the studies were covering the process of learning in its entirety. A predominant view on learning as an individual process may lead to an interpretation that language development after CI primarily depends on speech therapy, training, and structured teaching. It will downplay the importance of social dimensions for learning and thus the innate power of the family as a community of practice. In other words, a problem arises when the remaining

“open question” as to “what happens in the areas that are not discussed” (Illeris, 2009, p. 18), is in fact not discussed at all.

One of the main messages of contemporary learning theories is that a comprehensive view of learning implies the integration of both individual *and* social dimensions. In other words, given the interactional complexity of learning, viewing learning predominantly as individual would be reductionist. Research on language development after CI communicates dominant understandings of learning toward the practice field and hence toward the construction and development of family support systems. If the language development of the child with CIs is reduced—by research, by practitioners, and consequently by parents—to a predominantly individual process, what implications would that have? The research may convey to parents and practitioners that language development after CI largely depends on therapy, training, and structured teaching sessions in decontextualized settings. There are several dimensions to this notion that illustrate why a hegemonic perception such as this could be problematic, in particular within the family context.

Emphasizing the individual dimension in language learning after CI downplays the important social dimensions of learning. It undermines the innate power of the family as a community of practice to facilitate the child’s language learning through actively enhancing the opportunities for learning that are present in the family’s everyday life. Thoutenhoofd and colleagues (2005, p. 254) found that “intensive rehabilitation can be a strain on family resources.” Hardonk and colleagues (2011, p. 319) mention the “burden of therapy.” Bosteels, Van Hove, and Vandenbroeck (2012) describe parenting of DHH children as a process being reduced to language development, through following a path of intensive rehabilitation. They quote Jolien’s mother, who says, “you end up being a therapist, you’re no longer a mother or father” (p. 992). Quittner and colleagues (2010) emphasize that strategies such as parental use of facilitative language practices may reduce the stress associated with being both a parent and a language teacher, therefore enhancing the child’s learning opportunities. Families would be well served by knowing that therapy and structural training are only several of numerous alternatives when it comes to learning. The knowledge that there is much that parents can actively do in everyday family life to stimulate their child’s language learning, for instance based on facilitative language features, may ease some of the burden and stress.

Another reason why a hegemonic understanding of learning as a predominantly individual process may be problematic is connected to the view of the child as a person. Sfard (1998) addresses in this context the question of norms and values: If knowledge is conceived of as a commodity, this is likely to influence how it establishes people’s

identities and defines their social positions. In other words, describing children largely by the skills they lack, as emphasized by the need for therapy and training sessions, might have negative impacts on the child. Bosteels and colleagues (2012) point to the argument made by Landsman (2002), who explains the problem of conflicting forces influencing the parenting of children with disabilities. Parents are torn between loving the child and hoping to erase the disability; they are torn between a profound paradox of saying to the child “I love you as you are” and “I would do anything to change you” (Landsman, 2002, p. 1949). Foucault (1977) speaks of a *normalizing judgment*, individualizing persons by measuring gaps, determining levels, and fixing that which is considered special. The acquisition of language can be measured, and measurements will reflect certain “degrees of normality,” establishing over individuals “a visibility through which one differentiates them and judges them” (Foucault, 1977, p. 184). A perspective where learning is viewed predominantly as individual and decontextualized acquisition might lead to learners being “perceived as objects” (Foucault, 1977, p. 185), which might be particularly unfortunate within the family context. In particular within the realm of family support, a more contextualized, social approach to learning will enable a view of the child as more than an individual in need of fixing, thereby acknowledging the learner as an active participant in and contributor to the family’s community of practice.

In short, the main issue is which understandings of learning lie at the basis of the construction of family support services. The perspectives that are brought to the endeavors of designing support for learning “are important because they shape both what we perceive and what we do” (Wenger, 1998, p. 225). Hence, these perspectives require careful reflection.

The focus on learning through social interaction in general and the family’s community of practice in particular brings to the fore a task for practitioners who are guiding families: helping parents to enhance learning opportunities for their child within the informal context of the family’s everyday life. The family’s innate power to create opportunities for learning resides in Wenger’s concept of *building social infrastructures that foster learning* (1998). Families need guidance on how to build social infrastructures. They need to learn how they can scaffold their child’s social environment in order to enhance the child’s opportunities for learning and participation in the family’s community of practice.

There is a body of research confirming the role of family involvement in the child’s language development after CI. As noted by Brown and Nott (2006), there is also a body of research on general language development confirming the importance of the parents and the family

as the primary learning context in early childhood. This implies there is a central role for family support systems to teach parents how to facilitate language interaction. The crucial question however, as prompted by Brown and Nott (2006), is to what degree family support services are able to teach parents of children with CIs these facilitative features of parent–child interaction.

UNDERSTANDINGS OF LEARNING IN THE CONTEXT OF FAMILY LIFE

In summary, learning can be viewed as both an individual and a social process, but a comprehensive understanding of learning requires the acknowledgment of both dimensions. Exploring the literature brings to the fore a predominantly individual perspective on learning in the research on language development after CI. The chapter problematizes such a reduced understanding and discusses how it may convey messages to family support services that language learning after CI largely depends on therapy and structured, decontextualized training. Such a predominant understanding may downplay the family's innate power to facilitate language learning through opportunities that are present in the family's everyday life. The purpose has been to create awareness that the understanding of learning affects the way that learning is recognized, and hence it will have consequences for how support for learning is designed and how family support is constructed. An approach to learning that disregards "what happens in the areas that are not discussed" (Illeris, 2009, p. 18) may lead practitioners and parents to believe that the process of learning were covered in its entirety; social dimensions crucial to the process of learning may become overlooked while researchers' focus on measurable variables will influence what is conveyed as principal dimensions in the design of family support.

In the area of language development after CI, the child as a learner is more than a single individual, lacking certain skills that need fixing. When learning enters areas outside the institutionalized realm of schooling, and into the context of family life, there is a need for rethinking the concept of learning. The purpose of designing support for the child's learning in the family context requires reflection on how learning is understood. In concert with the sociological notion of primary socialization, Brown and Nott (2006, p. 160) state that the most critical issue in follow-up after CI should be "the understanding that a child's first language is the tool for the enculturalization of that child into the family group." The child is a partaker in the family's community of practice, learning to participate and participating to learn.

In 2007, Harry Knoors wrote that there is a need to establish a research agenda that systematically fills in gaps in current knowledge about

learning processes in DHH children, with a particular focus on the conditions in the child's environment (Knoors, 2007). Two years later, DesJardin, Ambrose, and Eisenberg (2009) wrote about the importance of providing hands-on training in facilitative language techniques for parents of children with CIs. Following this, Cruz and colleagues (2013) emphasize the need to teach parents how to use facilitative language features in everyday life and family contexts. Families' changing needs in this technological era of CI require more research on family perspectives to ensure that—in order to meet those needs—support services can adjust accordingly (Archbold & Wheeler, 2010).

In conclusion, research on language development after CI must expand its focus to include the family's community of practice as an important arena for the child's language learning. Likewise, family support services must not base their knowledge exclusively on research on language development after CI but extend their focus to studies displaying social perspectives on learning as they are present in the broader category of children who are deaf and hard of hearing. Moving the focus to the child's environment and directing it toward participation has implications for what it takes to understand and support learning (Wenger, 1998). For the child, it means that learning involves engaging in and contributing to the family's community of practice; for the family, it means that learning involves refining their practice (Wenger, 1998). There is an important role for support systems to help families refine these practices to facilitate the child's learning processes and enhance opportunities for learning in the family's everyday life. Correspondingly, future research needs to explore how support systems can help families make this happen and to investigate the nature of the interaction between families and their support systems.

Understanding learning in the context of family life implies becoming aware of more contextualized forms of learning. Comprehensive understandings of learning encompass the process of learning as individual *and* as social. Therefore, in the on-going process of providing family support after CI, becoming reflective to how learning is understood is vital.

Learning cannot be designed. Ultimately, it belongs to the realm of experience and practice. It follows the negotiation of meaning; it moves on its own terms. It slips through the cracks; it creates its own cracks. Learning happens, design or no design. And yet there are few more urgent tasks than to design social infrastructures that foster learning [. . .] Those who can understand the informal yet structured, experiential yet social, character of learning—and can translate their insight into designs in the service of learning—will be the architects of our tomorrow. (Wenger, 1998, p. 225)

NOTE

¹ From Sfard (1998).

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Paper II

Bruin, M., & Nevøy, A. (2014). Exploring the Discourse on Communication Modality after Cochlear Implantation - A Foucauldian Analysis of Parents' Narratives. *Journal of Deaf Studies and Deaf Education*, 19(3), 385-399.

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Paper III

Bruin, M., & Ohna, S. E. (2015). Negotiating Reassurance: Parents' Narratives on Follow-up after Cochlear Implantation. *European Journal of Special Needs Education, 30*(4), 518-534.



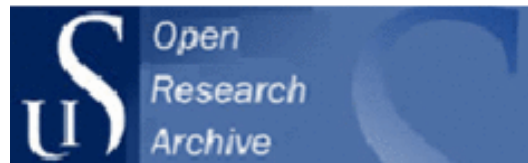
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Negotiating Reassurance: Parents' Narratives on Follow-up after Cochlear Implantation

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Abstract

This study presents an analysis of parental experiences on follow-up after cochlear implantation. Data were constructed in semi-structured, individual interviews with the parents of 14 children who use cochlear implants. Drawing on narrative analysis, the study explores parental responses to insecurity concerning children's learning and development, as well as the meaning professional support holds for parents. In their response to insecurity, the parents handle the 'trouble' of insecurity through constructing two narratives of self: the Parent-as-Learner and the Parent-as-Teacher. The parents use these narrative constructions to negotiate reassurance, holding themselves responsible for future outcomes. The parents' stories reflect a language of instrumentality, inducing a burden of responsibility. The study addresses the need to question to which extent parents should act as teachers and cautions that, while acknowledging the importance of parents' involvement for children's learning and development, this should not reduce the relationship to a functional, pedagogical one. The contribution of the study is to bring into conversation how the language of instrumentality affects the parents and how this invokes a need for rethinking parent support. Suggestions for further research are given.

Keywords: parent perspectives, parent support, parent insecurity, cochlear implants, narrative analysis

Introduction

This paper presents an analysis of parental experiences on follow-up after cochlear implantation¹ in Norway. The analysis displays parental responses to insecurity concerning the child's learning and development, as well as the meaning professional support holds for parents. In Western, post-industrial countries "good" parenting is at the forefront of much public discourse. The discussion is anchored in anxiety about children's educational future, protruding through an array of professional advice on how to bring up children (Vincent 2012, Nelson 2010). Since the middle of the last century, parenthood has changed from something "natural" toward an endeavour that has to be "worked at", something that needs to be learnt or at least can be continuously improved (Vincent 2000). The discursive construction of a "good" parent is based on notions of care and of taking responsibility for one's children; however, as parenthood becomes an 'educational project' parental responsibilities increase (Beck and Beck-Gernsheim 1995, in Vincent 2000, 23). Following Popkewitz (2003), 'the successful parent is a pedagogical one' (53), pedagogicalized by research and policy, evident likewise in Norwegian government policy documents (Norwegian Directorate for Education and Training 2012, 2010a). Furthermore, parenthood is on the Norwegian public agenda when it comes to media² and research (e.g., Nordahl 2007). It resembles a surrogate to schooling (Popkewitz 2003), 'regulating the present to ensure the future' (Popkewitz and Lindblad 2004, 232). These understandings induce responsibility, expecting parents to produce particular skills in order to ensure children's learning and development (Bloch and Popkewitz 2000).

¹ A cochlear implant is a surgically implanted hearing device that provides access to sound, and thus to spoken language, to a person diagnosed with profound hearing loss. Currently, about 90-95 % of children in Norway who are deaf are offered CIs (Kirkehei et al. 2011), often before ten months of age (source: Rikshospitalet Oslo).

² E.g., *Foreldrekompetanse. Kurs, utdanning og veiledning [Parenting skills. Courses, education and counselling]*, retrieved from <http://www.foreldrekompetanse.no>; *Hvem skal oppdra mor og far? (2012) [Who will educate mum and dad?]*, retrieved from <http://m.db.no>;

Western society has become a ‘risk society [...] where we increasingly live on a high technological frontier which absolutely no one completely understands and which generates a diversity of possible futures’ (Giddens 1999, 3). Risks arise the moment when decisions are to be taken, and the ideas of risk and responsibility are closely linked. The risk society is preoccupied with the future, creating notions of risk (Giddens 1999). Referring to Giddens, Nelson states that when risks are ‘viewed as the product of human action and decision-making rather than of fate’ (Giddens 1999, in Nelson 2010, 17), individuals might hold themselves responsible for ensuring future outcomes (Nelson 2010). Parents express anxiety about their child’s future, hoping it will entail academic qualification (Nelson 2010). Perceived future educational risks and the responsibility of decreasing them, puts parents under pressure. In addition, parents are children of their own times. In a rapidly changing society, parenthood speedily changes with it. Contrary to earlier, it might be difficult to rely on advice from the older generation, because their experiences are different (Thuen 2009); this counts in particular for parents of children who use cochlear implants (CIs), because this procedure is relatively new.

When a child is born with a disability, parents are forced to navigate in unknown and threatening territory. Parents are anxious; the unknown demands major readjustments to the situation and to previous expectations (Bjarnason 2010, McLaughlin et al. 2008). This is also the case for parents of children who are diagnosed with hearing loss; raising a child who is deaf or hard of hearing³ is about making complicated decisions (Marschark and Spencer 2006). Every day challenges cause stress and anxiety (Hintermair 2006, Zaidman-Zait 2008), increasing the insecurity of the “good” parenting discourse. Being a parent to a child who uses CIs involves further insecurity. Research states that parents decide on CIs because they expect the implants to facilitate spoken language, enabling interaction based on oral communication (Archbold et al. 2006, Kluwin and Stewart 2000), also pointed out in Bruin and Nevøy (2014). The concept of a “normal” life for their child is a central aim for parents (Sach and Whynes 2005, Bruin and Nevøy 2014, Young and Tattersall 2007), as well as the implants’ anticipated advantage regarding the child’s education. However, results after cochlear implantation are unsure; individual outcomes vary whilst the reasons remain largely unknown (Archbold and Wheeler 2010). Furthermore, parents are confronted with professional support characterized by conflicting opinions and alternative options (Bruin and Nevøy 2014). This further increases the insecurity embedded in the “good” parenting discourse. ‘Parenting a deaf child in this technological era is to face different choices’ and for many of these choices the long-term consequences are unknown (Archbold & Wheeler 2010, 237). Following Giddens (1999), different decisions will generate different future outcomes; therefore, they induce risk, responsibility, and insecurity: putting pressure on parents.

Consistent with extensive research highlighting the importance of parental involvement for educational outcomes (Harris and Goodall 2008), families influence language development after cochlear implantation (Cruz et al. 2013, Quittner et al. 2013, Klein and Wie 2014, Holt et al. 2012) and a considerable body of research points out the significance of parent support (e.g., see Glanemann et al. 2013, Zaidman-Zait and Young 2008, Jamieson,

³ The paper uses the term “deaf and hard of hearing” as a functional term, indicating persons diagnosed with various degrees of hearing loss, being aware that the term “deaf” has different meanings in different cultural contexts.

Zaidman-Zait, and Poon 2011, Poon and Zaidman-Zait 2013). According to the Norwegian Directorate for Education and Training, parents of children who use CIs, 'will need support and guidance from professionals with audiological expertise' (2010b, 16). However, the significance of parent support invokes issues in need of addressing. CIs are a technological innovation, and changing times require developing support services that are able to meet the parents' changing needs (Archbold and Wheeler 2010). This ambition involves taking into account the parents' views on follow-up; however, these perspectives are relatively absent from the literature (Archbold and Wheeler 2010).

Through narrative analysis (Riessman 2008, Bruner 1990, 1997, 1991), the study explores the parents' experiences with follow-up after cochlear implantation. The research questions are (i) how do parents respond to insecurity concerning their child's learning and development, and (ii) what significance do parents ascribe to professional support? Apart from the absence of parents' perspectives in the literature, there has been little attention to narrative analysis of parental accounts (e.g., see Young and Temple 2014). Hence, the study explores new territory. Through narrative inquiry of parental perspectives, the purpose of the study is to develop new knowledge that may contribute to designing support services tailored to match this era of changing times and parents' changing needs.

Analytical framework

In exploring the parents' stories on follow-up after CI, the study draws on a narrative analytical framework (Bruner 1990, 1997, 1991, Riessman 2008, Gubrium and Holstein 2009). In response to the research questions, narrative inquiry enables accessing meaning beyond the surface of a text, and therefore enables broader commentary (Riessman 2008). Because the field of narrative inquiry inhabits various approaches (Chase 2011, Riessman 2008), being explicit about the status attached to the data and the research's positioning is crucial (Silverman 2003). The following section clarifies these issues.

The study views storytelling as lived experience, viewing narration as 'the practice of constructing meaningful selves, identities, and realities' with regard to 'how narrators make sense of personal experience in relation to cultural discourses' (Chase 2011, 422). Hence, the framework takes on a constructionist perspective (Holstein and Gubrium 2011). The description of an experience or event is viewed as socially constructed and not as an objective blueprint of the actual event. The stories are understood as containing personal meaning attributed by the participants to their experiences. This enables accessing underlying narratives or stories from the interpretation of interview data through the way that people describe their worlds (Silverman 2003), poignantly described by Riessman (2008, 13) as 'a world behind the narrator (that is knowable)'.

Human beings make sense of the world by using the narrative mode for construing reality. However, Bruner (1990) emphasises that autobiographical accounts are not just descriptions of one's life. Narratives typically evolve around experienced trouble or discontinuity in people's lives (Bruner 1996, Riessman 2008). Through narrative construction people tell themselves and others who they are and display as such personal identities (Riessman 2008). Furthermore, eventually 'we *become* the autobiographical narratives'

(Bruner 1987, 15, original emphasis). Narratives are told with a purpose; to someone, at a specific time and place, and with various consequences (Gubrium and Holstein 2009). Narratives are ‘multifaceted textual windows on the world [...] dressed up by storytellers for the viewing’ (ibid, xv). The stories reveal ‘a strong rhetorical strand, as if justifying why it was necessary (not causally, but morally, socially, psychologically) that the life had gone in a particular way’ (Bruner 1990, 121). The notion reflects what Bruner calls the narratives’ justificatory function. A relevant question for analysis is what is being justified, for what purposes and for whom?

Following Riessman (2008), the current analysis combines features of thematic analysis, structural analysis, and dialogic/performance analysis. This enables different approaches; besides focussing on content, there is attention to how stories are told, to whom, and for what purposes. Through restorying experience, the narrative analytical framework enables reframing existing ways of thinking (Gubrium and Holstein 2009). A narrative analysis of parents’ stories will therefore enable challenging and reframing current ways of thinking about parent support.

Method and Analysis

When trying to understand the world from the subject’s points of view, the qualitative interview is useful in unfolding meaning of research participants’ experiences (Kvale and Brinkmann 2009); therefore, the empirical data were constructed through individual interviews.

Participants

Participants in the study are the parents of fourteen children with CIs, in fourteen families living in various parts of Norway, in cities as well as rural areas. All interviews took place within a three-month period, and were situated in either the participants’ homes or their office at work. For geographical reasons two interviews were held on the telephone. Ten of the interviews took place with the mothers (including the two phone interviews); in four interviews, both mothers and fathers were present. The couples supported each other’s narratives, and both parents were actively involved in the conversation; these interviews were among the longest. At the time of the interviews, the children’s age ranged from 3 to 11 years; all children were born after the year 2000. Ranged in age group 3-4 years, 3 children; age group 5-7 years, 8 children; age group 9-11 years, 3 children; eight boys and six girls. All parents are hearing, all families speak Norwegian.

Procedure

Fourteen semi-structured interviews were carried out; the aim was to obtain the parents’ perspectives on their experiences with follow-up after CI. An interview guide was developed with an outline of topics to be covered⁴; however, there was a deliberate aim for flexibility (Kvale and Brinkmann 2009) so that participants could speak about what was important to them. The interview data are seen as constructed through interaction between interviewer and participant (Holstein and Gubrium 2004, Kvale and Brinkmann 2009). The interviews were

⁴ For an overview, see appendix.

characterised by mutual conversation, where the interviewer followed the direction of the participants. The interviewer's questions were meant to promote an open dialogue, as well as providing clarity and understanding.

Prior to the interviews, the participants were informed about the interviewer being a parent to a child using CIs, acknowledging that 'the environments of storytelling shape the content and internal organization of accounts' (Holstein and Gubrium 2011, 350). This is why, next to an ethically invoked reason for being open about the interviewer's personal situation, there was an epistemological one; sharing a similar historical horizon (Gadamer 1993) has helped to create openness and a situation where interviewer and participant were regarded as mutual partners, jointly constructing narrative and meaning in conversation (Gubrium and Holstein 2002, Riessman 2008). Validity issues in qualitative research emphasise making explicit the researcher's position. Similar to Bruin and Nevøy (2014), this study refers to Ricoeur (1981, 220) who emphasises 'not to deny the role of personal commitment in understanding human phenomena, but to qualify it'. In this study, the researchers' position is qualified through applying the narrative analytical framework represented by Bruner (1990, 1991, 1997), Riessman (2008) and Holstein and Gubrium (2009).

All interviews were conducted in Norwegian, by the first author. The duration ranged from 55 – 115 minutes. The interviews were audiotaped and transcribed verbatim by the first author. Ethical considerations have been prevalent throughout the entire study. Norway has a population of 5 million inhabitants, which means that the group of children who are deaf is relatively small. Therefore, ensuring anonymity required the utmost care. Furthermore, caution was taken with the parents' vulnerable position as well as the researcher's role in meeting the participants and affecting the study (for a more detailed outline, see Kvale & Brinkmann, 2009).

Analysis

The narrative analysis explores how the parents respond to insecurity concerning the child's learning and development, and the meaning professional support holds for parents; it is characterised by an empirically driven, inductive process. Questions asked to the data were derived from the research questions and themes in the interview guide. The analysis centred on issues such as what needs to be learnt, who needs to learn, why, where and when? Questions about hopes for the child's future and the meaning of parent support were also applied. Nodes were created in NVivo10 and the interview transcripts were read repetitively by both authors, and categorized accordingly. In line with narrative theory (Riessman 2008) relatively large chunks of text were categorized, to maintain the context of a particular quote. To stay close to the empirical data, the analysis was conducted in Norwegian. The quotes in the presentation of the analysis were translated into English in the final phase of writing the manuscript. In concert with Temple and Young (2004), for ethical and epistemological reasons the utmost care to preserve meaning is required when seeking conceptual equivalence across languages. As in Bruin and Nevøy (2014), it is argued that the process of delaying the translation 'strengthens validity because it shields the analysis from being corrupted by translation' (390).

Through a subsequent process of hermeneutic interpretation, a shift in perspective took place, which involved a turn from the descriptive to the interpretive (Ohna 2004, Westin 1994). Two narrative presentations of self were identified, each expressing a story in which the narrators place themselves (Silverman 2011), the Parent-as-Learner and the Parent-as-Teacher. The construction of these narratives relates to Bruner's narrative model of the self (1997). The two narratives became new nodes in NVivo, each with subcategories called *aims* and *anxieties*. The data were read anew and analysed accordingly.

Presentation of the Analysis

In response to the research questions, the narrative constructions capture significant aspects in the interviews, which bring to the fore how the parents respond to the insecurity concerning the child's learning and development, and the meaning they ascribe to family support. At the core of all stories is a desire that the child will close the gap that being deaf has brought along, recapturing "normality". Even though a few parents mention the child's social participation in peer groups and family, in talking about their child's learning the parents mainly focus on language development. Reflecting the "good" parenting discourse and its insecurity, the parents' stories reveal a belief that the implants' promise of a "normal" life depends on the parents' knowledge and hard work. The future is considered conditional.

The following section presents the two narratives of the self: the Parent-as-Learner and the Parent-as-Teacher. All parents relate to both narratives, at different times and to varying degrees. Both narratives are presented in two parts, displaying the parents' views on (1) what they need to do, and (2) the conditional future. The parts carry empirically induced titles that express the parents' construction of meaning. Each narrative is presented through the parents' aims as well as anxieties. This is done, not to create a dichotomy, but to present each narrative on a spectre, where the one extremity reinforces the image of the other.

The Parent-as-Learner narrative: Knowledge is reassuring, not knowing is disconcerting

The Parent-as-Learner narrative is constructed through stories about learning how to support a child who uses CIs. It describes the parents' *aims* as learning how they can teach the child to use the implants, to develop listening skills and speech. The parents' *anxieties* are described as not knowing things one should have known, and a possible threat to future educational outcomes.

(1) We don't know enough, we need to learn.

The Parent-as-Learner narrative is constructed through stories about parents learning how to help the child to benefit from the CIs. 'We have to learn how to teach him to use the sound he now has access to' (mother of Tommy, age 10). The general understanding is that there is a lot that parents do not know, which they need to know. Therefore, parent support is regarded as highly important. For many, the most relevant knowledge is about language development. 'How should we stimulate listening skills?' (father of Tommy, age 10). He regards the parent support as helpful, because

We learned about sequence in language development [...] that was stuff we didn't know anything about. [...] One has to practice the sounds so one can learn to pronounce words.

We didn't think of that because normal hearing kids get that automatically (Tommy, age 10)

Tommy's mother explains that learning this 'was very reassuring'. Jonathan's parents appreciate getting the test results in a counselling session after assessment at the hospital. For the mother, the most important part is going through the results with the experts, getting advice on 'what to practice on at home, such as the sounds he does not get [...] and right pronunciation' (Jonathan, age 7). 'We got a lot of counselling about language, how to help Amelia to become better at speaking' (mother of Amelia, age 5). Oscar's mum explains one needs 'Knowledge. About stuff one didn't know anything about before' (Oscar, age 5).

The parents recount that, in the beginning, they yearned for information about 'what to do'. Henry's mother learnt 'techniques on how to work at home on listening skills and language development. That was terribly important to us [...] we were assigned weekly tasks we had to work on' (Henry, age 7). Because knowledge is considered reassuring, parents express anxieties about possibly not knowing:

All the time you have the feeling that there might be something you miss [...] that information comes to you coincidentally, and if that were the case you start wondering what you do *not* know that you *should* have known. (Mother of Annette, age 7)

Oscar's mum worries about parents who do not have access to the necessary knowledge. 'They're the ones who will lose' (Oscar, age 5). Not knowing enough might have future consequences. 'In a way, it *must* have negative consequences for the child' (mother of Lillian, age 6). Experiencing a lack of necessary expertise to make difficult choices is stressful, one tries to do the right thing all the time. 'Therefore we had to choose a few times, feeling petrified' (mother of Christian, age 9).

Gaining knowledge is seen as an important aspect of supporting the child; however, there are parents who are sceptical to some of the content offered by the parent programs. Lillian's mother recounts asking for information about books to read with the child, or tools to use in everyday life communication. 'That wasn't what I felt that I got' (Lillian, age 6). She explains they *did* receive information not relevant to them. 'We had a lot on phonetics [...] my husband has no clue why on earth he has to learn about *that*' (mother of Lillian, age 6). Likewise, Christian's mum explains that they learnt a method they could use at home. However, 'We didn't understand it [...] and I felt that in hectic everyday life we didn't have the resources to follow-up as required' (Christian, age 9).

(2) *Our child's future opportunities depend on what we know (or don't know)*

The narrative of Parent-as-Learner is constructed through stories about the parents' responsibility to learn, because the child's future depends on it. Having a child with CIs means investing time to stay informed, 'that is to say, if you want your child to have equal opportunities' (mother of Lillian, age 6). She explains it requires huge efforts and masses of time. 'I feel I can never relax [...] you HAVE to stay up to date, continuously'. A father recounts, 'We did *a lot* [...] it takes a huge effort. I took time off work approximately one day a week for about a year' (Oscar, age 5). After a while things get easier, 'Because you get more

knowledge, right?’ (mother of Lillian, age 6). Gaining knowledge is reassuring; it helps to relax. She explains, ‘[...] if only one was able to see the future. Had a crystal bowl!’

Even though eventually things become easier, parents report anxieties about the future. One does not know how things will develop, and not all parents trust the implants to work. The parents perceive the future as conditional; therefore, parent support and the knowledge associated with it are reassuring and vital. ‘We attend to absolutely all the courses we are invited to [...] To think as parents that one does not need to go, that’s so naive it’s unbelievable’ (mother of Oscar, age 5). Oscar’s father recommends new parents to ‘Take rather one course too many than one too little’. Also for Michelle’s mother, the professionals’ expertise is reassuring. ‘One struggles with lack of knowledge [...] and what about these feelings of guilt?’ (Michelle, age 6). The parent support has been ‘CRUCIAL, without it we wouldn’t have been where we are today’ (mother of Oscar, age 5). ‘It wouldn’t have been easy without. Not at all’ (mother of Henry, age 7). ‘Without it I don’t think he would have come as far as he has’ (mother of Jonathan, age 7).

The Parent-as-Teacher narrative: You have to be willing to work hard, but what if we do the wrong thing?

The Parent-as-Teacher narrative is constructed through stories about helping the child to learn. This involves structured and unstructured training sessions at home, consciously directed toward listening skills and speech. The Parent-as-Teacher narrative describes the parents’ *aims* as working hard through actively using acquired methods, promoting the child’s language development. *Anxieties* centre on not getting enough results, doing the “wrong” things or not doing “enough”.

(1) Language will not come automatically, we have to work for it

The Parent-as-Teacher narrative is constructed through stories about actively supporting the child’s learning and development. Parents worry about the differences in outcomes from CI, emphasizing their responsibility. ‘The most important thing is that the parents are willing to work with the child’ (mother of Maria, age 3). “Working” is a significant expression in the Parent-as-Teacher narrative, reflecting the parents’ preoccupation with listening and speech. As Henry’s mother explains, ‘It isn’t just the operation and then they hear normally, right? You have to work for it; we have actually worked for many, many, many, many hours, for many years’ (Henry, age 7). Madeline’s mum indicates this has influenced her role as a mother. ‘We worked at home three times a day [...] the first two years I felt more like a teacher than a mother, because I had it in me all the time’ (Madeline, age 5).

The stories express an understanding that the child’s language will not develop on its own; the benefits from the implants depend on hard work with the child. ‘It’s not like switching on the implants and assume they’re hearing’ (mother of Maria, age 3). Similarly, Michelle’s mum says, ‘The counsellors say that if we work with it, she’s able to do it’ (Michelle, age 6). The Parent-as-Teacher narrative suggests that the more parents “work”, the better educational outcomes; it expresses that hard work pays off. ‘It’s actually going well, but that’s because we work a lot with her’ (mother of Annette, age 7). Not “working” with the child risks getting no results. ‘Unfortunately, we see others who don’t get results [...] they

settle with not working, they just wait and see' (mother of Oscar, age 5).

The main worry expressed by the Parent-as-Teacher narrative is that the child's development will not progress as expected. Consequently, parents worry about not doing enough:

Maybe we should have read more together with him, helped him expand his vocabulary and explained more what things mean [...] There is this continuous fretting that, maybe, we should have done more. (Mother of Tommy, age 10)

Being a parent of a child with CIs means 'You have to be willing to work for it, in order to see results' (mother of Christian, age 9).

(2) How we work in the present (or don't), will affect the future

The Parent-as-Teacher narrative is constructed through stories describing that having a child with CIs requires more than usual. Parents describe processes that require much of their time and effort, and compare this with the needs of their other children. 'We had to work many hours every single day and every single week to teach him to listen and speak, because he had to practice much more than normally hearing children' (father of Tommy, age 10).

It requires much of the same, only ten times more, if you get what I mean? It requires just so extremely much more than we have done with his sister, for instance practicing listening skills and all that. We never, ever did that with his sister [...] so the first years were very demanding, working with him. (Mother of Henry, age 7)

Parents consider the present "work" as indicative of the child's future. The father of Maria (age 3) worries that maybe they should start working with the alphabet, to give their daughter a literacy head start. The mother remarks that the preschool will start working on this when Maria turns 5, and the father answers, 'I see that, but maybe that would be a little late for her, to start only a year before school starts. Maybe we should start a little earlier'. The mother of Christian (age 9) explains, 'I see that the foundation we build now will be extremely important further down the road. [...] It means everything.'

The Parent-as-Teacher narrative reveals that parent support is of great value; it provides methods to inform the parents' teaching. 'The reassurance is very important, that we know we have certain methods' (mother of Oscar, age 5). Madeline's mum appreciates the reassurance from the annual testing, confirming that their hard work leads to results. 'They see that what we do has effect' (Madeline, age 5). However, the responsibility this entails is frightening:

I am terrified for those black holes, I mean, how are we supposed to close the gaps but also discover them? That is the most frightening. That I won't know that until the day comes when you understand that something actually has passed you by' (Mother of Lillian, age 6).

Another mother worries, 'You become very afraid to do the wrong things, that we should destroy something that *could* have been good' (mother of Tommy, age 10). Therefore, professional support is viewed as an absolute necessity. For Oscar's father, it helps to have 'someone who knows the right way' (Oscar, age 5). Parent support is reassuring when securing the child's learning and development. It helps to define goals, 'according to what I thought he needed, practicing listening skills, vocabulary and so forth' (mother of Henry, age

7).

However, there are parents who subvert messages from the parent support. They challenge the professional knowledge, accepted by other parents as a way to learning. Madeline's mother points out that families are different. Therefore, she does not take for granted that what counts for many, automatically counts for them:

My husband is sceptical, 'Why do you do that? Why should we?' I actually find that a good thing. Instead of jumping at what scientists and other smart people say, think about why would that count for us? [...] That it's not only about *learning* the scientific stuff, but that it actually is something that either relates to our kid, or doesn't relate to our kid. (Madeline, age 5)

Christian's mother feels that the method they learnt does not suit their family. It did not make sense to them at all:

We *really* didn't get it. [...] We were supposed to use it in everyday situations, which became quite artificial, I felt. It's unnatural! [...] if we have to use this every day it will be very artificial and strange. (Christian, age 9)

In summary, the Parent-as-Learner and Parent-as-Teacher narratives show how the parents construct and handle the "trouble" of insecurity, and how they respond by searching for reassurance. The narrators place themselves in stories about working hard so that future educational outcomes may be ensured. Following Riessman (2008), the analysis displays thematic content, how the story is told, to whom and for what purposes. In their search for reassurance the parents tell themselves that, in order to get results, one has to learn and "work"; emphasising words like *must* and *work*. By telling the interviewer, the parents tell themselves that, because they acquire knowledge and work hard with the child, the child is doing well. It shows that the purpose of the two narratives is to negotiate reassurance: because the parents believe future educational outcomes to depend on gaining knowledge and working with the child, the narrative justifies this. By doing this, participants take on the identity of responsible parent, holding themselves responsible for future outcomes. The analysis shows that parent support is reassuring and important for parents, and that the majority accept the knowledge provided by professionals. However, a few express that not all of it appeals to them.

Discussion

The following section discusses the analysis' findings in three parts. First, the discussion centres on the research questions regarding the parents' responses to insecurity and the meaning professional support holds for the parents. The second part discusses how a parental burden of responsibility is invoked. The third part addresses the question to what extent parents should act as teachers, and makes a case for rethinking parent support. Narratives are connected to local context (Riessman 2008) and cultural discourses (Chase 2011). Therefore, a legitimate question is whether the findings in the analysis are exclusive to their Norwegian context. Through locating the findings in earlier research, the discussion demonstrates their relevance to a broader, international context.

The world behind the narrator

The narrative analysis brings to the fore how the parents respond to insecurity concerning the child's learning and development, and the meaning the professional support holds. In their response to insecurity, parents negotiate reassurance through constructing the Parent-as-Learner and the Parent-as-Teacher narratives, which function to justify their actions. Thus, the participants claim the identity of responsible parent, meaning they hold themselves responsible for future educational outcomes. In their search for reassurance, the participants emphasize the significance of parent support.

The Learner/Teacher narratives are in concert with Giddens' (1999) notion of risk society, with its hallmark of preoccupation with the future. Embedded in a belief that the future is conditional, the parents respond to the insecurity by acquiring knowledge and using this knowledge to teach their child. In accordance with Popkewitz and Lindblad (2004), they regulate the present to ensure the future. The narratives reflect instrumental reasoning, displaying parental attempts of improving the input-output ratio.

The Parent-as-Learner narrative expresses the parents' need to learn how to support their child. This notion reflects an understanding, strongly informed by the 'languages of developmental psychology, behavioural psychology and [...] neuropsychology' (Ramaekers and Suissa 2012, 3), suggesting a need for expertise 'to the extent that parents are expected to professionalize themselves' (ibid, 3). Parents think of themselves as teachers, with one or more educational targets in mind; raising children becomes something one *does*, as opposed to *be* a parent (Ramaekers and Suissa 2012).

The Parent-as-Teacher narrative expresses the parents' extensive ways of "working" with the child. From earlier studies, it is clear that the child's education is a major concern for parents of children who are deaf and hard of hearing (Archbold et al. 2002) and parents stretch themselves to great lengths to engage in the child's development (Archbold and Wheeler 2010). Similar to Christiansen and Leigh (2002), the parents in this study talk about consciously creating language opportunities, being 'constantly vigilant' (Ramaekers and Suissa 2012, 33). Bosteels and colleagues described parental encounters with 'heroic discourse of progress and technological advances' (Bosteels, Van Hove, and Vandebroek 2012, 993). Reflecting this, the parents in the current study take a similar responsibility for the implants' 'promises of cure on condition of parents' hard work' (ibid, 993).

The Learner/Teacher narratives express the parents' insecurity about educational outcomes, and how parents understand these as conditional. Similar issues have been reported in earlier research. In a large interview study with 216 participants, Sach & Whyne (2005) reported parental anxieties that 'the effectiveness of cochlear implants may be reduced by ineffectual educational support' (406). Bosteels and colleagues described being a parent to children who are deaf and hard of hearing as a process being reduced to language development, following a path of 'intensive rehabilitation' (993) to such an extent that participants described themselves as therapists instead of parents (Bosteels, Van Hove, and Vandebroek 2012). According to the authors, the parents emphasised their responsibility for ensuring optimal future opportunities for social integration in a mainstream society. In the current study, the analysis equally shows that the parents hold themselves responsible for future educational outcomes. In line with the narrative framework, a world behind the

narrators is exposed; beyond the parents' aims and anxieties, a burden of responsibility is revealed.

The burden of responsibility

Following Giddens (1999), the instrumental understanding that educational outcomes largely depend on the parents' responsibility to "work" with the child, creates a notion of risk. When risk is viewed as the result of human action, the parents will hold themselves responsible. Ramaekers and Suissa (2012) point out that the induced sense of responsibility may burden parents with a sense of guilt, through feelings of falling short (see also Furedi 2008). This is concurrent with the analysis, which shows that holding themselves responsible leaves parents feeling worried, always vigilant, investing considerable time and effort. Parents express anxieties about doing the "wrong" things, or not doing enough.

The analysis shows that the parents' perspectives on learning reflect a 'language of instrumentality' (Ramaekers and Suissa 2012, 16). The authors problematize this language within the parent-child relationship, stating that its validity is taken for granted. Moreover, the language of instrumentality is not sensitive to context. This is exemplified in the analysis by the few parents who describe that the knowledge they had been offered did not suit their situation.

The parents do not question the values of the language of instrumentality but rather take it for granted; apart from a few subverting voices, the parents assert a self-evident validity to the knowledge they acquire. The instrumental language of rehabilitation thus merges with the family context, causing a burden of responsibility. However, the parents do not speak explicitly of a *burden*; the burden remains implicit in the world behind the narrator. Following the self-evident validity of instrumentality, gaining knowledge and "working" with the child is an obvious task, employed by the responsible parent.

The analysis shows that the parents regard professional support as vital. The participants' emphasis on the significance of parent support creates a paradox. On the one hand, parent support is experienced as reassuring; on the other hand, its instrumental language may induce a burden of responsibility. The following question arises: Can support services meet the parents' search for reassurance with a different language, avoiding inflicting the burden of responsibility?

Rethinking parent support

It is not the intention of this paper to contradict the value of parental involvement for the education of children who have CIs or special educational needs (e.g., see Barlow and Humphrey 2012, Karasu 2014, Klein and Wie 2014). In finding a different language with which to meet the parents' search for reassurance, it needs to be acknowledged that, as mentioned earlier, family is important for the language development of children who are deaf and hard of hearing. 'Parents are the most important influence on learning' (Harris and Goodall 2008, 286). However, in pursuing the implants' "promises of cure", caution is required not to reduce the parent-child relationship to a primarily pedagogical and functional one (Suissa 2006).

Suissa (2006) brings forward the distinction between *parenting* and *being a parent*, a notion taken further by Smith (2010). The expression of *parenting* refers to a functional role; parenting becomes ‘a series of tasks with outcomes’ (Smith 2010, 362). The emphasis is on *doing* rather than *being* (Suissa 2006). *Parenting* refers to the language of instrumental reason, where ‘the experts will tell parents “what works”’ (Smith 2010, 361). The analysis shows that the Learner/Teacher narratives of the self reflect the expression of *parenting*. There are reasons of ethical nature why this line of thinking is problematic. The problem is ‘not the complexity of this task, nor its terrifying significance for our children’s development [...] but the fact that it is conceived as a task at all’ (Suissa 2006, 72). Even though the parents in the study invest considerable time and effort in the task, it is not the task itself inflicting the burden, but the implication that follows from it: If parents base educational outcomes on the performance of their task, what happens when outcomes are not as expected?

Following Suissa (2006), in constructing parent support that is able to meet the parents’ changing needs, the distinction between the parents’ role of teacher and that of parent needs to be discussed. The family is relevant to a child’s development; therefore, it needs to be debated how a burden of responsibility may be avoided. The analysis presents the significant meaning professional support holds for the parents. A central question is whether professional support can draw on a different language: emphasizing the social nature of language learning, underlining the value of casual everyday parent-child interaction for language development. Support services may encourage parents to take caution in asserting a self-evident validity to instrumental reasoning, thus avoiding creating a risk that implies their responsibility. In short, support services could stress the value of *being* a parent.

The study provides insights in how parents respond to insecurity concerning the child’s learning and development, as well as the meaning they ascribe to parent support. In line with the narrative framework, through restorying, the study reframes and challenges existing ways of thinking. It provides an understanding of how the language of instrumentality may induce a burden of responsibility. The study cautions that, while acknowledging the importance of parents’ involvement for their child’s learning and development, this should not reduce the relationship with their children to a pedagogical and functional one. This study brings into conversation how the language of instrumentality affects the parents, and addresses the need to rethink parent support. As such, the study has relevance for realms beyond those tied to cochlear implantation.

The findings of the study indicate a need for further research to gain a broader understanding of the parent-professional relationship, in the context of children with CIs as well as children with additional educational needs. Because narratives are connected to local context and cultural discourse, it would be productive to explore how parents respond to insecurity across various cultures. Furthermore, the question arises how parents’ demographic and socio-economic characteristics may influence their meaning making. Finally, apart from the parents’ perspectives, it would be fruitful to include the experiences and perspectives of the professionals who provide support and guidance.

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Paper IV

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Parental Involvement in Children's Learning: The Case of Cochlear Implantation—Parents as Educators?

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Appendix I Parent Questionnaire

Spørreskjema

Informasjon om utfylling av spørreskjema:

Takk for at du vil ta deg tid til å svare på spørsmålene. Det er i alt 24 spørsmål. Jeg er interessert i erfaringene dine med hensyn til det å være forelder til et barn med cochleaimplantat. Du kan selv velge hvor omfattende du ønsker å være i din besvarelse. For forskningsprosjektet er det flott å få utførlige besvarelser og rike beskrivelser, men du bestemmer selv hvor mye tid du ønsker å bruke på dette. Er du ikke norskspråklig, kan du eventuelt svare på engelsk, nederlandsk eller tysk, hvis det er enklere for deg.

Skjemaet kan fylles ut på følgende måter:

- Svarene kan skrives rett inn på surveyen på nettet, ved å gå til blå knapp nederst til venstre på skjermen. Du kan bruke det vedlagte Word-dokumentet for å få et forhåndsinntrykk av de spørsmålene som kommer til å bli stilt. I det elektroniske skjemaet kan du *ikke* lagre svarene dine. Besvarelsen må gjøres ferdig i sin helhet før du går ut av skjemaet.

eller

- Du kan skrive svarene dine først inn i Word-dokumentet som er lagt ved i e-posten som du har mottatt fra Cochleaklubben. Da har du anledning til å lagre svarene og komme tilbake til det ved et senere tidspunkt. Når skjemaet er ferdig utfylt kan svarene limes inn i det elektroniske spørreskjemaet.

Av hensyn til informantenes anonymitet skal ikke selve Word-dokumentet sendes til forskeren via e-post. Siden svarene vil bli behandlet elektronisk bør heller ikke Word-dokumentet sendes i posten.

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I spørreskjemaet nedenfor handler spørsmålene om tre fokusområder:

1. *Generell informasjon om familien,*
2. *Kommunikasjon i familien,*
3. *Foreldrenes møte med hjelpeapparatet.*

Fokusområdene nærmes fra to ulike tidsperspektiv:

- Fortid - den første tiden før og etter implantering, og
- Nåtid - dagen i dag.

Ikke alle spørsmålene er like relevante for alle aldersgrupper. Dersom du mener at noe ikke er relevant, skriver du dette. Hvis erfaringer har endret seg over tid er det veldig bra om du utdyper dette.

Besvarelsen din er fullstendig anonym.

Vi ber deg om å svare raskest mulig. Det elektroniske spørreskjemaet er operativt frem til 01.04.2012.

1. Fylles det ut ett skjema for hele familien, eller svarer foresatte hver for seg?
2. Hvilken foresatt fyller ut dette skjemaet: mor, far, annet
3. Hvem bor hjemme i familien deres?
Beskriv hvem som bor i familiens hjem og relasjonen de har i forhold til barnet med CI (for eksempel mor, far, søster, bror, bestemor, onkel, osv.)
Opplysninger om eventuelle andre barn: (utenom barnet som har CI)
Fødselsdato (måned/år), gutt/jente, hørende/hørselshemmet
4. Barnet som har CI/ barna som har CI (hvis det er flere):
Alder: født måned/år
Gutt/jente:

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Er barnet født døvt eller blitt døvt på et senere tidspunkt? I så tilfelle, når og hvordan skjedde dette?

Dato lydpåsetting CI: måned/år

Har barnet/barna ett CI eller CI på begge sider?

I tilfelle CI på begge sider: har barnet fått begge implantatene i én operasjon?

Hvis nei: dato for andre lydpåsetting:

Går barnet/barna i en spesialskole/barnehage for hørselshemmede, eller i nærskole/barnehage

Dersom barnet/barna har funksjonshemminger eller diagnostiserte vansker utover hørselshemmingen, kan du beskrive disse?

5. Hvilket språk/hvilke språk bruker familien?
Dersom familien er flerspråklig: hvilket språk er familiens første språk?
Hvilket språk er familiens andre språk?
Dersom barnet er flerspråklig, hvilket språk er barnets første språk?
Dersom barnet er flerspråklig, hvilket språk er barnets andre språk?
6. Brukes det tegn til tale i kommunikasjonen med det implanterte barnet / har det blitt
brukt tidligere? Beskriv.
7. Kan du beskrive hvilke veiledningstilbud familien mottar og fra hvilke instanser?

Kan du beskrive hva som er og har vært fokus for veiledningen?
Kan du beskrive utbyttet dere har hatt av denne veiledningen?
Hvilken instans føler dere at dere får mest støtte av?
8. Hvilke foreldreopplæringsprogram har familien valgt?
(for eksempel Se mitt språk/Hør mitt språk/AVT/annet).
Kan du beskrive utbyttet dere har hatt av disse opplæringsprogrammene?
9. Kan du beskrive hvordan kommunikasjonen foregikk i familien i den første tiden like før og like etter implantering?
Hvordan kommuniserte familiemedlemmene med barnet og hvordan kommuniserte familiemedlemmene seg imellom? Hvilke utfordringer møtte dere i familien i hverdagen? Kan du beskrive situasjoner som du

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syntes var spesielt vanskelige? Kan du beskrive situasjoner som du syntes fungerte bra?

10. Kan du beskrive hvordan kommunikasjonen foregår hjemme i dag? Hvordan kommuniserer familiemedlemmene med barnet og hvordan kommuniserer familiemedlemmene seg imellom? Hvilke utfordringer møter dere i familien i hverdagen? Kan du beskrive situasjoner som er særlig utfordrende for barnet? Kan du beskrive situasjoner som du synes fungerer bra?
11. Hvordan deltar barnet i en samtale på tomannshånd og i en gruppesamtale? Kan du beskrive likheter og forskjeller?
12. Kan du gi en konkret beskrivelse hvordan dere som foreldre støtter barnets deltakelse i familiens daglige kommunikasjon? Gjerne beskriv det som dere gjør når det gjelder å hjelpe barnet for å kunne ta del i familiens kommunikasjon. Er det noe som dere synes er spesielt viktig for dere?
13. Hvis det har vært endringer over tid i måten barnet og familien kommuniserer med hverandre, er det fint om du kan beskrive dette:
14. Kan du beskrive kommunikasjonen mellom barnet og jevnaldrende:
 - i fritidsaktiviteter
 - på skolen og i friminuttet?Kan du beskrive situasjoner som er særlig utfordrende for barnet?
15. I perioden like før og like etter implantering er barn og foreldre vanligvis i kontakt med ulike instanser, slik som for eksempel det kommunale støttesystemet (som for eksempel PPT), helsevesenet (alt fra fastlege til Rikshospitalet), Statped, (spesial)pedagogene i barnehage/skole, logoped, m.fl. Hvordan har dere erfart møtet med de ulike instansene i den første tiden før og etter implantering, kan du beskrive dette?
16. I hjelpeapparatet finnes ulike oppfatninger når det gjelder oppfølging av barn med cochleaimplantat. Eksempler på dette kan være valg av språk og kommunikasjonsform, men også valg i forbindelse med implantering eller ulike typer opplæringstilbud og veiledning etter implantering. Kan du beskrive hvilken påvirkning dette har hatt på deg og på dere som familie i beslutningsprosessene?

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Tror du at dette har hatt en påvirkning på de valgene som du/dere tok?
Hvis ja, kan du beskrive på hvilken måte?

17. Kan du beskrive om, og i hvor stor grad, støtten som dere fikk av hjelpeapparatet i den første tiden hjalp dere til å takle hverdagen og har hjulpet dere i å kunne støtte barnet i sin utvikling?
18. I den første tiden like før og like etter implantering: kan du beskrive om dere hadde behov som ikke har blitt møtt?
19. I all sannsynlighet er dere per i dag fortsatt i kontakt med ulike instanser når det gjelder oppfølging av barnet, slik som tidligere nevnt det kommunale støttesystemet, helsevesenet, Statped, (spesial)pedagogene i barnehage/skole, logoped, m.fl. Hvordan vil du beskrive nåværende samarbeid med de ulike instansene?
20. Kan du beskrive om, og i hvor stor grad, støtten som dere får og har fått av hjelpeapparatet opp gjennom årene har hjulpet dere til å takle den dagligdagse situasjonen og til å støtte barnet i sin utvikling?
21. Kan du beskrive om dere per i dag har behov som ikke blir/har blitt møtt?
22. Kan du beskrive hvilken betydning det har for dere å være i kontakt med andre foreldre i lignende situasjon?
23. Spørreskjemaet er innoom mange områder, men det er mulig at det finnes noe som er særlig viktig for deg men som ikke er blitt tatt opp. Dersom det er noe som du ønsker å dele om erfaringene dine med hensyn til det å være forelder til et barn med CI, gjerne skriv det ned her:
24. Forskningsprosjektet planlegger oppfølgingsintervjuer med ca. 10 foreldre som har deltatt i spørreundersøkelsen. Dersom du er interessert i å delta i intervjustudien, kan du skrive et egenkomponert passord her som består av tre syllaber og fire sifrer, for eksempel:

fotballkamp1967

Deretter sender du en e-post til marieke.bruin@uis.no hvor du skriver at du har lyst å delta i intervjustudien. Viktig: I e-posten skriver du ditt

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egenkomponerte passord. Av hensyn til din anonymitet skal du IKKE sende med en kopi av det utfylte spørreskjemaet.

Dersom du ikke ønsker å stille deg til disposisjon for deltakelse i oppfølgingsintervju trenger du ikke å gjøre noe.

Egenkomponert passord:

Appendix II Information letter, questionnaire



Stavanger, 16. februar 2012

Informasjon om forskningsprosjekt *Kommunikasjon og samspill i familier med cochleaimplanterte barn*

Prosjektet vil bli gjennomført som et doktorgradsarbeid ved Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS) ved Universitetet i Stavanger. Formålet er å undersøke kommunikasjons- og samspillprosesser i familier med cochleaimplanterte barn, samt å beskrive foreldres erfaringer i møtet med ulike institusjoner etter implantasjon og synspunktene disse representerer. For å få svar på disse spørsmålene vil samtlige familier som er medlem i familieforeningen Cochleaklubben bli spurt om å delta i undersøkelsen ved å svare på et elektronisk spørreskjema (delprosjekt 1). Deretter vil ca. 10 foreldre bli intervjuet (delprosjekt 2) og noen få familier vil bli spurt om å lage video-opptak i familien (delprosjekt 3). Prosjektet vil særlig se på hvordan kommunikasjon og samhandling innad i familien kan skape muligheter for læring og utvikling for det cochleaimplanterte barnet. Foreldrenes erfaringer ansees som svært viktige i denne sammenhengen.

Denne henvendelsen er en invitasjon til å delta i delprosjekt 1. Spørreundersøkelsen består av 24 åpne spørsmål, som vi ber deg å svare på

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skriftlig. Ved siden av noen enkle bakgrunnsspørsmål om barnet, slik som for eksempel barnets alder og alder ved implantering, vil spørsmålene omhandle dine personlige erfaringer med hensyn til kommunikasjon i familien, samt dine erfaringer med hensyn til det å måtte ta viktige valg på bakgrunn av ulike meninger og ulike muligheter når det gjelder oppfølgingen av barnet ditt. Når du klikker på lenken litt lenger nede på denne hjemmesiden, vil du komme til spørreskjemaet. Her vil du få kort informasjon om hvordan du kan fylle ut skjemaet. I slutten av spørreskjemaet vil du bli spurt om du ønsker å kunne bli kontaktet til intervju (delprosjekt 2), eller om du reserverer deg mot dette.

Forskning som omhandler foreldrenes perspektiver på samhandling og kommunikasjon med deres implanterte barn vil gi kunnskaper som vil hjelpe fremtidig tilrettelegging av foreldreveiledning, samt faglig veiledning av pedagoger i for eksempel barnehage/skole eller PPT. Når det gjelder CI har eksisterende forskning frem til nå i stor grad handlet om taleoppfattelse og taleproduksjon hos de implanterte barna og i mindre grad om kommunikasjonsprosesser i familien. Derfor er foreldres perspektiver et svært viktig bidrag til utvikling av kunnskaper om oppfølging av cochleaimplanterte barn.

Resultatene til forskningsarbeidet vil publiseres i blant annet vitenskapelige artikler og i en avhandling for doktorgraden i utdanningsvitenskap ved Universitetet i Stavanger. Alle deltakerne anonymiseres og det vil ikke være mulig å identifisere forskningsprosjektets deltakere i publiseringen. Det er frivillig å delta i prosjektet og deltakeren kan trekke seg når som helst fra prosjektet og uten begrunnelse.

Prosjektet er meldt til Personvernombud ved Norsk samfunnsvitenskapelig datatjeneste (NSD). Undersøkelsen gjennomføres i perioden 2011-2015. Dato for prosjektslutt er 31.12.2015 og da vil alt datamateriale anonymiseres. Jeg har taushetsplikt og alle opplysninger vil behandles konfidensielt. Eventuelle spørsmål rettes til undertegnede.

Med vennlig hilsen
Marieke Bruin

Doktorgradsstipendiat

Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS)

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Det humanistiske fakultet
Universitetet i Stavanger
e-post: marieke.bruin@uis.no
tlf: 51 83 35 69 / mobil: 99 34 26 30

Du kommer til selve spørreskjemaet ved å klikke på følgende lenke:

<http://www.itslearning.com/test/r.aspx?XS=zsaysagmetx>

Les nøye informasjonen om utfylling av skjemaet øverst i teksten. Husk å klikke på ”Fullfør” når du er ferdig med å svare på spørsmålene.

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Til familier som har barn med CI,
dette er til dere!

Se: www.cochleaklubben.no



Invitasjon
til å delta
i forskningsprosjektet
Kommunikasjon og samhandling i familier med barn som har cochleaimplantat.

Prosjektet gjennomføres som et doktorgradsarbeid ved Universitetet i Stavanger. Forskningen ønsker få frem foreldrenes perspektiver og erfaringer i forhold til det å ha et barn med cochleaimplantat. Fokuset er på foreldrenes erfaringer med hensyn til kommunikasjonen i familiens hverdag, samt erfaringene deres i møtet med de ulike instansene i hjelpeapparatet.

Foreldrenes stemmer ansees som svært viktige i utviklingen av kunnskap om oppfølging av barn med CI

Vil du fortelle om dine erfaringer i forhold til deres behov når det gjelder oppfølging av ditt implanterte barn?

For mer informasjon kan du ta kontakt med
Marieke Bruin
Doktorgradsstipendiat i utdanningsvitenskap
Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk
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**SVARFRIST
1. APRIL
2012**



Universitetet
i Stavanger

Appendix III Interview Guide

Intervjuene er semi-strukturerte, som søker å innhente beskrivelser av den intervjuedes livsverden med henblikk på å fortolke betydningen av de beskrevne fenomenene. Intervjuguiden anses således som veiledende, retningsgivende, og som et eksempel på mulige spørsmål, ikke som en fastsatt liste som skal følges. Intervjuet er således preget av åpenhet når det gjelder endringer i rekkefølgen og formuleringen av spørsmål, slik at det muliggjør å forfølge svarene som gis og intervjupersonenes fortellinger (jf. Kvale & Brinkmann, 2009: 138).

(Innledningsvis takke for samtalen, be om underskrift på samtykkeerklæring, spørre om tillatelse for lydopptak, opplyse om at lydopptak slettes ved prosjektets slutt og at informanten kan trekke seg når som helst og uten begrunnelse.)

- Forelderens besvarelse av spørreundersøkelsen er et innledende fokus i samtalen.
- I besvarelsen din i spørreskjemaet forteller du om kommunikasjonen i familien. Belyse nærmere? Svarer kommunikasjonen til forventningene? utfordringer? Krever tilrettelegging av kommunikasjonen noe ekstra fra deg som forelder? I den eventuelle veiledningen/oppfølgingen som mottas, hva er fokus? Fokuserer man også på kommunikasjon i familiens hverdag eller på andre ting? Storfamilien?
- Har kommunikasjonsformen endret seg over tid? Hvorfor?
- Barnehage/skole. Hvordan foregår kommunikasjonen der? Med jevnaldrende og med voksne? Hvordan er samarbeidet mellom dere og barnehagen/skolen? Gjør dere noe spesielt i forhold til skole/barnehage, mener dere at barnets behov blir forstått når det gjelder tilrettelegging for at barnet skal kunne være med i samtaler, lek og fellesaktiviteter? Ressurser? Tilfredsstillende? Hva mener dere er viktig når det gjelder ressurser i skole/bh sammenheng? Andre ting?

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- Fritidsaktiviteter/kontakt med jevnaldrende barn: Hva er dere opptatt av i forhold til dette? Har du en rolle i styring av kommunikasjonen i disse sammenhengene? På trening, i lek med jevnaldrende, osv.
- Hvilke tanker har dere med hensyn til det viktigste som barnet må lære i nåværende øyeblikk? Ser du særlige utfordringer? Hva med fremtiden? Hvordan ser du din egen rolle opp i dette? Hvilke oppgaver ansees som sentrale i denne forbindelse? For de foreldrene som har flere barn: oppleves dette som annerledes enn med de andre barna?
- Opplever dere forventninger til dere som foreldre, når det gjelder ansvar for å hjelpe barnet i oppfølgingen? Får dere nok støtte og hjelp i å kunne hjelpe barnet? Hvis ja, hva består hjelpen i og hva ansees som spesielt verdifullt? Hvis nei, kan dere benevne spesifikt hva dere savner og hvorfor?
- Hvilke erfaringer med, og forventninger til, har dere til hjelpeapparatet? (medisinsk/pedagogisk) Tilfredsstillende? Hvorfor? Kan dere si noe om hva som er fokus i veilednings- og oppfølgingsprogrammene som dere deltar i? Dekker det alle deres behov? Hvordan opplever du dine muligheter for å bidra med dine synspunkter?
- Hvilken betydning har foreldreveiledningen for deg og for dere som familie? (Hvilke aspekter ved den har størst betydning?)
- Hvilke forventninger og erfaringer har dere til det kommunale støtteapparatet? Tilfredsstillende? Vanskelig? Hvorfor? Hva oppleves som de mest sentrale oppgavene til det kommunale støtteapparatet? Hvordan opplever du dine muligheter for å bidra med dine synspunkter?
- Hva slags forskjell gjør implantatet for familien? Hva betyr denne teknologien for 1) barnet, 2) familien?
- Hva betyr kontakt med andre foreldre som har barn med CI for dere?
- Hvilken betydning tror dere kommer kontakt med andre foreldre til å ha for dere i fremtiden?

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- Hvilke forhåpninger og forventninger har dere for barnet i fremtiden?
Har de endret seg over tid?
- Hva krever det å være forelder av et barn med CI? Blir det enklere/vanskeligere med tiden?
- Hva forteller foreldrene om hvordan de ser på deres egen læring i prosessen etter barnets cochleaimplantering?
- Hva ville dere sagt til andre foreldre som står i begynnelsen av prosessen?

Appendix IV Information letter 1, interviews



Stavanger, den 20. november 2012

Informasjon om forskningsprosjekt *Kommunikasjon og samspill i familier med cochleaimplanterte barn*

Til deg som forelder.

Tidligere i år har du deltatt i spørreundersøkelsen i forskningsprosjektet Kommunikasjon og samhandling i familier med barn som har cochleaimplantat. I besvarelsen din har du svart at du er villig til å delta i oppfølgingsstudien. Dette er grunnen til at jeg tar kontakt med deg nå.

Dette er en invitasjon til å delta i oppfølgingsstudien, som vil bestå av intervjuer med foreldre til barn som har CI som tidligere har deltatt i spørreundersøkelsen. Forskningsprosjektet gjennomføres som et doktorgradsarbeid ved Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS) ved Universitetet i Stavanger. Formålet er å beskrive foreldres erfaringer etter cochleaimplantering.

Intervjustudien vil videreføre noen av dimensjonene som har kommet frem i spørreundersøkelsen. En liste over temaer som vil bli tatt opp i samtaler vil bli sendt i forkant av intervjuet. Intervjuene planlegges å være gjennomført i løpet av de første månedene i 2013. For å gjøre det lettest mulig for deg, vil samtalen gjennomføres enten hjemme hos deg, eller intervjuet kan finne sted via Skype dersom det av praktiske grunner vil være enklere. Samtalen vil vare i ca. én til halvannen time.

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Forskning som omhandler foreldrenes perspektiver på oppfølging og veiledning etter cochleaimplantering vil gi kunnskaper som vil hjelpe fremtidig tilrettelegging av foreldreveiledning, samt faglig veiledning av pedagoger i for eksempel barnehage/skole eller PPT. Når det gjelder CI har eksisterende forskning frem til nå i stor grad handlet om taleoppfattelse og taleproduksjon hos de barna som har CI og i mindre grad om kommunikasjonsprosesser i familien og familiens behov. Derfor er foreldres perspektiver et svært viktig bidrag til utvikling av kunnskaper om oppfølging av barn som har CI.

Resultatene til forskningsarbeidet vil publiseres i blant annet vitenskapelige artikler og i en avhandling for doktorgraden i utdanningsvitenskap ved Universitetet i Stavanger. Alle deltakerne anonymiseres og det vil ikke være mulig å identifisere forskningsprosjektets deltakere i publiseringen. Det er frivillig å delta i prosjektet og deltakeren kan trekke seg når som helst fra prosjektet og uten begrunnelse.

Prosjektet er meldt til Personvernombud ved Norsk samfunnsvitenskapelig datatjeneste (NSD). Undersøkelsen gjennomføres i perioden 2011-2015. Dato for prosjektslutt er 31.12.2015 og da vil alt datamateriale anonymiseres. Lydbåndopptak og videoopptak slettes. Jeg har taushetsplikt og alle opplysninger vil behandles konfidensielt. Eventuelle spørsmål rettes til undertegnede.

Dersom du ønsker å delta i intervjustudien, ber jeg om at du sender meg en e-post med dine kontaktopplysninger slik at jeg kan ta kontakt for å gjøre nærmere avtale.

Med vennlig hilsen

Marieke Bruin

Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS)

Det humanistiske fakultet, Universitetet i Stavanger

e-post: marieke.bruin@uis.no

mobil: 99 34 26 30

Appendix V Information letter 2, interviews



Stavanger, 26. februar 2013

Informasjon om forskningsprosjekt *Kommunikasjon og samspill i familier med barn som har cochleaimplantat, delstudie 2*

Prosjektet er et doktorgradsarbeid ved Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS) ved Universitetet i Stavanger. Formålet er å undersøke og beskrive foreldres erfaringer med oppfølging og veiledning etter cochleaimplantering. Foreldrenes erfaringer ansees som svært viktige i denne sammenhengen.

Delprosjekt 2 er en videreføring av det første delprosjektet og består av intervjuer med foreldre som har deltatt i delprosjekt 1. I intervjuene vil spørsmålene fokusere på foreldrenes erfaringer og synspunkter med hensyn til barnets kommunikasjon hjemme og i andre sammenhenger, slik som for eksempel skole/barnehage, fritidsaktiviteter eller i samspill med jevnaldrende barn. Videre vil foreldrenes erfaringer med oppfølging og veiledning stå sentralt, samt betydningen av kontakt med andre foreldre i samme situasjon. Forskning som omhandler foreldrenes perspektiver på samhandling og kommunikasjon med deres barn vil gi kunnskaper som vil hjelpe fremtidig tilrettelegging av foreldreveiledning, samt faglig veiledning av pedagoger i for eksempel barnehage/skole eller PPT.

Resultatene til forskningsarbeidet vil publiseres i blant annet vitenskapelige artikler og i en avhandling for doktorgraden i utdanningsvitenskap ved Universitetet i Stavanger. Alle deltakerne anonymiseres og det vil ikke være mulig å identifisere forskningsprosjektets deltakere i publiseringen. Det er

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frivillig å delta i prosjektet og deltakeren kan trekke seg når som helst fra prosjektet og uten begrunnelse.

Prosjektet er meldt til Personvernombud ved Norsk samfunnsvitenskapelig datatjeneste (NSD). Undersøkelsen gjennomføres i perioden 2011-2015. Dato for prosjektslutt er 31.12.2015 og da vil alt datamateriale anonymiseres og lydbåndopptak vil slettes. Jeg har taushetsplikt og alle opplysninger vil behandles konfidensielt. Eventuelle spørsmål rettes til undertegnede.

Med vennlig hilsen
Marieke Bruin

Doktorgradsstipendiat

Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS)
Det humanistiske fakultet
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e-post: marieke.bruin@uis.no
tel: 51 83 36 09 / mobil: 99 34 26 30

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Email sent to participants a week before the interviews, to confirm date and time

Hei,

Jeg gleder meg til å komme til ... neste ... for å snakke med deg/dere. Jeg takker for at dere vil bruke tid på denne samtalen med meg. Jeg vet hvor travel hverdagen er når man har et barn med CI fordi jeg er selv mor til en jente på 10 år som har CI. At dere prioriterer noe av tiden deres til dette forskningsprosjektet er derfor overhodet ingen selvfølge. Jeg stor pris på det.

Jeg håper at du/dere synes det er greit at samtalen blir tatt opp på bånd. På den måten slipper jeg å sitte og skrive mens vi snakker sammen, og kan jeg rette all min oppmerksomhet på det som vi snakker om. Lydbåndopptaket transkriberes senere i sin helhet, og det vil bli slettet ved prosjektets slutt, jf. vedlagt informasjonsskriv.

Temaer som vil bli tatt opp er deres erfaringer med hensyn til oppfølging og veiledning etter CI. Her er det snakk om ulike kontekster, som kan være for eksempel den medisinske konteksten, ulike spesialpedagogiske instanser, skole/barnehage, PP-tjenesten eller kommunen. Noen eksempler på spørsmål er hvilke tanker og erfaringer dere har med hensyn til barnets muligheter for å kunne delta i kommunikasjonen hjemme, men også i andre fellesskap slik som skole/barnehage, i fritidsaktiviteter samt i kontakt med jevnaldrende. Hvilke utfordringer møter dere, og hvordan føler dere at oppfølgingen og veiledningen klarer å gi dere verktøy til å takle disse utfordringer? Det vil være rom for at samtalen styres av det som opptar dere som foreldre. Du kan i den forbindelse gjerne tenke deg om i forkant av samtalen om det er noe spesielt du ønsker å nevne.

Jeg kan nås på mobil 99342630, dersom du har spørsmål eller dersom du ønsker å formidle en beskjed til meg. Da sees vi den kl

Med vennlig hilsen

Marieke Bruin

Appendix VI Consent statement, interviews



Samtykkeerklæring

Jeg/vi har fått informasjon om forskningsprosjektet *Kommunikasjon og samspill i familier som har barn med cochleaimplantat*, og bekrefter med dette at jeg/vi vil være med i delprosjekt 2 og bli intervjuet.

Jeg/vi er klar over at det er mulig å trekke seg fra deltakelse i prosjektet når som helst, og uten begrunnelse.

Denne samtykkeerklæringen vil bli oppbevart av prosjektleder så lenge prosjektet varer. Det innsamlede materialet vil bli anonymisert og lydopptak vil bli slettet etter prosjektavslutning.

Informanten(e) får en kopi av denne samtykkeerklæringen.

Sted

Dato

Informanten(e)s navn

Informanten(e)s signatur

Appendix VII Authorisation from Data Protection Official for Research at the Norwegian Centre for Research Data (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Hovudkontoret gate 29
N-2027 Biri
NSD AS
Tlf: +47 25 34 11 11
Faks: +47 25 34 96 99
nsd@nsd.uib.no
www.nsd.uib.no
Org nr. 905 217 884

Marteke Bruin
Institutt for allmennlærerutdanning og spesialpedagogikk
Universitetet i Stavanger
4036 STAVANGER

Vår dato: 06.01.2012 Vår ref: 2012/187/MSL Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 05.10.2011. All nødvendig informasjon om prosjektet forelå i sin helhet 06.01.2012. Meldingen gjelder prosjektet:

2011 *Family Factors - Affiliates and constraints concerning inchoate implanted children's participation within the family's communicative practice*
Behandlingsinstans: *Universitetet i Stavanger, ved instituttansvarlig leder*
Daglig ansvarlig: *Marteke Bruin*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i innhørskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjekter i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.asp>.

Personvernombudet vil ved prosjektets avslutning, 31.12.2015, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdís Namtvedt Kvalheim

Marie Strand Schildmann

Kontaktperson: Marie Strand Schildmann tlf: 55 58 31 52
Vedlegg: Prosjektvurdering

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Personvernombudet for forskning



Prosjektvurdering - Kommentar

Prosjektnr: 28341

Prosjektet er en studie av familier med barn som har cochleaimplantat. Formålet med studien er å belyse hvordan familien skaper vilkår for deltakelse og påfølgende muligheter for barnets utvikling og læring.

Utvalget består av ca. 135 familier med barn som har cochleaimplantat. Foreldrene til disse barna vil bli spurt om å svare på en elektronisk survey (del 1), og av dem ønsker man å intervju ca. 10 foreldrepar (del 2). Av denne gruppen vil 1 til 2 familier forespørres om deltakelse i en videoobservasjonsstudie (del 3). I videoobservasjonsstudien er utvalget både kjernefamilien (mor, far, det implanterte barnet og eventuelle søsken), men det er samtidig ønskelig å ikke stenge for et større familiebegrep hvor familien sees som storfamilie (besteforeldre/onkler & tanter/søskenbarn) og eventuelle andre signifikante voksne.

) Forespørsel om deltakelse i spørreundersøkelsen formidles til utvalget via foreldreforeningen Cochleaklubben.

Personvernombudet finner informasjonsskriv av 06.01.2012 i forbindelse med delstudie 1 tilfredsstillende. Informasjonsskrivene for delstudie 2 og 3 finnes tilfredsstillende, da dato for prosjektslutt og anonymisering er påført i informasjonen som gis i forbindelse med spørreundersøkelsen.

) I forbindelse med spørreundersøkelsen innhentes opplysninger i form av fødselsdato og kjønn på det cochleaimplanterte barnet, samt opplysninger knyttet til funksjonshemmingen. Videre innhentes generelle opplysninger om familien, kommunikasjonen i familien og foreldrenes møte med hjelpeapparatet. Fokusområdene nærmes fra to ulike tidsperspektiv: fortid - den første tiden før og etter implantering, og nåtid - dagen i dag. For de som ikke samtykker til videre deltakelse i intervjuundersøkelsen, vil denne spørreundersøkelsen være anonym, jf. telefonsamtale med prosjektleder den 06.01.2012. Spørreskjema besvares via It's learning. De som samtykker til videre deltakelse påfører spørreskjema en egendefinert kode/nøkkel og sender samme nøkkel i separat e-post til prosjektleder.

Intervjuguide utarbeides på bakgrunn av spørreundersøkelsen. Intervjuundersøkelsen vil omhandle de samme temaene og registreres i form av lydfiler. Ombudet legger til grunn for sin vurdering at intervjuguide sendes oss for gjennomlesing innen intervjuundersøkelsen igangsettes, jf. telefonsamtale med prosjektleder den 06.01.2012.

Observasjonsstudien (del 3) registreres i form av videoopptak. I forbindelse med observasjonsstudien tas det høyde for at det vil registreres opplysninger om tredje person (videoopptak hvor familiemedlemmer inngår). Tredje person informeres.

Det behandles sensitive opplysninger om helseforhold, jf. personopplysningsloven § 2, punkt 8 c.

Dato for prosjektslutt er 31.12.2015. Datamaterialet anonymiseres ved at verken direkte eller indirekte personidentifiserende opplysninger fremgår. Koblingsnøkkel, lyd- og filmopptak slettes. Indirekte personidentifiserende opplysninger fjernes, omskrives eller grovkategoriseres.

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RETTELSE TIL BEKREFTELSE PÅ STATUS

Vi beklager at vi har skrevet feil dato for prosjektslutt i vår bekreftelse på status sendt i dag, og bekrefter at vi har registrert 31.12.2017 som ny dato for prosjektslutt.

Med vennlig hilsen

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Agnete Hessevik
Rådgiver | Adviser
Seksjon for personverntjenester | Data Protection Services
T: (+47) 55 58 27 97

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data
Harald Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
postmottak@nsd.no www.nsd.no

Marieke Bruin skrev den 11.01.2017 11:26:

Hei Agnete,
Det står en feil i ny dato for prosjektslutt, det må vel stå «31.12.2017», istedenfor «31.12.2016»
Hilsen Marieke

Fra: Agnete Hessevik [<mailto:agnete.hessevik@nsd.no>]
Sendt: 11. januar 2017 10:54
Til: Marieke Bruin <marieke.bruin@uis.no>
Emne: Prosjektnr: 28341. Family Factors - Affordances and constraints concerning cochlear implanted children's participation within the family's communicative practice

BEKREFTELSE PÅ STATUS

Hei, viser til statusmelding registrert hos personvernombudet 02.01.2017, der du ber om forlengelse av prosjektet til 31.12.2017.

Personvernombudet forstår det slik at datamaterialet i hovedsak er anonymisert, men at du ønsker å beholde lydopptak til etter disputas. Det kan framkomme personidentifiserende opplysninger på lydopptak, og det må derfor tas høyde for at det fortsatt behandles sensitive personopplysninger i prosjektet.

Personvernombudet har nå registrert 31.12.2016 som ny dato for prosjektslutt. Vi forutsetter at de det gjelder får informasjon om at lydopptak fortsatt behandles og ny dato for prosjektslutt.

I tilfelle det skulle bli aktuelt med ytterligere forlengelse av prosjektslutt, vil vi gjøre oppmerksom på at forlengelse på mer enn ett år utover den sluttdatoen utvalget senest har blitt informert om ikke kan påregnes uten at det vurderes å gi informasjon til utvalget.

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Ved ny prosjektslutt vil personvernombudet rette en henvendelse angående status for behandlingen av personopplysninger.

Med vennlig hilsen

--

Agnete Hessevik
Rådgiver | Adviser
Seksjon for personverntjenester | Data Protection Services
T: (+47) 55 58 27 97

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research
Data
Harald Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
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Stavanger, 23. januar 2017

Til deg som deltok i forskningsprosjektet *Kommunikasjon og samspill i familier med barn som har cochleaimplantat*

Dette brevet sendes intervjudeltakerne i prosjektet for å informere om at dato for prosjektslutt har blitt forsinket, grunnet alvorlig sykdom i min familie. I samråd med Personvernombud ved Norsk Senter for Forskningsdata (NSD) har ny dato for prosjektslutt blitt satt til 31.12.2017. Etter prosjektslutt vil all data anonymiseres og lydopptak slettes.

Jeg ønsker å benytte anledningen og takke deg for ditt viktige bidrag til forskningsprosjektet. Prosjektet har resultert i fire publikasjoner i ledende internasjonale vitenskapelige publiseringskanaler:

- Bruin, M., & Nevøy, A. (2014). Exploring the Discourse on Communication Modality after Cochlear Implantation - A Foucauldian Analysis of Parents' Narratives. *Journal of Deaf Studies and Deaf Education*, 19(3), 385-399.
- Bruin, M. (2015). Research on language development: Discourses on learning and messages to family support after CI. In H. Knoors & M. Marschark (Eds.), *Educating Deaf Learners: Creating a Global Evidence Base* (pp. 93-113). New York, NY: Oxford University Press.
- Bruin, M., & Ohna, S. E. (2015). Negotiating Reassurance: Parents' Narratives on Follow-up after Cochlear Implantation. *European Journal of Special Needs Education*, 30(4), 518-534.
- Bruin, M. (2017). Parental Involvement in Children's Learning: The Case of Cochlear Implantation—Parents as Educators? *Scandinavian Journal of Educational Research*, 1-16. doi:10.1080/00313831.2016.1258728, published online January 12th.

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Dersom du er interessert i å motta en eller flere av publikasjonene, vennligst send meg en epost på marieke.bruin@uis.no og jeg skal sørge for at du får publikasjonene tilsendt. Selve avhandlingen forventes å bli ferdigstilt i løpet av noen få måneder. Dersom du har lyst å være til stede på disputasen, vennligst gi meg beskjed slik at jeg kan få sendt deg en invitasjon når dato for disputas foreligger.

Med vennlig hilsen
Marieke Bruin

PhD-kandidat

Institutt for grunnskolelærerutdanning, idrett og spesialpedagogikk (IGIS)
Det humanistiske fakultet
Universitetet i Stavanger
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Tel: 51 83 35 69 / mobil: 99 34 26 30

Appendix VIII Preliminary data-driven analysis questionnaire - Nodes

Nodes

Name		
<input type="checkbox"/> Barnehage		
<input type="checkbox"/> Behov som ikke blir møtt per i dag		
<input type="checkbox"/> Behov som ikke har blitt møtt tidligere		
<input type="checkbox"/> Deltakelse		
<input type="checkbox"/> (Å fjerne) Barrierer for deltakelse		
<input type="checkbox"/> Gruppesamtaler og lek i gruppe		
<input type="checkbox"/> Stillasbygging		
<input type="checkbox"/> Verktøy		
<input type="checkbox"/> Familiens språk		
<input type="checkbox"/> Tegn til tale		
<input type="checkbox"/> Foreldreopplæringsprogram		
<input type="checkbox"/> Utbytte av foreldreopplæringsprogram		
<input type="checkbox"/> Forståelse i nærmiljø og storfamilie		
<input type="checkbox"/> Kommunikasjonen i fritidsaktiviteter		
<input type="checkbox"/> Kommunikasjon i familien den første tiden		
<input type="checkbox"/> Kommunikasjonen i familien per i dag		
<input type="checkbox"/> Endringer over tid i familiens kommunikasjon		
<input type="checkbox"/> Kontakt med andre foreldre		
<input type="checkbox"/> Møte med hjelpeapparatet		
<input type="checkbox"/> Cochletten		
<input type="checkbox"/> Helsevesenet		
<input type="checkbox"/> Hjelpemiddelsentralen		
<input type="checkbox"/> Møtet med hjelpeapparatet den første tiden		
<input type="checkbox"/> Nåværende samarbeid med hjelpeapparatet		
<input type="checkbox"/> PPT		
<input type="checkbox"/> Skyldfølelse		
<input type="checkbox"/> Statped		
<input type="checkbox"/> Å bli lyttet til		
<input type="checkbox"/> Redgjørelse for valg av kommunikasjonsmodalitet		
<input type="checkbox"/> Skole		
<input type="checkbox"/> Må lære opp pedagogisk personale		
<input type="checkbox"/> Spm 23 tilleggsplysninger		
<input type="checkbox"/> Syn på læring AM		
<input type="checkbox"/> Syn på læring PM		

Appendices

Nodes

Name		
<input type="checkbox"/> Ulike faglige diskurser om oppfølging av barn med CI		
<input type="checkbox"/> Usikkerhet med hensyn til valg		
<input type="checkbox"/> Usikkerhet om fremtiden og behov for trygghet		
<input type="checkbox"/> Uttrykk for å lykkes		
<input type="checkbox"/> Veiledningstilbud		
<input type="checkbox"/> Fokus for veiledningen		
<input type="checkbox"/> Instans som gir mest støtte		
<input type="checkbox"/> Utbytte av veiledning frem til i dag		
<input type="checkbox"/> Utbytte av veiledningen i den første tiden		
<input type="checkbox"/> Vi har valgt riktig		

Appendix IX Analysis interview data – Nodes

Nodes

Name		
● Vilkår for læring på skolen og bh		
● Vilkår for læring hjemme		
● Vi som familie		
□ Språklig kommunikasjon		
● Skole barnehage		
● Fritidsaktiviteter og jevnaldrende barn		
● Familie og storfamilie		
● Problemet ligger i barnet		
● PPT		
□ Oppfølging og veiledning		
● Medmenneskelighet		
● Betydningen for foreldre		
● Behov		
□ Normalisering		
● Å nå sitt potensiale		
● Å fikse barnet		
□ Læring		
□ The teacher		
● Things to avoid ANXIETY		
● Things to aim for HOPE		
□ The learner		
● Things to avoid ANXIETY		
● Things to aim for HOPE		
□ The facilitator		
● Things to avoid ANXIETY		
● Things to aim for HOPE		
□ The advocate		
● Things to avoid ANXIETY		
● Things to aim for HOPE		
● Hvorfor må det læres		
● Hvordan må det læres		
● Hvor må det læres		
● Hvem må lære		
● Hva må læres		

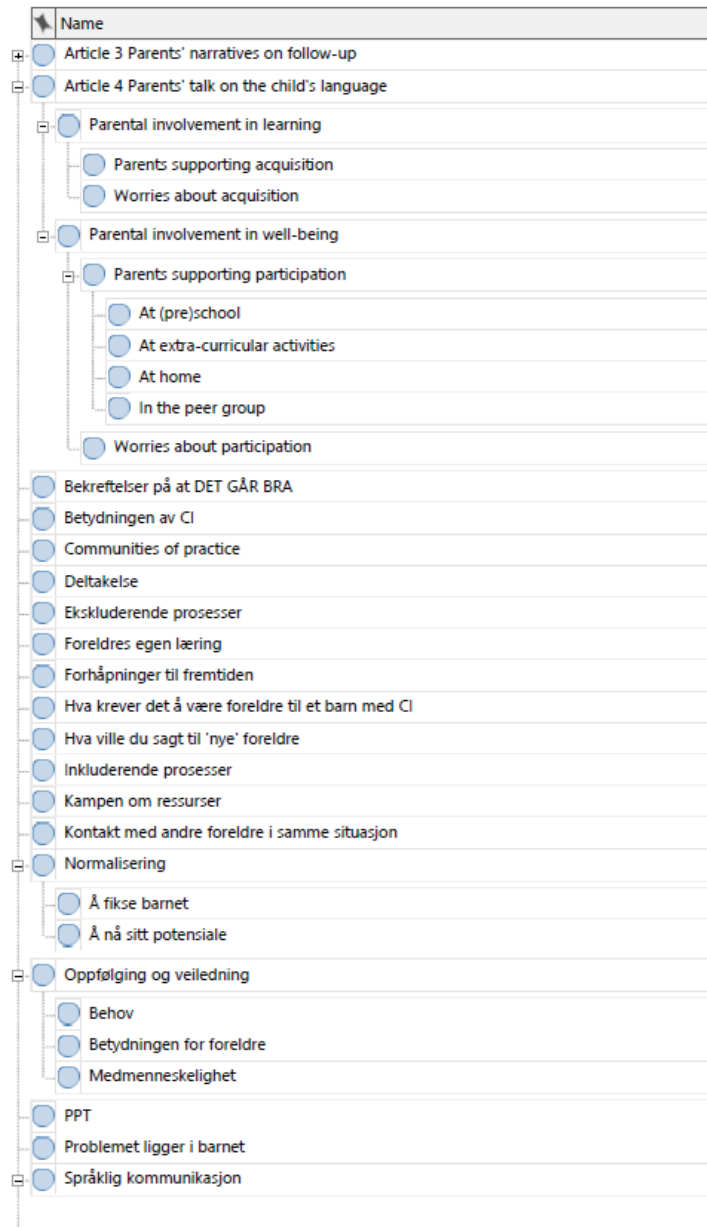
Appendices

Nodes

Name		
<input type="radio"/> Kontakt med andre foreldre i samme situasjon		
<input type="radio"/> Kampen om ressurser		
<input type="radio"/> Inkluderende prosesser		
<input type="radio"/> Hva ville du sagt til 'nye' foreldre		
<input type="radio"/> Hva krever det å være foreldre til et barn med CI		
<input type="radio"/> Forhåpninger til fremtiden		
<input type="radio"/> Foreldres egen læring		
<input type="radio"/> Ekskluderende prosesser		
<input type="radio"/> Deltakelse		
<input type="radio"/> Communities of practice		
<input type="radio"/> Betydningen av CI		
<input type="radio"/> Bekreftelser på at DET GÅR BRA		

Appendix X Analysis questionnaire data and interview data – Nodes

Nodes



Appendices

Nodes

Name
<input type="radio"/> Familie og storfamilie
<input type="radio"/> Fritidsaktiviteter og jevnaldrende barn
<input type="radio"/> Skole barnehage
<input type="radio"/> Vi som familie
<input type="radio"/> Vilkår for læring hjemme
<input type="radio"/> Vilkår for læring på skolen og bh