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Monica Londen

**COMMUNICATIONAL AND EDUCATIONAL CHOICES
FOR MINORITIES WITHIN MINORITIES
The case of the Finland-Swedish Deaf**

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The case of the Finland-Swedish Deaf

Abstract

The education of deaf children is complex and has been controversial throughout history. The main issue has been whether oral or manual communication should be used. Today Sign Languages are considered full-fledged languages, and therefore suitable and indeed desirable as the languages of instruction in deaf schools. The educational situation for Finland-Swedish deaf children is difficult as the only deaf school for Finland-Swedish children was closed in 1993. Finland-Swedish parents are thus forced to choose between a deaf school in Sweden, a Finnish deaf school or mainstreaming in school for normally hearing children for their deaf or hearing-impaired child.

The medical community views deafness as a medical problem that should be treated accordingly and emphasis is placed on the development of a spoken language. According to the socio-cultural view of deafness, however, deaf people who use Sign Language constitute a linguistic and cultural minority. Understanding deaf culture, its development and current situation is important when discussing the education and upbringing of deaf and hearing-impaired children. When choosing language and school for their deaf children hearing parents must be informed of the richness of Deaf culture and of the importance for deaf children to interact with other deaf people and be aware of their own cultural heritage. Meanwhile, the development of new, advanced hearing devices such as the cochlear implant has sparked yet another discussion on the role of Deaf culture and Sign Language in the Deaf community.

In this study educational choices for children belonging to a minority within a minority are examined. Focus is on Finland-Swedish families with deaf children. For hearing parents of deaf children decisions relating both to communication and education require them to reflect on their own conceptions and understanding not only of deafness but of language, identity, and culture. The parents need to decide which method of communication to use with their child, as their natural instinct of communicating in their own mother tongue is not suitable for a deaf child. This can initially be a source of conflict, choosing Sign Language indicates not only that the child's native language but also the cultural belonging and type of schooling will differ from that of the parents. By studying this minority population the significance of linguistic, cultural and educational values and beliefs in the upbringing of children is amplified and clearly elucidated. This study is grounded in

a hermeneutical phenomenological approach, with the concept of life-world as a basis. The empirical data for the study was obtained through the use of a questionnaire and in-depth interviews with Finland-Swedish parents of deaf or hearing-impaired children.

The results of this study show that the education of Finland-Swedish deaf or hard-of-hearing children raises complicated issues concerning language, culture and identity. Regardless of their communication method, all parents who took part in this study reported many problems that related to their child's education. Among the influential factors when choosing type of schooling for their signing child parents spoke of the need for instruction in Sign Language and the hope of maintaining the Swedish language and the Finland-Swedish culture. The main factors influencing the choice for families who were using oral communication included a wish for interaction between the hearing-impaired child and the hearing community, and the possibility of attending a school near their home. Furthermore, the belief that signing children are at risk of becoming socially isolated and have limited educational opportunities influenced the parents' choice of spoken language and mainstreaming for their deaf or hearing-impaired child.

Common to all parents of deaf or hearing-impaired children is the fact that both categories of parents want objective and up-to-date information about deafness and hearing-impairments, as well as emotional support and guidance. However, this is not always the case. In particular, parents of deaf or severely hearing-impaired children are dissatisfied with some of the procedures involved in early habilitation.

Keywords: Deaf education, Sign Language, Finland-Swedish deaf, educational choices, hermeneutics.

Monica Londen

**VAL AV SPRÅK OCH SKOLA FÖR FINLANDSSVENSKA DÖVA BARN
– EN MINORITET INOM EN MINORITET**

Abstrakt

Undervisningen av döva barn är en mångfasetterad fråga och har genom tiderna varit kontroversiell. Den stora frågan har varit om man skall använda det talade språket eller teckenspråk i kommunikation med döva barn. I dag anses teckenspråk vara fullgoda språk och sålunda även lämpliga och ändamålsenliga som undervisningsspråk i dövskolor. För finlandssvenska döva barn är skolsituationen dock synnerligen svår eftersom den enda finlandssvenska dövskolan lades ner år 1993. Vid val av skola för sina döva eller hörselskadade barn är finlandssvenska föräldrar sålunda tvungna att välja mellan dövskola i Sverige, finsk dövskola eller integrering i den allmänna skolan.

Enligt den medicinska synen är dövhet ett medicinskt problem som bör behandlas i enlighet därmed och man betonar vikten av att barnet utvecklar ett tal-språk. Enligt den sociokulturella synen på dövhet bildar döva som använder teckenspråk en språklig och kulturell minoritet. Förståelse för dövskulturen, dess utveckling och nuläge är viktiga aspekter när det gäller döva och hörselskadade barns fostran och utbildning. Då hörande föräldrar skall välja språk och skola för sina döva barn är det viktigt att föräldrarna erhåller information om dövsamfundet och om betydelsen av att deras döva barn träffar andra döva personer och sålunda blir medvetna om sitt eget kulturarv. I och med utvecklingen av nya tekniskt avancerade hörapparater som cochlea implantat har det nu uppstått en ny diskussion kring dövskultur och teckenspråkets betydelse inom dövsamfundet.

I den här studien undersöks val av språk och skola för döva och hörselskadade barn i finlandssvenska familjer, barn som sålunda hör till en minoritet inom en minoritet. För hörande föräldrar till döva barn tvingar beslut rörande både språk och utbildning föräldrarna att reflektera över sina egna uppfattningar om och förståelse av inte bara dövhet utan också språk, identitet och kultur. För föräldrar som väljer teckenspråk kan detta i början ge upphov till problem eftersom barnens modersmål, kulturtillhörighet och utbildning avviker från föräldrarnas. Betydelsen av språkliga, kulturella och utbildningsmässiga värderingar och uppfattningar vid fostran av barn framträder tydligt i denna studie. Arbetet baserar sig på en hermeneutisk-fenomenologisk forskningsansats med begreppet livsvärld som grund. De empiriska data för undersökningen bygger på ett frågeformulär och djupintervjuer med finlandssvenska föräldrar till döva och hörselskadade barn.

Resultaten av undersökningen visar att undervisningen av finlandssvenska döva och hörselskadade barn aktualiserar komplexa aspekter på språk, kultur och identitet. Oberoende av val av kommunikationssätt rapporterade alla föräldrar som

deltog i undersökningen många svårigheter i samband med barnens utbildning. För föräldrar till barn som använder teckenspråk påverkade behovet av undervisning på teckenspråk och önskan om att bibehålla det svenska språket och den finlandssvenska kulturen valet av skola. För familjer som använder oral kommunikation var önskan om en fungerande interaktion mellan det hörselskadade barnet och den hörande omgivningen samt möjligheten för barnet att gå i en närbelägen skola av betydelse. Tron att teckenspråkiga barn löper en risk att bli socialt isolerade och även har begränsade utbildningsmöjligheter påverkade också föräldrars val av talspråk och integrering i den allmänna skolan.

Samtliga föräldrar som deltog i undersökningen vill ha objektiv och aktuell information om dövhet och hörselskador samt vägledning och emotionellt stöd. Dessvärre får föräldrarna inte alltid det stöd de behöver. I synnerhet föräldrar till döva och gravt hörselskadade barn är missnöjda med vissa aspekter av den tidiga habiliteringen.

Nyckelord: Dövundervisning, teckenspråk, finlandssvenska döva, skolval, hermeneutik

Monica Londen

KIELI- JA KOULUVALINNAT VÄHEMMISTÖN VÄHEMMISTÖSSÄ Suomenruotsalaiset kuurot ja heidän erityisongelmansa

Tiivistelmä

Kuurojen lasten koulutus on monimutkainen ongelma, joka on kautta aikojen ollut kiistanalainen. Pääkysymys on ollut, tulisiko käyttää suullista vai manuaalista kommunikointia. Nykyään viittomakieliä pidetään täysimittaisina kielinä ja siten sopivina ja itse asiassa tavoittelemisen arvoisina opetuskielinä kuurojen koulutuksessa. Suomenruotsalaisten kuurojen lasten koulutuksellinen tilanne on erittäin vaikea, sillä ainoa suomenruotsalaisille lapsille tarkoitettu kuurojen koulu lakkautettiin vuonna 1993. Suomenruotsalaiset vanhemmat joutuvat näin valitsemaan kuuroille tai kuulovammaisille lapsilleen joko suomenkielisen kuurojen koulu, kuurojen koulu Ruotsista tai integroinnin normaalisti kuulevien lasten koulussa.

Lääketieteellinen yhteisö pitää kuuroutta lääketieteellisenä ongelmana, jota tulisi myös sellaisena käsitellä, ja pääpaino asettuu puhutun kielen kehittämiseksi. Viittomakieltä käyttävät kuurot muodostavat sosiokulttuurisesta näkökulmasta tarkastellen kielellisen ja kulttuurisen vähemmistön. Kuurojen kulttuurin, sen kehittymisen ja nykytilanteen ymmärtäminen on tärkeää pohdittaessa kuurojen ja kuulovammaisten koulutusta ja kasvatusta. Kieli- ja kouluvalintaa kuurojen lastensa puolesta tekeviä vanhempia on informoitava kuurojen kulttuuriin rikkaudesta ja siitä, miten tärkeää kuuroille lapsille on sekä vuorovaikutus toisten kuurojen kanssa että tietoisuus omasta kulttuuriperinnöstä. Uusien korkeatasoisten kuuloapuvälineiden kuten sisäkorvaimplantin kehittäminen on samalla virittänyt vielä aivan uuden keskustelun kuurojen kulttuurin ja viittomakielen roolista kuurojen yhteisössä.

Tässä tutkimuksessa tarkastellaan vähemmistön vähemmistöön kuuluville lapsille tarjoutuvia koulutuksellisia valintoja. Tutkimuskohteena on suomenruotsalaisia perheitä, joissa on kuuroja lapsia. Tehdessään kommunikointiin ja koulutukseen liittyviä päätöksiä kuurojen lasten kuulevat vanhemmat joutuvat pohtimaan käsityksiään ja ymmärrystään paitsi kuuroudesta myös kielestä, identiteetistä ja kulttuurista. Vanhempien on päätettävä mitä kommunikointimenetelmää he käyttävät oman lapsensa kanssa, sillä heidän luontainen halunsa kommunikoida omalla äidinkielellään ei ole kuuroille lapselle sopiva. Tämä voi alussa aiheuttaa konflikteja; viittomakielen valitseminen merkitsee sitä, että ei ainoastaan lapsen äidinkieli vaan myös sivistyksellinen identiteetti ja koulutustyyppi tulevat poikkeamaan vanhempien vastaavista. Lasten kasvatukseen liittyvien kielellisten, koulutuksellisten ja sivistyksellisten arvojen ja uskomusten merkitys vahvistuu ja selkiytyy tätä vähemmistöpopulaatiota tutkimalla. Tämä tutkimus nojaa hermeneuttiseen fenomenologiseen lähestymistapaan, jossa käsite elämismaailma muodos-

taa perustan. Tutkimukseen tarvittava havaintomateriaali saatiin käyttämällä kyselykaavaketta sekä suomenruotsalaisten kuurojen tai kuulovammaisten lasten vanhempien syvähaastatteluilla.

Tämän tutkimuksen tulokset osoittavat, että suomenruotsalaisten kuurojen tai huonokuuloisten koulutus nostaa esiin monimutkaisia kysymyksiä, jotka koskevat kieltä, kulttuuria ja identiteettiä. Valitusta kommunikointimenetelmästä riippumatta kaikki tähän tutkimukseen osallistuvat vanhemmat kertoivat monista lastensa koulutukseen liittyvistä ongelmista. Vaikuttavina tekijöinä koulutustyyppin valinnassa viittomakielelliselle lapselle vanhemmat mainitsivat viittomakielen opetuksen tarpeellisuuden sekä toiveen ylläpitää ruotsin kieltä ja suomenruotsalaista kulttuuria. Suullisen kommunikaation valintaa ohjaaviin päätekijöihin kuuluivat toivomus vuorovaikutuksesta kuulovammaisen lapsen ja kuulevan yhteisön välillä sekä mahdollisuus käydä koulua lähellä omaa kotia. Lisäksi pelko siitä, että viittomakieliset lapset eristäytyvät sosiaalisesti ja että heidän koulutusmahdollisuutensa ovat niukemmat, vaikutti siihen, että vanhemmat valitsivat puhutun kielen ja integroinnin kuuroille tai kuulovammaisten lapselleen.

Yhteistä kaikille kuurojen tai kuulovammaisten lasten vanhemmille on se, että molempien edellä mainittujen kategorioiden vanhemmat haluavat objektiivista ja ajan tasalla olevaa tietoa kuuroudesta ja kuulovammaisuudesta samoin kuin emotionaalista tukea ja opastusta. Valitettavasti tämä toivomus ei kuitenkaan aina toteudu. Aivan erityisesti kuurojen tai vaikeasti kuulovammaisten lasten vanhemmat ovat tyytymättömiä eräisiin varhaiskuntoutukseen liittyviin menettelytapoihin.

Avainsanat: Kuurojen koulutus, viittomakieli, suomenruotsalaiset kuurot, kouluvalinta, hermeneutiikka

For Nadia, Kevin and William

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Education can be considered the stronghold for all minorities and this particularly holds true for deaf people. The reason is that as most deaf children have hearing parents, the language and culture of the Deaf community cannot be transmitted from generation to generation, but rather in deaf schools or within the Deaf community. There is, however, no Finland-Swedish deaf school and the consequences of this for the education of Finland-Swedish deaf children is the focus of this study. I am deeply grateful to all parents of deaf or hearing-impaired children who participated in this study. They trusted me with sensitive information about their child as well as with their thoughts and experiences of raising a deaf or hearing-impaired child. Without their co-operation and willingness to share their experiences this book would never have been written. I hope their participation will prove beneficial and result in a broader awareness of both the Finland-Swedish Deaf culture and the educational situation for Finland-Swedish Deaf and hearing-impaired children

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Monica Londen

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1 Introduction

1.1 Background

The education of deaf children is both complex and controversial. The perennial underlying debate and conflict is whether oral or manual communication should be used with deaf children. The complexity and controversy stem from three inter-related issues, how, where and what deaf children should be taught (Moore, 1991). The main questions are (1) what the language of instruction should be, (2), in what educational settings deaf children should be educated, and (3) how the content of the curriculum should be structured (Moore, 1991, 35).

Traditionally, the view on deafness and deaf people's ability to develop cognitive skills such as language and thinking has been distorted. Throughout the history of deaf education a variety of different communication methods have been devised and educators have spent much effort in teaching deaf children to speak. Not even recent developments and research within the fields of deaf education have managed to obliterate incorrect, yet common, beliefs about deafness and cognition (Nelson, Loncke, Camarata, 1993). A majority of the earlier research on deafness has concentrated on the only ability the deaf lack, on the pathology of deafness, consequently suggesting that there is something fundamentally different with deaf people. The complexity surrounding deafness was put forward by Levine in 1960 but deafness has nevertheless been associated with specific personality traits (Nelson, Loncke, & Camarata, 1993), and deaf children, although highly fluent in a Sign Language, have been labelled linguistically deficient (Myklebust, 1964), and language disturbed (Nelson et al, 1993). In fact, hearing and speech have been considered necessary for the development of brain specialisation for language (Klima & Bellugi, 1979). Deafness – not the absence of a spoken language but deafness in itself – has also been considered to inhibit the acquisition of reading (Gormley & McGill Franzen, 1978).

During the past decades the recognition of Sign Language as a minority language has increased and Deaf awareness has grown, but even so the debate still remains among hearing educators of the deaf and within the medical profession. The increasing number of deaf children receiving cochlear implants also raises new, complex issues concerning the choice of communication method and schooling for children with a hearing loss. The conflict is amplified and complicated by the fact that 90% of deaf children are born to hearing parents with little, or no, prior knowledge of deafness. The status of Sign Language is increasing in Western societies and Sign Language is indeed often accepted as the language for deaf people but for hearing parents the choice of communication method for their deaf child can still be very troublesome. The reason being that although hearing parents rarely possess expert knowledge of deafness or hearing-impairments, they are forced at an early stage to make difficult decisions concerning the linguistic, educational and cultural path of their deaf or hard-of-hearing child¹. Early habilita-

¹ This mainly concerns profoundly deaf or severely hearing-impaired children as parents of children with mild to moderate hearing losses are likely to choose spoken language communication and education in a school for hearing children.

tion² is therefore crucial and since every family has different child-rearing beliefs as well as expectations it is very important that the starting point for the early habilitation in each specific case is the individual family (Ritter-Brinton & Stewart, 1992).

Education can be considered the stronghold for all minorities, but even more so for deaf people (Lane, 1993, 107). The reason is that as most deaf children are born to hearing parents, the language and culture of the Deaf community cannot (with the exception of Deaf parents with Deaf children) be transmitted from generation to generation but rather in deaf schools or in the Deaf community. Deaf³ people are a linguistic minority with the national Sign Language as their primary language and Deaf culture as their own culture. Parents must recognise the need for every child to be linked to their own history, language and culture. Therefore, in addition to having to learn a new language, choosing Sign Language indicates that hearing parents need to accept that the Deaf child's primary language and cultural belonging will differ partly from their own. Even so, deaf children need two languages, a signed language and a national spoken language in order to develop and function in society (Rainò, 1995; Smith, 1996; Svartholm, 1994).

In today's Western society parents' general awareness of and involvement in their child's education is notable as the overall level of education among parents is higher than ever before. Parents are aware of different educational programmes and also demand high-standard education for their children. This naturally also holds true for hearing parents of deaf children. The controversy surrounding deaf education contributes in making the parents' educational choices complex and difficult. The majority of hearing parents are forced to undertake considerable responsibility for their children's education and are, often without any outside help or support, forced to make difficult rearrangements with respect to both work and residence (Calderon & Greenberg, 1993; Marschark, 1993).

In this work hearing parents reasoning in choosing language and educational placement for their deaf or hearing-impaired children is at focus. The parents included in this study belong to the Swedish-speaking minority in Finland and con-

² Early habilitation, or early intervention, is the provision of services for disabled children and their families. The purpose of habilitation is to lessen the effects of the child's condition and to help the child and the family in their daily life.

³ Many authors (e.g. Padden & Humphries, 1988) make a distinction in written English between the upper case "D" spelling of **Deaf** and lower case "d" spelling of **deaf**. *Deaf* indicates people who belong to the deaf cultural community, and *deaf* indicates a lack of hearing. Capitalizing the D is congruent with the capitalization (in English) of other groups of people. According to Preston (1994) the distinction is however "conceptually useful but practically unworkable". In this work the two terms are used in the same manner as in Preston (1994), i.e. the capitalized Deaf refers to "the more generalized group of persons who are culturally and usually functionally deaf: the Deaf community, the Deaf world, Deaf culture and the Deaf." Following Preston's (1994) model, the lower case spelling of deaf is used for individuals (deaf children, deaf mothers) with no indication of whether this person identifies him or herself as a Deaf community member and a Sign Language user.

sequently their deaf or hearing-impaired child belongs to a minority within a minority⁴. Deaf people belonging to a minority within a minority also have rights, both human rights and human linguistic rights and should naturally be given both the opportunity and room to participate fully in the society and culture (Östman, 2002). However, the conflicts and decisions that parents with deaf or hearing-impaired children encounter, as well as their struggle to ensure that their child receives adequate education, clearly show this is not always the case. The situation for many deaf and hearing-impaired children raises complicated issues concerning language, culture, identity and education. These are indeed issues any parent may encounter and thus reflect upon. By studying the minority population in question the significance of linguistic, cultural and educational values and beliefs in the upbringing of children are, however, amplified and clearly elucidated.

1.2 Purpose and outline of the study

The overall purpose of this work is first to explore what method of communication⁵ Finland-Swedish parents with a deaf or hearing-impaired child use and what factors were experienced to influence this choice. Secondly, the aim is to study the parents' way of reasoning when choosing educational placement for their child, and also to delineate what factors are decisive in their selection of educational placement. Thirdly, the aim is to study the parents' conceptions and experiences of the early habilitation for families with deaf or hearing-impaired children.

Regardless of communication method, hearing parents of deaf children encounter many challenges concerning their child's education. This study focuses on families living in a bilingual context: deaf children of Finland-Swedish parents. These children belong to a minority within a minority and the challenges these children encounter are (generally) even more complex than for deaf children whose parents speak the language of a majority. The specific problems and choices this particular group of parents encounters during their deaf child's early habilitation and education are analysed as educational research has paid limited attention to this particular group. Moreover, in addition to disclosing challenges typical for cultural minorities, an examination of a population like the one in this study may also be expected to clearly reveal critical aspects and dimensions of the topic of interest.

⁴ Hearing-impaired adults who do not use Sign Language report communication problems when interacting with the hearing society but do not consider themselves a linguistic and cultural minority in the same manner as Deaf people do (Takala, 1995).

⁵ In this work method of communication refers to the type of communication the parents use with their deaf/hearing-impaired child. That is, either (1) manual communication using a natural Sign Language or signed Swedish/Finnish or (2) oral communication using spoken Swedish and/or Finnish. See Section 3.2 for a description of different methods of communication used with deaf/hearing-impaired individuals.

The focus of attention is the experiences and conceptions, the lifeworlds (Bengtsson, 1998; 1999), of the parents and of particular interest is how the parents arrive at their decisions regarding choice of both communication method and educational placement for their deaf or hearing-impaired child. For this a hermeneutical phenomenological approach has been implemented since the concept of lifeworld grounded in the phenomenological and hermeneutical traditions provide a good theoretical framework for the study. The phenomenological ability to describe and elucidate a phenomenon and the hermeneutical ability to interpret the meaning of the phenomenon are well suited for the purpose of this study. These approaches allow me to enter the lifeworlds of the parents in terms of the experiences they express, and consequently gain a new and deepened understanding of their situation.

Nonetheless, in order to understand the complexity and range of the problems facing parents in the selection of both communication method and educational programme we need to have a closer look at several topics. These topics include parenting, culture and identity, cultural and historical perspectives on deafness, language and deafness as well as educational options for deaf children. Few studies on deaf children and their parents' choice of communication method deal with the complex issue of already living in a bilingual context and possibly introducing a third language (Sign Language) and culture (Deaf culture) in the family. Below is an outline of Chapters 2–9. Chapters 2–5 are based on a review of the literature and end with a short summary.

Chapter two, entitled *Cultural and historical perspectives on deafness*, provide a background on deafness and deaf education, from the history and controversy of deaf education to deaf culture and the topical issue of cochlear implants.

Chapter three, *Linguistic and cognitive perspectives on deafness*, begins with a brief overview of earlier research on language and deafness followed by an overview of different methods of communication used in communication between deaf and hearing people. Here, as throughout the literature review, focus is mainly on deaf and hearing-impaired children who use Sign Language as their primary language. This chapter then deals with different aspects of Sign Language such as linguistic use of space, fingerspelling and visual attention in Sign Language communication. Deaf children's linguistic environment, which can be very different from that of hearing children, is also discussed. This includes topics such as early parent-child interaction, the development of Sign Language, literacy and psychosocial development. The development of Sign Language is briefly discussed. As the acquisition of a spoken language (and the role of speech therapy and hear training) is not an objective of the present analysis, this topic is not addressed in this chapter. Finally, in order to give the reader an example of how Sign Language is used for cognitive processes a discussion on short-term memory processes in deaf people is included.

Chapter four, *Hearing parents with deaf children*, deals with the complex decisions hearing parents of deaf or hearing-impaired children encounter. The chapter deals with hearing parents of deaf children as the parents interviewed for this study are hearing. Also, the case of hearing parents of deaf children raises interesting questions on parenting because native language and cultural identity are not always passed on to the next generation in the manner we are accustomed to. In

this chapter topics of interest are language, culture and identity, parental awareness, educational decision-making⁶ and parenting a deaf child as well as hearing parents' communicational choices.

Early habilitation and deaf education in Finland is the title of **Chapter five**. Here, the focus is on the current situation in Finland concerning the status of the Finnish Sign Language and services provided for both deaf people and for families with deaf children. This is followed by an outline of the different educational options for deaf children, followed by a more specific outline of deaf education in Finland, including the different educational options available for deaf and hearing-impaired children from Finland-Swedish families.

The research problems are defined in **Chapter six** and the concept of lifeworld and the phenomenological as well as the hermeneutical traditions that provide the framework for this study are outlined in **Chapter seven**. Methodological considerations, choices and problems of this study, as well as the collection and the analysis of the data are also described.

In **Chapter eight** the results from the empirical study are presented. A discussion on the validity and reliability is also included in this chapter.

Chapter nine consists of a general discussion of the habilitation and education of deaf and hearing-impaired children relating to the results of this study.

⁶ In this work the term educational decision-making is used when discussing factors that the parents experienced as being relevant when choosing educational placement (inclusive education in a school for normally hearing children or deaf school in either Finland or Sweden) for their deaf/hearing-impaired child. However, a review of the literature on the psychology of decision-making is not the focus of this work. See Plous (1993); Beach (1997); Kahneman & Tversky (Eds.) (2000).

2 Cultural and Historical Perspectives on Deafness

2.1 Two perspectives on deafness

An impairment that causes a hearing loss can either be **conductive, sensorineural or combined/mixed** (Mäki-Torkko, 1998, 17). A **conductive** hearing-impairment indicates that the middle ear is impaired (Luotonen & Väyrynen, 2000). A **sensorineural hearing-impairment** involves the inner ear, auditory nerve or central auditory pathways (Mäki-Torkko, 1998, 17). If defects of both conductive and sensorineural types are present it is a **mixed or combined hearing-impairment** (Mäki-Torkko, 1998, 17). Hearing is measured by an audiological⁷ assessment that combines frequency (or pitch) measured in Hertz and loudness (or intensity) measured in decibels (Meadow, 1980). A normal conversation is approximately 60 dB; a whisper about 30 dB and a shout at close range is 80–90 dB. The results of an audiological assessment is called an audiogram but “the measurement of practical interest is the loss of pure tone receptivity in the better ear” (Marschark, 1993, 14). Hearing loss is usually classified according to the following different categories (Marschark, 1993; Heiling, 1993):

Hearing loss	Category	Ability to comprehend speech
0–25 dB	normal	minor difficulty hearing low speech
26–40 dB	mild	only difficulty hearing low speech
41–55 dB	moderate	often difficulty hearing normal speech
56–70 dB	moderately severe	often difficulty hearing loud speech
71–90 dB	severe	can usually only hear very loud speech
>91 dB	profound	cannot hear speech

The decibel-levels for each category do however vary slightly in different sources of information. The Finnish Parental Association of Deaf Children (Kuulovammaisten Lasten Vanhempien Liitto – Hörselskadade Barns Föräldraförbund r.y.) uses the term hearing-impaired as a common name for all hearing-impairments and for an individual child the term that best corresponds to his or her specific degree of hearing loss (Virpiranta-Salo, 2000). A **hearing-impaired child** can, with the use of hearing aids, learn language through listening (Virpiranta-Salo, 2000). For the hearing-impaired child it is very important to be able to see the face of the person who is talking, as lip-reading provides additional support. A **severely hearing-impaired child** can hear some sounds with hearing aids, but not enough to learn a spoken language easily (Virpiranta-Salo, 2000). The development of speech can be enhanced by the use of Sign Language, Signed Swedish (or Finnish) or Signs as support (Virpiranta-Salo, 2000). A **deaf child** cannot learn a

⁷ Audiology is the science of hearing, hearing-impairments as well as the assessment, treatment and habilitation of hearing-related disorders.

spoken language through hearing and the child's first and most important language is therefore Sign Language.

Deafness can be seen from two different perspectives; the medical view and the socio-cultural view (Lane, 1984; 1993; Padden & Humphries, 1988). The **medical view** emphasises the degree of the hearing loss and encourages the use of technical aids in order to stimulate the residual hearing and develop the child's spoken language. Although this perspective does not necessarily exclude the use of Sign Language it does view deafness as a medical problem that should be treated accordingly. It seems that focus here is more on the condition and how to best cure, or at least minimise, the hearing loss with less attention being paid to the individual.

According to the **socio-cultural view**, Deaf people who use Sign Language constitute a linguistic and cultural minority (Padden & Humphries, 1988). Following this view, defining who is Deaf is influenced not by hearing status but principally by the use of Sign Language as the first language (Söderfeldt, 1994a). The importance of the Deaf community and Deaf culture are the central components of this view. This perspective is fairly new within scientific research, the first notification of Deaf people as a cultural group can be found in the Dictionary of American Sign Language published in 1965 (Jokinen, 2000).

In literature, the term *deaf* is often used for individuals who cannot hear regardless of whether they belong to the Deaf community or not. The terms hearing-impaired and hard-of-hearing are used to mark the difference between profoundly deaf children and children with a hearing loss. Finally, as Schein and Golocovsky (1995, 43) propose, the perspective from which deafness is viewed influences the approach to the early habilitation and the attitudes towards deaf people in general. Generally the two perspectives also differ in opinions concerning education for deaf children: the medical perspective supports an oral educational programme whereas the socio-cultural perspective favours a deaf school using a signed language as the language of instruction.

Knowledge and awareness of the two approaches to deafness are essential for parents with deaf and hearing-impaired children. In order to understand completely both deafness and its consequences for the overall development of their deaf child parents need accurate and versatile information on the two perspectives on deafness and their respective view on communication, culture and education. One of the research questions for this study deals with the parents' experience of the early habilitation of their child and the information they received.

2.2 The history of deaf education

The history of the Deaf, their language and education is a history of oppression, disapproval and ignorance of deaf people's rights and needs, and, above all, of their language (Lane, 1984, 1993). Throughout history, deafness has been examined from a pathological perspective and the main goal among hearing educators has been to decrease the extent of the deafness, and through oral training make the deaf as hearing and speaking as possible (Heiling, 1993). Although the history of the Deaf constitutes an intriguing subject, a detailed survey is beyond the scope of

this work. See Lane, (1984) and Wallvik, (1997) for comprehensive and fascinating accounts. In order to understand the situation today, in particular the current problems and challenges of deaf education, the background is briefly outlined in this chapter.

The Spanish monk Pedro Ponce de León (1520–1584) is considered the first teacher of the deaf. Ponce taught deaf children from the Spanish upper class to read, write and speak (Wallvik, 1997). In the seventeenth century many doctors and teachers believed that deaf people could be educated, and in 1648 John Bulwer wrote the first English doctoral thesis about deaf education (Wallvik, 1997).

The eighteenth and nineteenth centuries and the oral movement

In the late eighteenth century, three schools for the deaf were, independently of each other, established in Edinburgh, Leipzig and Paris. The debate on deaf education that still persists originated in this period. On the one hand, there was Samuel Heincke (1727–1790), founder of the school in Leipzig, a firm believer in the oral method which forbids the use of gestures and signs (Wallvik, 1997) and also the oralist Thomas Braidwood (1715–1806) who established the school in Edinburgh (Lane, 1984). On the other hand, there was Abbé Charles-Michel de l'Épée (1712–1789), founder of the school in Paris, who believed in the use of signs in the education of the deaf, and who is considered to be the “father of the Deaf”. In 1774 de l'Épée was asked to teach two deaf sisters to read and write French, and fascinated as he was by the girls signing, he learned their language (Lane, 1980, 1984). In addition, he created methodical signs to be used when teaching the structure of French grammar. The French Sign Language had however developed long before de l'Épée met the deaf sisters and contrary to the myth among hearing people, de l'Épée is not the inventor of Sign Language (Lane, 1984). Lane (1984, 58–59) writes: “The language of the deaf is transmitted each time a deaf mother holds her baby to her breast and signs to it; no hearing person has anything to do with this.”

Later on, de l'Épée founded a school for the deaf, which counted a steadily increasing number of pupils (Lane, 1980). Examining the signs used by his pupils, de l'Épée was convinced that signs and gestures are deaf people's natural language (Lane, 1980). But the time was not ripe to consider Sign Language to have a grammar of its own. During de l'Épée's lifetime, many new deaf schools were founded and in 1815 Thomas Gallaudet (the teacher of a deaf girl in Hartford, USA) visited de l'Épée's school and asked an instructor named Laurent Clerc to help him organise a school for the deaf in the US (Lane, 1980). That same year a school was founded in Hartford (Lane, 1980). In the years to follow, the Deaf in the US had a thriving life, and from a mixture of Clerc's French Sign Language and the dialect used on Martha's Vineyard, USA (see Section 2.5) American Sign Language (ASL) was gradually formed. Gallaudet College, the only Deaf University in the world, was established in Washington, DC in 1864 (Lane, 1980).

In 1880 the blooming of the Deaf culture and language came to a sudden stop. Although the oral movement had made some progress earlier the 1880 Congress of Milan was the beginning of a new era for it, one led by Alexander Graham Bell (Lane, 1984; Wallvik, 1997). At the congress, hearing educators of the Deaf decided to ban the use of Sign. The only language of instruction was to be a spoken

language and children who used signs were to be punished (Lane (1984). The cultures and languages of Deaf communities were, for a long period of time greatly affected by the oral movement and have only fairly recently begun to prosper again. Lane (1984, 387) describes the impact of the Milan congress as follows:

The meeting was conceived and conducted as a brief rally by and for opponents of manual language. Setting aside the speeches of welcome and adieu, and the excursions and visits, we find that the Milan congress amounted to two dozen hours in which three or four oralists reassured the rest of the rightness of their actions in the face of troubling evidence to the contrary. Nevertheless, the meeting at Milan was the single most critical event in driving the languages of the deaf beneath the surface; it is the single most important cause – more important than hearing loss – of the limited educational achievement of today’s deaf men and women, eighty percent of whom in America, are engaged in manual or unskilled labor.

The philosophy behind the oral movement is that the use of signs inhibits the acquisition of spoken and written language. Consequently, children should be forbidden to use Sign. However, despite tremendous efforts and various teaching methods, oral education has not succeeded in helping deaf pupils to reach high achievement levels (Lane, 1993; Svartholm, 1994). According to Svartholm (1994), this only shows how speech and lip-reading are inappropriate for true and meaningful communication among deaf people (Svartholm, 1994). Also Petitto and Holowka (2002, 29) assert that “early simultaneous bilingual (and bicultural) language exposure does *not* cause language delay and confusion and is actually best for the developing child”. Moreover, one neglected area in oral schools is the need for child – child interaction; focus has instead traditionally been on hearing adult – deaf child communication (Wallvik, 1997).

Nevertheless, the oral movement gained a foothold and continued its progress. Deaf pupils were treated badly and despite ambitious goals, few pupils developed intelligible speech. The stories of deaf people growing up in the shadow of the strong oral movement are stories of oppression and negligence. Many deaf adults remember their school years as terrifying and humiliating. These experiences, combined with the fact that the hearing society has viewed deaf people and their (Sign) Language in an unfavourable way, have contributed to the negative attitudes many deaf people have of themselves and of their language (Burns, Matthews, & Nolan-Conroy, 2001).

The twentieth ad twenty-first centuries and awareness of Deafness

During the last decade or two, the awareness of deafness has grown and Sign Language has received more acknowledgements in the education of deaf children. The post-modern society’s general acceptance of multiplicity and the increased recognition and acknowledgement of different minorities (such as cultural, linguistic and sexual minorities) have also influenced the situation for Deaf people. Deaf communities now demand acceptance of their minority rights as well as better education for deaf children. Despite a more positive attitude towards Sign Lan-

guage and an increased knowledge of deafness, movements emphasising only oral communication for deaf and hard-of-hearing children still exist. One such movement is the auditory-verbal therapy that does not support the use of Sign Language (Schmid-Giovannini, 1998).

2.3 Historical background to deaf education in Finland

The first teacher of deaf children in Sweden-Finland was Abraham Argillander (1722–1800). In 1762, twelve years before de l'Épée was asked to teach the two deaf French sisters whilst still exploring the use of Sign in the communication with and education of deaf children, Argillander wrote an article on how to teach deaf people. The article was published in the Proceedings of the Royal Swedish Academy of Sciences in 1771 (Jossfolk, 2001). The article included a detailed description of how he – using both signs and written texts – strived to teach his, assumedly, one and only pupil Wolfgang Henrich Helsingius to read and write (Jossfolk, 2001). Step by step and using certain phonetic rules he taught his pupil the Swedish alphabet. Unfortunately Argillander did not continue his work within deaf education and it was to be nearly another hundred years before anything significant in the field of special education took place in Finland. The changes in special education were then brought on by influence from the Scandinavian countries, mainly from Sweden (Jossfolk, 2001, 69–71).

Carl-Oscar Malm and the establishment of deaf schools in Finland

The pioneer in deaf education in Finland was, without doubt, Carl-Oscar Malm (1826-1863). His deafness was diagnosed when his speech development was delayed (Wallvik, 1997). At the age of eight he was sent to Stockholm to be educated by J.G. Holz at the Manilla School.⁸ After six years of private education he transferred to the school's regular programme and was rumoured to be the best pupil the school had ever had (Wallvik, 1997). Although he began working as a teacher at the Manilla School, Malm wanted to return to Finland to teach deaf pupils (Pesonen, 1985). In 1846, at the age of twenty, he established the first school (Den privata dövstumskolan) for the deaf in Finland, a small private school in Borgå⁹ (Porvoo) in southern Finland (Wallvik, 1997). Deaf children from both Swedish and Finnish-speaking homes attended the school in which the so-called Manilla-method, i.e. signs, the handalphabet and written texts, were used as the medium of instruction (Jossfolk, 2001; Wallvik, 1997).

⁸ The Manilla School is now the largest Deaf school in Sweden with around 150 pupils. The school also has many teachers who are deaf.

⁹ The prescriptive rule about place names in Finland is always to use the Finnish names in English texts. However, since this study deals mainly with the Swedish-speaking population in Finland, I have chosen to use the Swedish place names, with the Finnish place name given in parenthesis.

In addition, Malm wanted to establish a state school for the deaf and was encouraged by his many prominent friends, among them J.L. Runeberg, the national poet of Finland (Wallvik, 1997). During the late 1850s progress was made and after many discussions on a suitable location for the school it was decided that Åbo (Turku) was the best location (Wallvik, 1997). In 1860 the school started operating with Carl Henrik Alopaeus as the principal and the curriculum followed that of the primary school with Sign as the language of instruction (Wallvik, 1997). Alopaeus emphasised that deaf children's communication needs to start at home with Sign Language (Wallvik, 1997).

Meanwhile the school in Borgå had temporarily closed down but it started operating again in 1859 and became a state school in 1863 (Wallvik, 1997). During the same period two other state schools for deaf children were established in Finland: in 1862 a school was founded in Kuopio and in 1863 the school in Peder-söre (Pietarsaari), a private school that had opened in 1861, became a state school (Wallvik, 1997). In addition, a private school (The Heffata School in Hvittis) opened in 1884 (Wallvik, 1997). This school was operated during a period of eleven years, gradually receiving increased governmental support, and was finally moved to Jyväskylä and become a state school (Wallvik, 1997). In addition a few small, private schools operated in other parts of Finland (Jossfolk, 2001).

Instruction in all schools was given in Sign Language, however, with much attention given to the teaching of reading and writing (Wallvik, 1997). In 1874 the Kuopio school started oral training, and in 1877 all deaf schools in Finland discussed whether to follow Kuopio (Wallvik, 1997). It was decided that oral training was to be implemented with the younger pupils, although older pupils were still entitled to education through the medium of Sign (Wallvik, 1997). The reason for the transition to a more oral mode was that pupils seemed to benefit from speech training (Wallvik, 1997). The fact that the oral movement started its progress both in Finland and elsewhere well before the Milan Congress in 1880 is seldom mentioned (Wallvik, 1997). In 1886 the first local deaf association in Finland was founded in Åbo (Edlund, 1999).

In a decree issued by the Emperor Alexander III in 1892, it was proclaimed that the education of the deaf and the blind in Finland was to be reorganised (Wallvik, 1997). This proclamation stipulated that the education was to be more oral, and that children from Swedish- and Finnish-speaking homes thereafter were to attend separate schools (Wallvik, 1997).

Finland's fifth state school for the Deaf was established in the city of St. Michel (Mikkeli) in Central Finland in 1893 (Jossfolk, 2001). In the beginning signs were used in this school but gradually oral communication dominated, and by 1943 the school used oral communication only (Wallvik, 1997).

Current developments in deaf education in Finland

In section 5.4 the current educational options for deaf children in Finland are presented. Here it will suffice to point out that Sign Language is again finding its way into the education of deaf children. An example of this is the 1992 report by the Finnish Association of the Deaf on the education of the deaf in which the following principles were put forward (Finlands Dövas Förbunds utbildningspolitiska pro-

gram, 1992). According to the principles there is, first, a need for a complete acceptance of deaf people as a linguistic and cultural minority. Second, the language of instruction has to be Finnish Sign Language (FinSL). Finnish Sign Language or Finland-Swedish Sign Language (FinSSL) should be taught as a primary language and Finnish or Swedish as a second language. Thirdly, there has to be large enough signing environments with deaf teachers and other deaf adults working in the schools in order to provide a normal linguistic context for deaf pupils (Finlands Dövas Förbunds utbildningspolitiska program, 1992).

Despite recent general improvements in deaf education and attitudinal changes towards Sign Language the educational situation for deaf children from Finland-Swedish homes is not satisfactory. First of all, the future for the Finland-Swedish Sign Language is bleak (Reuter, 2002). During Carl-Oscar Malm's lifetime the Finland-Swedish Sign Language prospered but following the subsequent period of oralism the language was disregarded and is currently one of Finland's smallest and least known minority languages with approximately 150 users (Hoyer, 2002). Secondly, the only deaf school for Finland-Swedish children was closed in 1993 and with that the stronghold for deaf children from Swedish-speaking families ceased to exist (Hoyer, 2002; in press).

2.4 The controversy of deaf education

Throughout history the education of deaf children has been surrounded by great controversy. The main issue has been whether an oral or manual language should be used in the communication and education of deaf children. (See Section 3.2 for a description of different methods used in communication with deaf people). This debate is still prevalent and arises whenever deaf education is discussed. Nearly all families with a deaf child will, at some point, encounter the oral-manual controversy (Sinkkonen, 1994, 15).

The oral method and the acquisition of a spoken language

Advocates of the oral method suggest that the use of signs inhibits the acquisition of spoken and written language (Lane, 1984; Svartholm, 1984), and also that it has a negative effect on the child's motivation for learning speech (Sinkkonen, 1994, 15). Proponents of this method also suggest that a deaf child dependent on Sign Language cannot be integrated in the hearing society as well as deaf children using oral communication (Sinkkonen, 1994, 15). In addition, parents naturally want their young child to live at home during the early school years and may therefore opt for the neighbourhood school.

As Swisher points out (1989, 239), acquisition of the spoken language (i.e. acquisition of both speech and the linguistic system) is probably the major educational challenge for deaf children. The ability to speak, read and write the language of the society greatly facilitates the life of a deaf person, but learning to speak requires much training and an educational programme specifically focusing on the production and perception of a spoken language (Geers & Moog, 1987, 84). To complicate matters further, not all deaf children can acquire good spoken language competence despite intense training. Predicting who will and who will not

do so, is not a simple task as many factors influence this acquisition (Geers & Moog, 1987). Among the factors considered to influence spoken language skills are residual hearing, family involvement and learning ability (Geers & Moog, 1989). The Spoken Language Predictor Index (SLP), developed to predict a young deaf child's potential for learning a spoken language, measures five factors: hearing competence, language competence, non-verbal intelligence, family support and speech communication attitude. The SLP index which can be used on children as young as three years of age can provide recommendations for which educational programmes is suitable for a deaf child. According to Geers and Moores (1987) children receiving high scores on the SLP index have great potential for learning a spoken language and can thus be placed in oral programmes. Children with low SLP scores benefit more from educational programmes using signed communication.

The difference of the linguistic background of deaf children, different school placements, and the difficulty predicting the most suitable educational programme for young deaf children are only some of the factors that contribute in making deaf education a complex and multifaceted issue (Geers & Moog, 1987; Swisher, 1989).

Educational programmes in Finland

In Finland the debate over which communication mode should be used with deaf and hearing-impaired children, whether oral or manual, presumably is accentuated by the fact that an oral educational programme, i.e. one focusing on speech production and speech perception, does not exist. The choice stands between inclusion¹⁰ in a school for normally hearing children and a deaf school (with varying degrees of the quantity and quality of Finnish Sign Language used). One can assume that this limited range of educational options *influence* parents' selection of communication mode for their deaf or hearing-impaired children. However, one cannot assume that this *facilitates* the selection of communication mode. Choosing oral communication does indeed mean that the child will receive his or her education in Swedish or Finnish but also that the child nearly always will be the only hearing-impaired or deaf child in the school. Consequently many hearing-impaired children experience difficulties in mainstream classrooms.

Bilingual education in Sweden

In Sweden the issue of the significance of Sign Language for deaf children's cognitive and psychosocial development is not an issue anymore (Ahlström, 2000). Swedish Sign Language is considered the main mode of communication for children born deaf or severely hearing-impaired (Kristina Svartholm, 1998 personal communication). The use of Sign Language in deaf school is not debatable any longer and bilingualism for deaf people is highly valued (Ahlström, 2000). The movement towards a more signing environment for deaf children started in the

¹⁰ In this work inclusion, inclusive education, integration and mainstreaming are used alternately.

1970s with parents of deaf children and the Deaf Associations working together (Inger Ahlgren, 1998, personal communication). First came the demand for Sign Language for deaf children; educational issues, such as bilingual education, were introduced later. Interestingly, the teachers of the deaf (mostly hearing) were the last ones to become convinced about the importance of Sign Language for deaf children (Inger Ahlgren, 1998, personal communication). Also in Denmark bilingual education is highly valued and bilingualism (Danish Sign Language and Danish) is the main goal in the education of deaf children (Mahshie, 1995).

Finally, in reviewing the literature on deaf children's development and educational achievement it is important to evaluate critically the test conditions as well as the cultural and historical setting under which the results have been obtained (Heiling, 1993). During the past twenty years the education for the deaf and the status of Sign Language (primarily in Sweden, Denmark, and the US) has improved. Although research within these fields has now rapidly increased, surprisingly few Sign Language studies were conducted until the last decades (Söderfeldt, 1994a). A majority of the research has been carried out on deaf people who received an oral education, and may, therefore, not always apply to today's signing and bilingual deaf children (Heiling, 1993).

2.5 Deaf culture

Deaf people have a rich cultural heritage with Sign Language as the life-giving and cohesive factor (Bragg, 2001; Padden & Humphries, 1988). Deaf culture is connected both to the history of deaf education and to the history of Sign Language. The language of Sign plays a major role in the Deaf community. The Deaf want to be seen as an ethnic minority with its own language, values, rules and traditions, and not as a disabled group. And when given the opportunity, both deaf and hearing people can participate in the community on equal terms (Groce, 1985). For more than two hundred years Martha's Vineyard had a high incidence of hereditary deafness, and the hearing community learned Sign Language early on. This bilingualism erased the language and cultural barrier between the deaf and the hearing (Groce, 1985). Deaf culture cannot be seen as completely distinct from the hearing culture, they coexist. Also, like Sign Language, Deaf culture is not universal. Deaf people from different countries often share the same experiences, values and traditions but the Deaf cultures of different countries are specific, i.e. there is the American Deaf culture (Lois, 2001; Preston, 1994), the Finnish Deaf culture, etc.

The Deaf community

Defining what "deaf" is and who is deaf can be a difficult task. The Deaf community is composed of members with varying degrees of hearing loss (Söderfeldt, 1994a). There do in fact exist individuals with a total loss of hearing who do not consider themselves part of the Deaf community. There are also signing, hearing individuals (hearing children of deaf parents, Sign Language interpreters, spouses or girl/boyfriends of Deaf people) who consider themselves part of the Deaf community. Hearing signing individuals, however, do not achieve the same position in

the community as Deaf children with Deaf signing parents (Jokinen, 2000). Membership in the Deaf community must be achieved through identification with the Deaf world, shared experiences of being deaf or hearing impaired and by participating in the Deaf community (Higgins, 1980). Thus, signing is necessary but not sufficient for membership in the Deaf community.

The core of the Deaf community consists of two groups of Deaf people; first the innermost group which consists of deaf people with deaf parents (5–10% of the members), and second, deaf people with hearing parents (90–95% of the members). In addition, hearing children of Deaf parents, or hearing siblings to Deaf individuals can also be part of the inner core within the Deaf community. In the US this particular group of people is called CODA – children of deaf adults.¹¹ As a common name for these three groups of members we can, in Finnish, also use the term “*viittomakieliset*”, users of Sign Language or Deaf (with the capitalised D, see footnote 1) (Malm & Östman, 2000). This term not only refers to a person who uses Sign Language, but also to a person who does not consider deafness as a disability but views deaf people as members of a linguistic-cultural group for whom Sign Language is the native or first language (Malm & Östman, 2000). The rules concerning membership in the Deaf community are fairly complicated. (For a more detailed analysis see Jokinen, 2000). Here it will suffice to say that the most important criteria for becoming a member of the Deaf community are the use of Sign Language and a positive attitude to Sign Language, deafness and the Deaf community (Jokinen, 2000, 79–88).

In many Sign Languages (including American Sign Language, Finnish Sign Language, Swedish Sign Language) there are two different signs for what hearing people call deaf. The first sign indicates a culturally Deaf person (a member of the Deaf community) with a fluent Sign Language, and the other sign indicates a deaf or hearing-impaired person who does not identify her/himself with the deaf culture even though the person’s Sign Language may be fluent. This distinction, which is very important among the Deaf, is not made in English, Finnish nor in Swedish, the reason probably being that hearing people only focus on the fact that the person cannot hear (Bergman, 1991). As was discussed in Section 2.1, the medical (or pathological) view on hearing-impairments and deafness does indeed define deafness as a lack of or reduced hearing, whereas the cultural (or socio-cultural) view values the use of Sign Language and participation in the Deaf community (Söderfeldt, 1994a).

Deafness is a complicated construct with widespread implications and the controversy of deafness as an issue of culture versus pathology is not limited to communication and education for deaf children. Wohar Torres (1995) analysed the

¹¹ Families consisting of Deaf parents and hearing children may come across other linguistic and educational challenges as compared to families with hearing parents with deaf children but this situation is not the focus of this work.

post-modern perspective on both deafness and therapy and describes the importance of mental health therapists to show linguistic and cultural sensitivity to Deaf clients. According to the Wohar Torres (a hearing Mental Health Therapist working with deaf or hearing-impaired individuals) (1995), applying a social constructionist approach to Deaf clients results in a more successful and collaborative therapy.

Attitudes among hearing people

Hearing people often view deafness as a disability that needs to be cured and throughout history hearing educators of the Deaf have tried to turn deaf children into hearing children. In fact, the history of Deaf people and their culture is a history of oppression and ignorance of Deaf people's rights and of Sign Language. Hearing people have attempted to control many aspects of deaf people's lives, for example through laws prohibiting deaf people from marrying each other, or from having children (Preston, 1994), or, as in Finland as late as 1991, from becoming qualified teachers (Sacks, 1990, 25). Deaf pupils have also been prohibited from using Sign Language at school. During the past decade Deaf awareness has grown and Deaf people in many countries are themselves working for better opportunities and for the recognition of Sign Language and Deaf culture (Anderson, 1994).

Hearing people's worry that deaf parents produce more deaf children is unjustified as the vast majority of deaf parents have hearing children (Preston, 1994). Many deaf parents want deaf children, a fact hearing people often react very strongly to (as is shown by the example in Section 4.2). However, after reflecting on issues like cultural identity many, but not all, hearing people do comprehend the deaf parents. For deaf parents a deaf child means a person who fundamentally is identical to themselves (Preston, 1994). This is eloquently expressed in the following quotation from Preston (1994, 17):

When Barbara was born, it wasn't until about three days later that I had this funny feeling about her. I started wondering if she was deaf or hearing... My first child. I kept wondering to myself. Is she deaf or is she hearing? I was holding her in my arms near the metal food tray. I picked up a spoon and dropped it on the tray. I couldn't believe it. I was really upset. I did it a second time because I just couldn't believe it. I dropped the spoon again, and it was the same thing. I even did it a third time. I thought, oh my God, she's hearing. What am I going to do? I have a hearing daughter! My husband came in and I said, My God, our daughter's hearing. He was just as surprised, but he told me it was fine, it was going to be okay. I'm the third generation deaf. There was no question but that we would have deaf children. Then I find out that my daughter was born hearing. What on earth am I going to do with her? I don't even know how to talk to her... It never occurred to me that my child would be hearing. I was really surprised. I was scared. I wanted to be close to my children. I've always been very close to my family, and I wanted the same for me and my children. The hearing world and the Deaf world are such separate worlds. I worried that we would never connect, or that we would drift apart.

The recognition of Sign Language and Deaf culture

Lucas (2001, 2–3) reports on three specific events having vast sociolinguistic value for the recognition of Sign Language and Deaf culture. First, the incidents at Gallaudet University in March 1988 are considered to have initiated the sociolinguistics of Sign Language (Lucas, 2001, 1–3). These events included the demand for a Deaf president (at Gallaudet University) and the recognition of Sign Language as a communication system used within the deaf community and as an indicator of identity for Deaf people.

The second event is the 1989 publication by Bob Johnson, Scott Liddell and Carol Erting at the Gallaudet Research Institute of the paper “Unlocking the curriculum” in which deaf education in the USA is meticulously analysed (Lucas, 2001, 2–3). According to the article deaf children fail to achieve at grade-level. Two main reasons for this are presented: first, due to language-related issues, instruction is not accessible to deaf children and secondly, due to values and attitudes among the educators, deaf children are expected to perform below grade level (Johnson, Liddell, & Erting, 1989).

The third event, that also took place in 1989, was the international conference Deaf Way that took place in Washington, DC and was attended by nearly 6,000 deaf people. Deaf Way was the first conference ever concentrating on the language, culture and history of Deaf people and has since been regarded as a sociolinguistic event empowering Deaf people from all over the world (Lucas, 2001, 3).

There are approximately 70 million Deaf people, of these 80% living in developing countries. The World Federation of the Deaf is an international, non-governmental central organisation of national associations of the Deaf (Mäkipää, 1989). The federation bases its work on the United Nations charter and works for the rights of deaf people all over the world. Deaf people in many countries face discrimination and the aim of the World Federation is to ensure that deaf people have the same human and social rights as other people (Proceedings, XI World Congress of the World Federation of the Deaf, 1991). The World Federation of the Deaf collaborates with many international organisations. The federation has a B-category status in the United Nations System and is represented in the Economic and Social Council, UNESCO, the International Labour Organisation, and in the World Health Organisation (Mäkipää, 1989). The World Federation of the Deaf was established in 1951 which makes it one of the oldest international organisations of disabled people (Mäkipää, 1989). In 1991 the World Congress of the Deaf was held in Finland.

Understanding deaf culture, its development and current situation is important when discussing the education and upbringing of deaf and hearing-impaired children. When choosing language and school for their deaf children hearing parents need to be informed of the richness of Deaf culture and of the importance for deaf children to interact with other deaf people and be aware of their own cultural heritage. Meanwhile, the development of new, advanced hearing devices such as the cochlear implant has sparked yet another discussion on the role of Deaf culture and Sign Language in the Deaf community.

2.6 Cochlear implants on prelingually deaf children

The cochlear implant

The issue of cochlear implants on deaf children is the most recent topic of great controversy among the Deaf community and the medical profession as well as among educators and parents of deaf children.

A hearing aid amplifies sound but the cochlear implant is a device that electrically and directly stimulates the auditory nerve fibres in the inner ear (cochlea) by detouring damaged inner ear structure (DELTA, 2003, www-document). The cochlear implant consists of both internal and external components. The internal components are surgically implanted under the skin. These include a bundle of twentytwo tiny electrode bands inserted into the cochlea (inner ear) (Stewart-Muirhead, 1998). The electrodes are connected to a receiver/stimulator, which is placed under the skin in the bone behind the ear. The external components include a speech processor worn on a belt or kept in a pocket, a transmitting coil held in place over the implanted receiver/stimulator by magnets, a microphone (resembling a hearing aid) worn behind the ear, and two wires that extend from the earpiece microphone to the transmitter coil and the speech processor (Söderfeldt, 1994b).

Like hearing aids, the cochlear implant allows the deaf or hearing-impaired individual to perceive sounds, but sounds produced through electrical stimulation of the cochlea differs from normal hearing (Stewart-Muirhead, 1998). The sound is transmitted to the speech processor and then converted into a special signal that then can be interpreted by the brain as sound information (Stewart-Muirhead, 1998). Auditory training and speech therapy are necessary for optimising the benefits of a cochlear implant.

As previously mentioned, cochlear implants on prelingually deaf children has led to yet another issue of great controversy and debate within the Deaf communities, Deaf Associations and audiologists^{12, 13}. In the US cochlear implants were approved in 1983 on deaf adults (Blume, 1997) and in 1990 on prelingually deaf children (Allen, Rawlings, & Remington, 1993). The first cochlear implants were performed in Finland in the early 1980s, and in 1998 about thirty children born deaf had received the implant (Jauhiainen, 1998). By August 2000 the number of children in Finland who had received the implant was sixty (Hasan, 2000). The number of deaf or severely hearing-impaired children receiving a cochlear implant is steadily increasing and today over 7,000 children with a congenital deaf-

¹² An audiologist is a physician specialised in medical audiology. Using audiometers and a range of other different tests an audiologist measures the nature and extent of an individual's hearing loss and coordinates the technical results with medical, educational, and psychological information to make a diagnosis and decide a course of treatment and rehabilitation (U.S. Department of Labor, www-document).

¹³ Here, only implants on children born deaf are discussed. It must be pointed out that the controversy surrounding the cochlear implant – and the Deaf communities' work against the implant – mostly concerns children born deaf as compared to deafened adults or post-lingually deaf children.

ness and altogether 10,000 individuals around the world have received a cochlear implant (Rahko, 1999).

It is not surprising that parents want their children to be part of their culture and to learn their language(s). The fact that a cochlear implant will make the deaf child hearing may therefore be difficult for many hearing parents to ignore (Vernon & Alles, 1994). A cochlear implant may be seen as a cure for the deafness as well as for the parents' own sorrow of having a deaf child (Vernon & Alles, 1994). Reports on how implanted deaf children have learned to hear and speak naturally amaze hearing people (e.g. Harjula, 1998). One must however remember that the beneficial effects of a cochlear implant on the speech and hearing ability depends on several different factors, such as the age of the onset of the hearing-loss and previous spoken language ability (Vernon & Alles, 1994; Hasan, 2000). Unfortunately this type of information seldom reaches the parents (Vernon & Alles, 1994). Consequently many authors underscore the necessity for both audiologists and audiological assistants¹⁴ as well as for other people working with parents (of deaf children) to give them up-to-date information on all aspects of cochlear implants (Malm, Mäkipää, & Wallvik, 1999; Vernon & Alles, 1994). For example, that before the operation it is not possible to give a reliable prognosis on the level of hearing that will be achieved (Hasan, 2000). The information needs to be diversified, enabling the parents to scrutinise the issue of cochlear implants and the consequences for the deaf child's cognitive and psychosocial development from all perspectives. Christiansen and Leigh (2002), for example, provide information relevant for parents considering a cochlear implant for their deaf or hearing-impaired child. It is also very important that children with a cochlear implant receive adequate therapy or training in order to optimise the benefit of the implant (Estabrooks, 1999; Hasan, 2000). Moreover, parents need to be aware of the fact that a child with an implant requires much time, effort and support from the parents.

Studies on the effects of cochlear implants

The need for objective information aimed at the parents is of vital importance since the benefits of an implant for children born deaf are, according to some authors, questionable and not yet scientifically well-documented (Lane, 1994; Malm *et al.*, 1999; Rose, Vernon, & Pool, 1996; British Deaf Association, 1994). One reason for the lack of scientific research is that due to the relatively short period of time during which implants have been performed on young children, few longitudinal studies on the long-term effects of cochlear implants on the children's speaking and hearing abilities have been conducted. Many studies do indicate that with an implant deaf children sense an acoustic perception of background sounds, but also that this does not necessarily mean that the children's ability to speak or hear other people's speech improves (Allen *et al.*, 1993; Preisler & Ahlström, 1994).

¹⁴ The definitions and educational background of professionals working in the field of audiology varies in different countries. In Finland an *audiological assistant* is called *hör-selvårdsassistent* and in Sweden *audionom*.

Furthermore, Rose *et al.*, (1996) emphasise the need for studies on cochlear implants conducted by researchers independent of those economically benefiting from performing the surgery, selling the implant or providing post-surgical rehabilitation. The same authors also point out that the failure rate of cochlear implants (as measured for instance by the percentage of children not wearing the device) needs to be carefully and independently examined before implants can be considered an option in the early habilitation of children born deaf. Moreover, few studies have taken into account the emotional, social and communication consequences for both the child and the family that continuous speech and hear training have (Preisler & Ahlström, 1994). A psychosocial study of deaf children with cochlear implants has been conducted in Sweden (Preisler, Tvingstedt, & Ahlström, 1999). The findings of the study suggest that an implanted child's emotional, linguistic and social development is largely dependent on the attitudes of the people in the child's immediate environment. According to the study, a positive development is supported by many factors. Among these factors are: the parents' confidence in having the child implanted, the fact that there existed a working communication between the child and other people prior to the surgery, that the child was not pressured to achieve, and, in particular, not pressured to develop speech (Preisler *et al.*, 1999).

Regardless of one's opinion of the cochlear implant, the numbers of both children and adults receiving the implant are increasing, and it is therefore in the best interest of the deaf child if the two approaches work together in the early habilitation. A child born deaf may benefit from a cochlear implant, and in one-to-one interaction may successfully use a spoken language, but in the classroom and group interaction Sign Language may be helpful. One must thus remember that the research discussed in the previous sections indicates that a signed language is the only language a deaf child can learn without formal instruction, and that the acquisition of a signed language does not hinder the acquisition of a spoken language. Although there are disagreements on some specific linguistic developmental issues, research results show that deaf children learning Sign as a first language follow the same linguistic developmental stages as do hearing children and that deaf children of signing parents receive as much and equally complex linguistic input as hearing children. Furthermore, since linguistic competence is largely determined by the early linguistic experience it is necessary to provide deaf children with a rich, complex, meaningful and fully accessible linguistic environment in early childhood as well as access to the Deaf community. A cochlear implant may improve the child's perception of sound but does not necessarily allow the prelingually deaf child to perceive and produce unconditionally a spoken language.

2.7 Summary

The language and culture of deaf people have been oppressed and many misconceptions about deafness, deaf people and Sign Language still prosper. Throughout history the education of deaf children has been disputed, the principal question being whether signed or oral communication should be used. The Frenchman Abbé

de l'Épée (1712–1789) had a great impact on the education of deaf children worldwide and in Finland Carl-Oscar Malm (1826–1863) was the pioneer of deaf education. Both de l'Épée and Malm advocated the use of Sign Language but following the 1880 Congress of Milan the prospering of Sign Language slowed down and deaf children were prohibited from using Sign Language in schools. The main goal with education for deaf children was to teach them to speak.

There are two perspectives on deafness. First, the medical perspective which focuses on the medical problems resulting from a hearing loss and emphasises technical hearing aids, speech therapy and spoken language. Second, the sociocultural approach, according to which Deaf people constitutes a linguistic (Sign Language) and cultural minority. During the past decades the status of Sign Language as well as awareness and recognition of Deaf culture and the rights of deaf people has increased.

The development of new and advanced technical aids surely has improved the quality of life for many hearing-impaired people but at the same time the technical development brings yet another source of ample conflict and controversy within the education, habilitation and culture of deaf people. The availability of the cochlear implant forces parents of deaf and hearing-impaired children to make a difficult decision early on that will affect the future linguistic, cultural and educational path of their child.

3 Linguistic and Cognitive Perspectives on Deafness

3.1 Earlier research

Earlier research on Deaf people's language ability has mainly focused on the comprehension of spoken and written language, and on comparisons of deaf children's results with the results of hearing children (Furth, 1973; Hakkarainen, 1989; Söderfeldt, 1994a). Researchers have been more interested in the so-called "language deficits" in deaf children (Svartholm, 1994) and have compared writing and reading skills between groups of deaf and hearing children (c.f. Hakkarainen, 1989). Hakkarainen concluded that the reading abilities of deaf fifteen-year-olds equal those of hearing seven-year olds. Other studies show similar results (c.f. Myklebust, 1964; Paul & Quigley, 1986). Studies from the Nordic countries on deaf children's reading ability are rare, mainly because extensive testing of schoolchildren is not at all so common in the Nordic countries as it is, for example, in Great Britain and the US (Heiling, 1993). Given that deaf children's primary language is a signed language, comparing hearing and deaf children on tasks measuring writing and reading skills is, however, biased. Hakkarainen (1989) states that deaf children do not have a well developed internalised language system onto which the written language may be structured. This conclusion is not compatible with more recent findings showing that deaf children learning Sign early in life go through the same language developmental stages as hearing children do (see Section 3.4.2), consequently developing an internalised language structure based on Sign Language (Petitto, 1995). When attempting to resolve why deaf children lag behind their hearing peers in reading and writing skills, the reason has often been attributed to the deaf children themselves, implying that deafness involves cognitive deficits that affect the acquisition of language (Svartholm, 1994, 61). Today it seems clear that deaf signing children who receive adequate education (i.e. with sign as the medium of instruction) are at age level regarding academic achievement (Svartholm, 1994). The main reason for the frequent comparisons of deaf and hearing children is most likely the fact that it was only recently that signed languages have been accepted as deaf people's native language and as the language of instruction for deaf children. Earlier, signed languages were considered as a form of communication insufficient for higher learning and thinking. Traditionally, deaf education was predominantly oral (Lane, 1994), in Finland and Sweden until the mid-1970s (Ahlgren, 1994), and in the US until the early 1970's (Wallvik, 1997). (The oral movement and its impact on deaf education and the deaf population are mentioned in Sections 2.2–2.4).

Many interesting studies on language proficiency and different aspects of cognitive functioning in deaf children have been conducted (Meadow, 1980). One difficult and demanding task when studying deaf children is finding children with similar background variables, such as linguistic input (Meadow, 1980). A misconception in early studies on cognitive performance of deaf children is the denial of Sign Language as a tool for higher cognitive functioning, and the denial that a Sign Language is the primary language for many deaf people and a spoken language the second language. Recent studies (c.f. Drasgow, 1998) and observations

made in Sweden (Svartholm, 1994) show that Sign Language competence influences positively both spoken language literacy and the academic achievement of deaf children. Sign Language thus allows its users to function cognitively and develop as well as their hearing peers.

3.2 Methods of communication

This study does not investigate the development or acquisition of language in deaf or hearing-impaired children but prior to a further discussion on the linguistic and educational challenges facing their families different methods that can be used in communication between deaf and hearing individuals need to be presented. Only by looking at different methods of communication can we begin to understand parental choices relating to communication and education for deaf or hearing-impaired children.

Spoken language

The development of speech is influenced by the level of residual hearing, the degree of hearing loss and the child's age at the onset of hearing loss (Evans, 1982; Swisher, 1989). For profoundly deaf children, acquisition of speech is very difficult, and few deaf children with severe congenital hearing loss achieve a level of speech that is easily comprehended by others (Evans, 1982). Hearing aids amplify sounds and thus allow hearing-impaired people to receive auditory information; unfortunately, the quality of the auditory information perceived is rarely comparable to that of normal hearing (Swisher, 1989).

Lip-reading

Linguistic input occurs as the deaf individual looks at the person who is talking and observes the movements of this person's lips and the tongue. This source of input is available to deaf people regardless of what other communication method is used (Swisher, 1989, 242). Lip-reading is both demanding (Sacks, 1990) and limited (Swisher, 1989). First, lip-reading requires constant attention to the person who is talking. Thus, comprehending discussions in larger social settings is strenuous (Swisher, 1989). Second, lip-reading can be very fragmented, some sounds are not visible on the lips and some sounds look exactly the same (Evans, 1982, 35; Swisher, 1989, 243). Not surprisingly, lip-reading skills correlate with better hearing and good language skills. Learning a language through lip-reading can be seen as more or less an impossible task for a child born deaf (Swisher, 1989).

A Signed Code for a Spoken Language

Another method of communication, devised by educators of the deaf, is to use a manual code for a spoken language (Swisher, 1989). In signed systems the signs of a natural Sign Language are used as glosses for the words of the spoken language, and the word order follows that of the spoken language (Evans, 1982, 73): the aim is to represent visually the spoken language (Swisher, 1989). This system is often used by deaf people in communication with hearing people since it is easier for hearing people to follow a signed communication if it is based on a

spoken language structure (Ahlgren, 1984; Evans, 1982). Hearing parents learning manual communication often use a signed code for a spoken language, for example Signed Swedish or Signed Finnish, in the beginning and then gradually convert to natural Sign Language.

Pidgin Sign Language

Pidgins are communication systems that develop when people with no common language interact. Pidgins can be considered simplified mixtures of the original languages as well as of features that do not exist in any of the original languages (Ann, 2001). Pidgins can thus not be classified as natural languages or anybody's native language. However, pidgins can become creolised when the next generation uses the language system and can then be classified as both a natural and native language (Ann, 2001). Pidgin Sign Languages evolve in the same manner as spoken pidgins.

Cued Speech

If residual hearing combined with lip-reading does not allow for a complete recognition of speech reception, a system named Cued Speech can be used. Cued Speech is a manual system intended to facilitate lip-reading by providing additional information on the hands (Evans, 1982, 40). The use of twelve handshapes provides the supplemented information. The combination of the handshapes and the shapes of the lips "provide a one-to-one correspondence with the phonemes of a spoken language" (Evans, 1982, 40).

Sign Language

Sign Language is discussed in more detail in Section 3.3. Here it will suffice to say that natural Sign Languages are systems of symbolic communication that fulfil the criteria of a genuine language (Poizner, Klima, & Bellugi, 1987; Sinkkonen, 1994). To some extent, however, signed languages also make use of gestures – a feature present in spoken languages as well (Volterra & Erting, 1994) – and a form of lip-reading where the person who is signing articulates certain words or sounds.

Fingerspelling

Fingerspelling is a language system that also can be used in communication with deaf people. Fingerspelling is, however, a fairly unnatural method of communication; it is rather one aspect of a natural Sign Language, namely the representation of the spoken language orthography (Padden, 1991). Fingerspelling is described in more detail in Section 3.3.2.

Total Communication

Total Communication is not viewed as a method but rather as a communication philosophy in which a combination of oral and manual elements are used in order to maximise the amount of linguistic input (Evans, 1982). Total Communication started as an educational movement and rapidly received much attention worldwide (Evans, 1982). Since natural Sign Languages and spoken languages do not share the syntax or the morphology, it is impossible simultaneously to speak a

grammatically correct verbal language and sign a natural Sign Language (Woodward & Allen, 1987). In Total Communication the word order frequently follows that of the spoken language (Kyle & Woll, 1985). Manual elements such as finger-spelling and signs are present in “to supplement the inadequacy of lip-reading” (Evans, 1982, 13).

The use of print

Deaf people can also receive linguistic input through written text. However, learning language solely from print is difficult as there are no naturally occurring conversations nor do the contextual “here and now” help to provide additional linguistic information (Swisher, 1989, 245). In addition, as reading is dependent on syntactic and semantic predictions as well as on experience-based schemata for reading which deaf children may not have, learning from print can be very difficult (Swisher, 1989, 245).

3.3 Sign Language

Traditionally, our knowledge of the human capacity for language came from studies on spoken languages, and it has been assumed that the organisational properties of language and the sounds of speech are inseparable (Poizner *et al.*, 1987). Research on Sign Language has altered this belief, and has contributed to our understanding of human language (Petitto, 1986). One important finding is that the critical period for language acquisition is modality-free and as decisive for native fluency in signed languages as in spoken languages (Mayberry, 1994). According to Jackendoff (2002, 97) everyone learning a signed language will achieve some competence but to achieve native fluency and proficiency one must be exposed to Sign Language from birth as competence may decline with age of first exposure. In addition research on brain organisation for Sign Language can contribute to our knowledge, not only on language processing but also on cerebral hemisphere specialisation, and on the brain’s ability to functional adaptability (Poizner *et al.*, 1987, 2). Another discovery is the incredible plasticity of the mind: in the absence of accessible language input deaf people create their own communication system in the same way as hearing people do. Research on deaf-blind people also shows this incredible plasticity and adaptability of the brain in its capability to convey meaning through touch only, that is, deaf-blind people receive language by touching the other person’s signing hands, face or body (Mensch, 1998).

Research on Sign Language

Signed languages are systems of symbolic communication, evolved over generations of Deaf people, which have been formed into natural languages independent of spoken languages (Poizner *et al.*, 1987, 1). Deaf communities in different countries use disparate sign languages and although there are universals in different sign languages there is no universal sign language (Markowicz, 1980). When deaf signing people with no common Sign Language interact, they rapidly develop a pidgin (Sacks, 1989). It has also been documented that deaf people who are not

exposed to a natural Sign Language develop a gestural system that does not show the properties of natural languages but that may have a very simple syntax and morphology (Goldin-Meadow & Feldman, 1977; Padden, 1989).

Counting the number of languages in the world is by no means easy and the figures vary from 5,000 to 10,000 (Woll, Sutton-Spence, & Elton, 2001) and also over 1,000 different Sign Languages (Östman, 2002). Although research on Sign Language and different aspects of deafness is fairly new, it is now expanding at a fast pace. In addition to being crucial for an improvement of the status of Sign Language and the rights of Deaf people, research on different aspects of deafness contributes to our understanding of both the nature of language, and the relationship between language and cognition. Comparisons between signed and spoken languages show that the fundamental processes in the visual and auditory mode are strikingly similar (Bellugi, 1991). That is, signed and spoken languages “have the same kind of organisational principles, the same kind of rule systems, and the same grammatical complexity and expressive power” (Bellugi, 1991, 12).

For a long period of time, language was considered to equal speech and everything we knew about human language came from studies on spoken languages (Klima & Bellugi, 1979). However, as has been pointed out by Linell (1982), there is a written language bias in linguistics, i.e. linguistic research has been dominated by studies of monological written language and linguists have, consciously or not, based their view of language on the prevailing norms for written language. Only within the last decades, perhaps partly due to the technical possibilities of making audio and video recordings of naturally occurring conversations are linguists beginning to develop an understanding of the fundamentally dialogical nature of language and the growing knowledge of the structure of spoken interaction.

Even so, traditionally linguists have defined the concept of language in terms of complex organisational properties inseparably linked to speech. Signed languages use the hands, the face and the body as articulators, not speech and the vocal tract as is done in spoken languages (Klima & Bellugi, 1979). Nevertheless, despite the differences in resources provided by the two forms of communication, signed languages have been demonstrated to be highly constrained, following general restrictions on structure, grammar and organisation comparable to those proposed for spoken languages (Klima & Bellugi, 1979).

There is no written form of signed languages, which to some extent complicates research on Sign Language. Signs presented in print are usually marked by using the letterform of the word in the respective spoken language with a capital letter, for example TABLE. A sign that requires a gloss of several words has those words connected by hyphens, for example GIVE-TO (Fischer & Siple, 1990). As Bellugi *et al.* (1975) note, there is no relationship between the form of the spelled word and the sign, i.e. a sign in ASL represents not an English word but a concept.

William C. Stokoe and Sign Language Structure

In the late 1950s, when William C. Stokoe, a linguist and teacher at the world's only university for the deaf, Gallaudet University in Washington DC, began his research on ASL, signed languages were not considered true languages by lin-

guists or educators (Wilbur, 1980). Signed languages were labelled iconic, concrete and primitive, resembling gesture and mime. Stokoe, however, believed that sign was more than a collection of iconic unrelated gestures. Stokoe's observations led to further studies and finally to the discovery that the manual communication of deaf people is in fact a language in the full linguistic sense of the word (Bouvet, 1990; Radetsky, 1994; Sandler, 1990). In 1960 Stokoe published *Sign Language Structure* in which he presented the groundbreaking paradigm that still influences today's research on signed languages. Stokoe (1993) named the Sign Language analogue of phonology in oral languages cherology, i.e. sign formation. Stokoe (1993) defined three parameters that were carried out simultaneously in the formation of a particular sign. These are the handshape (dez), location (tab) and movement (sig) of the sign (Stokoe, 1993). Further studies of ASL have shown that the phonology of ASL consists of four basic articulatory parameters (Drasgow, 1998, 331):

1. Hand configuration, i.e. the shape of each hand. In ASL there are 40 distinct handshapes.
2. Place of articulation, i.e. the signing space or the allowable area on the signer's body in which signs can be produced.
3. Orientation of the articulator(s), i.e. the orientation of the hand(s) in relation to the body. In ASL there are approximately 10 distinct orientations.
4. Movement, i.e. the motion of the hands within the signing space.

The emerging research on Sign Language has also acknowledged that sign languages has a highly articulated grammar and that Sign is as complex and expressive as spoken languages (Poizner *et al.*, 1987). Today new technology allows for more sophisticated studies on Sign Language and on authentic conversations in Sign Language. However, the accumulated information about signed languages and manual communication cannot be compared to our broad knowledge of verbal languages (Söderfeldt, 1994a). It has been documented that American Sign Language (ASL) is organised in a twofold fashion; first, sign-internally and secondly, sign-externally. The sign-internal organisation corresponds to the phonological level in spoken languages whereas the sign-external organisation (the connections of signs) corresponds to the grammatical level in spoken languages (Poizner *et al.*, 1987, 3). Many signs that initially may seem simple or iconic are actually complex structures made of an indefinite number of three-dimensional spatial patterns (Klima & Bellugi, 1979). Nevertheless, as in spoken languages (Peirce, 1932; Haiman, 1980) some iconicity is present in signed languages as well (Klima & Bellugi, 1979), in fact, some signs are so iconic that a non-signer can understand their meaning (Bellugi, Klima, & Siple, 1975). Even so, contrary to popular beliefs, this iconicity does not facilitate the acquisition of a signed language (Haukioja, 1991; Meier & Willerman, 1995).

In addition to showing that American Sign Language is a natural language with a grammar different from English, the breakthrough research of Bellugi and her colleagues at the Salk Institute in San Diego on the neurolinguistics of sign language shows that ASL, like spoken languages, is predominantly processed in the left hemisphere of the brain, thus supporting the view that spoken and signed languages involve the same neural mechanisms (Poizner *et al.*, 1987). The study of Sign Language offers a new perspective and the possibility for a broader understanding of the underlying principles of language (Emmorey, 2002; Radetsky, 1994).

3.3.1 Linguistic use of space in signed languages

One feature that distinguishes signed languages from spoken languages is the unique role of space. Visual-spatial information, like gestures, which is typically used for non-linguistic functions in spoken languages is used for linguistic purposes in signed languages (Petitto & Bellugi, 1988). That is, space is physically used for representation (Padden, 1990). In ASL, and presumably in all other natural sign languages as well, linguistic information is organised in layers. This information is simultaneous, concurrent and multileveled and this dimensionality is not evident in spoken languages where information is transmitted linearly, sequentially, and temporally (Bellugi, 1991; Petitto & Bellugi, 1988). This difference is clearly due to the two different modalities: the visual-gestural mode enables a multi-layered structure whereas the oral/aural mode does not (Petitto & Bellugi, 1988). In addition, in signed languages facial expressions and other parts of the body convey linguistic information. For instance, facial expressions can mark syntactic structures such as topics, relative clauses and questions, or function as adverbs or quantifiers (Klima & Bellugi, 1979). This flexibility provides ASL with a great number of possible inflections, both spatial and kinetic, that can modify the root sign (Petitto & Bellugi, 1988). The linguistic use of space in signed languages is extremely diverse and therefore difficult for a non-signer to observe (Petitto & Bellugi, 1988).

Moreover, verb agreement is marked through the use of spatial position in the signing space, and discourse topics can be distinguished from each other by the place where the signs are articulated (Padden, 1990). Modifications of space can provide grammatical information such as person, number and temporal aspects (Petitto & Bellugi, 1988).

The spatial modifications of the language structures are what initially make Sign Language seem so different from spoken languages. Paradoxically, the use of space for linguistic purposes is the reason both for the non-acceptance of signed languages as natural languages and a defining characteristic of the unique grammar that makes Sign a natural language (Sacks, 1989). An in-depth description of the linguistics of Sign Language is beyond the scope and purpose of this work. For overview descriptions, see for example Fischer & Siple (Eds., 1990); Malm, (2000); Pimiä & Rissanen (1987); Rissanen (1985) and *Se vårt språk! Näe kieleemme* (2002).

3.3.2 Fingerspelling

Fingerspelling is a language system, although not an independent one (Padden, 1991). Fingerspelling is only one aspect of a Sign Language, namely the representation of English orthography (Padden, 1991; Sutton-Spence & Woll, 1993). ASL and fingerspelling frequently complement each other but it is nevertheless essential to distinguish between the two systems. As opposed to the signs in a Sign Language, which have developed naturally within the Deaf community, the manual alphabet was developed by hearing educators (Sutton-Spence & Woll, 1993).

Fingerspelled signs are articulated in a distinct area in front and on one side of the body primarily used for this purpose. In fingerspelling one hand configuration corresponds to one letter in the alphabet (Padden, 1990, 191). One major function of the manual alphabet is to spell the names of people and places; in addition fingerspelling may be used when the receiver is not familiar with a sign translation (Sutton-Spence & Woll, 1993).

The role of fingerspelling is complex and not strictly defined. Its use varies with, for example, the age of the signer, the regional dialect, educational background and the extent to which voice accompanies signing (Sutton-Spence & Woll, 1993). The same authors point out that although mouth patterns accompany fingerspelling they vary depending on the context.

The extent to which fingerspelling is used also varies among different signing communities. It is used in most signing communities but more widely in North America than in many other countries (Padden, 1991). Fingerspelling is also an important factor in the reading process. When encountering an unknown word deaf children often stop and fingerspell that particular word (Neuroth-Gimbrone, 1994). Hirsh-Pasek (1987, 445) has shown that a native signer “can decode or recode print, through translation of print into English phonemes via the manual alphabet”, particularly when reading unfamiliar words.

Developmental studies show that young deaf children use fingerspelling that appears to be English fingerspelling but in fact is not a representation of written English (Sutton-Spence & Woll, 1993). Children learning Sign Language often attempt to fingerspell before they learn to read, and signers with no knowledge of written English are still able to use fingerspelling (Padden, 1991; Sutton-Spence, 1993). The earliest attempts to fingerspell by young deaf children is usually to spell the child’s own name, and studies show that deaf children successfully do this at the average age of 3 years, 11 months (Padden, 1991).

Even young deaf children reflect on the difference between signing and fingerspelling. In her discussion on the acquisition of fingerspelling by deaf children, Padden (1991, 210) concludes that deaf children, as do hearing children, have a conception of the connection between fingerspelling and other language systems. In hearing children this connection is, however, based on speech but in deaf children the connection seems to be dominantly orthographically based. The acquisition of language, according to Padden (1991), thus appears to go beyond learning only the primary language. It also involves acquiring the interaction between the primary language and other surrounding languages.

3.3.3 Visual attention in Sign Language communication

Regardless of language modality and culture, a child has to learn the appropriate eye contact behaviour of that particular modality and culture. Rutter and Durkin (1987) view this acquisition as one of the major achievements of communication skills with consequences for the child's overall social development. D'odorico and Levorato (1994) state that mutual visual attention is the first opportunity for the mother and infant to communicate. The pattern in spoken language communication is to direct the eye-gaze away from the listener at the beginning of an utterance, and then back at the listener at the end of the utterance (Rutter & Durkin, 1987). The authors point out that although there are individual differences the pattern of eye-gaze signalling is acquired by eighteen months of age in hearing children (Rutter and Durkin, 1987).

Parental speech and the early social context influence the child's language acquisition (Harris, Clibbens, Chasin, & Tibbits, 1989; Hoff-Ginsberg, 1986). Maternal speech frequently relates to the objects and actions in the environment that the child is attending to (Harris *et al.*, 1989). This joint attention, as well as the linguistic and non-linguistic social routines that develop between parent and infant, facilitate the child's understanding of the connection between language, objects and actions (Harris *et al.*, 1989; Tomasello & Farrar, 1986). In other words, the parent is scaffolding the child's acquisition of language (Ninio & Bruner, 1978). How this scaffolding takes place is, however, not yet fully understood. As Hoff-Ginsberg (1986) points out, there is no simple, exact explanation of how maternal speech influences the child's language acquisition; one explanation is that the mother gives the child linguistic input that exemplifies and clarifies consistencies in the language. Furthermore, Hoff-Ginsberg (1986) suggests that maternal speech encourage a language that, in fact, is more sophisticated than the child's linguistic level. According to Tomasello and Farrar (1986, 1454) the mother's and child's joint attention provides the child with a "predictable referential context" which gives meaning to the linguistic input the child receives. In line with this, the results of many studies (c.f. Barnes, Gutfreund, Satterly, & Wells, 1983; Rocissano & Yatchmink, 1984) indicate that maternal responsiveness to the child's attention and behaviour is positively associated with the child's language acquisition, including vocabulary size.

Visual awareness in deaf signing individuals

In spoken communication visual attention to the speaker is not required, and during conversation, hearing people can focus on objects in the environment. However, effective communication in signed languages demands consistent visual attention to the signer, a signed message cannot be received – in the same way a spoken message can be "overheard" – if the receiver is not watching the signer (Baker, 1977). An obvious consequence is that hearing people are not as consistent in their visual behaviour as are deaf people who are accustomed to visual communication (Swisher, 1992). The fact that deaf people receive both language input and information about people and objects in the environment through the visual channel greatly influences conversational turn-taking and joint attention (Swisher, 1992)

as well as the use of attention-getting methods (Baker, 1977). For example, eye-gaze behaviour is very different in hearing and Deaf cultures. This different use of conversation regulators often tends to cause problems in deaf-hearing interactions (Baker, 1977). Hearing people view the deaf person's eye-gaze as inappropriate, whereas deaf people view the hearing person's eye-gaze behaviour as hostile.

Joint attentional focus is a determining factor for effective communication in signed languages as well as in spoken languages. The attentional requirements for children learning signed languages are, however, quite different from those for hearing children learning a spoken language (Harris *et al.*, 1989). In fact, visual attention to the parents (or carers), and appropriate visual turn-taking behaviour are prerequisites for the development of communication skills in a deaf infant, and since it is unlikely that such visual attention behaviour is innate, the deaf child has to learn this particular skill (Swisher, 1991a; 1992).

Conversational turn-taking in ASL (and in other natural signed languages) is different from that of English (spoken languages). Nevertheless, ASL turn-taking is as systematically organised and equally complex as it is in other languages and cultures (Baker, 1977). Preliminary findings suggest that although signed languages have certain constraints and resources that are different from spoken languages, signed languages cannot be considered qualitatively different from spoken languages (McIlvenny, 1991). Swisher (1992) points out that the question of when and how young deaf children learn the pattern of visual turn-taking is very important because this ability has an impact on the deaf child's ability to receive language and information about the environment. As Swisher furthermore states, this ability clearly influences the accessibility of classroom instruction for the deaf child.

Swisher (1992, 93) proposes two significant developmental milestones that shape the evolution of young children's visual awareness and build up the intricate system making visual interaction possible: the child's increasing curiosity in objects at about 4–5 months, and the development of mobility. Again, hearing children can look at an object and simultaneously receive language input, but deaf children must learn to process sequentially both types of information, that is, learn to divide their vision between language input and observation of the environment (Swisher, 1992). To facilitate language input, parents may constantly ensure that the child visually attends to their signing, but this procedure does not provide for a good model of the conversational turn-taking present in adult discourse (Swisher, 1992). Moreover, as Swisher (1992) notes, this procedure is insufficient as soon as the child learns to crawl or walk. Hearing parents not accustomed to manual communication are surprisingly successful in helping the deaf child to discover the physical world, but not equally successful in directing the child's attention to the social environment and to the social partner who provides important linguistic input (Koester, Karkowski, & Traci, 1998, 6).

Peripheral vision in deaf individuals

Thus, the need for visual consistency and visual attention is crucial for Deaf people, and very different from the visual behaviour of hearing people. The use of peripheral vision is also different in these two groups (Swisher, 1993).

As Swisher (1991a) points out, the question of peripheral vision in deaf people primarily has communicational implications in general, and as communication is used in education it indirectly has implications for instruction and teaching methods. If it is possible to receive signed information without having to have direct face-to-face contact with the signer, more input can simultaneously be perceived, which in turn may influence the acquisition of English or another language (Swisher, 1991a). Moreover, deaf children may more easily than hearing children be disturbed by visual information in the peripheral visual field. The author also argues that if deaf children have superior peripheral vision this needs to be considered in the classroom, for example, during visual presentations or the placement of assistants or interpreters (Swisher, 1991b). The issue of deaf children's ability to perceive information presented in the peripheral visual field is something inexperienced hearing teachers of deaf children may be unaware of.

3.4 Deaf children's linguistic environment

Bearing in mind the large diversity of deaf children's early linguistic environment, it is difficult to give a uniformly valid description of deaf children's acquisition of a first language. Nonetheless, two separate groups can be distinguished – deaf children with deaf signing parents and deaf children with hearing parents – although it must be stressed that the diversity within these two groups may be as large as between the two groups. Many factors, such as the child's cognitive and social skills, directly or indirectly influence language learning (Marschark, 1993). For a deaf child growing up in a hearing family, the onset and consistency of signed communication are crucial for the acquisition of, and competence in Sign Language. Equally important in determining the success of Sign Language acquisition are the surrounding attitudes to, and the social approval of Sign Language. As will be discussed in the following section, the early linguistic environment – which is significant for the development of language in all children – takes a new form when the deaf child has no biological prerequisites to perceive the language(s) spoken in its environment. Some hearing parents of deaf children choose oral communication which according to many theorists may be unfortunate for the deaf child in that early language experience becomes limited (Marschark, 1993).

3.4.1 Early parent – child interaction

Parent-child interaction influences the child's cognitive development and parent-child interaction also has far-reaching implications for the child in becoming a member of a "particular culture at a particular historical moment and in a particular physical environment" (Meadows, 1996, 35). If, however, the parent-child interaction is troublesome it may affect the child's early cognitive development.

Hearing parent – deaf child interaction

For the majority of deaf children the only language that is fully accessible to them is not their parents' native language and this difference in communication modality may initially lead to difficulties in early parent-child interaction. Hearing par-

ents seldom know what it means to be deaf, or how to communicate with their deaf infant. There is, in fact, evidence that hearing parents experience difficulty in organising their signed communication when the child needs to divide his or her visual attention between language input and the focus of conversation, such as a book or a toy (Swisher & Christie, 1989). For example, mothers may point to a picture in a book and immediately begin signing about it, as if the child could look at two things at the same time. Early visual attention and infants' responses to visual and vibratory stimulation do, in fact, frequently constitute an obstacle to an early detection of a hearing-impairment (Wedell-Monnig & Lumley, 1980).

It is thus obvious that hearing parents who choose to sign with their deaf children face two difficult tasks. First, the parents have to learn Sign Language; learning a new language in adulthood is a difficult task in itself. Ideally they should do this in a very short period of time in order to give the child a rich linguistic input early in life. Second, the parents need to learn the communicational rules in signed languages, not least how to attend to the child's visual attention. Furthermore they have to teach the child the rules of visual turn-taking, rules they may not even be aware of themselves (Swisher, 1992). Hearing parents and hearing teachers do indeed experience difficulty in getting the child's attention before starting to sign (Swisher & Christie, 1989). Also, hearing mothers spend much more time than deaf mothers getting the attention of the child (Gregory & Barlow, 1989). In short, it is by no means an easy task to change an internalised communication mode, i.e. switching from an oral mode to a visual mode. Hearing parents need guidance and help in becoming aware of the need among deaf children for visual attention, and how their own behaviour may facilitate or hinder communication (Koester et al., 1998; Swisher & Christie, 1989). This applies to all deaf children because regardless of communication mode, deaf children depend heavily on the visual modality (Koester *et al.*, 1998).

Maternal responsiveness tends to be limited in dyads with a hearing mother and a hearing-impaired child (Meadow, Greenberg, Erting, & Carmichael, 1981; Spencer, Bodner-Johnson, & Gutfreund, 1992). A lack of maternal responsiveness has been linked to social-emotional problems in hearing-impaired children (White & White, 1984). Further, in Tomasello and Todd's (1983) study, the mother's directiveness, that is, her verbal or non-verbal attempts to control the child's attention or behaviour, was found to be negatively associated to the proportion of object labels in the child's vocabulary. The authors suggest that adult directiveness complicate the child's ability to establish joint attentional interaction.

Ahlström (2000) conducted a study on the communicative and social development of hard-of-hearing children and her findings show that although many factors influence the development of communication skills in hearing-impaired children the use of a completely accessible language is significant. Also important are the attitudes towards play among the adults in the child's environment (Ahlström, 2000).

Attentional and communicative strategies used by deaf parents

Observations of deaf adults, accustomed to the requirements of manual communication, in particular observing how they interact with their children, can therefore

provide crucial information about how to make sure deaf children receive linguistic input and how to avoid breakdowns in communication (Swisher, 1991b). Several studies have examined this phenomenon. These studies do indeed reveal that deaf mothers develop attentional and communicational strategies that meet the needs of a deaf child (Harris *et al.*, 1989; Maestas y Moores, 1980; Spencer *et al.*, 1992; Swisher, 1992; Van Den Bogaerde, 1994). One observation from Maestas y Moores' (1980) study is that all deaf mothers used affective and cognitive components in their communication with their infants, although individual differences were documented. Analogous communicational strategies are present in the interaction between hearing mothers and hearing children (Maestas y Moores, 1980; Launer, 1982). Maestas y Moores (1980) reports seven characteristics of parental strategy, for example the use of different sensory channels, "baby-talk" in sign, the use of space to facilitate communication and the use of objects in the environment in a linguistic sense. Harris *et al.* (1989) report similar strategies to the ones presented by Maestas y Moores (1980), but categorise the different strategies as follows: (1) the mother signs within the child's pre-existing focus of attention; and (2) the mother manipulates the child's focus of attention. Strategies of the first type include signed remarks that are "produced at different spatial locations, depending on the physical features of both the sign and of its non-verbal context" (Harris *et al.*, 1989, 88). The spatial location of the signs were occasionally altered, for instance by signing directly on the child's body, or in the child's signing space instead of in the mother's signing space which would be the normal procedure (Harris *et al.*, 1989). This behaviour was common when the mother was reading to the child sitting in her lap. The mother reaches around the child in order for the child to perceive both the sign and the book or object (Harris *et al.*, 1989). Launer (1982) has reported observations similar to these results. She observed that deaf mothers sometimes signed directly on the object at focus in order to facilitate the child's comprehension of the connection between the sign and the object.

In the classification made by Harris and her colleagues (1989), the second main strategy employed by the deaf mothers was to manipulate the child's focus of attention in order to make her signing as well as the context accessible to the child. Typically, the mother would relocate an object so the child could watch both the signed utterances and the object. The mothers were also found either to tap or move the child in order to make both the sign and its non-verbal context salient for the child. Harris *et al.*'s (1989) analysis shows that, although individual differences existed, all four deaf mothers included in the study preferred to sign within the child's pre-existing focus of attention, that is, the mothers rarely tried to control the child's focus of attention.

Observations made by Launer's (1982) and Erting, Prezioso, and O'Grady Hynes' (1990) of motherese in American Sign Language suggest similar findings. Launer (1982) observed how a deaf mother would sometimes move or hold the child's hand in order to form a particular sign. Launer (1982, 3) writes that mothers often signed first on their own body, then on the child's body in order to clarify the sign. This type of direct manipulation is not available in spoken languages, but in signed languages it allows the mother to facilitate both the child's kinaesthetic and visual awareness of language.

These findings thus suggest that deafness, in itself, does not hinder the acquisition of early language, or affect the quality of early social interactions. Knowledge about the visual and social interaction between deaf parents and their children may encourage hearing parents of deaf children to learn more about communicational strategies that have proven to be effective in visual communication. The establishment of joint attention between a mother and her deaf child, and the deaf child's acquisition of visual turn-taking behaviour also has long-lasting effects. As has previously been mentioned, the educational system (in many countries) seems to fail deaf children as hearing peers frequently outperform deaf children on academic tasks. The poor performance of deaf children tends to be explained by the lack of a solid language base on to which they could build content learning. Early social interactions in which the deaf child can learn language and the appropriate linguistic behaviour as well as facilitate cognitive development are thus crucial. For designing successful teaching methods for deaf pupils, and for understanding other perspectives on deafness, knowledge about both cognitive development and deafness *per se* is undoubtedly of great value.

However, for an understanding of all the nuances involved in the acquisition of language in a culture that is seldom passed down from one generation to the next, but from deaf adults to deaf children in schools or in other interactive settings, it may prove insufficient to apply exclusively cognitive theories. For example, situated learning, the model of apprenticeship proposed by Rogoff (1990), can provide a new way of studying deaf mothers in interaction, and consequently of learning from deaf mothers. Also Erting et al. (1990, 106) emphasise that the cultural knowledge of visual-gestural communication deaf mothers have enables their deaf infants to acquire the underlying principles required for further language socialisation early on. The sociocultural tradition (e.g. Säljö, 2000) should not however be limited to studies on the linguistic interaction of deaf mothers. Bonkowski, Gavelek, and Akamatsu (1991) maintain that Vygotsky's sociohistorical theory can provide powerful and profound insights to our understanding of the cognitive development in deaf children both with or without access to a rich and early language environment. Applying a vygotskian approach not only delineates cognitive difficulties among deaf children but can also empower parents and teachers interacting with deaf children, which, in the end, also strengthens the deaf child (Bonkowski *et al.*, 1991).

3.4.2 The development of Sign Language

The acquisition of language is a very complex phenomenon and many theories on language learning exist but as the purpose of this work is not to investigate the development of language in deaf children an overview of this topic is not included. Nevertheless, in order to understand the linguistic situation for deaf children some aspects of the development of Sign Language are discussed in this section.

Studies on Sign Language and on the development of language in deaf children provide evidence that deaf children exposed to a signed language acquire it in much the same way as hearing children learn the language(s) spoken in their environment (Bonvillian & Folven, 1993; Drasgow, 1998; Hoffmeister & Wilbur, 1980;

Meier, 1991). Also, studies on language acquisition in deaf children offer a new way of investigating the critical period for language acquisition. The timing of linguistic input greatly influences the native fluency of a language (Lenneberg, 1967; Volterra & Erting, 1994). Needless to say, studies on how a limited or a complete absence of language input affects language acquisition cannot be conducted. However, as Mayberry and Eichen (1991), Mayberry (1994), and Volterra and Erting (1994) point out, studies of deaf children learning Sign Language at different ages offer insights into several aspects of language acquisition. These include language acquisition with little or no adult linguistic input and the link between early exposure and language development.

Regardless of modality, language development follows similar patterns. For example, according to several studies, deaf children babble manually before they produce true lexical signs (Maestas y Moores, 1980; Petitto, 1995)¹⁵. At the age of approximately twelve months both deaf and hearing children are at the one-word/sign stage, and between 18–24 months, both groups of children enter the two-word/sign stage (Bonvillian & Folven, 1993; Meier, 1991). As Meier (1991) points out, although additional comparisons between the acquisition of ASL and English is troublesome due to the differences between these two languages, deaf and hearing children achieve corresponding linguistic developmental stages at approximately the same ages. However, one issue of disagreement concerns babbling in the manual mode; according to Inger Ahlgren (personal communication, April 3, 1998) it is extremely difficult to determine whether deaf children's early gestures are linguistic. For a more detailed discussion on gestures in deaf and hearing children see Volterra and Erting (1994).

The use of gestures in signed languages

Pointing at locations and objects in the environment are important features in signed languages and the emergence and role of gestures in signed languages are intriguing and offers new insights into prelingual communication for both manual and oral communication (Volterra & Erting, 1994). Another interesting feature showing the similarity between the development of spoken and signed languages is that both hearing and deaf children go through a transition from a gestural to a linguistic system (Petitto, 1986; 1994). This transition is perhaps best shown by the acquisition of pronouns. In spoken languages, deixis can be thought of as a verbal surrogate for pointing but in signed languages deixis (pointing to a location in space) is pointing (Marschark, 1993). Pointing gestures used in spoken languages as non-verbal supplements are similar, if not identical, to the pronominal signs in ASL (Pizzuto, 1994). Given the transparency of the pointing gestures, it seems natural that deaf children would easily learn the personal pronouns, yet some stud-

¹⁵ Although this pattern of Sign Language development mainly describes the situation for deaf children of deaf parents, several of the above mentioned observations also hold true for deaf children with signing hearing parents if their children are exposed to Sign Language early in life.

ies indicate that this is not the case (Petitto & Bellugi, 1988). According to these analyses, deaf children learning a signed language produce the same kinds of mistakes as hearing children do. Even though deaf children use the pointing gesture for objects and locations at approximately nine months, they cannot use the pointing forms for YOU and ME until 17–20 months (Petitto, 1994, 157). This is exactly the age range when hearing children begin systematically to use verbal pronouns (Petitto 1995; Petitto & Bellugi, 1988). However, it must be noted that several scholars (Inger Ahlgren, personal communication, April 3, 1998) disagree with the results indicating deaf children's pronominal mistakes. See Ahlgren (1990) for a discussion on deictic pronouns in Swedish and Swedish Sign Language and Meier (1990) for a discussion on person deixis in ASL. Marschark (1993, 84) suggests that deixis (pointing to a location in space) should be seen as a linguistic gesture used by fluent signers, as well as a non-linguistic gesture in pre-linguistic children.

Onset of Sign Language production

Another area concerning Sign Language development that researchers disagree on is the onset of language production (Meier & Newport, 1990). There is support for the claim that deaf children (learning a signed language) produce their first signs earlier than hearing children produce their first words (Hoffmeister & Wilbur, 1980; Meier, 1991). If so, one reason may be that the motor skills and motor centre of the brain required for signing mature earlier than the motor skills and speech centre required for speaking (Bonvillian, Orlansky, & Novack, 1983). Another essential issue here is the difficulty in determining exactly when a child produces a first sign or a first word. Many words and signs are intelligible to the parents but not to anyone else (Hoffmeister & Wilbur, 1980). Even so, according to some studies (c.f. Hoffmeister & Wilbur, 1980; Bonvillian *et al.*, 1983) it appears that a deaf child produces her first sign two to three months earlier than a hearing child produces her first spoken word. However, current studies have not confirmed these results. Petitto's (1995) research on deaf children learning Sign, and on bilingual hearing children learning both Sign and speech, suggest conflicting results regarding an earlier emergence of signing. Moreover, both hearing and deaf children use prelingual gestures in a similar fashion (Espéret, 1996), but since deaf children's gestures and language are in the same modality, some gestures may be mistaken for signs (Petitto, 1994). This single modality (as opposed to a modality change for hearing children) does, however, provide an ideal chance to explore the link between pre-linguistic communication and language (Volterra & Erting, 1994).

Despite the conflicting results regarding the age at which one word/sign utterances are produced, and the difference in modality, the linguistic and conceptual development in both visual and auditoral language mode follows the same pattern. Still, the processing of spoken and signed languages partly requires different cognitive processes (Petitto & Bellugi, 1988). A deaf child acquiring a signed language has to deal with several simultaneous tasks within the same visual event: spatial perception, spatial transformations, memory, and spatially processed grammatical structures. Additionally, the young deaf child must learn the non-language spatial capacities that function as prerequisites to the linguistic use of space (Bellugi, O'Grady, Lillo-Martin, O'Grady Hynes, van Hoek, & Corina, 1994).

Of major concern for many hearing parents and educators of deaf children is the belief that the acquisition of a signed language hinders the acquisition of a spoken language. Many studies have proven this theory wrong (Mahshie, 1995; Preisler & Ahlström, 1997; Svartholm, 1994). The acquisition of a natural Sign Language supports the acquisition of a spoken language. Svartholm (1994) argues for the benefits of a Signed Language in the deaf child's language development, including second language learning. According to Svartholm (1994, 63):

... speech alone or invented mixtures of speech and signs (such as Signed Swedish, for example) are – to say the least – clearly unsatisfactory as a basis for normal first language development [in deaf children].

3.4.3 The development of literacy

Reading is a very multifaceted, flexible, and sophisticated cognitive activity involving many component skills. As Perfetti (1984, 48) asserts, word representations and the processes of word identification that are determined by these representations are crucial in the reading process. Perfetti (1984) also underscores the role of lexical access, orthographic structure and knowledge of the alphabetic principle. Access to semantic and syntactic information is also important in the reading process (Samuels & Kamil, 1984).

Although there is extensive knowledge of the reading process, there is no complete and unambiguously accepted model of reading acquisition (Juel, 1991). A detailed discussion of the different models of reading is not necessary here (c.f. Samuels & Kamil, 1984), but in order to get an overview of the factors influencing the reading process, three models will be briefly mentioned here.

Bottom-up theories (Samuels & Kamil, 1984) emphasise the importance of word recognition, and assume that letter features, letters, words and phrases are combined, from smaller to larger units, in order to develop meaning. Research on eye-movements and fixations provides support for a bottom-up theory of reading. There is, however, evidence suggesting that a bottom-up theory is not sufficient in explaining the complex reading process; for instance, the notion that context plays a significant role in developing meaning is not easily accounted for in a bottom-up approach (Carpenter & Just, 1986). Neither does this theory take into account the background knowledge that even young children bring to the reading process (McKeown, Beck, Sinatra, & Loxterman, 1992; Pearson, Hansen, & Gordon, 1979).

Top-down theories reject the belief that the precise processing of letter, word and phrase perception and identification is the key to successful reading (Samuels & Kamil, 1984). Rather, the focus is on word identification. The background knowledge the reader brings to the reading process is essential (Goodman, 1967). Prediction is also very important in reading. However, one weakness of this model is that it does not recognise processes such as decoding (King & Quigley, 1985).

Interactive models emphasise the reader's active processing of the text, including the reader's goal to construct a model of what the text means (Perfetti & Curtis, 1986). Here, the role of background knowledge in constructing meaning

from text is of great importance. Background knowledge and story schemas are structures essential for text processing (Anderson & Pearson, 1984). Studies on deaf children's schema development indicate not only that deaf children – naturally – bring their world knowledge to the reading process, but also that the story structures of deaf children are not equally well developed as those of hearing children (Akamatsu, 1988; Schirmer, 1993). An exception is deaf children of deaf parents: this particular group of deaf children perform equally well as hearing children (Schirmer, 1993). These results suggest that teaching methods that elaborate deaf pupils' story schema may improve their reading comprehension (Schirmer, 1993).

Language modality and reading

Language modality influences the processing of linguistic stimuli. Research findings show that deaf children unsuccessfully try to map their own primary language on a written language (Fok, van Hoek, Klima, & Bellugi, 1991; Rodda & Grove, 1987). The fact that deaf children, when learning to read and write, have to change modality, and that there is an unfit match between a sign and a written word probably accounts for many of the difficulties deaf children have in the learning of reading skills. Moreover, many features of signed languages add up to complicate the mapping of a written/spoken language onto a visual language even further. Differences in syntax and morphology do not independently explain why it is so hard for native signers to learn how to read. The fact that the deaf child has no support in his or her own language on how to – in a spoken language – express, for instance, time, how to ask questions, and how to understand tenses, may account for some of the difficulties. So, taken together, the difference in visual and orthographic representations, as well as fundamental differences in the grammar of signed and spoken languages may to some extent explain why deaf children are poor readers and writers. In addition, the fact that spoken languages are sequential, while signed languages are more spatially organised, may initially impede the deaf child in acquiring a spoken language.

However, a main reason for the difficulties seems to lie in educational instruction. The instruction in the national language for deaf children has been poor, and has not served as a base for emerging literacy. Deaf children need to learn a verbal language as a second language (Kristina Svartholm, personal communication, April 3, 1998). Despite deaf children's difficulties and the obvious differences in the reading process, a crucial question is whether reading truly is different for deaf people and for hearing people (Paul, 1998). The answer to this obviously has significant educational implications. As Paul (1998, 62) points out, even though the literacy development of deaf children and that of hearing pupils are qualitatively comparable, deaf pupils' literacy development often lags behind the literacy development of hearing pupils. This, naturally, has consequences for the deaf children's learning and educational performance.

Strategies in deaf readers

For hearing individuals speech-recoding is essential in the reading process, and this strategy is also available to some deaf readers, particularly to better deaf read-

ers (Hanson, 1985), and to those with intelligible speech (Conrad, 1970). For deaf people a speech-based code is, however, difficult to use, and therefore deaf readers also use manually coded strategies, such as fingerspelling-based and sign-based strategies (Hanson, 1985). The recoding strategy based on fingerspelling is frequently used by deaf individuals with unintelligible speech (Locke & Locke, 1971); according to Hirsh-Pasek (1987) this strategy is also used by children, although not spontaneously.

The use of sign is another recoding strategy available to hearing-impaired children, i.e. printed information is transformed into sign representations (Stofoen-Fischer & Ae Lee, 1989). But since there is no relationship between printed English words and ASL, it has been suggested that recoding into signs does not enhance word identification (Hirsh-Pasek & Treiman, 1982).

Stofoen-Fischer and Ae Lee's (1989) study on the effectiveness of graphic representation of sign in developing word identification skills for hearing-impaired readers, as well as Robbins' (1983) study on the effects of signed text on the reading comprehension of hearing-impaired children show that graphic representations of sign have several advantages for the deaf beginning reader. The graphic representation enhances the association between the printed words and the concepts they represent.

In an experiment on recall of words with or without sign equivalents, deaf subjects performed well in the words with the corresponding sign but poorly on the words with no sign equivalent (King & Quigley, 1985). Furthermore, deaf subjects understood connected prose better when the syntax of the printed information had been changed to the syntactic order of ASL. These and similar results support the view that deaf people process information in Sign Language, and do not translate signs into corresponding English words. Moreover, the key to successful reading may in part depend on establishing a connection between the two language systems (Davey & King, 1991). Studies on skilled deaf readers may suggest ways to develop the ability to read in the larger deaf population (Kelly, 1992).

Deaf children do not learn to read through old-fashioned drills and therefore meaningful texts and teaching materials are necessary. Rather, storytelling, discussions on good texts written for children (not easy to read texts), and comparisons of signed and written texts, are the keys to successful instruction of the national language. Both Inger Ahlgren (personal communication, April 3, 1998) and Kristina Svartholm (personal communication, April 3, 1998) stress that a necessary condition for successful education of deaf children is the use of Sign Language as the language of instruction. Equally important is the viewpoint that deaf children should be taught in the same fashion as hearing children. According to Ahlgren nothing indicates that deaf individuals differ from hearing individuals as to information processing or learning. They simply need to receive instruction in a Sign Language. For a further discussion on bilingual education in Sweden, see Svartholm 1993; on second language learning in deaf individuals, see Ahlgren, 1982, 1984, Svartholm 1984, 1990, 1994; and on Sign Language as the first language, see Ahlgren 1994.

According to both Inger Ahlgren and Kristina Svartholm (personal communication, April 3, 1998), an interesting question is why Finland, with a long tradition

of linguistic minorities and experience of teaching Swedish as a foreign language to Finnish-speaking people, cannot utilise this knowledge of Swedish as a second language in the education of deaf children.

Metacognition

Finally, metacognition is also an important component in emerging literacy. Metacognition is used to describe the control an individual has over his or her own cognitive functioning, such as thinking, learning and problem-solving (Brown, 1980, 453), but is also linked to the development of good reading skills (Strassman, 1992). In fact, studies suggest that deaf pupils' metacognitive awareness is lower than that of hearing pupils (Strassman, 1992). The teaching of metacognitive awareness may turn out to be an important component in the teaching of reading to deaf pupils as well as in improving deaf readers' comprehension of written texts (Fox, 1994).

3.4.4 Language and psychosocial development

It is widely recognised that language has a major impact on many areas of a child's development and although the acquisition of language is beyond the objective of this study a discussion on the connection between language and psychosocial development in deaf and hard-of-hearing children is included. According to Chomsky (1975), the ability to learn a language is biologically based; that is, all humans are born with this ability. Others (e.g. Anderson, 1983) argue that language learning is possible through our general cognitive capacity. Without a further discussion on the biological foundations of language acquisition vs a more general cognitive theory, it seems reasonable to conclude that learning a language does indeed – in addition to the biological prerequisites – demand an accessible linguistic input (Drasgow, 1998). We cannot achieve complete mastery and native fluency in a language to which we have but limited and conditional access. Regardless of the disagreement on the nature of language acquisition, the significance of language for human life remains indisputable. Even so, many children born deaf are not given the opportunity to discover unconditionally the world of language early in life.

Various studies suggest that deafness greatly influences not only the linguistic environment but the child's psychological, social and emotional development as well. Many early studies (c.f. Myklebust, 1960) present deaf children as children living in a more or less emotional and social vacuum with deafness being a possible risk factor (depending on certain developmental, medical or psychosocial circumstances) for behavioural and social problems (Vostanis, Hayes, & Du Feu, 1997). However, along with more positive attitudes towards deafness (Marschark, 1993) and the increased knowledge of Sign Language communication, deaf children's psychosocial development is viewed from a new perspective.

According to Meadow (1980), for children born with a profound congenital hearing loss the fundamental deprivation is not that of sound, but of language. This statement, however, needs to be refined because only profoundly deaf children not given access to a natural Sign Language are at risk of language depriva-

tion¹⁶ (Sacks, 1989; Svartholm, 1994). As Marschark (1993) argues, a hearing loss does also affect one's social and cognitive development. Indeed, a lack or loss of hearing limits social interaction, but it does not mean that the quality of the available social interaction needs to be affected. And as far as cognitive development is concerned, studies from Sweden indicate that deaf children who receive adequate instruction through the medium of sign perform as well as hearing age-mates on academic tasks (Svartholm, 1994).

Behavioural problems in deaf children

Even so, behavioural problems of deaf children are present both at home and in school (Marschark, 1993). According to Sinkkonen (1994) even children with mild to moderate hearing losses are at risk vis-à-vis developmental problems. Rarely does deafness *per se* lead to behavioural problems; the underlying reason can be difficulties in – or a lack of – parent-child or teacher-child communication. However, as Sinkkonen (1994) points out, not all psychological problems in hearing-impaired children can be attributed to poor communication.

It is thus of great importance to analyse the reasons for possible behavioural problems in deaf children. Even hearing children under the age of two are capable of expressing anger or frustration through a verbal language, and perhaps more importantly, the message is (more or less) understood by other people. Bearing in mind that many hearing-impaired children are not identified (and thus have not learned manual communication) before the age of two, deaf children growing up in a hearing environment are not fully able to express their needs or feelings. To what extent deaf children's psychosocial development qualitatively differs from that of hearing children can depend on the child's early social context. As is evident from Sections 3.4.1, 3.4.2 and 3.4.4, deaf children's early linguistic and social environment may match that of hearing children. However, if, for instance, the interaction between mother and infant is impaired, then the psychosocial development too, tends to be affected. According to some authors, the use of only spoken language does not allow deaf or hearing-impaired children to develop social competence (Preisler & Ahlström, 1997). A child possessing the ability to express herself, her feelings and needs, and who in return is understood, respected and able to communicate freely, reaches self-awareness and acquires the tools necessary for interpersonal relations and empathy (Heiling, 1993). Heiling further points out that earlier studies unambiguously indicate that early Sign Language exposure has a positive influence on the child's general development (e.g. Greenberg, 1983; Heiling, 1999; Preisler, 1983). Hjemlquist's (2003) interesting study on the mentalising ability (theory of mind skills) in non-native signing children also emphasise the need for an accessible mode of communication. Hjemlquist's (2003) study suggests that deaf children's lack of a mode of communication result in a delay of mentalising skills. The delay is caused by the absence of an accessi-

¹⁶ The situation for children who are hard-of-hearing or deaf and benefit from conventional hearing aids or from cochlear implants is not dealt with here.

ble communication that enables both efficient ways of sharing experiences and the ability to direct one's own attention as well as the attention and action of other individuals (Hjelmquist, 2003).

Nevertheless, good communication skills are not sufficient in preventing deaf or hearing-impaired children from developing emotional problems; in fact, behavioural or emotional difficulties in both hearing and deaf children can arise from the same etiological factors (Sinkkonen, 1994). Sinkkonen (1994, 134) concludes that there does not exist a typical deaf personality; a language disorder such as dysphasia may result in psychic consequences and a metapsychological profile similar to those of deaf children with large communication problems (regardless of the child's hearing status or mode of communication).

Play behaviour in deaf children

Although the view on, and definitions of young children's play behaviour is not unanimous, there is a general agreement on the significance of play for the child's development (Piaget, 1962; Vygotsky, 1978; Spencer & Deyo, 1993). Symbolic play tells us a great deal about the child's cognitive, social, linguistic and symbolic skills (Spencer, Deyo, & Grindstaff, 1990; Spencer & Deyo, 1993). Communicational skills have been shown to influence the development of play patterns (Sinkkonen, 1994). Play thus has a strong developmental aspect; through play children can practise the use of symbols and actions (Spencer *et al.*, 1990) as well as adherence to rules and self-control (Vygotsky, 1978).

Spencer and Deyo's (1993) review of the literature indicates that some features of deaf children's play seem to be different from those of their hearing peers. The differences lie in both the social and the cognitive domain and are shown by an increase in solitary play and a decrease in object substitution or in the time engaged in play. In essence, as regards to play behaviour, deaf children are behind hearing age-mates (Spencer & Deyo, 1993).

However, not many studies on symbolic play in young deaf children have been conducted and in the earlier studies, the consequences of an impeded or delayed language development present in many deaf children were confused with the consequences of deafness (Spencer *et al.*, 1990; Spencer, Deyo & Grindstaff, 1991). The diversity of the deaf population is evident in many areas and in studies on the development of deaf children both the subjects' background variables and the research methods must be scrutinised (Meadow, 1980). For example, in studies on play behaviour in deaf children it is important to report whether the parents are deaf or hearing. When studying deaf children of hearing parents the effects of deafness may be confused with the effects of the deviant early language environment which many of these children experience (Spencer *et al.*, 1990).

In an attempt to investigate further the role of auditory deprivation on symbolic play, Spencer *et al.* (1990) conducted a study on four deaf toddlers with deaf mothers. A group of four hearing toddlers with hearing mothers also participated in the study. The results from this study show no difference in frequency or level of symbolic play between the deaf and hearing subjects. The authors point out that more studies are needed, but the preliminary results show that auditory deprivation need not influence symbolic play. The factor determining the tendency for,

and the level of, symbolic play seems to be linguistic competence. The deaf children included in Spencer *et al.*'s study had similar early linguistic experiences to the hearing children. These findings are consistent with the results of Vygotsky (1978) and Casby and McCormack (1985) on deaf children. According to these results, language competence and the ability for symbolic play are related.

Cornelius and Hornett (1990) conducted a study on the functional, constructive, dramatic, and social play behaviour in hearing-impaired kindergarten children who used different means of communication. One group of children was using oral communication and another group a combination of signed and oral communication. No significant difference in hearing loss was evident between children from the two groups. The findings from this study indicate that the children using signed communication had higher levels of social play behaviour and lower levels of aggression compared to the children using oral communication. The children in the oral communication group did not communicate with each other (for example to exchange rules and create or continue a specific play situation) as much as the children in the signing group. Furthermore, the children using oral communication demonstrated more solitary play compared to the children using manual communication. Ahlström's (2000) study shows the significance of a shared communication method in developing play, especially in fantasy and role-play, and in the interaction between hard-of-hearing children or deaf children.

3.4.5 Sign Language and short-term memory

The objective of this study is not to give a comprehensive account of research relating to Sign Language but to investigate the decision processes relating to language and education among hearing parents of deaf or hearing-impaired children. However, research relating to Sign Language has (or should have) significant value in the habilitation and education of deaf and hearing-impaired children. Hearing parents' choices of communication method and educational placement for their deaf or hearing-impaired children may partly be linked to the parents' beliefs about language, learning and cognitive functioning. Given the many myths about Sign Language, parents need to know that learning a natural Sign Language can be compared to learning any other language. Furthermore, and contrary to earlier beliefs, Sign Language provides its users with the tools necessary for higher psychological and cognitive processes. Cognitive functioning in the medium of Sign Language is here exemplified by research on how deaf individuals use Sign Language for short-term memory recall.

Short-term memory, or working memory, provides us with the ability to connect stored information with the present, thus enabling us, for example, to solve problems or make plans for the future (Goldman-Rakic, 1992). As Goldman-Rakic (1992, 73) points out, the human working memory may well be "the most significant achievement of human mental evolution". Extensive research has been conducted on human memory, including memory processes used by deaf individuals (Tsui, Rodda, & Grove, 1991). In fact, short-term memory processes in deaf children seem to have been of more interest than in hearing children (Marschark, 1993). Several studies on short-term memory show that the ability to use a phonet-

ic code correlates with memory span (e.g. Hanson, 1982). The question of whether pre-linguistic deaf people use phonetic or articulatory coding in short-term memory of both linguistic and non-linguistic information has led to several interesting studies (e.g. Conrad, 1970; Conrad, 1972; Locke & Locke, 1971). As a result of these studies new insights into the biological foundations of language have emerged (Hanson & Lichteinstein, 1990). As will be discussed briefly below, there is, however, some disagreement on the nature of short-term memory coding in deaf people. As Sigel and Brinker (1985) point out, the reasons for this disagreement are both the methodologically different studies, and the differences in language background among the deaf subjects.

In a famous paper, Miller (1956) proposed that the capacity of short-term memory is dependent on the familiarity of the stimuli and on the number of symbols – or so-called chunks needed for the encoding of the stimuli. As stated by Miller, the number of chunks we are able to remember in an immediate recall experiment is seven plus or minus two. According to Simon (1979a) the number is closer to four. However, the important issue is the fact that the capacity, if measured in chunks and not in bits¹⁷, is fairly constant, i.e. the capacity is not dependent on the type of stimuli (Simon, 1979a). In studies on short-term memory for lists of unrelated words the principal unit of short-term memory has been considered to be a word (Drewnowski & Murdock, 1980). Analogously, signs can be considered the principal unit in studies on short-term memory for Sign Language.

Short-term memory coding of sign stimuli

Recall for acoustically similar sequences is much lower than recall for acoustically non-similar sequences (Baddeley, 1966). This provides support for the assumption that literate hearing individuals make use of phonetic coding in short-term serial recall of linguistic information (e.g. Conrad, 1971; Hintzman, 1967), and not of coding based on semantic or formal similarity (Baddeley, 1966). Further evidence supporting the view that short-term memory does not, at least to a great extent, rely on semantic or formal similarity can also be found in studies on memory processes in deaf signers. Where hearing people make phonological mistakes (Baddeley, 1966), deaf people make – if the stimuli are true ASL signs – mistakes based on visual similarity between signs (Bellugi, Klima & Siple, 1975). Studies (Bellugi *et al.*, 1975; Poizner, Klima, & Bellugi, 1987) have shown that adult deaf native signers¹⁸ store information presented in signs. That is, they do not translate the information found in signs into the oral/aural modality.

¹⁷ A bit indicates the amount of material, for instance number of digits or words, and a chunk refers to a particular amount of information that has specific psychological significance (Simon, 1979a).

¹⁸ The research *Remembering in Signs* conducted by Bellugi and her colleagues at the Salk Institute focuses specifically on deaf people whose primary and native language is ASL.

Short-term memory coding of sign stimuli is based on elements of ASL, that is, movement, hand configuration, and place of articulation. Further evidence for the use of Sign Language coding are results showing that lists of formationally similar signs are more difficult to recall than lists of formationally different signs (Hanson, 1982; Poizner, Bellugi, & Tweney, 1981). Also that deaf subjects have difficulty remembering lists of written words whose corresponding signs are formationally alike, thus indicating that Sign Language is used in short-term memory functioning (Shand, 1982). Conrad (1972) concluded that short-term memory prospers on speech-like input. Hanson and Lichteinstein (1990) however, support Klima and Bellugi's (1979) notion that short-term memory is language based, but conclude that although short-term memory coding in Sign clearly occurs, deaf subjects do not on every occasion recode printed words into sign.

Memory spans in deaf individuals

The results of several studies (Bebko, Lacasse, Turk, & Oyen, 1992; Belmont, Karchmer, & Pilkonis, 1976; Bellugi, Klima, & Siple, 1975) indicate that both deaf children and deaf adults generally have shorter memory spans than age-matched hearing individuals on tasks measuring verbal or sequential processing. Deaf subjects recall approximately one item less than hearing subjects (Bellugi *et al.*, 1975). Nevertheless, and more importantly, the two subject groups produce similar serial position curves. The fundamental short-term memory processes in deaf native signers and hearing people thus show significant similarities (Bellugi *et al.* 1975). But is the short-term memory capacity in deaf people smaller than in hearing individuals or is there another explanation for the evidence presented in Bellugi's *et al.*'s study (1975)? The answer seems to lie more in the nature of the stimuli and the modality of the two languages, that is, in the differences between how signs and words are produced and coded. Findings also suggest that deaf children tend not to use rehearsal strategies spontaneously to the extent that hearing children do (Bebko *et al.*, 1992).

A reasonable explanation is, first, that if deaf signing people both code and rehearse (or repeat) sign stimuli in signs, and not in a spoken language, even though the responses are written words, they have less coding and rehearsal time than the hearing subjects do. A study by Klima and Bellugi (1979) suggests that signs take longer time to produce than words. This also holds true for implicit signing vs implicit speech, i.e. the rate of implicit signing equals that of overt signing (Bellugi *et al.* 1975), and the rate of implicit speech equals that of overt speech (Landauer, 1962). Rehearsal is crucial for retaining information in short-term memory (Simon, 1979b; Squire, 1987). If we – as Bellugi and her colleagues (1975) do – view rehearsal as implicit speech/signing, then it is obvious that the deaf subjects have less time for rehearsal. This is, in fact, shown by the smaller primacy effects in Bellugi *et al.*'s (1975) study of remembering in signs.

Secondly, in this experiment the deaf subjects were asked to write down the responses, i.e. to give an English equivalent of the sign stimuli. This required the subjects not only to translate the stimuli from one language to another, but also to translate the stimuli from one *modality* to another. On the basis of these two experiments, it is of course impossible to determine how much of the difference in

memory capacity between the two subject groups can be explained by the additional process, required by the deaf subjects, of translating the word from one modality to another.

Thirdly, although the signs used in Bellugi *et al.*'s (1975) study can be considered both common and fairly easy, a spoken language is often a second language for Deaf people. The deaf subjects may, naturally, hesitate as to what English translation is the most appropriate, a mental process that may have an impact on the memory span. It is also notable that most if not all, early studies on memory in deaf people used written English words as stimuli. As the familiarity with the stimuli influences the capacity of short-term memory (Simon, 1979c), this clearly placed the deaf subjects in a disadvantaged position.

A smaller memory span in the deaf may therefore well be attributed, at least partly, to the longer rehearsal time needed in the visual modality, and not to dysfunctional memory processes due to deafness in itself. An experiment with two different conditions, one being identical to that in Bellugi *et al.*'s (1975) study, and one in which deaf native signers would respond in the same modality as the stimuli is presented, i.e. in Sign Language, could possibly answer more questions about the nature of short-term memory coding in deaf individuals. It would also be important to examine further memory functioning in small deaf children. It seems plausible that Sign Language coding in short-term memory is accessible to young deaf children whose primary language is Sign. Yet apart from findings indicating that deaf children use spatial memory codes in recalls of non-verbal stimuli – and not temporal or sequential codes frequently used by hearing subjects – no research has been conducted to show whether Sign Language coding is indeed conceivable (Marschark, 1993). Finally, it must be remembered that deaf children perform as well as, or better than hearing children on tasks measuring spatial or visual processing (Marschark, 1993).

3.5 Deafness and bilingualism

Bilingualism was earlier associated with many negative circumstances. Generally, members of weak or oppressed language minorities have had to learn the language of the majority or dominant group, while those belonging to the majority (or dominant group) did not have to learn the language of the minority (Skutnabb-Kangas, 1981). This is of course still the case with immigrants, who must learn the national language of the new country. In addition, bilingualism in itself has been thought, even by linguists, to have negative effects on children's cognitive and linguistic development. For example, in Finland, especially during the 1960s and 1970s parents speaking different languages were advised to teach their children one language first, then the other. Today the attitude is different, bilingualism and language skills generally are often highly valued and both parents use their own mother tongue in communication with their children from the very beginning: the children thus grow up learning two languages simultaneously, according to the principle one person – one language. Another example is the popularity of English, German and French schools in Finland. Also, during the last years, Swedish im-

mersion programmes (day-care and primary school) for children from the Finnish-speaking majority have become very popular (see Buss & Mård, 2001; Laurén, 1999).¹⁹

Given Finland's official bilingual status, and the increase of immigrants and other language groups in Finland, as well as the increased awareness of the benefits of language skills, one would perhaps believe that there exists a positive attitude towards linguistic minorities in Finland. Yet the fact is that the attitudes towards, for example, the Swedish language and the Swedish-speaking minority in Finland are not overtly positive. Putting the fairly complex relationship between the Finnish majority and the Swedish minority aside for the moment (see McRae, 1997), it must be noted that Swedish speakers are guaranteed services in many areas in their mother tongue.

However, concerning Deaf people, the rights of linguistic minorities are often disregarded. The most neglected yet most important area is a total approval of Finnish Sign Language as a deaf person's native language, and also the need for deaf children of all ages to be educated – if the parents so wish – through the medium of Finnish Sign Language.

Definitions of mother tongue

In order to define and discuss the issue of bilingualism, we must first have a definition of language, especially mother tongue or native language. Many criteria as to what a native language truly is have been presented. Skutnabb-Kangas (1981, 1994) gives the following definitions of mother tongue, with the criterion in parenthesis:

- * the language(s) the individual learned first (origin)
- * the language the individual masters best (competence)
- * the language the individual uses the most (function)
- * the language the individual identifies with (internal identification)
- * the language the individual is identified as a native speaker of by other individuals (external identification)

As Skutnabb-Kangas (1994) points out, the above mentioned criteria apply to deaf people as well as to hearing people. Deaf people may for the most part depend on

¹⁹ Immersion is a voluntary educational programme for children from the majority language group and is a meaningful and pedagogical method of second language learning (The centre for immersion and multilingualism, 2003, www-document). In several subjects the instruction is given in a language that is not the children's first language. Immersion programmes follow the national curriculum and the objective is that pupils develop their own first language while also achieving a high proficiency in the immersion language and the culture of that second language. A significant feature of immersion is that since the children are from the language majority there is no threat to their own first language. That is, in Finland, Finnish-speaking children attending immersion schools learn Swedish.

Finnish, for example at work (the third criterion) but even so do not consider Finnish their native language. In fact, many Swedish-speaking people in Finland experience the same situation, so this situation is not unique for Deaf people. For the majority of deaf people the third or fifth criterion are the most appropriate, provided that they master Sign Language best and identify with the Deaf community. Exceptions do, of course, exist. If the deaf person has a low self-esteem and a low deaf identity she may rather identify with the hearing world. The definitions by function and competence are applicable only if we are allowed to use our first language and the language we identify with. Sign Language is a deaf child's mother tongue according to all of the previously mentioned criteria if the child receives her education in Sign Language and is growing up in a Deaf signing family who strongly identifies with Sign Language and the Deaf community (Skutnabb-Kangas, 1994). Unfortunately, this is an ideal case. The author continues by saying that even today, it is possible for a deaf individual to grow up without having a natural language as the individual's native language. It is, in fact, possible that some deaf people fail to achieve proficiency in any language.

According to Skutnabb-Kangas (1994), a definition of an individual's mother tongue should include a combination of origin and internal identification as this points to an increased awareness of linguistic rights. This type of definition is not always applicable; it requires an approval of the individual's internal identification by society at large. A deaf individual's internal identification with Sign Language results in a conflict concerning the validity of this internal identification in a society not accepting the language of the Deaf community. This is a conflict usually putting the more powerless individuals – in this case the group of Deaf people – in an inferior position (Skutnabb-Kangas, 1994).

Bilingualism in Deaf communities

Finding a universally accepted definition of the term bilingualism is not an easy task (Anderson, 1994), and it is even more difficult to find an accepted definition of bilingualism in deaf people. The notion that either deaf people or deaf communities can be bilingual has been considered questionable mainly for two reasons. First; natural Sign Languages have not been looked upon as true languages, and secondly, as deaf people may not be comfortable using a spoken language they may not be considered "balanced bilinguals", which, in turn, sometimes has been connected to bilingualism (Ann, 2001, 42).

The diversity regarding linguistic background and bilingualism varies greatly within the Deaf community and there exist many different types of bilingualism. Some of them are listed below (Ann, 2001, 43), with *x* indicating any natural Sign Language:

- * native signers of *x*Sign Language who are fluent in a spoken language (reading, writing and speaking);
- * native signers of *x*Sign Language who read and write a spoken language fluently but do not speak it;
- * native signers of *x*Sign Language who are fluent to varying degrees in reading and writing a spoken language;

- * deaf signers of xSign Language as a second language who read and write a spoken language fluently but do not speak it;
- * second language xSign Language signers who first learned a signed version of a spoken language
- * native signers of xSign Language who learned another sign language as a second language;
- * first/second language xSign Language signers who speak a spoken language.

As with hearing communities there is also a great heterogeneity of linguistic experience and proficiency within the Deaf community (Ann, 2001, 43). Even so, according to many theoretical positions on bilingualism in deaf people (c.f. Svartholm, 1994) the definition of a bilingual deaf individual should not include the ability to *speak* a language. A deaf person should be considered bilingual when she signs fluently and is able to read and write (Hansen, 1989). According to Ulfsparré (1990) the bilingual situation of deaf people should be called *the two languages of the Deaf*. The first language for deaf people needs to be a Sign Language, the second language needs to be the national language (Svartholm, 1994). This has far-reaching implications for the education of deaf children: the national language should be taught as a second language for deaf individuals. As was listed above, it must also be noted that both deaf and hearing people can, of course, become bilingual in different Sign Languages. But there is little research on this type of bilingualism in deaf people; a few studies have investigated how a foreign accent influences the acquisition of a second Sign Language (Ann, 2001). Finally, studies on signing-speaking individuals offer a new and interesting dimension on early bilingualism (see Petitto & Holowka, 2002).

The majority of deaf people live in societies that are strongly dominated by hearing people and their language(s) and values, and therefore Sign Languages do interact with spoken languages. The frequent contact between spoken and signed languages guarantees, that “most deaf individuals are bilingual to some extent in a spoken language of some form” (Ann, 2001, 41).

Opponents of Sign Language frequently point out that we live in a hearing world and that in order to get ahead, a deaf person must learn both to speak and to use her (possible) residual hearing. Indeed, the possibility to build oneself a position in society largely depends on language and individuals with poor language skills have difficulties finding a job. Although deaf people constitute an example of this – a majority of the Deaf in Finland hold jobs with a fairly low educational level, (Ansaharju, 1991) – the reason is not the exposure to and acquisition of Sign Language. Rather, the reason is the inadequate instruction and consequently the poor knowledge of the national language(s). According to many authors achieving native fluency in a signed language does not inhibit the ability to learn to read, write and possibly speak the national language (Drasgow, 1998; Preisler & Ahlström, 1997). Proponents for oral communication do, however, argue that exposure to Sign hinders the acquisition of a spoken language (Schmid-Giovannini, 1998).

3.6 Summary

Deaf children have traditionally been measured on standardised tests administered in a verbal language, which is not the first language for all deaf children. It is thus of no surprise that deaf children have been labelled poor readers and have performed poorly on academic tasks. New research indicates that the literacy development in deaf children qualitatively follows the same pattern as in hearing children (Paul, 1998). This finding has great educational consequences because it implies that deaf children should be instructed in the same manner as hearing children, and that similar teaching material should be used but that deaf children must be educated in a Sign Language. Deaf children do not need easier or adapted textbooks; rather they need regular textbooks supplemented with signed explanations and discussions. Furthermore, given the importance of phonological coding for both short-term memory and literacy skills, more research is needed on how to improve deaf pupils' phonological and morphological awareness as well as research on metacognitive strategies important in the reading process.

Play has been linked to the development of many cognitive skills as well as to the development of social behaviour and language. Several studies report play behaviour in deaf children that qualitatively differs from that of hearing children. The quality of play in deaf children is linked to both the child's mode of communication and communicational proficiency. Signed communication tends to increase interactive and social play behaviour and to decrease aggressive behaviour. Thus, given the significance of play for the child's cognitive, linguistic and psychosocial development, it is important to encourage and help deaf and hearing-impaired children to engage in play if the children do not spontaneously do so.

Another crucial issue is that deaf children need to be taught the majority language as a second language. Deaf children educated bilingually often achieve high reading and writing skills. Furthermore, as recent studies provide evidence that early exposure to a signed language has permanent linguistic benefits and that Sign Language competency is positively related to spoken language literacy it is clear that deaf children need to be educated in Sign Language.

4 Hearing Parents with Deaf Children

4.1 Parenting in today's society

Technology, industrialisation and urbanisation are identified as factors making daily life in today's society more complicated and impersonal (McKenry & Price, 2000). The rapid changes in family-structure, education and social trends are sources of stress for both parents and children and as a result, many parents feel inadequate and unsure about their parenting skills. The social constructions of childhood have also changed dramatically (Jenks, 1996, 13), and parents may not have – and thus are not able to pass down to their children – the coping strategies needed in the post-modern society (Buchanan, 1998, 7). It can also be strenuous for parents to juggle the increasing expectations and responsibilities of both family and employment. Newberger (1980, 45) writes that “parenthood is at best a difficult process and at worst an experience of failure and a source of stress and disability for many families”.

New theories on parenting and child-rearing are continuously set forward but Gardner (1998, 22) urges us not to comply with every approach on bringing up children, as new theories often tend to refute earlier ones and not necessarily bring us any closer to the truth.²⁰ Van Manen (1990, 47) also points out that few books on parenting actually discuss the meaning of parenting, rather the parenting books focus on giving advice, as if parenting were a “how to do” skill that we can readily learn from books. Van Manen (1990, 47) maintains that similar books do not provide us with an understanding of “the nature of parenting”.

It is however becoming more and more apparent that parenting must be considered a part of an extended social context, that is, one that contains historical, cultural, political and economic influences (Buchanan, 1998, 7). It is thus widely recognised that changes in society reflect our view on parenting, the upbringing and education of our children. Poikolainen (2002) reports that parental educational consciousness is influenced by socio-cultural elements but also by the parents' own beliefs, conceptions and experiences of child rearing as well as conception of human nature.

Today gender roles and traditional values are changing, as are the definitions and beliefs of what constitutes a “family” (McKenry & Price, 2000). Nevertheless, parents are generally considered to be answerable and responsible for their

²⁰ Throughout modern history educators have paid attention to how parents should raise and support their children's development. In 1628 Comenius, one of the greatest and most prominent thinkers in pedagogy and didactics wrote *Informatorium maternum (Swe: Modersskolan)*. In this writing Comenius presents his thoughts on the upbringing and education of young children; children between the ages of one and seven should be educated at home in a systematic and well-organized manner (Comenius, 1989). Comenius's ideas had great influence on childrearing and education and as a result the general view on children slowly changed. Another publication with great impact on childrearing is Pestalozzi's (1933) *Kuinka Gertrud opettaa lapsiansa*.

children's behaviour. Parental attitudes and parental awareness as well as the manner in which a child is brought up is considered to influence strongly the child's overall development and potential to function in society (Buchanan, 1998: Gardner, 1998). In addition, the relationship and interaction between child and parent(s) as well as the capacity to find compensatory experiences for negative life-events, are essential for a child's emotional well-being and ability to cope at times of stress and conflicts (Buchanan, 1998, 5). Traditionally, parents also play an important role in providing their youngster with the tools needed to enter adulthood successfully (Buchanan, 1998, 5).

Uljens (2001) also calls attention to the effect and challenges that contemporary society has on education, educational research and parenting. According to Uljens we live in a society that, among other things, no longer believes in continuous progress and is characterised by decentralisation, administration and the rapid development of the media and technology. Furthermore, society is characterised by the fact that national politics have little effect on the global economy, which in turn results in political crisis and insecurity about the future. Another defining character of today's society is life-long learning, without, however, allowing the individual to fully reach her potential (Uljens, 2001). Uljens (2001) claims that the consequence of today's society is that politicians, authorities, educational administration, employers and employees, as well as both parents and youngsters, are irresolute in their conception of what role education and upbringing need to take on the individual, collective and cultural-societal level.

Importantly, Uljens points out that upbringing and learning (*bildung*) are the two processes enabling an individual first to become part of a culture and second eventually to take over the culture. Moreover, pedagogy is the tool through which culture is maintained and modified (Uljens, 2000). Referring to Harva's and Kant's ideas of what education is, Uljens (2000, 23) points out that the role of education is clear as only "education makes man a man". People thus need to be educated and learning is, in fact, considered a civil duty. In this sense, pedagogy is both repressive and liberating: the individual obtains her freedom, albeit only under certain conditions (Uljens, 2001).

The education and upbringing of children in today's society is indeed a challenging task, even for parents and educators of hearing children or children belonging to a language majority. But for a hearing parent of a deaf child the above discussion of allowing – through education and upbringing – an individual to become a member of a culture is more complicated and multifaceted. Many of the issues concerning cultural identity, language and education that can be taken for granted for the majority of parents tend initially to be sources of distress, conflict and disappointment for hearing parents with deaf children. Integrating a hearing-impaired or deaf child in a school for hearing children will give the child an opportunity to enter and acquire the culture, language and traditions of the hearing community. It will not, however, give the child a chance to learn about the history and culture of deaf and hearing-impaired people. This is something the parents, if they feel it is for the good of the child, must arrange for outside school. As for deaf signing children (from the Finland-Swedish community) the civil duty of learning is nearly impossible to achieve on equal terms as for other children. The Finnish

constitution does acknowledge Sign Language as a minority language but no school in Finland can offer education with the Finland-Swedish Sign Language as the medium of instruction. Parents of these deaf signing children, who belong to a minority within a minority, are faced with many conflicts concerning their child's education and the freedom of educational choice is limited. It could, in fact, be described as a no-win situation.

Both parenting and the child's development take place within an interacting ecological framework (Buchanan, 1998). There is a close connection between factors within the child and factors within the parents and the family including the shared environments of brothers and sisters. The factors within the family interact with elements outside the family such as the school, and, in turn, the school interacts with the extended environment and society on the whole, including economic conditions, attitudes, values and societal expectations (Buchanan, 1998, 4).²¹

Peers and socialisation

Recently, findings from the fields of deafness and language learning in deaf children have been the subject of many different areas of research. One topic relating both to parenting and deafness is set forward by Harris (1998). The author discusses the effect of peers on socialisation. Harris argues that children's peers have a much stronger effect on socialisation (that is, how children acquire the norms and values of society) than the children's parents and that, in fact, parents have little or no effect. Gardner (1998) objects to the fact that Harris's arguments depend largely on the language and language acquisition in deaf people and on the loss of foreign accents among children of immigrants. Gardner continues by stating that the case of deafness and deaf adolescents has not to do with the personality, character or temperament, that Harris claims to discuss, but with the immense disparity between hearing adults and deaf children. Because of the language difference between deaf children and hearing parents, the children have no choice but to turn to resources outside the home, such as adult teachers, peers and the media (Gardner, 1998).

²¹ Bronfenbrenner's (1979) theory on interacting ecological framework has had a great impact on developmental psychology. According to Bronfenbrenner the key to development can be found in a person's interaction with both others and the environment. We all function in more than one environment, with each environment having its own rules, roles and norms. Bronfenbrenner (1979) named the four different environments or systems **the microsystem, the mesosystem, the exosystem and the macrosystem**. **The microsystem** is the immediate environment in which an individual functions; **the mesosystem** is two microsystems interacting, such as the interaction between a child's home and school. **The exosystem** is an environment that is external to the person, one in which the person is not directly involved but which nonetheless has an impact on the person. Finally **the macrosystem** is the wider cultural context.

Gardner's discussion reminds us yet again that the process of socialisation is unique for deaf children of hearing parents, as compared to most other children. This needs to be recognised by parents and teachers of deaf children. As is discussed throughout this work, interaction with other deaf people, both peers and adults, is essential for a deaf child. Nevertheless, like any other child, a deaf child certainly needs his or her parents for guidance and support. An interesting question discussed in this study is whether hearing parents of deaf and hearing-impaired children (as part of the early habilitation) receive enough guidance and information to support the development of their child.

Gardner (1998) leaves little doubt concerning the role of parents for a child's socialisation and ability to grow into a functioning individual within the family's prevailing culture and society. Even when it comes to the choice of peer groups parents do play a significant part as parents encourage or discourage certain groups of friends and because they choose the child's schools and after-school activities (Gardner, 1998, 22). In fact, Gardner eloquently, and without disregarding the effects of peers or other influences on the child's personality gives a strong emphasis to the role of parents for the child's socialisation.

4.2 Language, culture and identity

Children are born into a culture and not merely into a family, and the culture with all its assumptions influences children from birth throughout their entire life (Gardner, 1998). Gadamer (1989) strongly emphasises that we exist through tradition and that we are at all times influenced by the historical-cultural context in which we live. Even though we are not always conscious of the cultural premises directing our lives, we develop "an unconscious mental model of our culture" facilitating our everyday life and the situations we encounter (Lane, 1993, 161). For hearing parents of deaf children this mental model does not always help in passing down to their children traditions, values and the culture into which they are born. The model has to be altered in order to match the needs of a deaf child. For hearing parents of deaf children this can be a dilemma and source of great conflict, for choosing Sign Language indicates not only that the child's native language but also the cultural belonging will partly differ from that of the parents. For this hearing parents are not prepared, and the task of raising a deaf child may initially seem both difficult and frightening. The parents need to decide which language to use with their child, as the parents' natural instinct of communicating in their own mother tongue may not be suitable for a child with a hearing loss. This is a complex issue few parents even in bilingual societies are faced with. How parents deal with this unexpected task and how they reason on issues such as language and cultural belonging are topics of interest in this study.

Language is connected to our identity, self-awareness and inner being, but even so it does not only exist in the minds of people since language is to a great extent situated in a social context (Jackendoff, 2002). Language connects people: individuals speaking the same language often feel they, on a psychological level, have a special bond. This especially holds true for individuals belonging to a linguistic minority (Malm & Östman, 2000). Malm and Östman (2000) also claim that the

language tie tends to be stronger than other human characteristics. People speaking a majority language do not question, or even reflect over, the right to use their language (Malm & Östman, 2000). However, people speaking a minority language cannot assume to be understood by everybody, or even be allowed to use their own language (Malm & Östman, 2000).

Our linguistic development is linked to our cognitive, social and personality development, as well as to our self-esteem and identity (Linell, 1978). Most of us take language for granted and we use language almost all the time. Yet rarely do we reflect over the significance of language, the nature of language and what life without a language would be like. Deprived of language we would, to a much greater extent, have to refer to ourselves and to our own personal experiences, lacking the capacity for planning for the future or for formulating questions (Skutnabb-Kangas, 1981). There are several examples of what impact language – or the lack of language – has on the individual, the cases of Genie (Curtiss, 1977) and the Wild Boy of Aveyron (Lane, 1976) perhaps being the most famous ones. Schaller (1990) tells the story of a deaf man with no spoken or signed language. Schaller was determined to teach him ASL and in the beginning the deaf man repeated Schaller's signs, mime and movements with an expression indicating that he did not understand the meaning of concepts or symbols. When he finally broke through and understood the implication of language and communion of minds he was demanding and eager to discover the world he had lived in for so long, but did not fully comprehend (Schaller, 1990). Kegl, Senghas and Coppola (1999) report a sensation of modern linguistics; how a new and complex Sign Language emerged in Nicaragua a decade after previously isolated deaf children with no method of communication apart from simple gestures or home-signs (see below) were brought together in deaf schools. In the 1980s the new Government made a push towards providing schooling for deaf children and what happened when the deaf children interacted is both remarkable and unique and has been the focus of many reports and studies. Kegl *et al.*'s study on the development of Sign Language in Nicaragua also tells the story of how many deaf people grew up with no access to Sign Language or social interaction with other Deaf people, and their mental expansion when they were introduced to the language of Sign.

Home-signs

Goldin-Meadow and Feldman (1977) studied the communication in a group of profoundly deaf children with hearing parents encouraging the children to use speech only. The children attended an oral education programme that did not accept the use of Sign. The findings of this study showed that the children invented their own communication system using gestures and so-called home-signs.

Sinkkonen (2000) also mentions the use of home-signs in deaf children not being exposed to a natural signed language. Although Sign Language can be arduous for hearing parents to learn, Sinkkonen emphasises the significance of signed communication for deaf children. It is important for the child to be able to express thoughts and emotions without having to concentrate on the communication itself and by using Sign Language the deaf child does not need to spend an unreasonable effort on receiving or transmitting a message. Continuous frustration at not having

a well-functioning language leads to temper tantrums, discouragement and finally despair, and according to Sinkkonen (2000) this certainly has a negative effect on the child's self-esteem and self-identity.

Padden and Humphries (1988, 119) consider the examples of home-signs fascinating, home-signs show that an individual's need to communicate is so strong that in the absence of a language an individual tries to create one. Furthermore, the authors write that culture and language are passed down from one generation to the next, and emerge to correspond to the specific biological features of a particular cultural or linguistic group. The conditions of communication for hearing children of hearing parents and deaf children of deaf parents are adequate and thus do not require any form of invented gestural or other invented language systems.

In becoming a member of a society, language thus plays an irreplaceable role. Through language we learn, for instance, about past generations and consequently pass our culture and our traditions to our own children. This is a vital part of upbringing, and a part that we often take for granted. For hearing parents, choosing Sign Language and thus raising a child in a language, and into a culture that is not their own may indeed seem intimidating and even impossible as our mother tongue is so strongly connected to our identity and ability to express our emotions.

The minority situation for Deaf people

As Romaine (1989) points out, the majority language is usually attributed positive qualities, while the non-dominant minority language is often viewed negatively. Although bilingualism and multiculturalism is becoming more common in Europe the fact that Sign Language as a minority language is connected with many negative qualities may certainly discourage some hearing parents from choosing Sign Language as the native language of their child. Currently, only eight countries world-wide – Finland being one of them – have acknowledged the national Sign Language in the constitution, and in around thirteen other countries the national Sign Language has some legal status (Burns, Matthews, & Nolan-Conroy, 2001, 191). Even though public awareness of Sign Language is increasing many hearing people consider Sign Language to be “a need” of Deaf people and not a natural language (Burn *et al.*, 2001, 191–192).

The minority situation for deaf people does resemble that of other linguistic minorities, but it also has significant differences (Smith, 1996, 9). People belonging to the Deaf community have their own language and culture. (The Deaf community and Deaf culture is presented in more detail in Section 2.5). Furthermore, many deaf people have experienced discrimination both in school and in their professional life, many have assimilated the hearing society's negative view on their language and culture and most deaf individuals are, at least to some extent, bilingual (Jokinen, 2000; Lane, 1993). Communication difficulties arise in everyday situations such as the receiving of information and services as well as participating in different social groups in school, working-life or during leisure activities (Jokinen, 2000).

What connects deaf people as a group is above all their language and their shared experiences of being deaf and Sign Language users. It is important to note that for deaf people it is not the absence of sounds, but the existence of Sign Language, that makes the group a group (Malm & Östman, 2000). At the same

time, we must also bear in mind that deaf individuals, like hearing individuals, belong to many different social groups and that deaf people share many characteristics, but certainly not all (Jokinen, 2000).

Jokinen (2000) also points out that deaf individuals may have difficulties maintaining a strong sense of identity and self-esteem. Indeed, according to many theoretical positions, culture and language are closely linked to one another. Knowledge, norms, values, language and social group are all parts of our culture, and culture, in turn, is part of our everyday life. However, if the language of a particular culture is discriminated against or has low status in society, it may influence the group cohesion and, above all, the individual's self-esteem and identity (Linell, 1978). As Lane (1980) states, speakers of a dominant language have two ways to eradicate a non-dominant language: either by replacing it or dialectising it. Since a signed language and the national spoken language are unrelated it seems unlikely that native signers could consider their language to be a dialect of a spoken language. In spite of this – and paradoxically (presumably) with the welfare of the deaf child as the main goal – the speaking majority in supposedly all countries have from time to time tried to dialectise Sign Language and assimilate Deaf people with the hearing majority (Lane, 1980). Also Cohen (1995) points out that hearing educators of the deaf have through all times tried to cure deafness, but have rarely themselves bothered to find out anything about Sign Language and Deaf culture.

A minority language can also be discriminated against in a more subtle way, for instance by the absence of bilingual caregivers and teachers in day-care and school settings or by the teaching of the majority language during native language lessons (Jokinen, 2000). The minority language is looked upon more as a burden, a burden that inhibits the acquisition of the majority language, than as a resource. This does indeed inhibit the acquisition of the majority language through the children's native language. According to Jokinen (2000) this is happening to the majority of deaf children world-wide as 90% of the world's deaf children attend oral education programmes. As a result, many deaf children perform poorly in school, which has, in turn, led to many problems regarding alienation and even mental health problems.

Attitudes towards deafness

Hearing people's lack of knowledge of or contact with deaf people is bound to affect the attitudes hearing people have towards deafness and Sign Language. We are imbued with the view that many medical shortcomings can be fixed. For many hearing people deafness is a disability that, if possible, should be eliminated in order to give deaf and hearing-impaired children a chance in life. Technical advances (such as improved hearing aids and cochlear implants) have contributed to the widespread opinion that deafness can be cured; that deaf children can learn to hear and speak – the consequence being that there is no need for Sign Language or a socio-cultural approach to deafness. When a child is diagnosed as deaf or hearing-impaired, the health resources and support systems provided by society tend to concentrate on the hearing loss, rather than on the child's total development of which deafness is only one of many features. Many deaf people, however, feel they live productive and happy lives, feeling whole as deaf individuals.

The ethics surrounding disability can indeed be complex and the opinions of the able-bodied majority very strong. This is demonstrated by the reactions to a deaf American lesbian couple wanting their children to be deaf (Driscoll, 2002). The couple hoped for a deaf child as they strongly felt that they could more successfully parent and guide a deaf child than a hearing child and therefore used a fifth-generation deaf man as a sperm donor (Driscoll, 2002). Reactions to the couple's choice have been very strong: politicians, moral philosophers, mothers, and also members of the Deaf community have been shocked over the couple's decision of wanting a deaf child (Driscoll, 2002). The debate on so-called perfect designer babies is of current interest but the possibility of designing in disability was presumably never an issue (Driscoll, 2002).

The Deaf community

The Deaf community is of great importance as a transmitter of Deaf culture and Sign Language, as a place where Deaf people are able to communicate freely with everyone. For many deaf children the deaf club constitutes their first contact with other deaf people. This contact is very important, for the deaf child needs both deaf adults as role models and peers to play and interact with. Unfortunately, many hearing parents hesitate to contact the local deaf club. They are perhaps still unsure about their signing abilities and the concepts Deaf world and Deaf culture may be unfamiliar (Sacks, 1989). Like deaf parents of hearing children, they are distressed by having a child different from themselves (Preston, 1995). Both parents and experts (c.f. Erting, 1988; Padden & Humphries, 1988; Sacks, 1989) emphasise the value of the Deaf community for deaf people. According to Erting (1988), deaf children need deaf role models. Interaction with other deaf people helps deaf children to develop a strong identity and promotes their linguistic competence. Padden and Humphries (1988) claim that research on Deaf culture gives a new perspective on culture and the relationship between the individual and culture. In most descriptions on language and culture, children are considered to have adult models that pass down the language and culture. The child is also considered to have its parents as role models concerning values, attitudes and conception of life (Padden & Humphries, 1988). For many deaf people the situation is quite different, they are set aside from their history and culture. The deprivation and isolation which many young deaf experience before they come in contact with their own culture and history clearly shows the individual's need to be linked to her past (Padden & Humphries, 1988).

Intergenerational interaction in families with deaf children

A discussion on some characteristics of intergenerational interaction in families with deaf children will conclude this section. Intergenerational interaction is defined as the relationships between generations in a family (Hurme, 1988). Hurme (1988) conducted an interesting study on (among other things) the interactions, mutual aid and support as well as affective relations of child (age twelve), mother and grandmother in Finnish families. Her study showed that the bond between adult daughter and mother varied greatly among the seventy families studied, from having a strong relationship to barely being on speaking terms. The adult mother

was more dependent on her husband than on her own mother and the grandmother was not very important for the grandchild either. Still, the relationship between grandchild and grandmother was not unaffectionate, rather affected by the twelve-year old child's numerous leisure activities (Hurme, 1988).

Bearing in mind that the majority of deaf people have hearing parents and also that many deaf people have hearing children, the intergenerational constellation regarding linguistic and cultural belonging in families with deaf members is intriguing. Hearing parents with a Deaf signing child may someday have a grandchild who is hearing. In other words, the grandparents have a child whose primary language is not their own native language yet a grandchild, who, in addition to being fluent in Sign Language and acquainted with the Deaf community, shares their culture and spoken language. For many hearing children of deaf adults the native language is a Sign Language but the national spoken language is also a primary language and therefore they typically have one foot in the hearing world and one foot in the deaf world. The hearing grandparents may of course also be fluent in Sign and active in the Deaf community but (compared to the language situation for the hearing child of deaf parents) Sign Language is not their native language. The deaf child in the middle generation does bring both his or her parents and children into the Deaf community and the world of Sign Language but there may still be a strong linguistic and cultural connection between the grandparent and grandchild.

This said, it does of course not imply that the relationship between hearing grandparent and hearing grandchild is always a good one or that the hearing parent – deaf child relationship or deaf parent – hearing child relationship is not good. The birth of a deaf child in a hearing family (see Section 4.4) or a hearing child in a deaf family can initially put a lot of strain on the family. Even so, and more important, we must bear in mind that the long-term relationship and attachment between hearing parent – deaf child, or deaf parent – hearing child does not need to be negatively affected by difference in native language. Here the aim is only to point out how the intergenerational constellations of hearing grandparent – deaf child/parent – hearing grandchild and deaf grandparent – hearing child/parent – deaf grandparent are interesting when looking at transmitting language, culture and traditions. Whether hearing or deaf, the desire to give one's own language and culture to one's children is strong, but in families with both deaf and hearing family members the cultural continuity is subject to more reflection and awareness than in most other families. For hearing parents with deaf children learning Sign Language and becoming members of the Deaf community the generational continuity of language and cultural tradition is partly held back. Within the Deaf community the passing of the national Sign Language and national Deaf culture from one generation to the next is constantly broken (except for families with deaf parents and deaf children). That is, the continuity found in most other cultures is not found in Deaf communities.

4.3 Parental awareness and educational decision-making

It is widely accepted that parental beliefs (Hirsjärvi and Perälä-Littunen, 1998; McGillicuddy-De Lisi, 1992), parenting strategies (Applegate, Brant, Burlison, & Delia, 1992), family structure (Carlson & Corcoran, 2001) and parent-child interaction as well as genes (Meadows, 1996) affect child outcome. In addition, educational availability, employment and socio-political issues within the family's broader sociological context influence the child's social and cognitive development (Meadows, 1996, 58). Despite the wide range of factors affecting child outcome four main factors, that may occur simultaneously or interactively, can still be discerned (Carlson & Corcoran, 2001). These factors are economic status, parental socialisation, childhood stress and maternal psychological well-being (Acquilino, 1996; Carlson & Corcoran, 2001; Richards, 1996).

Economic status

A family's low income has a negative influence on the child in several respects. Low-income families may not be able to provide the child with the nutrition, housing or material goods needed for a positive, healthy social and cognitive development (Carlson & Corcoran, 2001; Hanson, McLanahan, & Thomson 1997). Children growing up in a low-income neighbourhood also tend to receive less positive socialisation and less positive peer influence than children living in more affluent neighbourhoods (McLanahan & Sandefur, 1994). This is particularly true in countries like the U.S but similar tendencies can be observed in other countries as well. Also, continuous economic stress may limit low-income parents' psychological resources for positive parenting.

Socialisation

The home environment and parenting behaviour is significant for the child's socialisation and for the cognitive and emotional development of the child, for the home should provide a rich and warm environment fostering learning and development (Carlson & Corcoran, 2001). According to Hirsjärvi and Perälä-Littunen (1998, 9) it is reasonable to conclude that "parents' ways of thinking and understanding are important components of their practice", that is, the way in which parents reason about children and parenting determine how they raise their offspring. The parent-child interaction is the basis for the development of a child's character and there is also a connection between parent-child interaction and the child's cognitive development, such that children receiving more parental scaffolding perform better cognitively and educationally than children receiving less parental scaffolding (Meadows, 1996, 95). Meadows (1996) continues by pointing out that although this correlation certainly exists it is not simple to point out the specific factors in parental beliefs and parental behaviour that positively influence a child's cognitive development.

Another factor influencing the socialisation of children is whether the parents live together or apart. Divorce results in life changes for children; change of school and move to another residential area (and change of school), a change in the relationship between child and parents, as well as a change in the relationship between

the child and the non-residential parents' relatives (Richards, 1996). Moreover, single parents tend to have less time and parental resources to monitor and encourage the child's socialisation process as compared to parents living together where both parents can take part in the every-day child rearing (Carlson and Corcoran, 2001).

Stress

Several different types of changes are brought on the family: societal changes, life transitions, family events. Whether "good" or "bad", changes in family structure and conditions result in stress responses. Changes are part of normal life and often desirable but changes in residential location and household composition as well as conflict between parents are considered to raise the level of stress in children (Carlson and Corcoran, 2001). The impact of change depends on the family's resources and coping ability, for change is troublesome only if the family or family members are unable to cope with the degree of stress (McKenry & Price, 2000). Tension and problems at home may decrease the amount of positive parental influence and increase the degree of negative peer influence (Carlson and Corcoran, 2001).

Maternal Psychological Well-being

It is recognised that maternal psychological well-being is another factor within the family structure that may influence children's behavioural and cognitive development.

Family background is thus a significant factor in predicting children's social and academic functioning and this naturally also holds true for deaf children (Ritter-Brinton & Stewart, 1992, 85). For example, parental acceptance and family adaptation to the child's deafness correlate with achievements in reading and mathematics (Bodner-Johnson, 1985; Ritter-Brinton & Stewart, 1992).

Parental awareness

As was mentioned above, it is not clear exactly how parent-child interaction influences the child's cognitive development. Nonetheless, it seems reasonable to conclude that there certainly is a connection. The four levels of parental awareness as identified by Newberger (1980, 47) also put much emphasis on parent-child interaction. In her work "parental awareness can be thought of as an organised knowledge system with which the parent makes sense out of the child's responses and behaviour and formulates policies to guide parental action" (Newberger, 1980, 47). With greater awareness comes a deeper understanding of both the child and of more complex parent-child interactions. In each higher level the characteristics of the lower levels are incorporated in both the parents' behaviour and their growing awareness of their child as well as of themselves as parents. The four levels of parental awareness described by Newberger (1980) are:

Level one. Egoistic orientation

Parents functioning at level one are unable to view the child as a unique individual. Hence parental behaviour is more focused on parental needs and wants and believing these to be needs of the child.

Level two. Conventional orientation

Parents functioning at level two engage in childcare methods as defined by the culture, tradition and authority in a firm belief that these rules apply to every child without room for individuality for any child (Newberger C., 1980; Newberger, E.H, 2001).

Level three. Subjective-individualistic orientation

At level three parents are not governed by externally derived rules of what constitutes good parents or good children, rather the parent-child interaction is at focus and parents strive both to identify and meet the needs of each individual child.

Level four. Process or interactional orientation

The parent is aware of the child being a “complex and changing psychological self-system” (Newberger, C., 1980, 50) and at this level the parent-child relationship is a mutual one allowing both parent and child to develop and change. Parents at this level have a higher degree of self-awareness (as compared to parents functioning at the three previous levels of parental awareness) and strive both to meet and balance the needs of parent and child (Newberger, C., 1980, 50; Newberger, E.H., 2001, 23)

Parental educational decision-making

Choosing a school for one’s children is not a single event at a particular time but rather a complex, serious and multi-layered social process involving many different participants. Although the decision-making of education and school in a study conducted by David (1996)²² often involved many participants, regardless of type of family, mothers were nearly always involved in the family’s educational decision-making. Fathers were not as frequently involved and comparing families with single mothers, two-parent families and families with one step-parent it emerged that family structure did not explain fathers involvement. In some single mother families the father was involved in the educational decision-making whereas this was not always the case in two-parent families. According to David’s study the commitment of fathers in relation to educational decision-making is more dependent on the social and cultural characteristics of the families. Even so, although both parents often take part in the educational decision-making this process seems by and large to be a maternal responsibility and a result of the mother’s hard work and commitment to child-care and childrearing (David, 1996). In the study the child was also found to be involved in the choice of secondary school but rarely as having the decisive responsibility (David, 1996).

²² David’s studied educational decision-making in relation to secondary schooling in families living in London.

David (1996) found three factors that influenced the choice of school: the performance or academic achievement of the school, the atmosphere of the school and the location of the school (how close the school is to the child's home). Taken individually these factors were not decisive; rather it was a mixture of all three factors. As the author points out, this finding is not congruent with (British) government policies that parents view the school's educational performance as the most significant factor in their educational decision-making (David, 1996).

A conflict prevalent for most families with deaf children is the choice of educational placement, which indeed is closely related to the selection of the communication mode. In short, many families are faced with the decision of either placing the young child in the neighbourhood school or sending him or her to a special school far from home (Moore, 1991). By attending the neighbourhood school the child can live at home, which of course is desirable, but in a school for deaf children with a trained staff and a training programme structured for deaf pupils the child may receive a better education. Earlier, many schools for deaf pupils were residential and due to long distances and limited transportation the children spent little time with their families (Moore, 1991, 35). Today, deaf children in many residential schools travel home for the weekend.

4.4 Parenting a deaf or hearing-impaired child

Most views on parent-child interaction, parenting strategies, parental awareness and educational choices are based on the normally developing child. However, fostering, educational decision-making and parent-child interaction takes a new form in hearing parent-deaf child communication when there is initially no shared native language for both parties to convey needs, wants, rules and explanations. In most families a shared language (or in the case of bilingual families, two languages) and the child's acquisition of language is taken for granted and is seen as a tool for further interaction and learning. However, in families with children whose acquisition of language is delayed by deafness for example or a language disorder such as dysphasia, the concept of communication and language needs to be reconsidered. More importantly we must recognise that despite initial stress responses the hearing parent-deaf child interaction need not be permanently affected (Hintermair, 2000). Establishing a functional communication is however the most important step for the development of a good parent-child relation as well as an acceptance and understanding of the deaf or hearing-impaired child (Hintermair, 2000).

Parents of deaf or hearing-impaired children encounter a range of dilemmas, challenges and rewards which they did not expect during their transition to parenthood. Bringing up a deaf or hearing-impaired child partially differs from the average parenting, and having a child with hearing loss often means that the following three issues are integrated in the role as parents.

Parenting relying on support

Parents of children with special needs are more dependent on social support, professional assistance and the help of society than parents of normally developing children. As was mentioned in Section 4.4, when the child's hearing loss is diag-

nosed, parents need support and information in order to learn more about hearing-impairment/deafness and to learn about hearing-impaired/deaf children's development, habilitation programmes, communication methods and educational options.

In times of crisis, such as the birth of a child with a disability, a strong family bond and a good relationship between husband and wife are important factors in the coping process (Hintermair, 2000). When faced with a difficult life event social support is also of immense value and enables the individual to become aware of his or her own beliefs and conceptions. The significance of sharing experiences with a person in a similar situation is well known, as well as empirically proven, and thus clearly very important in helping parents of deaf or hearing-impaired children to relieve their stress (Hintermair, 2000). However, hearing parents' existing social networks rarely provide sufficient or adequate support in coping with their child's loss of hearing. The contacts with other parents of deaf or hearing-impaired children thus prove to be extremely important and many parents report receiving the best emotional and social support from other families with deaf or hearing-impaired children. If the social support and information given to families with deaf or hearing-impaired children is carefully planned and adapted to each individual family the negative effects of the disability are reduced (Hintermair, 2000).

Pedagogical reflection in parents of deaf or hearing-impaired children

Becoming a parent is a significant life event and a major change for the family unit but the adjustment to parenthood and to childrearing is even more complex if the child does not meet the parents' expectations of their (unborn) child. A child not responding or behaving as normally expected may first result in stress and conflict for the family, but not to forget, in due course, also in deep feelings of joy and reward, and thus loved and treated as any other child. This can be the case if a child born to hearing parents is diagnosed with a hearing-loss. Most, if not all, parents expect to develop an easy mode of communication with their child but in the case of deaf children their (hearing) parents' expectations are dashed. The discrepancy between expectations and reality may at first be a source of stress and grief. Parents of children with special needs are provoked in self-reflection and an awareness of their childrearing beliefs in a profoundly different manner compared to the average parent.

Although many parents today often have a general knowledge of child development and educational matters, they are not considered to have or to need an expert knowledge on education. Generally, parents can rely on love for their children, tradition and common sense when bringing up their child. They do not need to legitimize their view on childrearing, child development or education. But for parents of deaf children this may not prove to be enough. In order to help their child receive the best start in life and a good education parents often become experts on the development, special needs and education of hearing-impaired or deaf children. As parents begin to view these issues from different perspectives and to consider alternative (communicational and educational) solutions, their reasoning and thinking become increasingly flexible. By necessity and since their child cannot automatically follow the educational course which hearing siblings or other

children generally follow, the parents' pedagogical thinking and awareness are developed and elaborated. For the teacher of mainstreamed hearing-impaired or deaf children this can be a challenging situation, for the parents often possess a pedagogical knowledge and awareness not usually needed. Furthermore, the parents may well have a pedagogical knowledge that exceeds the teacher's on the particular matter of education for deaf or hearing-impaired children.

Future-oriented parenting

The upbringing of children with a hearing-impairment is more future-oriented than for most other children. Parents of hearing-impaired children need earlier than most other parents to make decisions concerning their child's language and education and to be aware of how one choice may influence the child's future educational choices and possibilities.

4.5 Hearing parents' communication choices

Lenneberg (1967) argued that language acquisition is determined by maturational factors and that native fluency in a language can only be achieved by exposure to linguistic stimuli during a critical period. Bearing in mind that 90% of deaf children have hearing parents, and that many hearing losses are not detected until the age of approximately two and a half (Mäki-Torkko, 1998), early accessible linguistic input for the many deaf children is limited. The selection of a communication mode for deaf children in hearing families is typically done by the mother, and the three main factors that influence her choice is the child's degree of hearing loss, the available services (such as pre-school programmes) and her own level of education (Kluwin & Gonter Gaustad, 1991). Higher levels of education are linked to the selection of manual communication (Kluwin & Gonter Gaustad, 1991).

The early habilitation and choosing a method of communication

As hearing parents rarely have any experience or background knowledge of deafness or different methods of communication, it may be initially difficult for them to understand fully the impact a loss of hearing has on the child's linguistic, cognitive and psychosocial development. Diversified information on deafness and communication is thus of crucial importance.

One problem, however, is that the information which parents receive during early habilitation may be contradictory. No matter how hard parents try to make a sensible decision they do not always know who to listen to, and regardless of the choice the parents make someone is bound to judge them. It is therefore absolutely indispensable to give the information on deafness to the parents in small portions and on repeated occasions. The parents will need to meet the experts several times, giving the parents a chance to process possible feelings of disappointment, sorrow, and guilt (Sinkkonen, 2000).

As nearly all deaf children (90%) have hearing parents, a child's deafness can initially be seen as a challenge for the family (Sinkkonen, 1994, 19). Parents experience a range of different emotions, beginning with shock and disappointment but resulting in an intrapsychic equilibrium and acceptance of the child's deafness

(Sinkkonen, 1994, 20). Nevertheless a deaf child in a hearing family can at first be a source of possible stress and it is plausible that the parents' capacity to cope with this potentially lifelong stress factor may influence the deaf child and the hearing family (Calderon, Greenberg, & Kusche, 1991, 195).

Early parent-child communication

Achieving efficient parent-child communication is a priority and should receive a great deal of recognition in the early habilitation (Ritter-Brinton & Stewart, 1992, 85). Parallel with the emotional distress of learning that their child has a hearing loss, the parents need to choose what communication mode should be used with the child. Parents of deaf children too often end up being their child's teacher rather than a parent (Nowell, 1991; Sinkkonen, 2000). Instead of enjoying their child, the anguished parents worry about whether they are doing the right thing regarding early intervention and education of their deaf child (Sinkkonen, 2000). Parents have an irreplaceable role in stimulating their child's early cognitive development, and although there are many plausible explanations for why this is so, there is a connection between parents' behaviour and their children's cognitive development (Meadows, 1996). Ahlström's (2000) study on the communicative and social development in hard-of-hearing children indicates that a supportive child-oriented communicative style has a positive outcome on the child's overall development. No less than any other parents should parents of deaf children provide a loving and enriching environment for the child (Nowell, 1991). Consequently they should not focus on being a teacher for their child (Nowell, 1991). It is also important to understand that spontaneous play has a much greater impact on the child's development of language than continuous training (Sinkkonen, 2000). Preisler's study (1983) shows that parents trying to articulate very clearly (as if the children could lipread) do in fact look angry and the facial expression is somewhat distorted. It is therefore absolutely necessary that the parents receive early support, which must include relevant information on deafness and appropriate solutions for the type of problem situations that a hearing family with a deaf child may encounter (Calderon *et al.*, 1991). Furthermore it is crucial to ensure that the child has an accessible first language and that the family has social support and interactions that also includes the deaf child (Mahshie, 1995, Calderon *et al.*, 1991).

Parents who use Sign Language with their child and have continuing interaction with adults who are deaf or hearing-impaired show significantly reduced social isolation and strong acceptance of their deaf or hearing-impaired child (Mapp & Hudson, 1997; Hintermair, 2000). According to Hintermair (2000) there are three possible reasons for these results. One explanation could be that good signing skills and frequent interactions with hearing-impaired adults lead to a wider social network in which the child is also integrated. Another reason could be that parents with a large and well-functioning social network are not reluctant to try new things and therefore learn how to sign. As a result they are able to integrate hearing-impaired/deaf individuals in their lives.

As Kluwin and Gaustad (1991) and Montanini Manfredi (1993) suggest, the choice of communication mode goes beyond the oral vs manual debate and also influences the social and personality development of the deaf child. The commu-

nication method undoubtedly will influence the cultural belonging with its respective values and norms and also the choices of school and peer groups. According to Sinkkonen (1994) a variety of factors do influence this decision. However not many studies have investigated why parents choose a particular method. Kluwin and Gaustad (1991) conducted a study with 192 parents of deaf adolescents on the selection of communication mode. The child's degree of hearing loss was found to be the most influential factor. The child's pre-school placement and the level of maternal education were the next two most influential factors. A higher level of education was found to correlate with the use of signed communication. For hearing parents, the selection of signed communication must be seen as a conscious choice since it demands an understanding of the consequences of learning and using a second language in communication with their child (Kluwin & Gaustad, 1991). The authors thus suggest that the selection of communication mode is highly mother-oriented, and also that if families choosing signed communication are to be increased, early intervention services should focus on less educated mothers.

Nevertheless, hearing fathers of deaf children should not be neglected in early habilitation programmes. Hadadian and Rose (1991) conducted an investigation of hearing parents' attitudes and the communication skills of their deaf children. The findings indicate that "as a group, hearing fathers and mothers of hearing-impaired children have relatively similar attitudes towards deafness" (Hadadian & Rose, 1991, 276). The findings also indicate that the deaf child in most cases had more contact with the mothers than with the fathers and, furthermore, that in most cases the mother is the more competent signer. In addition, the findings of the study indicate that there seems to be a significant correlation between the fathers' scores on the Attitude to Deafness Scale and the language scores of their deaf children.

Parents of deaf children are frequently concerned with the acquisition of the national language and in the past, studies on deaf children's language development have focused on the effects of the communication mode and educational programme on the acquisition of a spoken language (Evans, 1995, 324). However, not much attention has been paid to deaf children's communicational competence in natural settings (Evans, 1995). Studies demonstrating deaf children's abilities to use language for numerous purposes in a variety of natural settings may prove important in helping hearing parents realise that the use of signed communication does enable the deaf child to be both a competent and socially adaptive communicator.

Parents may also worry that learning Sign Language is difficult, and that their initial signing skills are not enough to ensure a rich and normal language development for the child. This worry is fortunately unjustified as parents need not necessarily function as the primary language models, for somehow deaf children pick up a grammatically correct Sign Language as long as they are exposed to signing in other settings (Londen, 1992). Deaf children learning Sign together with their parents quickly outperform them. But deaf children with no, or limited, competent language models are at great risk vis-à-vis linguistic development (Marschark, 1993). Multiple, engaging, and competent language models are thus essential (Erting, 1988; Nelson, Loncke, & Camarata, 1993). Another significant difference in the language input which deaf children of hearing parents receive, as opposed to

the situation for deaf children of deaf parents or hearing children of hearing parents, is the amount and quality of non-direct language (such as other people's conversations or television). Normally, children acquire part of their language through similar indirect language input, but for many deaf children this opportunity is not available (Marschark, 1993). A similar disadvantage is also evident in the classroom where much information never reaches a mainstreamed the severely hearing-impaired or deaf child.

Educational issues

Nevertheless, some parents choose to mainstream their deaf child in the neighbourhood school for normally hearing children. The reason is often that there does not exist another possible alternative and that the parents want their child to be educated in the same school as hearing siblings and hearing children from the neighbourhood.

For some Swedish-speaking parents in Finland the decision of what mode of communication – oral or signed – they prefer to use with their child does not resolve the issue of choice of communication. For some parents there is the additional concern of whether Finnish, Swedish or Sign Language should be used. The use of Finnish may provide the deaf child with more educational options in Finland whereas using Sign Language or spoken Swedish provides the deaf child with a wide variety of educational options in Sweden.

It should again be observed that these deaf children and their parents are faced with a difficult decision. In 1993 the only school in Finland for deaf children of the Swedish minority was closed. As a result, the deaf children from this minority group are not able to receive education in Sign Language in Finland together with other deaf children, unless they opt for a Finnish deaf school, thus forcing the deaf child early on to learn an additional language. The situation for Finland-Swedish deaf children mainstreamed in schools for normally hearing pupils is not satisfactory either. Given the fairly low prevalence of hearing-impairments – roughly one per thousand (Sinkkonen, 1994) – there is but a small chance that the neighbourhood school has more than one deaf child (Moores, 1991). This also holds true for the typically small Swedish schools in Finland. Of major concern is thus whether the educational and socio-emotional needs of deaf children integrated in the neighbourhood school are taken into consideration (Moores, 1991). These are important issues that parents have to bear in mind when planning to integrate their deaf child in a school for hearing children.

4.6 Summary

Raising a child is a demanding task and post-modern society with its rapid development in areas such as technology, education, social trends and family structure does not facilitate the challenges for today's parents. Economic status, parental socialisation, childhood stress and maternal psychological well-being as well as parental awareness and early parent-child interaction have been linked to child outcome.

The vast majority of deaf children have hearing parents who are rarely familiar with deafness, hearing-impairments or Sign Language. When the child's hearing loss has been diagnosed the parents thus need information about deafness/hearing-impairments as well as emotional support, including a chance to meet other parents with hearing-impaired children. The parents' coping process is greatly facilitated by interaction with other families (with deaf or hearing-impaired children).

Parents need objective, straightforward and multifaceted information about different methods of communication available for deaf children. Nevertheless, the process of choosing a primary language as well as school placement for their deaf child can be highly troublesome and have far-reaching consequences not only for the deaf or hearing-impaired child but also for the whole family. Language and culture are connected to our identity and inner-being and attributes we expect to pass on to our children. Hearing parents with deaf children need, however, to reflect on language and cultural belonging in a manner different for most other parents.

5 Early Habilitation and Deaf Education in Finland

5.1 Legal status of the Finnish Sign Language

Finland, with a population of about five million, is a bilingual country with Finnish and Swedish as the two national languages. The Swedish-speaking population is small, around 6%. Due to historical reasons, the position of the Swedish language is, nevertheless, quite strong. There are Swedish schools (from kindergartens to secondary schools), a Swedish university (located in Åbo) as well as Swedish mass media, theatres and other cultural institutions. Bilingualism in different countries obviously differs: in Finland bilingualism is of an exceptional type due to the possibility for self-identification: everyone is free to choose which language group she belongs to. Apart from the Finnish and Swedish-speaking groups there are also other linguistic and cultural minorities in Finland: the Sámi in Northern Finland, the Romani people, the Russian speakers and Deaf people.

There about 8,000 deaf individuals in Finland, of whom around 5,000 use Sign Language. Each year between fifty and eighty children are born deaf in Finland (Ojala & Norris, 1994). Between the years 1965 and 1996, approximately fifty deaf children from Swedish-speaking families were born (Hoyer, 1998). Deaf people who belong to the Finland-Swedish minority in Finland, and hence make up a minority within a minority, amount to about 150 (Hoyer, in press). One reason for the relatively small number of Swedish Deaf people living in Finland is that many of these individuals have moved permanently to Sweden (Edlund, 1999; Hoyer, 2000b).

The Finland-Swedish Sign Language

The Sign Language used by the Finland-Swedish Deaf people is an independent language (Hoyer, 2002) and should by all means be considered a Nordic language (Östman, 2002). The Finland-Swedish Sign Language is related to the Finnish Sign Language (Östman, 2002) which in turn is related to the Swedish Sign Language (Hoyer, 2000a). The Finland-Swedish Sign Language is continuously influenced by the Swedish Sign Language (Hoyer, 2000b). Even so and although there naturally exists slang and dialects within both the Finland-Swedish Sign Language and the Finnish Sign Language, Finland-Swedish Deaf have few problems understanding Finnish signers (Hoyer, 2000b; in press). From 1997 to 2002 the Finnish Association of the Deaf conducted a research project on the Finland-Swedish Sign Language (Hoyer, 2002). This research project resulted in the publication *Se vårt språk! Näe kieleemme!* (2002), which consists of a video and a dictionary with phrases in Finland-Swedish Sign Language translated into both Swedish and Finnish. The level of research in the Nordic countries on Sign Languages maintains a high international standard and this also concerns the research being conducted on the Sign Languages in Finland (Östman, 2002). See for example Hoyer (2000a) for a study on kinship terminology in the Finland-Swedish Sign Language and Hoyer (in press) for a study on the sociolinguistic situation of Finland-Swedish Deaf people.

The legal status of the Finnish and Finland-Swedish Sign Languages

For people in Finland the inclusion of (Finnish) Sign Language in the Finnish constitution 1995 (Laki No: 969, 14 §) was an important milestone (Rainò & Savolainen, 1999). This indicates that Deaf people should be guaranteed services by the authorities in Sign Language. Currently, only eight countries worldwide have included the national Sign Language in the Constitution, and in an additional nineteen countries Sign Language is, in some form, mentioned in other laws (Rainò & Savolainen, 1999). Finland was the second country (after Uganda) to give Sign Language an official status in the Constitution (Östman, 2002). A major achievement is also the 1998 publication of the Finnish Sign Language dictionary (*Suomalaisen viittomakielen perussanakirja*, The Finnish Association of the Deaf, 1998). Furthermore it may be pointed out that although the Finnish Deaf community is small, it is active both nationally and internationally.

The Research Institute for the languages of Finland was established 1976 and comes under the administration of the Ministry of Education. According to a 1996 Law (Laki 591, asetus No: 758), The Research Institute is obliged to study and develop the languages of Finnish, Swedish, Sámi, Finnish Sign Language, and Romany – the language of the Romani people in Finland (Rainò & Savolainen, 1999). The Research Institute for the languages of Finland supports research in many different areas of the above mentioned languages and provides guidelines for the use of Finnish, Swedish and Sámi. Since June 1997, the Research Institute has also had a Finnish Sign Language board that offers advice and recommendations concerning the use of Finnish Sign Language (Rainò & Savolainen, 1999), but not on the Sign Language used by Deaf people from the Swedish minority. In the year 1991 a Sign Language Centre was established at the Finnish Association of the Deaf (Rissanen, 2000). The Sign Language Centre handles the Deaf Association's general Sign Language issues, an interpreter service, research on Sign Language, arranges courses in Sign Language and provides information on Sign Language (Rissanen, 2000). In 1994 the Finnish Broadcasting Company started with news in Finnish Sign Language (YLE Finnish Broadcasting Company, 2003, www-document). At first the news was only broadcast on weekdays but starting in 1995 the news in Sign Language has been broadcast daily. Both the editor-in-chief and the signer are Deaf with Sign Language as their native language, and the journalist working in the news team is hearing with knowledge of Sign Language.

The status of Finnish Sign Language has thus improved during recent years. However, of major concern for the Deaf community in Finland is the fairly strong tendency for oralism, indicated for instance by the steadily rising number of prelingually deaf children receiving cochlear implants but no Sign Language. Cochlear implants were discussed in more detail in Section 2.6. At this point suffice it to call attention to the fact that the benefits of cochlear implants on small prelingually deaf children are controversial and do not automatically enable the child to understand and produce speech (Preisler & Ahlström, 1994; Söderfeldt, 1994b).

5.2 Early habilitation and services for deaf people in Finland

Although the situation for deaf people in Finland has improved during the past few decades there are still several areas where deaf people are not granted the same equity as hearing people. Of major concern is the accessibility to and quality of education. The improvement of the status of Sign Language also influences the acknowledgement and recognition of deaf people by the hearing majority. However, deaf people and Deaf culture still tend to be side-stepped.²³ Even among professionals working with deaf children the attitudes towards using Sign Language are sometimes surprisingly negative. Speakers at a seminar on the Satakieliprojekti (a project on the habilitation of children with cochlear implants) held in September 2002 in Vasa (Vaasa), clearly expressed the opinion that Sign Language is not to be used with deaf children with cochlear implants (Jan-Ola Östman, personal communication, October, 2002). The seminar favoured a monolingual (spoken language) approach, focusing on the development of speech and hearing. This approach can be set against the situation in Sweden where Swedish Sign Language is recommended for children with cochlear implants and where many deaf children with cochlear implants attend a deaf school and become bilingual and bicultural.

Deaf people in Finland are, of course, entitled to the services offered by society. For a report on hearing-impaired adults' views of Finnish society see Takala (1995). In addition, there are services aimed specifically at deaf people. For a complete and thorough guide to information and services for families with deaf or hearing-impaired children see "*Nyckelinfo för det hörselskadade barnets familj*" (2000). In this section a few services for deaf and hearing-impaired people are briefly described.

In Finland there are five University Hospitals with an Auditory Unit and sixteen Central Hospitals with hearing centres (Virpiranta-Salo, 2000). Of the five University Hospitals those in Helsinki, Kuopio and Uleåborg (Oulu) also have an audiological and a phonetics ward (Virpiranta-Salo, 2000). The first examinations and guidance provided for a child with a suspected hearing loss are mainly carried out at the five University Hospitals or the central hospital Keski-Suomen keskussairaala (Virpiranta-Salo, 2000).

When a child's hearing loss is diagnosed, a habilitation scheme is planned. The habilitation includes medical habilitation through a technical aid service, habilitation therapy (primarily communication therapy), home guidance-counselling service including Sign Language instruction, as well as adaptation training (Virpiranta-Salo, 2000). Representatives of the following occupational groups are always included in the habilitation team: doctors (one or more of the following: ear spe-

²³ For example in the 1997 Finnish governmental publication Suomen Kulttuurivähemmistöt (*Cultural Minorities in Finland. An overview towards Cultural Policy*), Deaf people as a cultural group are not mentioned.

cialist, senior physician, senior rehabilitation physician, phonetician²⁴, audiologist, audiological assistant and speech therapist (Virpiranta-Salo, 2000). If available, a rehabilitation adviser, social worker, psychologist, or a nurse is also involved. The child's parents are rarely included in the habilitation team; they only participate in the final habilitation meeting (Virpiranta-Salo, 2000).

The parents are, nevertheless, responsible for both the child's up-bringing and habilitation and have the right to receive pertinent information to help them in their decisions concerning their deaf or hearing-impaired child's habilitation and education (Airaksinen & Lehto, 2000).

In Finland there are twenty home guidance counsellors working with families with deaf children (Virpiranta-Salo, 2000). Two home guidance counsellors work with Finland-Swedish families; one works in the hospital district of Nyland (Uusimaa) and Åland, the other in the hospital district of Vasa and the hospital district of Central Ostrobothnia (Edlund, 1999). The assignment of the home guidance counsellors is to work as a contact between the families and the Auditory Units, schools and day-care centres but mainly to support the deaf or hearing-impaired child's language development. Another important part of the home guidance counsellor is to inform the parents and schools about technical aids, services provided to families with deaf children, educational options, parental organisations and courses of interest (Edlund, 1999).

In Finland, all families (including siblings) with a deaf or hearing-impaired child are offered adjustment courses. Both the Finnish Federation of Hard-of-hearing People and the Parental Federation of Deaf and Hearing-impaired Children arrange adjustment courses. The adjustment courses arranged by the Finnish Federation of Hard-of-hearing people focus more on technical aids and speech-training whereas the adjustment courses arranged by the Parental Federation concentrate more on deafness, Sign Language instruction and the Deaf community (Virpiranta-Salo, 2000).

However, as is the case with many other families with special needs children, early intervention programmes must be individually designed to meet the specific needs of a particular family (Meadow-Orlans, 1995). The Finnish Association of the Deaf was established in 1905 and is the oldest association for disabled people in Finland (Edlund, 1999). The objective of the social and habilitation programme of the Finnish Association of the Deaf is to guarantee deaf people the social services and other sources of help provided by society. This is carried out through a countrywide network of fifteen habilitation counsellors. The main priority is to provide deaf people with individual guidance in Finnish Sign Language.

²⁴ Phonetics is the science of speech processes, that is, the production, perception, and analysis of speech sounds from both an acoustic and a physiological point of view, and a phonetician is a person who applies phonetics in his or her work (Collins English Dictionary, 2003, www-document).

According to the Finnish law on services for disabled people an interpreter service in Sign Language and Finnish/Swedish is a subjective right of hearing-impaired people. A hearing-impaired person is entitled to 240 hours of interpreter service per year. The interpreter service is intended for everyday situations, studies, work, leisure activities and for obtaining information. The law does not stipulate how many hours of the interpreter service are intended for the different purposes, that is up to the deaf or hearing-impaired person to decide. Currently there are twenty-three Interpreter Units across Finland but families report many difficulties with obtaining interpreter service. The most common problems are the lack of interpreters, slow decision-process, difficulty receiving an interpreter on short notice and the fact that the interpreter service is only granted for twenty hours at a time. (Nevalainen & Virpiranta-Salo, 2000)

Disabled people in Finland are entitled to compensation for aids installed in the home, for deaf people these include an acoustic alarm-clock, text-telephone and a vibrating fire alarm (Nevalainen & Virpiranta-Salo, 2000).

5.3 Educational options for deaf and hearing-impaired children

There is no doubt that language proficiency is a prerequisite for both cognitive development and academic achievement. Only through a natural language can children acquire world knowledge, organise information and express themselves (Drasgow, 1998). Drasgow (1998, 337) also points out that early exposure to ASL provides deaf children with sufficient and flexible language skills, “so that when they enter school they can *continue* to learn rather than *begin* to learn”. Most hearing children enter school with extensive world knowledge. To what extent and *how* children’s background knowledge actually is used in the classroom is, however, debatable (Resnick, 1987). Putting this interesting discussion aside, most hearing children do enter school with a solid enough language and knowledge basis that enables further learning.

Deaf culture is situated in the hearing world and therefore knowledge of the national language(s) does indeed improve the deaf individual’s possibility to function and participate in society. A high-standard education and competence in Sign Language combined with a well developed literacy in the majority language is therefore the main objective for the recent approach to bilingual education for deaf children (which is discussed in section 5.3) (Mahshie, 1995).

The need for deaf people to be able to participate in the hearing society has certainly influenced the main dispute in deaf education, that of oral vs manual communication. Many hearing parents who choose to speak with their deaf child feel that orally trained children have more opportunities, that they are stronger academically, socially and linguistically than manually educated children (Moore, 1991). The important issue here is to examine the consequences and outcomes of both approaches. According to Montanini Manfredi (1993), the choice of school programme goes beyond the manual vs oral debate. The author points out that the choice of school also affects the deaf child’s development of social relationships and social abilities, as well as personality and identity (Montanini Manfredi, 1993, 54). A frequently neglected issue in the education of the deaf, is the lack of deaf

adult role models for deaf children in the schools (Erting, 1988; Londen, 1992). Deaf adults have similar background knowledge and experiences as deaf children. This has implications for deaf children's motivation and ability to learn (Padden & Humphries, 1988), and as Lane (1984, 300) writes, "instructing a deaf child as if he were not deaf generally suits his parents, if they are hearing, but it never suits his education".

Although deaf parents generally tend to have a lower socio-economic status (which has been linked to lower academic achievement) compared to hearing parents, deaf children from deaf families perform slightly better on academic skills compared to deaf children from hearing families. However, in Sweden the rate of deaf pupils attending college or university equals that of the hearing population (Inger Ahlgren, personal communication, April 3, 1998). Nevertheless, it is important to note, that regardless of parental hearing status, the average deaf child lags behind his or her hearing peers in most, if not in all, academic areas. As deaf children have no cognitive deficits, the educational system in most countries thus seems to fail many deaf children (Johnson, Lidell, & Erting, 1989). In fact, about 80% of the deaf population worldwide receive no education (*Proceedings, XI World Congress of the World Federation of the Deaf, 1991*).

Below the different educational alternatives for deaf children are briefly described. In Section 5.4 an outline of the educational options in Finland and in Section 5.5 the current educational options for Finland-Swedish deaf pupils are presented.

Deaf schools using Sign Language

Deaf schools can be residential schools or day-schools. Traditionally residential schools have been more accepting of Sign Language, considered to be the centres of deaf subculture (Meadow, 1980). In fact, given the inconsistency of generation change within the deaf community, schools for the deaf have a significant impact on the continuation of Deaf culture, on the pupils' signing skills and on Deaf awareness. Nevertheless, some schools for the Deaf use a Total Communication approach.

The aim of Deaf schools using visual communication is to provide the deaf child with a linguistically, culturally and socially accessible learning environment and to support the pupils self-esteem and deaf identity. The advantages of good residential schools are clear but the main disadvantage is that young children often have to live away from home. Understandably many parents are reluctant to send their young child away to school.

Oral education

Oral educational programmes for deaf and hearing-impaired children focus on speech training and lip-reading. Sign Language is not used, being in fact often prohibited, and parents are encouraged not to use Sign with their children. To the amazement of hearing people one can find deaf or hearing-impaired children attending oral schools who speak well and seem to hear when spoken to. However, only a small number of deaf children educated orally reach intelligible speech and satisfactory lip-reading skills (Evans, 1982; Lane, 1993). Among many, Lane (1993)

points out that we must consider several factors when evaluating the success of oral education. Whether the hearing loss is pre- or post-lingual has a decisive effect on the child's ability to speak and master a verbal language (Heiling, 1993; Lane 1993). Apart from the onset of the hearing loss the severity of the hearing loss does indeed also influence the development of speech and ability to lip-read. In addition, we must evaluate the orally educated child's ability to communicate in different settings and not only with family members and teachers (Lane, 1993). With the rising number of deaf children receiving cochlear implants the demand for oral educational programmes is likely to increase, as will the need to structure the instruction in order to meet the specific needs of these children.

According to advocates of manual communication, a predominantly oral environment does not provide deaf children with a good basis for the acquisition of social and linguistic behaviours. Moreover an oral educational programme²⁵ conveys in their view the message that deafness is not accepted.

Inclusion

Inclusion (or mainstreaming) indicates that the deaf or hearing-impaired child is integrated in a school for normally hearing children. Many issues need to be considered in order to facilitate the daily classroom situation for the hearing-impaired child: where in the classroom the pupil is sitting, the acoustics in the classroom and the size of the class, to name but a few (Mattus & Ojala, 2000). The need for learning support must also be evaluated and the teacher needs information and guidance (Mattus & Ojala, 2000). Deaf children integrated in regular school settings may have a personal Sign Language interpreter or an assistant. A deaf or hearing-impaired child mainstreamed in the neighbourhood school can live at home in a normal family environment and attend the same school as hearing siblings and hearing peers from the vicinity. This fact is highly valued by some parents.

Another reason for mainstreaming is that both parents and some educators often believe that deaf children integrated in schools for normally hearing children perform better academically, socially and linguistically (Moores, 1991). It has also been asserted that the cost of educating deaf children in residential schools is more expensive than educating them in regular school settings (Moores, 1991).

Today there is a strong tendency towards inclusive education for children with disabilities. Even though this multifaceted issue is not to be discussed in this work, one must bear in mind that for a deaf signing child inclusion can be considered a form of segregation. The question is whether a hearing school can support a deaf signing child socially, linguistically and cognitively. Although placement in a public school is an available option for deaf signing children few parents in Finland choose this alternative. The parents of signing children value highly the linguistic and social benefits of interactions with both deaf peers and adults and consequently they choose education in a deaf school. Nonetheless, the parental interviews show that when

²⁵ This regards deaf pupils and not hearing-impaired pupils who benefit from spoken language input.

considering the entire group of parents they are strongly divided in their beliefs about the appropriateness of mainstreaming deaf children. The beliefs are very much linked to their choice of communication method (see Section 8.3.4 and 8.3.6).

In countries such as Sweden and Denmark, where focus is on Sign Language and bilingualism for deaf children, mainstreaming is now often limited to hearing-impaired children who can participate and function in a school for normally hearing children without an interpreter or assistant. The reason is that deaf children must be allowed to be children, and children cannot play through an interpreter. Mainstreaming a deaf child in a school for normally hearing children is socially devastating for the deaf child (Inger Ahlgren, personal communication 1998; Kristina Svartholm, personal communication, 1998).

Bilingual deaf education

The latest movement in the education of the Deaf underscores the two languages and the two cultures of the deaf child. The Deaf communities as well as hearing educators and parents of deaf children now consider deaf children's achievement of bilingualism to be a very important part of the children's development and education.

The pioneering work of this movement originates in Denmark and Sweden, but has now gained more and more support in other countries as well (Hansen, 1989; Neuroth-Gimbrone, 1994). The national language is taught as a second language. Although the concept of bilingual education and second language learning is achieving more attention, research on these specific areas is scarce. The fact is that not many educational programmes have yet implemented this method (Drasgow, 1993). Proponents of this view believe that it is devastating to bring up a deaf child without any exposure to sign, without providing a good language base, and without installing an understanding of the child's own history and culture, all factors which are crucial for further learning (Mahshie, 1995). Interestingly, the need for deaf children to learn two languages was put forward by Carl Oscar Malm as early as 1852.²⁶

A basic rule behind bilingual education is the acceptance of Sign Language as deaf children's first language, and, furthermore as the language underlying speech learning, and thus fundamental for bilingualism (Bouvet, 1990). In Sweden, Swedish Sign Language is considered to be deaf people's first language, and according to a 1981 Swedish Parliament Bill deaf people "need to be bilingual in order to function among themselves and in society at large" (Svartholm, 1993, 291).

²⁶ According to Malm (1852, 69): "Emedan döfstumma elever måste lära sig två språk, hvilka användas i skolan, nemligen pantomim- och skriftspråk, så inhämtas skriftspråket af dem, medelst det förra, nästan lika som främmande språk studeras af de fullsinnade på deras modernmål". "As deaf-dumb pupils have to learn two languages that are used in school, namely pantomime and a written language, they learn the written language through the use of the former language, almost like pupils without a hearing loss study foreign languages through their mother tongue".

The goal of bilingual education is to provide deaf children with an environment fostering communication, achievement and a normal language acquisition (Bouvet, 1990, 146). Many support the view that deaf children's poor reading skills and academic performance are due to the use of either a spoken language or diverse communication systems (such as Total Communication²⁷) as the language of instruction (Johnson, Liddell, & Erting, 1989; Svartholm, 1993).

Both Inger Ahlgren (personal communication, April 3, 1998) and Kristina Svartholm (personal communication, April 3, 1998) strongly stress that the issue with deaf education in Sweden no longer is whether manual or oral communication should be utilised. Rather, the issue relates to bilingual education and to the need for an acceptance of Swedish as a second language for deaf pupils as well as the need for this language to be taught accordingly. In addition, the fact that learning Swedish as a second language is different, and perhaps more difficult, for deaf children than it is for hearing children learning it as a second language must be recognised. Therefore, as was discussed in Section 3.5, both Ahlgren and Svartholm point out that it is unrealistic to expect all deaf pupils to learn to write perfectly. It must be considered sufficient if deaf children learn to write a completely understandable Swedish without having to master all the nuances and the entire spectrum of grammatical variability of written language. Speech, which to a great extent depends on residual hearing, cannot be main priority either. In Sweden, parents of deaf signing children accept that their children do not speak, and therefore do not train them to speak and listen. This does not necessarily apply to parents of deaf children receiving cochlear implants. Ahlgren stressed the need to give the parents realistic expectations concerning the child's ability to speak, and the assumption needs to be that speech is not essential in the education of deaf children.

The well-known knowledge gap between hearing and deaf pupils is, in Sweden, steadily decreasing. Nevertheless, it seems that even in Sweden deaf pupils finish school with a somewhat lower level of knowledge than hearing pupils. This may be considered to be the major challenge for the education of deaf children. The reason for the still existing knowledge gap is a built-in difficulty with deaf education, namely the need to use teaching material in Swedish before the pupils master this language. Although teaching material in Swedish Sign Language is being introduced, this material needs to be further developed (Inger Ahlgren, personal communication, April 3, 1998; Kristina Svartholm personal communication, April 3, 1998).

To summarise, although the experiences of bilingual education are positive and allow deaf children to learn and develop literacy in the national language, the challenges of bilingual education are many. Among other things a successful bilingual educational programme requires fluent signing skills on the part of the teachers, more knowledge of the teaching of the national language as a second language for deaf pupils and more deaf teachers (Davies, 1994; Skutnabb-Kangas, 1994).

²⁷ Total communication indicates simultaneous use of speech and signs.

5.4 Education for deaf children in Finland

In Finland children begin school in the year of their seventh birthday and all children permanently living in the country are subject to the compulsory nine-year basic education which is free of charge. “The objective of basic education is to support pupils’ growth towards humanity and ethically responsible membership of society, and to provide them with the knowledge and skills necessary in life” (National Board of Education, 2003, www-document). Furthermore, according to the Basic Education Act 628/1998 “the instruction shall promote equality in society and the pupils’ abilities to participate in education and to otherwise develop themselves during their lives” (The National Board of Education, 2003, www-document).

Before starting comprehensive school children attend pre-school for one year. Deaf children (and other children with special educational needs) can, if their parents so wish, follow an eleven-year comprehensive education plan and begin pre-school in the year of their fifth birthday (instead of the year of their sixth birthday). Deaf pupils often attend a two-year pre-school programme followed by the nine-year comprehensive education.

Education for hearing-impaired children

Today many hearing-impaired pupils in Finland are mainstreamed in the public education, as educational groups aimed specifically at hearing-impaired pupils are rare. Some hearing-impaired pupils receive their education together with pupils who are deaf or dysphatic²⁸ (Parkkola & Ääri-Vähäkylä, 2000).

A hearing-impaired child attending the public education follows the curriculum for the basic comprehensive education and in addition individual targets are set up (Parkkola & Ääri-Vähäkylä, 2000). The habilitation counsellor is involved in the education of a mainstreamed hearing-impaired child. Additional support and guidance can also be obtained from the support centres at the state schools for deaf children (Parkkola & Ääri-Vähäkylä, 2000). When a hearing-impaired pupil attends a school for normally hearing children much attention is paid to heartraining, the production and comprehension of speech, lip-reading but also to the physical environment such as acoustics, lighting and where in the classroom the pupil is sitting (Parkkola & Ääri-Vähäkylä, 2000).

Education for deaf children

For deaf pupils centralised education is considered the best alternative and, in fact, according to Parkkola and Ääri-Vähäkylä (2000) the majority of deaf children in Finland attend a state or community school for deaf children. Many of the schools now work hard to improve the level of instruction and have realised the need for

²⁸ Dysphasia is a language development disorder resulting in delayed speech and language development. Difficulties in reading, writing and mathematics as well as difficulties with motor coordination and perception are also common in children with dysphasia.

deaf children to be educated through the medium of Sign with Finnish taught as a second language. One problem with the deaf education in Finland is the small number of qualified deaf teachers. Fortunately, in 1998 a special training programme for deaf teachers of the deaf was started in Jyväskylä. According to the Basic Education Act 628/1998 Sign Language can be the language of instruction and, if the parents so wish, Finnish Sign Language an academic subject. This has been the choice of many parents although due to practical reasons, such as heterogeneous classes and few teachers, the instruction can be given using the method of Total Communication (Parkkola & Ääri-Vähäkylä, 2000).

Currently there are three state schools and thirteen community schools for deaf and hearing-impaired children in Finland, all of which are Finnish (Nyckelinfo, 2000). The community schools are rarely separate schools. They are usually adjacent to schools for normally hearing children. In addition there are three schools with separate classes for deaf children and five vocational schools or institutes for deaf pupils: Kuulovammaisten Ammattikoulu ja Kehittämiskeskus, Nikkarilan Ammattioppilaitos, Dövas Folkhögskola, Pohjois-Savon Opisto and Turun Kristillinen Opisto.

The three state schools are Merikartanon Koulu in Uleåborg (Oulu) in Northern Finland, Haukkarannan Koulu in Jyväskylä in Central Finland, and Mikael-School in St. Michel (Mikkeli) also in Central Finland. The school in St. Michel is the only school with secondary level education for deaf pupils in Finland.

In the school year 1998 to 1999 a total of 1,289 pupils attended the schools for deaf children (Edlund, 1999). Of these pupils 218 were deaf, 124 hearing-impaired (most of whom use technical aids and spoken language) and twenty-six had both a visual impairment and hearing-impairment or were deaf-blind. The remaining 921 pupils were hearing with disabilities such as dysphasia, autism or MBD²⁹. Pupils belonging to this group typically constitute separate educational groups, although a few are integrated with deaf or hearing-impaired pupils (Edlund, 1999). In several schools many of the pupils thus have disabilities and needs different from those of deaf or hearing-impaired pupils. In the school year 1999 to 2000 a total of 198 deaf pupils attended the special schools in Finland (Parkkola & Ääri-Vähäkylä, 2000).

During the school year 1998 to 1999 a total of 250 teachers worked in the nineteen schools (Edlund, 1999). Of these 223 worked full-time and twenty-seven part-time and 194 of the total of 250 teachers were special needs teachers (Edlund, 1999). In addition, a total of eight assistant teachers were employed in the state schools and a total of 161 assistants in all nineteen schools (Edlund, 1999).

²⁹ MBD is an abbreviation for minimal brain dysfunction. Although the term DAMP (Deficits in motor, attention and perception) is more frequently used in Finland today (to indicate the same condition) the term used in Edlund's (1999) report is MBD and therefore also used here.

In this section the three state schools – C.O. Malm School, Merikartanon Koulu and Mikael-School – and one community school, Albert’s School, are briefly presented. Albert’s School is chosen because it currently has a few Finland-Swedish. The Finland-Swedish pupils do not constitute a class of their own so they receive their schooling in Finnish Sign Language and written Finnish. Albert’s School and the Helsinki Board of Education have been planning – if enough families are interested, to start an educational group for Finland-Swedish pupils. In addition to the pupils attending Albert’s School there are approximately five pupils from bilingual (Finnish and Swedish) families in the other schools for deaf children in Finland.

C. O. Malm School

C.O. Malm School is located in Åbo (Turku). The main goal of the school is to give the deaf and hearing-impaired pupils the education and skills needed to participate fully in society, to pursue further education and to succeed both in their employment and personal life (C.O. Malm School, 2003, www-document). The school has pupils who are deaf, hearing-impaired or have a visual and a hearing impairment. In the school year 1999 to 2000 the school had forty-seven pupils and eight educational groups (Edlund, 1999). C. O. Malm School provides a signing environment, Finnish Sign Language is used with deaf pupils and spoken Finnish with pupils who are hard-of-hearing, have cochlear implants or a language disorder. Some pupils who are hard-of-hearing are partly integrated in an adjacent Finnish school (C.O. Malm School, 2003, www-document).

Merikartanon Koulu

Merikartanon Koulu (the School for the Hearing Impaired in Oulu) was established in 1898 and currently has around sixty pupils, some of whom are not hearing-impaired but have a language disability such as dysphasia. Almost all the deaf children from the northern parts of Finland attend this school and some of the pupils live in the school’s own home for pupils. A centre for deafness and dysphasia is also operating at the school. According to the school’s guidelines the primary language for deaf pupils is Finnish Sign Language and for hearing-impaired and dysphatic pupils it is Finnish. The goal is to give all pupils good language skills and to ensure that the deaf pupils reach a bilingual status. The school’s motto is “Hands – the key to thinking”. (Merikartanon Koulu, 2003, www-document)

A state commissioned Resource and Tutorial Centre which provides extra courses for both pupils and teachers as well as producing teaching material and conducting research operates at Merikartanon Koulu (Merikartanon Koulu, 2003, www-document).

Mikael-School

Mikael-School in St. Michel was established in 1893 and is now a residential school with a two-year pre-school programme, a comprehensive school programme and a secondary school programme enabling the pupils to then take the national matriculation examination (Mikael-School, 2003, www-document). Languages, national culture and heritage, peace education, equality and a respect for nature

and work are emphasised in Mikael-School (Mikael-School, 2003, www-document). Most pupils live in the school's pupil home but travel home every weekend and the school provides the travel expenses (Mikael-School, 2003, www-document). A state commissioned Resource and Tutorial Centre providing extra courses for both pupils and teachers as well as producing teaching material and conducting research also operates at Mikael-School. (Mikael-School, 2003, www-document)

Albert's School

One of the community schools for deaf children is Albert's School in Helsinki. Albert's School profiles itself as a bilingual school with Finnish Sign Language as the primary language and language of instruction, Finnish as the second language and the language of the educational material (Albert's School, 2003, www-document). The goal is to educate bilingual and bicultural pupils with a high self-esteem and respect for other people, languages and cultures (Edlund, 1999). The deaf pupils receive instruction in Finnish Sign Language and the hearing-impaired pupils in signed Finnish (simultaneous use of speech and signs following the syntax of spoken Finnish). Speech therapy is considered an important part of the education.

The school is located in the same building as a Finnish primary school. Between 1992 and 1993 Albert's School had around thirtyfive pupils, and from 1998 to 1999 the school had seventyfive pupils (Edlund, 1999). Of these pupils, 70% are deaf with Finnish Sign Language as their primary language, 25% hearing-impaired with Finnish as their primary language and 5% are pupils with language disabilities who use signs to support the spoken language (Edlund, 1999). Three of the deaf pupils come from Finland-Swedish families. According to a report by Edlund (1999) one of the Swedish pupils, a girl in ninth-grade, was very content with Albert's School and was glad that she had not been mainstreamed with a Sign Language interpreter in a Swedish school. Having attended Albert's School she has acquired Finnish and can now continue her education in Finland. At home the girl communicates through Sign Language with Finnish articulation. Her knowledge of Swedish is poor and she is, in fact, not very interested in the Swedish language (Edlund, 1999). According to Edlund's report the other two pupils from Swedish-speaking homes are also satisfied with Albert's School and specifically emphasised the importance of deaf friends.

5.5 Educational options for Finland-Swedish deaf and hearing-impaired children

In Finland, children normally start school the year they turn seven. The goal is that every child should have an equal opportunity to receive the nine-year compulsory basic education. The basic education is given in primary schools, years 1–6 and secondary school, years 7–9. Children from Swedish-speaking families receive instruction in Swedish. However, as there are not as many Swedish schools, many Swedish-speaking children have longer school journeys than their Finnish-speak-

ing peers. Sometimes families move to areas with Swedish schools because the parents are determined that their child should attend a Swedish school. Today, marriages across the two language groups are very common, which has resulted in many children growing up bilingually. In Helsinki 52% of the children in Swedish-speaking primary schools come from bilingual homes, in some areas this figure is as high as 90% (Sergelius, 1999). The majority of the children from bilingual homes attend Swedish schools.

Deaf and hearing-impaired children from the Swedish population belong to a minority within a minority and are not able to receive education in a deaf school teaching Swedish as a second language. Parents of these children are faced with many difficult decisions regarding their children's future education. For instance, in the past twenty years no deaf pupil from the Finland-Swedish population attending a deaf school in Finland has completed secondary education (Svedlin, 1996). A few Swedish pupils mainstreamed in schools for normally hearing children have, however, completed their secondary education, as have the pupils who received their schooling in Sweden. In 2002, one deaf pupil who was mainstreamed with a Finland-Swedish Sign Language interpreter in a Swedish-speaking secondary school in Helsinki completed her matriculation examination.

In 1993 the only Swedish school (Borgå Dövskola, established by Malm) for deaf children was closed. Even before its closure many problems existed, one being the small size of the pupil population and the long school journeys for many of the children. The Swedish population in Finland is geographically widespread, the majority lives along the coast in Southern and Central Finland (Ostrobothnia, Pohjanmaa), as well as on the monolingual Åland Islands (Ahvenanmaa). Parents in Ostrobothnia were thus faced with the option of sending their young child up to several hundred kilometres to the Borgå deaf school or integrating the child in the local hearing school. Borgå Dövskola was a residential school, most children stayed there during the week and travelled home for the weekend. The school was besieged with problems and conflicts. Parents were not content with the quality of education or the teachers' signing abilities, and during the late 1980s and early 1990s the number of pupils steadily decreased as parents sought other alternatives. Some families moved to Sweden in order for their children to receive high-quality education in Sign Language. Other families placed their deaf child in a hearing school or in a Finnish deaf school.

One issue that further complicates the educational placement for deaf and hearing-impaired children from both Finnish and Finland-Swedish families is that there does not exist an oral educational programme in Finland as there is in many other countries. Basically, parents in Finland have to choose between a deaf school and inclusion in a school for normally hearing children. Children using a spoken language usually attend schools for normally hearing children but are often the only deaf or hearing-impaired child in the school and may have severe problems being properly integrated.

Today, deaf children from the Swedish population in Finland have four alternatives when deciding how to receive the compulsory basic education. These options are Ytteresse School, mainstreaming in a school for normally hearing children, a Finnish deaf school or education in Sweden.

Nursery school Snäckan and Ytteresse School

Ytteresse is located in Ostrobothnia, one hundred kilometres north of Vasa (Vaasa) and thirty kilometres east of Jakobstad (Pietarsaari). In Ytteresse there is a special day-care centre called Snäckan, established in 1981. Snäckan has a signing environment, the majority of the personnel sign and there is one deaf assistant. The assistant is not responsible for pedagogical matters but is an important linguistic role model for the deaf children. In the school year 1999–2000, three deaf or hearing-impaired children attended Snäckan. Adjacent to the day-care is Ytteresse School, a primary school for hearing children that has specialised in the inclusion of deaf children. Since the autumn of 1997 the school has had one deaf pupil. The class with the deaf child has two hearing teachers, one of whom is a native signer. During the after-school activities (at Snäckan), children from the school and from the day-care are together, in order to optimise the signing environment. The deaf assistant is also present during the afternoon activities.

All teachers receive some Sign Language instruction. Children who attended Snäckan before entering school learned Sign and many are now fairly good signers. The school and the day-care centre collaborate and many activities are shared in order to provide the deaf pupils with more social – that is, signing – interactions. The personnel at the school are ambitious, enthusiastic and very involved in deaf education and working for the improvement of the quality of the education for deaf pupils. Yet no matter how good the intentions are, the school cannot provide its present or future pupils with a rich signing environment and complete accessibility to either the instruction or pupil interaction. As the number of deaf pupils is very small, there is limited chance of choosing friends, and interaction with signing peers is also restricted. There is thus a risk of social isolation. Furthermore, as there are no deaf adults working in the school, the deaf pupils have no adult role models.

Martin Björkvik (Personal communication 1998) at Ytteresse School and Charlotte Snellman (Personal communication 1998) at the Snäckan day-care centre, are also well aware of the need for deaf children to socialise with other deaf children. The day-care and the school are, to the best of their capability, trying to fulfil this need. Snellman points out that the deaf teacher at the day-care is invaluable as a role model for the deaf and hearing-impaired children. Frequently the deaf children and the deaf teacher discuss similar experiences. These are discussions in which a hearing person certainly cannot help the child understand the particular topic discussed; sometimes a hearing person cannot even participate.

Although the deaf pupil receives individual instruction during native language lessons and during reading lessons, Swedish is not yet taught as a second language for deaf pupils. Nor does deaf pupils receive native language instruction in Sign Language. The principle in Snäckan and Ytteresse School is, however, that Sign Language is the base for further development and learning in deaf children. Members of the staff have experience of receiving deaf children without any Sign Language who initially show frustration and behavioural problems but later calm down and show more so-called “normal” behaviour once Sign Language communication starts. There has been a tremendous increase of interest in and awareness of the Swedish language coinciding with a child’s development of Sign Language.

Although many of the deaf or hearing-impaired children attending Snäckan do enjoy working with the computer programmes encouraging the use of their voice, it should be remembered that for these children speech can under no circumstances be seen as sufficient, it is merely a complement to their overall language development. Both at Snäckan and Ytteresse School the pupils work extensively with different texts and storytelling to stimulate and facilitate the learning of Swedish. In addition, teaching material from Sweden designed for deaf pupils, for example *Adams bok*³⁰ (Christersson, 1995), is used for learning to read.

And finally, few deaf children live close to Ytteresse School. If the family does not move close to the school the young child will have to travel long distances. Sending a seven-year-old from Åland to Ytteresse (570 km) for the school week does not allow for a normal family life. This problem is, of course, relevant for many deaf children attending residential schools, but one major difference is, however, present. For many children in residential schools the importance of a signing environment and having deaf friends as well as deaf adult role models by far outweighs the long distances to school. This is not the case at Snäckan and Ytteresse School where the number of deaf or hard-of-hearing children is approximately half a dozen. That is, the pupils could be travelling long distances to a largely hearing and speaking environment.

Inclusion in a school for normally hearing children

Many deaf or hearing-impaired children who are integrated in a school for normally hearing children require an interpreter or a personal assistant. The community does pay for this service but as further mentioned in Sections 8.3.5 and 8.4, there are not always enough interpreters or assistants to meet the needs.

The advantage of mainstreaming is the school's proximity to home, for the child can thus live at home and attend school with children from the neighbourhood. This is a factor that is viewed as highly influential in the selection of school for Finland-Swedish parents of hearing-impaired children in Finland (Dahlbäck, Friberg, & Hägglund, 1997). The disadvantage is that the children's psychosocial and linguistic developments tend to suffer. If there are no signing friends or school personnel, the deaf child is at a risk of being isolated. Attending school with the help of an interpreter or assistant does not provide the pupil with possibilities for developing normal ties of friendship. The adult – child interaction may work fine, but it is not always possible or desirable to play and interact with an interpreter. There is also a chance that the deaf or severely hearing-impaired child becomes too dependent on the interpreter or assistant. This has amply been documented, for example in Kristinaskolan in Sweden. When previously mainstreamed pupils are

³⁰ *Adams bok* (Christersson, 1995), (ENG: Adam's book) is a book about a deaf boy who attends a deaf school. The teaching material consists of two books (one of them translated from Swedish Sign Language), two videoprogrammes and one teacher guide. In addition *Adams bok* is available as a linked book, linklist and video on CD (Specialpedagogiska Institutet Läromedel, www-document).

transferred to this school they tend to have developed a complete trust in and need for an assistant (Bengt Danielsson, principal at Kristinaskolan, personal communication, October 6, 1998). After one term or less the pupils, however, overcome this, and develop a strong aspiration and trust in their own abilities. Deaf adults who have attended school with an interpreter also tell stories of dependency and isolation. Furthermore, mainstreamed children may miss out on Deaf culture and on the possibility of developing a Deaf identity. This does of course depend on the child's contact with deaf friends and the Deaf community outside school.

A Finnish deaf school

Some Swedish-speaking families with deaf children place their child in a Finnish deaf school (see Section 5.4 for an outline of the Finnish deaf schools), thus enabling the child to receive instruction in Sign Language in Finland. The advantage of this option for a signing child is obvious, as the child is exposed to a meaningful and supporting social, cognitive and linguistic environment. The disadvantage is that since the second language in the school is Finnish, the deaf child has to learn yet another foreign language. In fact, some parents realise the necessity of changing the home language to Finnish (that is, change to Finnish Sign Language accompanied by Finnish – not Swedish – articulation) to enable the child to enter a Finnish deaf school. Typically one parent uses Finnish and the other Swedish with the child, especially if the family has other hearing children. Finnish and Swedish are not related languages, and structurally very different, an issue which may have an impact on the process of learning to read for deaf children from Swedish-speaking homes who attend a Finnish deaf school. These children learn to read in their third language (if Finland-Swedish or Finnish Sign Language is the primary language and Swedish the second).

A deaf school in Sweden

Sweden has a well-developed educational system on all levels (i.e. from day-care to high school, vocational schools, and some university courses) for deaf pupils. A consequence is that quite a few deaf pupils from the Swedish population in Finland move to Sweden in order to receive education. Instruction is given in Sign Language; Swedish Sign Language is taught as a mother tongue and Swedish as a second language. The bilingual education with deaf and hearing teachers and the positive attitudes towards Sign Language make it possible for deaf pupils to achieve good results. The reading and writing levels of many deaf pupils equal those of hearing pupils (Kristina Svartholm, personal communication, April 3, 1998). The Sign Languages in Finland and Sweden are different, for example the manual alphabet is different in the two countries, but pupils from Finland generally pick up the Swedish Sign Language very quickly.

Although the Swedish schools are very good and provide deaf children with a meaningful social, cognitive and linguistic environment, moving to Sweden is not always feasible or in the best interest of the child and his or her family. Factors that need to be considered are numerous. First, the parents' occupation and the prospect of finding a job in Sweden and secondly, the financial burden of possibly having two homes (one in Finland and one in Sweden). Third, hearing siblings

who perhaps have already started school in Finland, and the prospect of leaving friends and relatives may seem very difficult. Cultural differences should not be forgotten either. Although the Swedish language is important, there are cultural differences between Swedes and Swedish-speaking people from Finland. To the surprise of many Finnish-speaking people in Finland, Swedish-speaking people from Finland tend to be culturally more “Finnish” than they are “Swedish”. The questions of identity and sense of belonging in this group are interesting but not to be discussed here. It suffices to say that growing up in Sweden means missing out on both the Finland-Swedish deaf and hearing cultures as well as on the Finnish deaf and hearing cultures.

After completing their education, many pupils become Swedish citizens and remain in Sweden. This is naturally difficult and sad for parents remaining in Finland but it also has consequences for the continuity of the Finland-Swedish Deaf culture (Londen, 1992). The age structure among deaf people from the Swedish population in Finland is thus distorted, as it consists of young children and people over fifty years of age (Londen, 1992). Of the thirtysix deaf individuals (belonging to the Swedish minority in Finland) born between the years 1969 and 1987, twentyeight live in Sweden, one in the US and seven in Finland (Edlund, 1999). There is also an urgent need in Finland for well-educated deaf individuals working in all areas concerning deaf people, education being perhaps, at this time, the most critical one.

If a family chooses to move to Sweden and actually becomes registered there, the Swedish municipality will pay for the education. However, if the parents remain permanent residents in Finland, the Finnish government pays for the child’s travel (during weekends and holidays) to and from Sweden.

See Table 1 for an overview of the four alternatives previously accounted for. Further advantages and disadvantages, as experienced by the parents who have chosen a particular type of school, are discussed in Section 8.3.

Table 1. Advantages and disadvantages of the educational opportunities for Finland-Swedish deaf or hearing-impaired children.

Educational placement	Advantages	Disadvantages
Ytteresse school and Snäckan	Specialised in mainstreaming deaf pupils Signing teachers Personnel ambitious and motivated to improve the conditions for deaf pupils.	Long school journeys for many Swedish deaf children Limited peer group Not total access to the instruction or pupil interaction
Inclusion	Normal family environment Short school-trips The same educational path as hearing siblings and peers from day-care or pre-school	No peer group Difficulty finding an assistant or interpreter Limited access to the instruction or pupil interaction Less contact with Deaf culture or deaf adults
Finnish deaf school	Instruction in Sign Language Large peer groups Deaf teachers and role models Bilingual education	Teaching material in Finnish Possibly a change of (spoken) home language Possibly long school-trips
Deaf school in Sweden	Instruction in Sign Language High standard of education Bilingual education Large peer groups Deaf teachers and role models	Practical family matters Financial burden Cultural differences Deaf pupils remain in Sweden No Finnish

5.6 Summary

The main issue in deaf education has been whether oral or manual communication should be used. Generally, three main educational options for deaf or hearing-impaired children are deaf school, oral educational programme or integration in a school for normally hearing children. Today, many studies have proven speech and lip-reading to be insufficient for a full linguistic competence of deaf children. The new movement in the education of the deaf emphasises the two languages and the two cultures of the deaf child. Deaf children using Sign Language need to be educated through the medium of Sign, and preferably also by deaf teachers. The national language should be taught as a second language. Bilingual programmes for deaf children have proven successful, in some cases improving deaf pupils' reading and writing ability to the level of age-matched hearing pupils.

However, for deaf pupils integrated in hearing schools it is of major importance that this group of children also receives the attention and support services they need. The school and the teachers need information on the impact that hearing loss has on the child's communication and learning. If necessary, mainstreamed children should be granted an assistant or an interpreter.

For the small minority of Finland-Swedish deaf children the educational choices are limited. Since 1993 there has been no school for Finland-Swedish deaf signing children and thereafter parents have come upon many intricate decisions when choosing school placement for their deaf signing children. Currently the choices stand between Ytteresse School, a Finnish deaf school, a deaf school in Sweden or inclusion. All four alternatives have their drawbacks and cannot be considered completely satisfactory for a deaf child from a Finland-Swedish family.

In this chapter, the available educational options have been presented, in Chapter 8 hearing parents' ways of reasoning in choosing communication method and educational placement for their deaf or hearing-impaired child are examined. First, however, a statement of the research problems and a discussion on the methodological approach for this study are presented.

6 Statement of the Research Problems

The education and upbringing of deaf children raises many challenging and difficult issues for parents who themselves are hearing. These parents encounter complex issues involving language, education, culture and identity. The fact that the education of deaf children has traditionally been, and to some extent still is, controversial certainly does not facilitate the parents' decision-making regarding language and education for their deaf or hearing-impaired child. For the small group of deaf children in Finland belonging to the Swedish minority, the possibility of receiving adequate education in their homecountry is more or less non-existent. There is no school for Finland-Swedish deaf children and the available educational opportunities for these children can under no circumstances be considered satisfactory. These families are thus faced with difficult and agonising decisions when choosing a school for their deaf or hearing-impaired child.

Despite the fact that this group of deaf children is small we should not focus on the size of this minority within a minority. Rather we need to focus on the fact that in addition to being part of the Deaf culture, these deaf children grow up between two hearing cultures (the Finland-Swedish and the Finnish) with all the challenges and consequences this brings. In addition to the principle concerning adequate education for any child raised in a language minority, the focus of this work is the parents' ways of reasoning (concerning education and early habilitation) in this rather unique situation involving three languages and three cultures.

Generally there tend to be many choices concerning, for example, educational placement for bilingual children growing up in a multilingual/multicultural society and the increased number of options can be viewed as positive. On the other hand, the growing number of options and possibilities can also be viewed as a factor increasing the conflicts and difficulties that parents encounter. Hearing parents who learn that their child is deaf or hearing-impaired are, naturally, in grief and in great demand of support as well as objective and appropriate information concerning both the development of children with a hearing loss and other aspects of deafness. Nevertheless, information given to parents as part of early intervention often focuses on the medical – and not on the socio-cultural view of deafness (see Section 2.1); thus the information is more concerned with the technical aids and oral training. Although many deaf children are exposed to Sign Language early in life quite a few parents choose oral over manual communication. One important question is thus whether, and in what direction, the information that parents received influenced their choice of communication method and also the overall role of the early habilitation in providing support and information to families with deaf or hearing-impaired children. This study involves families with deaf or hearing-impaired children from the Finland-Swedish minority and consequently the research problems apply to this particular group.

The challenges facing the education and early intervention for Finland-Swedish deaf and hearing-impaired children are numerous. In order to improve the education for these deaf children and to provide their families with appropriate support and services we need insight into the parents' educational reasoning and understanding of factors influencing their choice of both communication method

and educational placement. Also needed are knowledge and an awareness of their experiences as parents of deaf or hearing-impaired children in a bilingual or multilingual society.

The research problems are as follows:

- 1) What method of communication do hearing parents living in a bilingual society use with their deaf or hearing-impaired child?
- 2) What factors influence parents' choice of communication method for their deaf or hearing-impaired child growing up in a bilingual society?
- 3) How do hearing parents with deaf children experience the educational decision-making when there is no straightforward choice of school that provides the compulsory basic education for their deaf child who belongs to a minority in a minority?
- 4) What are the parents' experiences of the early habilitation for their deaf or hearing-impaired child?

7 Methods of the Study

7.1 Methodological approach

In cultures with a compulsory and institutionalised school system parents are at some point and to some extent forced to make decisions about schooling for their children. Choosing a school for one's child can be a difficult process but should still be considered a normal and anticipated part of bringing up a child. Having to choose a primary language for one's child, on the other hand, is an entirely different process and something parents (especially parents living in monolingual cultures) rarely anticipate. However, for hearing parents of deaf or hearing-impaired children it is reality and the decisions relating both to communication and education require the parents to reflect on their own conceptions and understanding not only of deafness but of language, identity, and culture.

Hearing parents' communicational and educational choices for their deaf or hearing-impaired children are the focus of this study. Eighteen in-depth interviews with parents were conducted and in addition the same parents completed a questionnaire. The study is qualitative with a phenomenological hermeneutical approach and based on the concept of lived experience, lifeworld. The objective is to understand and interpret the parents' experiences within the context they are living, that is, how they arrive at their decisions regarding both choice of language and school placement for their deaf or hearing-impaired child. The families taking part in this study are Swedish-speaking³¹ but live in a bilingual society surrounded by both the Swedish and Finnish languages and the Finland-Swedish and Finnish cultures.³²

In qualitative research it is essential that enough qualifications and features are represented in the individuals studied (Ruth, 1991). The parents interviewed for this study allow for an examination of the phenomenon from many different viewpoints. Included in the sample are parents who use different methods of communication with their deaf or hearing-impaired children. The families represent the whole of Swedish Finland as well as all four educational opportunities presently available for Finland-Swedish deaf or hearing-impaired children.

The methodology of this study has features from both phenomenology and hermeneutics. The approach is phenomenological in the sense that the lifeworlds of hearing parents with deaf children are at focus. The aim is to describe and elucidate aspects experienced to be of importance for the parental communicational and educational decision-making processes for their deaf child, as experi-

³¹ Three of the families taking part in this study are bilingual, i.e. one parent is Finnish-speaking and the other parent Swedish-speaking. These families are included in the study since the children in question go to Swedish-speaking day-care centres or schools.

³² For the families living on the monolingual Swedish-speaking islands of Åland (Ahvenanmaa) the influence of the Finnish language and culture is, however, less than for the families living on mainland Finland.

enced by the parents themselves. This is achieved by approaching the parents' lifeworlds with openness to their experiences. The approach is hermeneutical in the sense that the parents' experiences are interpreted in the light of the cultural, historical and other specific features of the Swedish-speaking population in Finland. The aim is thus to create an overall understanding of linguistic and educational reasoning and reflection among parents of deaf and hearing-impaired children in the very specific societal and linguistic context of raising a deaf or a hearing-impaired child in a hearing family that belongs to a language minority. The process of reaching such an understanding is achieved by an interpretive research procedure and the results are expected to deepen our understanding of the parental decision processes relating to both language and education for deaf or hearing-impaired children.

The parental decisions with respect to both communication method and educational placement for deaf or hearing-impaired children from the Swedish minority in Finland have not previously been studied. The results presented here provide new knowledge on how parents belonging to a language minority reason when choosing method of communication and educational placement for their children who cannot, without effort, follow the mainstream public education. However, the results also provide knowledge on how parents of deaf or hearing-impaired children experience several aspects of parenting (a child with a hearing loss) that are not specific to parents belonging to a language minority. This includes results relating to the choice of primary language (spoken or signed), the attitudes towards cochlear implants and experiences of early habilitation as well as difficulties facing mainstreamed deaf or hearing-impaired children. One major challenge for all hearing parents of deaf children (that is including parents of language majority), is the unexpected and difficult reflection over issues such as the nature of parent-child interaction and communication as well as linguistic and cultural identity. However, since these particular research problems are marked and amplified in a language minority lacking a straightforward educational path for its deaf or hearing-impaired children this choice of population truly brings out the challenges of bringing up a deaf or hard-of-hearing child in a hearing family.

Despite extensive knowledge on parenting, language, deafness, hearing-impairments, education and deaf education, we have to listen to the voices of hearing parents with deaf or hearing-impaired children in order to understand their lifeworlds, the questions and dilemmas they meet and the choices they make. With the parents' experiences as a starting point, innovative thinking and a discussion on pedagogical implications for the habilitation and education of deaf and hard-of-hearing children from the Finland-Swedish minority are possible.

7.1.1 Lifeworld research

The nature of our being in the world is complex, tacit and often unspoken and hence difficult to grasp. The lifeworld is the immediate and pre-reflective world as it is come upon in daily life (Bengtsson, 1998: 1999). The phenomenological aim is to reach beyond the immediate experiences in an attempt to bring out the pre-reflective level and to describe the contents and structure of an individual's aware-

ness and knowing (Bengtsson, 1998; Hardy, 1999). In lifeworld research the belief is that the complexity, tacitness and pre-reflection of the world is accessible to us and that people's experiences can be captured by allowing the phenomenon³³ to present itself to our consciousness (Dahlberg, Drew, & Nyström, 2001; van Manen, 1990). Knowledge and lived experiences are always connected to an individual since an experience is always someone's experience (Husserl, 1999). In order to receive knowledge about a particular phenomenon we therefore have to turn to the persons who are affected by it or who are part of it (Berndtsson, 2001, 93). That is, only by focusing on the individuals' experiences can we form an understanding of a phenomenon's complexity.

Husserl (1999) introduced the concept of lifeworld (*Lebenswelt*) as a result of his thoughts on "the natural attitude". In the natural attitude we are completely absorbed by the present without intentionally analysing the present activity or situation. We are not consciously aware of the range of possibilities available to us in every situation and therefore the natural attitude does not constitute an appropriate framework for science (Dahlberg *et al.*, 2001, 46). However, we only have access to an experienced world, and a central dimension of the experienced world is expressed by Husserl's concept of "natural attitude" (Husserl, 1999). The notion of lifeworld is a principal component of phenomenology (Bengtsson, 1998, 1999a; Uljens, 1992) as Husserl maintains that all science and research have their grounding in the natural attitude. The aim is to make the complexity as well as the unspoken and the tacit visible in order to allow a systematic scientific analysis. See Uljens (1992) for a synopsis on Husserl's ideas and perspective on lifeworld.

Lifeworld was put forward as an epistemological idea with the purpose that lifeworld theory and phenomenology would be the principal constituent of all philosophy and human science research (Husserl, 1999). Relying on the epistemological and methodological tools of phenomenology and the concept of lifeworld, the aim within this tradition is both to discover and describe individuals' lived experiences in a manner that contributes to our understanding of the world (Van Manen, 1990; Warnke, 1987). Merleau-Ponty (1995) further developed the theory of lifeworld and emphasised our interaction and relation to the world and asserted that lifeworld is fundamental for knowledge and also that lifeworld invariably comes before knowledge. Of importance in Merleau-Ponty's approach to lifeworld is the subjective body, that is, the way in which we gain access to the world through our body (Dahlberg *et al.*, 2001).

The idea of lifeworld came to be the most discussed part of Husserl's later work and the concept became greatly appreciated in many areas as the wide meaning of the word lifeworld allows for a philosophical approach to experiences from everyday life (Gadamer, 1976, 183). However, a mere interest in everyday experi-

³³ The word phenomenon originates from the Greek word "*phainesthai*", and etymologically phenomenon means something that is experienced, or how something presents itself to someone (Heidegger, 1993).

ence does not necessarily mean that the researcher approaches the concept of lifeworld from a phenomenological perspective (Uljens, 1993). In *Social construction of reality*, Berger and Luckmann (1966) present their ideas on the foundations of knowledge in everyday life, which have had a major impact on the field of phenomenological sociology and research on everyday life. Also Van Manen (1990, 7) has put forward a methodological approach to researching lived experience and he describes Husserl's concept of lifeworld as follows:

This is the world of the natural attitude of everyday life which Husserl described as the original, pre-reflective, pre-theoretical attitude. In bringing to reflective awareness the nature of the events experienced in our natural attitude, we are able to transform or remake ourselves in the true sense of *Bildung* (education).³⁴

We can understand this in the sense that we both pass and lose the pre-reflective dimension at the exact same moment we catch it and the intentions, emotions or actions becomes visible (Uljens, 1992).

Even though hermeneutics and phenomenology are philosophical disciplines with separate traditions the two approaches do have interconnections that bear a part in our seeking of increased and deepened understanding of lived experiences. Van Manen (1990, 2) asserts the significance of hermeneutical phenomenology for pedagogy – the need for a phenomenological sensitivity and the hermeneutical ability to interpret. The objective of this study is to understand the communicational and educational choices Finland-Swedish hearing parents of deaf children have to make. In order to increase our understanding we must focus on the lifeworlds of the parents. As was previously mentioned we can best understand the meaning of the parents' actions and decisions when entering and sharing their everyday life. The following discussion clarifies why qualitative research interviews focusing on the parents' lifeworlds and relying on a phenomenological and hermeneutical approach provide the appropriate tools to deepen our understanding of the parental choices relating to communication method and education for their deaf or hearing-impaired children.

7.1.2 Phenomenology

Husserl (1999) writes that in addition to being a complex scientific discipline phenomenology is first and foremost a philosophical method and a philosophical attitude of thought. Phenomenology focuses on the unique subjective experiences of individuals and dismisses the natural sciences' and positivistic ideals of universal

³⁴ *Bildung* is a difficult word to translate, Van Manen uses the term education while Rorty (1979) introduced the concept eidification.

laws based on empirical knowledge (Helenius, 1990). Since individuals' experiences are considered unique, empirical generalisations are not plausible within the phenomenological tradition by using quantitative probability as a starting point (Van Manen, 1990). Yet phenomenological research may also be empirical and has to achieve validity beyond the specific data. A richly described empirical material may well reveal a deeper and multifaceted picture of the phenomenon at hand and therefore allow for generalisation. Consequently, in this sense the empirical results may be helpful in interpreting the world in a novel fashion. The starting point of phenomenological research is thus the concrete and daily experiences of the lifeworld and the aim is to achieve a deeper and scientific (i.e. structured and systematised) conception of the nature, intention and meaning of these daily experiences. Van Manen (1990, 9) writes that although phenomenology does not give the necessary tools to "explain and/or control the world", phenomenology does provide us with a consciousness that allow us to approach and capture the world of lived experiences. Following is a brief discussion on intentionality and openness within phenomenological research.

Intentionality

The concept intentionality is a central component of phenomenology and describes the essence of human awareness as it refers to our immediate and strong connectedness and relation to the outside world (Uljens, 1992). Within the notion of intentionality focus is on the relationship between an individual and the objects or actions in the world that constitutes the individual's experience (Uljens, 1992). The relation between the individual and his or her intentions towards the outside world is characterised by its initial unconsciousness (Van Manen, 1990). However, as our actions, behaviour and feelings are at all times directed towards something, our consciousness is related to a specific content and through the outside world we may become aware of our intentional objects (Uljens, 1992; Van Peursen, 1977). See Uljens (1992) for a discussion on intentionality and its significance in Husserlian phenomenology. Here it will suffice to say that in this study intentionality becomes visible through the aim of describing and understanding the noematic consciousness of the subjects. As has previously been mentioned the aim is to describe and explore the parents' intentions, reasoning and orientations relating to choice of communication and education for their deaf or hearing-impaired child. In other words, the aim is to describe and clarify towards what the parents direct both themselves and their child when choosing a certain method of communication or type of school for their child.

Openness

In phenomenological lifeworld research one needs to be aware of the researcher's interaction and "being" in the world and how this relationship influences the research process. The objective of life-world research is an openness to the phenomenon, an openness that whilst complying with the scientific attitude and by setting the presuppositions aside allows the phenomenon and its meaning to present itself in its true manner and perhaps in a novel fashion (Dahlberg *et al*, 2001, 97). Berndtsson (2001) writes that openness and inquisitiveness together constitute neces-

sary tools for phenomenological research as the open mind allows for an awareness of the pre-understanding that in turn may lead to the emergence or construction of new knowledge. Dahlberg *et al.* (2001, 97) writes:

Openness is the mark of a true willingness to listen, see, and understand. It involves respect, and certain humility toward the phenomenon, as well as sensitivity and flexibility. To be open means to conduct one's research on behalf of the phenomenon.

The concepts of pre-understanding and openness must be acknowledged but as Berndtsson (2001) writes we should not view them entirely as problematic. A researcher does not approach a field of study without any presuppositions but how the researcher deals with the presuppositions is the main issue. In this study my previous experience with deaf education and encounters with parents of deaf children allowed me to approach the phenomenon more openly and to understand the different views and the complexity facing Finland-Swedish families with deaf or hearing-impaired children. The main task was not to let my own presumptions influence my understanding of the parents' choices. Putting my pre-suppositions aside was facilitated by the parents' open and sharing attitude. By opening the door to their lifeworlds and allowing me to share some very personal, sensitive, difficult and joyous experiences concerning both their hearing-impaired child and their own thoughts, I was able to view the phenomenon from different perspectives. The concept of pre-understanding is discussed in more detail in the section on hermeneutics.

Approaching an individual's lifeworld with an open mind raises the question of intersubjectivity; that is, our being in the world (Uljens, 2001). Here it suffices to say that through the research interviews (for this study) an intersubjective situation was created and the outcome of these situations was later transcribed and analysed. When discussing lifeworld research one must remember that although a researcher may enter, and indeed share, the life-world of another person it is not possible for the researcher to capture fully the range of emotions or experiences exactly as perceived by the subject (Berndtsson, 2001; Dahlberg *et al.*, 2001). This was also subject to discussion during the interviews: one parent pointed out that a person who does not have a deaf or hard-of-hearing child can understand a parents' joy when his or her deaf child (following a cochlear implant) actually reacts to speech. Nonetheless, by entering another individual's lifeworld and through observing emotions, behaviour and through imagination it is possible to put oneself in the other individual's situation and consequently learn and understand more about that person and his or her lifeworld (Gadamer, 1997). Again, as was mentioned above, through the interviews the parents allowed me to enter their lifeworlds and they openly communicated and shared their feelings and experiences of parenting a deaf or hearing-impaired child and particularly of choosing a method of communication and school placement. Through the phenomenological approach it was possible to describe and clarify factors the parents experienced as being influential, but in order to interpret the choices and their meaning we will turn to hermeneutics.

7.1.3 Hermeneutics

Gadamer (1976, 10) writes that “the genuine researcher is motivated by a desire for new knowledge and nothing else”, but how to go about in order to increase our knowledge is naturally the principal question. Hermeneutics is central to human science research and Gadamer’s (1976) aim with the hermeneutical tradition was to develop a theoretical basis that allows for research within different fields of society that consequently deepen our understanding of the world. The concept of hermeneutics originates from the Greek verb ‘*hermeneuein*’, which “means to interpret” and the Greek noun ‘*hermenia*’ which means “interpreting” (Dahlberg *et al.* 2001). It was the task of the Greek god Hermes to communicate and interpret, i.e. translate the messages from the gods to the people.

Schleiermacher (1768–1834), who emphasised the hermeneutical struggle to avoid misunderstandings (Gadamer, 1997) also put forward a systematic method for interpreting, first biblical texts, then any kind of texts. Along with Dilthey (1833–1911), he was a predecessor of the early Romantic hermeneutics (van Manen, 1990). Schleiermacher’s approach has been considered inadequate for modern human science research (Warnke, 1995) but recent interpretations of Schleiermacher’s writings show that his ideas are constructive and indeed of current interest for modern philosophy (Bowie, 1998). For Schleiermacher hermeneutics is an “art of interpretation”, it is an “*art*” because our understanding of others’ experiences of the world is not solely based on acquired objective rules (Bowie, 1998). In order for an understanding to take place we have to make sense of the ever-changing world in all its complexity (Bowie, 1998). In other words, we have to relate the rules to a specific context and this is where understanding becomes an art.

The hermeneutic tradition as it developed during the twentieth century following the phenomenological turning-point³⁵ provides us with a theoretical basis that allows for a deeper understanding of what it means to be human in certain existential situations (Gadamer, 1976; Warnke, 1995). Considering that the specific situation of being a Finland-Swedish hearing parent of a deaf or hearing-impaired child growing up in bilingual (or multilingual) society is at focus in this study, the phenomenological hermeneutical approach is considered appropriate.

Pre-understanding

The subject and the researcher both live in a specific historical and cultural context that influences human understanding, actions and behaviour. Our understanding of the world is related to our present place, prior history and the culture we live in and we have a pre-understanding of different phenomena in our world (Heidegger, 1993). Even though we may not have a specific belief about a certain phenomenon through the tradition we are situated in we do possess some pre-understanding that influences our conception or behaviour (Gadamer, 1989). The hermeneutic con-

³⁵ Hermeneutics was further developed from the phenomenological philosophy and concepts such as lifeworld and pre-understanding were brought to attention.

cept of pre-understanding is challenging and raises some important questions on the nature of scientific research. The crucial question is whether it is possible to alienate ourselves from our pre-understanding of the world. In order to enable a philosophical and scientific scrutinisation the aim may be to capture without any bias the world as individuals in the natural attitude experience it (Gadamer, 1976; Husserl, 1999). When approaching the daily experiences of the subjects, the researcher avoids reductionism and through the process of “bracketing” seeks to put his or her pre-understanding on the side, not allowing it to influence the openness and understanding of the phenomenon. One must, however, bear in mind that phenomenological reduction implies that the researcher engages in a critical analysis of his or her own pre-understanding and not that these presumptions all of a sudden are non-existent (Gadamer, 1976). In hermeneutics it is argued that in our interpretation we cannot alienate ourselves from our pre-understanding in the manner suggested by Husserl’s concept of bracketing. On the contrary, according to hermeneutic reasoning our pre-understanding offers us the very access to the phenomenon in question and as researchers we are not capable of describing the experiences of other individuals as such, that is, objectively. Nevertheless, our own awareness of our theories, expectations and hopes helps us to hold these back in our interpretative work so we are able to tune ourselves towards the voices expressed in the data (Gadamer, 1997).

Through my previous knowledge and experience of the opposing views within deaf education I could pose questions relating to this; one could say that my pre-understanding avoided limiting my understanding of the phenomenon. The thoughts, feelings and experiences communicated by the parents (in the in-depth interviews) also made more sense when I could relate them to current issues in the habilitation and education for deaf and hearing-impaired children.

Hermeneutical reflection and the hermeneutical circle

Here, hermeneutics will mainly be discussed in light of Gadamer’s ideas. Gadamer opposed the use of one single method for scientific research, particularly within research relating to different aspects of being human. Rather, he maintains that hermeneutics primarily is a scientific tradition with no strict specific rules of scientific inquiry attached to it. Instead it is the phenomenon that determines the method of obtaining knowledge (Gadamer, 1976). Moreover, the historical and cultural context and its influence on the researcher must be taken into consideration: the researcher does not exist in a vacuum, rather in a lifeworld coloured by tradition, culture and history. Warnke (1987, 168–169) reflects on Gadamer’s view on how all knowledge is grounded within our cultural, political and historical tradition:

We never come upon situations, issues or facts without already placing them within some context, connecting them with some other situations, issues or facts and, in short, interpreting them in one way or another. The parameters of these interpretations, moreover, derive from our circumstances and experience and these circumstances and experience are always already informed by the history of the society and culture to which we belong.

As was discussed in Chapter 3, we are born into a world and grow into a culture. We then “live”, that is, we are influenced by our culture and we (generally) uphold and transform it throughout our life. We may not consciously be aware of the cultural premises directing our life but nonetheless we have an unreflected mental model that contributes to our understanding of the world we live in and facilitates handling the situations we encounter. Within the culture influencing us we find society as a whole with its tradition and history but also our upbringing, education and family life, and all of these features form and influence our emotions, thoughts and understanding (Gardner, 1998; Van Manen, 1990). The past, that is, our culture and history hence provide the basis for our being both in the present world but also in our future world. This influence may be tacit and difficult to pinpoint and bring to light. Nevertheless, as meaning has a connection both to the past and present, as well as to the future, interpretation must take into consideration the historical context (Gadamer, 1976). Understanding is gained through an interpretation that can be characterised by two reciprocal processes, the process of moving between the interpreter’s past and present, and the process of moving between the parts and the whole (Gadamer, 1989). These processes gradually enable meaning and knowledge to emerge. Important nonetheless is the fact that the interpretation is subject to influence from what Gadamer calls “prejudices” (Gadamer, 1989). Our prejudices are related to the culture we live in and they predispose us to “anticipate the meaning of a thing or a text long before we fully understand it” (Dahlberg *et al.*, 2001, 83). Gadamer used the concept of *horizon* to indicate the perspective through which we approach an object and “understanding is always interpretation and meaning is always a ‘fusion’ of the horizons of the interpretation and the object” (Warnke, 1987, 82). The concept *horizon* is thus used to describe our understanding and how – through the influence of history – a horizon of understanding emerges, a horizon that also influences the potentiality and limits of our understanding (Dahlberg *et al.*, 2001).

The interpretation of meaning is characterised by the **hermeneutical circle** (Gadamer, 1989). Understanding is gained through a circular process starting from the phenomenon itself, and can be characterised by the process of moving back and forth between the meaning of the parts and the meaning of the whole in relation to our research questions. Through the whole, the parts are given meaning and the whole is understood through the parts. Starting from a vague conception of the whole text the parts are interpreted and related to the whole in an ongoing process (Kvale, 1997). Moreover, Bernstein (1987) points out how the hermeneutical circle facilitates the search for the “new” by drawing our attention to the prejudices that can make us blind to both the meaning and the truth to be found in the texts we are interpreting. The hermeneutical circle should not be seen as a vicious circle misleading the researcher, rather as a circle enabling a continuous deeper understanding of the meaning of the phenomenon (Gadamer, 1989; Kvale, 1997). The main task for the researcher is to get into the circle in a correct and suitable manner. The role of the hermeneutical circle and its practical use is clarified by Kvale’s (1997) description of how a researcher approaches and analyses qualitative interviews. First, the researcher reads the entire interview in order to get an overview or general meaning. Then the more specific topics or details are

brought to her attention and related to the overall meaning of the interview text. Thereafter the researcher moves back and forth between the parts and the whole gradually obtaining a deepened meaning of the text. This procedure also characterised the analysis of the parental interviews in this study.

In addition to the presuppositions and the hermeneutical circle Kvale (1997) puts forward five other canons of interpretations in hermeneutical research based on the work of Radnitsky. The interpretation of a text can be considered completed when a “**good gestalt**” has been achieved, that is, when the text does not show any logical contradictions and the meanings of the themes constitute a coherent and momentous whole. Moreover, the interpretations of the different parts of the interview should be **tested** against the overall meaning of the text. It is also important to acknowledge the **autonomy of the text**, and what the text – in this study the transcriptions of the interviews – in itself asserts about a specific topic. Furthermore, in order to acquire an interpretative sensitivity, the researcher must possess enough **knowledge about the theme** of the text. Finally, from every interpretation a new and creative understanding should emerge enabling one to view the phenomenon in a novel and deeper fashion.

Sometimes researching lifeworlds gives us new knowledge or a deeper understanding that may not be comfortable, for it can be difficult to accept that things are not what we presupposed (Gadamer, 1976). However, as mentioned earlier, Gadamer asserts that a true researcher is motivated by a desire for new knowledge, and even when a more elucidated understanding appears uncomfortable it cannot be pushed away by anyone genuinely seeking new knowledge. The objective of research is to produce true knowledge needed to develop and improve procedures and strategies in a variety of areas (Puolimatka, 2002). Through research findings the wider audience is given a chance, and importantly also the right, to find out how things truly are (Puolimatka, 2002). Therefore the objective of qualitative research has to be true and accurate analyses of the social world, even in cases when the truth is uncomfortable and threatening (Puolimatka, 2002). Human experience takes place within and with the world and despite the outcome the role of hermeneutics is to mediate between different lifeworlds (Gadamer, 1976). The dynamic force of hermeneutics can be found in the alternation between the parts and the whole, between pre-understanding and understanding, and between closeness and distance (Berndtsson, 2001).

It is reasonable to say that the focus of interest within hermeneutics is on the interpretation of texts and other cultural products with the goal of obtaining a valid and mutual understanding of the meaning of the text (Kvale, 1997). Traditionally hermeneutics focused mostly on biblical texts but the concept of *text* has been broadened to include, for example, discourses and interpretation in general. A text can be considered a process or an event and as such the text is communicating something to the reader (Gadamer, 1997). Researching lived experiences is therefore made possible by interpreting texts that derive from the study of lifeworlds. Interpreting the texts is not a question of reproducing them, but rather a creative process incorporating all meaning-related processes (Melberg, 1997). Kvale (1997) writes that the spoken discourse, such as interviews, is transformed into texts that then are to be interpreted and furthermore that this interpretation can be

viewed as a dialogue with the text. Dialogue is the essence of human understanding (Melberg, 1997) and language is thus the researcher's main tool when approaching the phenomenon (Gadamer, 1976). Hermeneutics has been utilised for many different reasons and purposes within pedagogics (From & Holmgren, 2000). In this study knowledge of the parents' lifeworlds and an understanding of their choices are obtained by interpreting the transcriptions of the in-depth interviews and by analysing their answers to the questionnaire.

7.2 Methodological considerations

I have no friends or relatives with a hearing loss and therefore no personal experience of deafness, hearing-impairments or the Deaf community. Having completed an introductory course to Sign Language I took an interest in the education of deaf and hearing-impaired children and wrote my Masters Thesis in education on deaf children and their language. My interest in the field of deaf education continued and has since led me to formal studies in deaf education and to numerous seminars on many aspects of deafness and hearing-impairments. These include seminars on cochlear implants, oral communication for deaf and hearing-impaired children, Sign Language and the psychosocial development of deaf children. Protracted discussions with parents and teachers of deaf or hearing-impaired children (in addition to the structured parent interviews), as well as encounters with deaf and hearing-impaired people have also contributed to my understanding of deafness and the opposing views on communication and education for deaf and hearing-impaired children.

As a part of this research I conducted four interviews (two in Finland and two in Sweden) with professionals working or doing research in the field of deaf education. In addition I visited four schools for deaf or hearing-impaired children. The purpose of these interviews and visits was to broaden my understanding of the research domain. The aim was to seek new insights and receive the necessary tools to structure both the interview questions and the questionnaire as well as to reach a deeper understanding of the parental decision processes and to increase my interpretive sensitivity of the parents' experiences.

Expert interviews

As was mentioned above, in order to get a comprehensive understanding of the phenomenon of interest, interviews were carried out with professionals working within the field of deafness and deaf education. The objective was to gain knowledge on current issues, difficulties and challenges within the education of deaf and hearing-impaired children. Two experts from Stockholm University were interviewed, as were two teachers representing the only available form of education with Finland-Swedish Sign Language as the medium of instruction in Finland (Ytteresse School and Snäckan Day-care). It must, however, be pointed out that the interview questions do not directly address the research problems. Rather, as previously mentioned, these interviews served the purpose of approaching the field and context of deaf education. They can also be seen as a complement to the review of the literature and therefore some of the results from the interviews are intertwined in the theoretical background.

The themes of these interviews were identical but the specific interview questions differed according to the person's field of expertise. The themes were:

- (a) deaf children's language development,
- (b) the role of Sign Language in deaf education
- (c) the teaching of Swedish to deaf pupils, and
- (d) deaf children's social development and behaviour.

Interviews with the following people working in the field of deaf education have been conducted:

Dr. Inger Ahlgren, Associate Professor at the Department of Linguistics, Stockholm University. The interview was conducted on 3 April, 1998 at the Department of Sign Language at Stockholm University.

Dr. Kristina Svartholm, Professor of Swedish as a second language for deaf people at the Department for Scandinavian Languages, Stockholm University. The interview was conducted on 3 April, 1998 at the Department of Sign Language at Stockholm University.

Special day-care teacher Charlotte Snellman, principal of the special day-care centre Snäckan in Ytteresse, Finland. The interview was conducted on 23 January, 1998 at Snäckan.

M.Ed. Martin Björkvik, teacher at Ytteresse School, Finland. The interview was conducted on 23 January, 1998 at Ytteresse School.

The interviews with Ahlgren and Snellman were both recorded and later transcribed by the researcher, together twenty-six pages. During the other two interviews the researcher took notes. The interviews with Ahlgren, Svartholm and Björkvik lasted forty-five minutes each, and the interview with Snellman lasted one and a half hours, that is, the interviews with the experts lasted altogether three hours and forty-five minutes.

Visits to schools for deaf children

Visiting four different schools for deaf and hearing-impaired children and observing classroom instruction and interaction allowed for an understanding of deaf education that could not have been picked up solely from the literature. The visits broadened my preconception and understanding of practical matters within the field of deaf education. The observations were unstructured and served more as a way to get a feeling of the atmosphere, modes of communication and educational methods at the different schools. The visits also provided a good opportunity to perform unstructured interviews with teachers and principals at the schools. The focus of the observations were:

- (a) the interaction between the teacher(s) and the pupils,
- (b) the interaction between the pupils,
- (c) the means of communication used in the classroom.

Two visits to Ytteresse School in Ostrobothnia (in January 1998 and May 1999), a visit to the special day-care centre Snäckan (in January 1998), a visit to Western Pennsylvania School for the Deaf in Pittsburgh, USA (in May 1998), and to Kristinaskolan in Härnösand, Sweden (in October 1998) were carried out.

Ytteresse School and Snäckan

As previously mentioned, Ytteresse school is a Swedish-speaking school for normally hearing children that has specialised in the mainstreaming of deaf and hearing-impaired children. The school has 150 pupils in grades 1 to 6, and one hearing teacher native in Finland-Swedish Sign Language.

During the visit to Ytteresse school observations were made during three lessons for the first-graders; during a mathematics lesson, during a native language lesson (Swedish) and during a science lesson. The class has twenty-nine pupils, one of whom is deaf, and two teachers, both of whom are hearing but one with Finland-Swedish Sign Language as his native language. During the mathematics and science lessons the deaf pupil was together with the rest of the class but during the native language class the deaf pupil received individual instruction (by the teacher fluent in Sign) in a room specially designed for the purpose. The room is soundproof and has a television and VCR enabling the teacher to utilise video material or to watch educational programmes specially designed for deaf pupils.

A visit to the special day-care centre Snäckan was also conducted. This furnished the opportunity to observe the children in action and to interview the principal Charlotte Snellman. Furthermore, a detailed description and demonstration were given of the technical equipment and computer programmes used in the speech and language training, and in the stimulation of the deaf pupils' residual hearing. The principal is fluent in Sign, one assistant is deaf and the other teachers are all fairly good signers. Approximately fifty children attend Snäckan.

Western Pennsylvania School for the Deaf

Western Pennsylvania school for the Deaf (WPSD) was established in 1869 and was the first day school for the deaf in the United States (Western Pennsylvania School for the Deaf leaflet). The number of pupils amounts to approximately two-hundred and ten, divided as follows:

- a pre-school programme for children from 2–6 years of age,
- an elementary school programme for pupils 6–13 years of age,
- an upper school programme consisting of grades seven through twelve.

WPSD used to be an oral school but has during the past decades evolved into a school depending on Total Communication (that is, different and individualised means of communication are utilised). American Sign Language has, however, a strong position and the environment is predominantly signing. A centre for deafness, providing services for deaf or hearing-impaired people of all ages, also operates at WPSD.

At WPSD I toured the school and sat in on a fourth-grade mathematics lesson with nine pupils and a deaf teacher using both speech and Sign. Short visits to

different classes in the pre-school were also conducted, as well as an unstructured interview with the principal of the elementary school.

Kristinaskolan

Kristinaskolan in Härnösand (Sweden) is a school for deaf and hard-of-hearing pupils from Northern Sweden. Kristinaskolan is a special school with the same goals and guidelines as the regular primary school. Approximately ninety pupils (of which the majority is deaf) are enrolled in the school. The goal is that the pupils at the school become bilingual. Sign, written texts and speech are used in the learning process. In addition to classes for deaf pupils, in which Swedish Sign Language is the language of instruction, there are classes for pupils who are hard of hearing in which both speech and Sign are used. The school has deaf, hearing-impaired and hearing teachers. A centre for deaf and hearing-impaired children is also operating at Kristinaskolan.

The visit to Kristinaskolan was arranged by DHBS³⁶ for parents and teachers from Finland. During the two-day visit we toured the pre-school, the primary school (grades 1–6) and the residential homes for pupils not living in, or nearby, Härnösand. All these pupils travel home on Friday afternoon, spend three nights at home and return to Härnösand on Monday morning where the lessons resume by noon. At the school I visited a third-grade mathematics lesson, a fifth-grade history lesson and a physical education lesson. In addition, the school had arranged three talks on issues concerning the education at Kristinaskolan and the special needs of hearing-impaired individuals.

Some reflections from the interviews and school visits

Visiting the fairly large schools WPSD (Western Pennsylvania school for the Deaf) in the US, and Kristinaskolan in Härnösand, certainly made the limited signing and social environment for the deaf children attending Ytteresse school and Snäckan day-care centre seem extremely poor. It became obvious that the environment at Ytteresse School and day-care centre does not allow for a social or linguistic development compared to that of deaf children attending deaf schools, or, of course, that of hearing children. Observing what may be the reality for deaf pupils and comparing this to the situation for Finland-Swedish deaf children only emphasised the magnitude of the challenges facing deaf education in Finland, particularly the education of Finland-Swedish deaf children.

The interviews and visits also facilitated the understanding of some of the more general challenges of education for deaf and hearing-impaired children. For example, the long distances to school for many of the pupils, the need for deaf teachers as role models, and the need for the hearing teachers to be proficient in Sign Language and different features of deafness and hearing-impairments.

³⁶ The parental organisation for deaf and hearing-impaired children from Swedish-speaking families.

The visit to Kristinaskolan nicely clarified the significance of recognising the different needs for children who are deaf and children who are hard of hearing and benefit from spoken language input. These two groups of children should not be considered a homogeneous group with similar needs or problems. Regardless of the child's hearing status the school did, however, emphasise the need for Sign Language. According to the school, Swedish Sign Language gives the children the opportunity to develop full communication should spoken language communication prove insufficient. As has been discussed earlier, in one-to-one interaction spoken language may be sufficient for hearing-impaired children but in classroom settings and other social gatherings with background noises and several persons talking simultaneously, the effort of listening tends to be too demanding. In the real context of a deaf school this particular problem as well as other practical challenges were readily perceived. Also, entering the lifeworld of a hearing-impaired woman with one foot in the hearing world and one foot in the deaf world elegantly pointed out social and educational challenges, problems and solutions on a more personal level. This experience increased my awareness of the different needs for hearing-impaired and deaf children and therefore strengthened my sensitivity to and understanding of the parents' views and experiences relating to this particular issue.

7.3 Collection of data

Subjects

This study focuses on the decision processes relating to communication method and education among parents of deaf and hearing-impaired children belonging to the Finland-Swedish minority. Three of the eighteen families are, however, bilingual, i.e. one parent speaks Finnish as his or her native language and the other parent speaks Swedish. With the exception of one parent who is hearing-impaired, all parents are hearing.

Eighteen families from the Swedish Finland participated in this study. The families are from Östnyland, the Helsinki area, Västnyland, Åland and Österbotten (Ostrobothnia). At the time of the study the children, eleven girls and seven boys, ranged in ages from two and a half years to eighteen years. The age range when the children's hearing loss was diagnosed is six days to five years and eight months, with the mean age being twentyfour months (with thirtyone months being the mean age for children in Finland) and the median age also twentyfour months. Three of the eighteen children have a cochlear implant.

Of the eighteen families, ten had no previous experience or knowledge of Sign Language, deafness or hearing-impairment when their child was diagnosed with a hearing-impairment. Eight families had some experience, mainly with distant deaf relatives.

Procedures for contacting subjects

Habilitation counsellors and other health-care professionals are obliged to observe silence, that is, they cannot reveal the names of the families of deaf or hearing-impaired children. Therefore the procedure to get in contact with the families was

the following: letter with information about the purpose of the study and a request to participate was sent to a habilitation counsellor and to the head of the Swedish parental organisation for deaf and hearing-impaired children (DHBS r.f.) who then forwarded the letter to the families in question.

In Ostrobothnia the letter was mailed to ten families together with information about DHBS's annual summer camp for families with deaf or hearing-impaired children. The families were also informed that the interviews would take place during the summer camp and thus that they would not cause any extra arrangements on the part of the parents. Ten families in Ostrobothnia received the request and seven responded, that is, all families who participated in the summer camp participated in the study³⁷. The habilitation counsellor in Southern Finland mailed the letter to twenty Swedish families with a deaf or hearing-impaired child. Twelve families responded (one family was excluded from the study because the child's hearing loss is very mild, and thus not relevant for this study). The major reason for the low participation in Southern Finland is that many of the children have a mild to a moderate hearing loss, the parents may thus correctly have assumed that they and their child do not belong to the target group for this study. In addition, a few families who had learned shortly before this study took place that their child had a hearing loss assumed that they were not suitable candidates for this study since they had not yet started the early habilitation process. One of these families did, however, contact the researcher when the habilitation had begun and was then included in the study. That is, altogether eighteen families participated in the study – for the questionnaire N=18 and for the interviews N=17.

7.3.1 The questionnaire

The questionnaire (see Appendix 2) consists of nineteen questions and was administered to all eighteen families who participated in the study. The parents completed the questionnaire immediately before being interviewed, with the exception of two mothers who filled out the form after the interview and returned it by mail. The aim of the questionnaire was to obtain information about background variables such as the child's current age, age when the hearing impairment was diagnosed, and current parent-child communication mode. Furthermore, questions about the information on Sign Language, deafness, hearing-impairment, cochlear implants, and hearing aids received during the early intervention were included. The questionnaire also asked the parents to express their opinion on the different school opportunities available for Finland-Swedish deaf children (Finnish Deaf school, Deaf school in Sweden, mainstreamed in a school for normally hearing

³⁷ One of the families did however, due to personal matters, only fill out the questionnaire and did not participate in the in-depth interview.

Kvale (1997) defines twelve features of the mode of understanding in the qualitative research interview and combined, these features attempt to characterise the main structures of this particular type of interview. These features are marked in *italic* writing and are intertwined in the following discussion on issues relating to the parental interviews for this study.

The interviews with the parents

Seventeen families took part in an in-depth interview concerning school matters and conceptions of the early habilitation for their deaf or hearing-impaired child. Of the seventeen interviews, ten were conducted with both parents and eight with the child's mother only. All interviews in Ostrobothnia took place during the DHBS family summer camp in June 1998. Regarding the interviews with families from other parts of Finland, the parents chose the time and place: three interviews took place at the University of Helsinki, two at the Light House (The Finnish Association of the Deaf) in Helsinki and the remaining six families opted for the interview in their homes. These interviews took place during October 1998 to December 1998, with the exception of one interview that took place in September 2000. This family contacted the researcher after having taken part in the early habilitation and was then included in the study.

The topic of a qualitative interview is the interviewee's *lifeworld* and his or her relation to it (Kvale, 1997). The aim is to describe and understand topics of interest and how the interviewee experiences and perceives these particular themes. The qualitative research interview is therefore focused on specific themes and the resulting interview can be analysed according to either the described lifeworld or the person describing his or her lifeworld. The interview aims at interpreting the *meaning* of topical themes in the interviewee's lifeworld. The main task is to understand the meaning or implication of what the person being interviewed is communicating. A qualitative research interview should focus both on what the interviewee is actually saying and what is implied between the lines. Furthermore, through the spoken word and not quantitative measures the qualitative research interview aims to obtain a diversified portrayal of different *qualitative aspects* of the interviewee's lifeworld and uninterpreted, nuanced *descriptions* conveying the qualitative diversity of the phenomenon. This is achieved by letting the person interviewed describe as precisely as possible what she is experiencing and how she acts. The question of why the interviewee experiences and acts the way she does is then a task for the researcher. (Kvale, 1997)

The interviews were conducted by the researcher and a research assistant (a Sign Language interpreter who teaches Sign Language to families with deaf, hearing-impaired or dysphatic children). In general the interviews lasted 45–60 minutes, although two interviews lasted up to two hours. Altogether the seventeen interviews with the parents lasted fourteen hours and twenty minutes. All interviews were audio-recorded and later transcribed verbatim, altogether 296 pages. One interview was conducted in Finnish, the others in Swedish. The researcher transcribed eleven interviews and an assistant transcribed six. The assistant had previous experience of transcribing from audiotapes, also received instructions on how the interviews were to be transcribed, and in addition received a model-

transcription of an interview transcribed by the researcher. The role of the research assistant during the interviews was to help the researcher, mainly by taking notes had the interviewee(s) refused a tape-recording of the interview, which no one did. Another assignment of the assistant was to ask specific questions regarding the teaching of Sign Language at home. Of the seventeen interviews, fourteen were conducted by both the researcher and the assistant, two by the researcher only and one by the assistant only.

The *focus* of the qualitative research interview is on certain themes in the life-world of the person being interviewed, that is, the interview is not strictly structured, nor is it completely unstructured. In line with a life-world approach to research all interview questions were not rigidly planned in advance (Dahlberg *et al.*, 2001). Such a procedure would not allow for a sensitivity and an openness to the phenomenon as it would present itself during the interviews. The themes and principal questions in all interviews did, however, follow a structure planned in advance and the themes were chosen in order to obtain extensive data on issues corresponding to the research problems of this study. That is, questions relating to methods of communication used with the deaf or hearing-impaired child, educational problems and educational solutions as well as experience of the early habilitation were included. To clarify, the themes were:

- (a) previous encounters with deafness and hearing-impairment
- (b) method of communication used with their deaf/hearing-impaired child
- (c) factors experienced to influence the selection of communication method
- (c) the role of Sign Language for their deaf/hearing-impaired child
- (d) educational problems facing a family with a deaf/hearing-impaired child
- (e) factors experienced to influence the educational choice for the deaf/hearing-impaired child
- (f) experiences of the early habilitation.

Additional questions were of course posed and the nature of these additional questions depended on the answers to the previous questions. The sequence and realisation of the research interviews thus followed that of Dahlberg *et al.* (2001, 159):

The goal is to move towards the unexpected, the unknown, and unreflected, in order to reflect upon and disclose the phenomenon. The interviewer's task is to devise questions and directions that facilitate the deepening and clarifying of thoughts and ideas, thereby assisting informants in revealing their experiential life.

In qualitative research interviews general opinions are not of interest, rather it is *specific* situations and events from the interviewee's lifeworld that are at focus (Kvale, 1997). Even so, Kvale (1997) points out that general questions can provide relevant and interesting information. The interviewer should be open, curious and sensitive to what the interviewee is communicating because the aim is to collect as rich and *deliberately naïve* descriptions as possible. By having certain

themes as a basis for the interviews it was possible to grasp general information and by posing additional questions it was possible to obtain information about more specific situations and experiences in the parents' lifeworlds.

The descriptions and remarks of the person being interviewed may vary depending on the *sensitivity* of the person conducting the interview. The knowledge obtained during the interview is derived from the *interpersonal situation* and interaction. Kvale points out that the reciprocal, cognitive and emotional influence of the interviewee and interviewer need not be a source of error but rather a source of strength in the qualitative research interview. It is not often that another person is so sensitive to and interested in your lived experiences and because of this a research interview may well be an enriching and *positive experience* for the person being interviewed. It may result in a new and deeper understanding of one's life-situation. (Kvale, 1997)

After the interview three families commented that they had been ill at ease and, in fact, reluctant to take part in the interview. One reason for the reluctance was that despite meetings³⁸ and reports³⁹ on the educational for deaf and hearing-impaired children from the Swedish population in Finland as well as promises from the decision-makers, the situation for their children had not improved. The fact that the interviews concerned their children, which naturally can be emotionally troublesome, may also have influenced the parents' willingness to participate in the study. Still another reason may have been that I was a complete stranger to sixteen of the eighteen families. I had met two of the mothers at Sign Language classes and seminars at the Finnish Association of the Deaf. However, despite the initial reluctance on part of some of the parents the interviews proceeded smoothly and without any trouble or unwillingness. Many parents volunteered to answer additional questions later on if needed, and to help in other ways. This did, in fact, happen on one occasion. Despite the request from the researcher to pause for a moment, one mother continued talking when the audiotape was full and the side of the tape had to be changed. Some words were not recorded and later the mother was presented with a transcription of that particular question and asked the same question (as during the initial interview) again.

³⁸ The meetings were arranged by Finland's Swedish Special Education Resource Centre (Finlands svenska specialpedagogiska resurscenter) held in Helsinki 17 January 1998 and in Ytteresse 24 January 1998.

³⁹ Dahlbäck, A. (1998a). *Döva och hörselskadade barns skolsituation*. Finlands svenska specialpedagogiska resurscenter.

Dahlbäck, A. (1998b). *Tillägg till Rapport om skolgångssituationen för hörselskadade och döva finlandssvenska barn*. Utbildningsstyrelsen. Vasa: Lärum-förlaget AB.

Dahlbäck, A., Friberg, A., & Hägglund, B. (1997). *Rapport om skolgångssituationen för hörselskadade och döva finlandssvenska barn*. Utbildningsstyrelsen. Vasa: Lärum-förlaget AB.

In research interviews the person being interviewed sometimes expresses ambiguous remarks or remarks with many different meanings. This *ambiguity* may adequately reflect the contradictions in the interviewee's lifeworld. The interview may, however, result in new insights and consequently a *change* in how the person being interviewed describes or looks upon different themes or events within his or her lifeworld (Kvale, 1997). A few parents commented on the in-depth interview as being an enriching experience as it made them consciously reflect upon issues they had not given much thought to earlier.

For ethical reasons, and in order to preserve the parents' anonymity it is not possible to account for all data reported in the interviews, or to account for the entire interviews. In Chapter 8 excerpts from the interviews are presented. The quotations are translated into English but the original texts in Swedish can be found in Appendix 1. As can be found in the original texts the parents occasionally used a word or expression in Finnish or English. In order to preserve anonymity quotations from the one interview conducted in Finnish have been translated into Swedish. For the same reasons some background information such as town of residence has been altered or is not mentioned at all, it may simply read city xx in a quotation.

7.4 Analysis of the data

In qualitative research questions about the true nature of a particular phenomenon and which factors that influence the phenomenon are typically asked. To be able to reflect on such issues and to be able to answer the research problems, I have, during a period of over ten years, followed the discussions, developments and events concerning the field of deaf education. However, as Larsson (1993, 197) points out, preconceptions needs to be put aside, although this is a far from trivial task. The most important point is to eliminate the influence of a preconception during the collection of the data and yet to allow for this influence during the analysis, as the researcher him- or herself is an important tool in qualitative research. As discussed in Section 7.1 the researcher must critically analyse his or her pre-suppositions. The major priority in this study has been to encounter all the parents of children who are deaf or hearing-impaired with an open mind in order to understand fully the true nature, and the parent's perspective, experience and conceptions of the phenomenon studied.

The Questionnaire

When the collection of the data was completed the eighteen questionnaires were analysed first. To begin with, each of the nineteen questions were looked at separately from each other, that is, simple calculations such as the frequencies (for example for the number of families using a specific method of communication), the mean and median ages (for questions 1 and 3) were determined. Of the nineteen questions all but two – question (2), "*the sex of the child*", and question (4), "*method of communication*" – were open-ended questions. A chart of all responses to the open-ended questions was made. Secondly, the data was categorised in order to answer the research problems. Research problem 1 (method of communi-

cation) is answered by question (4) in the questionnaire (see Appendix 2) and research problems 2 and 3 (educational problems and educational choices) by questions (15–19). In order to discuss factors influencing the parents' educational choice for their deaf or hearing-impaired child the data was categorised according to the child's current educational placement.

Research problem 4 (experience of the early habilitation) is not directly dealt with in the questionnaire; rather, questions (6) and (9–14) provide background information on the sources and quantity of information the parents received during the early habilitation. The six remaining questions in the questionnaire provide background information.

The purpose of the questionnaire was outlined in Section 7.3. In addition, the purpose was to strengthen the trustworthiness of the interviews.

Interviews with the parents

The following step in the reduction of the data was to analyse the interviews with the parents. The themes of the interviews are very similar to the ones in the questionnaire but the interviews provide a more in-depth analysis.

Everything that was said during the interviews was transcribed verbatim. If the mother and father answered simultaneously both responses were transcribed. Only on a few occasions are some words of either parent impossible to comprehend. The transcriptions do not follow the procedures common to conversational discourse analysis, nevertheless, some simple features of this type of transcribing are present; for example, words that the interviewees emphasised are written in capital letters.

One comment about the use of the Swedish pronouns *jag* (Eng: *I*), *man* (Eng: *one*) and *du* (second person singular⁴⁰, Eng: *you*) is necessary. In Swedish it is fairly common to use both the indefinite pronoun *man* (*one*) and the personal pronoun *du* (*you*) when referring to oneself and/or to people in general. This means that *du* is nowadays also used generically. When using *man* and *du* in this way a speaker may be said to generalise from his or her own experience. In the parental interviews the parents frequently alternate between *jag* (*I*), *man* (*one*) and *du* (*you*) even in the same sentence which may seem confusing to anyone unfamiliar with this feature of spoken Swedish.

The following symbols are used in the quotations:

- ... some words of the original transcript are omitted
- [--] one or more sentences are omitted
- [] researcher's comment

In qualitative research the material first has to be organised so categories aimed at facilitating the analysis and presenting the central characteristics of the phenome-

⁴⁰ In Swedish a distinction is made between second person singular you (Swe: *du*) and second person plural you (Swe: *ni*).

non are distinguished (Lincoln & Guba, 1985). The starting point of the analysis of the interviews was to be found in the material, that is, the data was not analysed according to a fixed process chart, rather with an open mind to see what could be discerned. In order to do so I first read the transcripts of all interviews several times with a particular theme or question in mind (I also listened to selected parts of the interviews, especially of the interviews I had not transcribed myself). The reason for this course of action was to get a feeling and an overall understanding of the data. That is, to approach the texts according to the principles of hermeneutical reflection and the hermeneutical circle, consequently allowing for the parts and whole to interact in order for a deepened understanding of the interview texts gradually to emerge.

The themes correspond with the research problems. The next procedure was to pick out information relating to these research problems, the information was then entered in a chart so a comparison of the different responses (to a particular research problem) was possible. Not surprisingly, the family's method of communication stood out as a factor influencing the parents' conceptions and experiences of the issues investigated in this study. That is, regarding most issues one could find similar thoughts and conceptions in parents who use oral communication and parents who use manual communication. Although the linguistic variety in the families is remarkable⁴¹ – eight different methods of communications were reported – categorising the responses according to the families' mode of communication (oral or manual) emerged as being the most sensible way of both analysing and presenting the data. Thirteen families did report using some form of manual communication. However, included in the "Sign Language group" are only the ten families who reported using either Sign Language, Sign Language combined with signed Swedish or Signed Finnish, only Signed Swedish or Sign Language combined with speech.

The families who use a spoken language, with or without a signed representation of Swedish or Finnish, were grouped together in the "the spoken Swedish group". The reason for this classification is that the parents in the latter group themselves commented on the fact that the use of signs is limited and should not be considered their child's primary mode of communication.

During the process of analysis the responses from the different families were compared with each other, and with responses to other themes or research problems. The intention with this procedure was to examine possible connections between the responses to the different themes, such as the relation between choice of communication mode and educational preference, or choice of communication and conceptions of the early habilitation. The findings from the study are presented in the next chapter.

⁴¹ Both in the questionnaire and the interviews the parents stated the mode of communication they use with their child. Table 2 (Section 8.2) presents the different methods of communication in the families.

8 Results

8.1 Outline

In this chapter the results from the questionnaire and the parent interviews are presented in three different sections: **choice of communication method** (Section 8.2), **educational decision-making** (Section 8.3), and **early habilitation** (Section 8.4). These sections correspond to the research questions. As outlined in Chapter 6 the research questions are:

- 1) What method of communication do hearing parents living in a bilingual society use with their deaf or hearing-impaired child?
- 2) What factors influence parents' choice of communication method for their deaf or hearing-impaired child growing up in a bilingual society?
- 3) How do hearing parents with deaf children experience the educational decision-making when there is no straightforward choice of school that provides the compulsory basic education for their deaf child who belongs to a minority in a minority?
- 4) What are the parents' experiences of the early habilitation for their deaf or hearing-impaired child?

In Section 8.2 the results relating to research question 1 and 2 are presented, in Section 8.3 the results relating to research question 3 are discussed and finally in Section 8.4 the results to research question 4 are presented.

The results of the questionnaire give a clear picture of the educational problems and choices facing the families in question, and also of inconsistencies (such as information given to parents) in the early habilitation of the deaf or hearing-impaired child. The results are significant for an initial understanding of the difficulties involved in the education and habilitation of Finland-Swedish deaf or hearing-impaired children as well as an initial understanding of factors influencing the parents' choice of communication methods and educational placement.

The in-depth interviews with the parents (the parents who completed the questionnaire were also interviewed) of deaf or hearing-impaired children partly cover the same issues as the questionnaire. The interviews, however, enable a more detailed analysis and they revealed the many difficulties facing the families, and in particular the complexity of the educational opportunities and the experiences of the early habilitation. A lack of support and expert knowledge on deafness, cochlear implants and on different means of communication, were frequently reported in the interviews. A partial overlap between the results from the questionnaire and the interviews has not been possible to avoid. In Sections 8.2 and 8.3 the results from the interviews are presented according to the families' method of communication, that is, the results from families using Sign Language are grouped together as are the results from families using spoken language.

Regardless of the families primary method of communication the parents reported similar experiences of the early habilitation. The parents' experiences of the early habilitation are therefore not presented according to the families' method

of communication, rather according to the different themes that emerged as being significant for the parents in the early habilitation (see Section 8.4).

The excerpts from the parent interviews are translated from Swedish or Finnish and are numbered in consecutive order throughout the entire Chapter 8. The original excerpts in Swedish can be found in Appendix 1.

8.2 Method and choice of communication

In this section the data from the questionnaire regarding method and choice of communication in the eighteen families is presented. That is, the results presented in this section answer the first and second research questions (1. What method of communication do hearing parents living in a bilingual society use with their deaf or hearing-impaired child? 2. What factors influence parents' choice of communication method for their deaf or hearing-impaired child growing up in a bilingual society?). The question as to whether the information given to the parents as part of the early habilitation influenced their choice of communication is set forth in Section 8.2.4.

For an outsider the group of deaf children is often thought of as a homogenous group with uniform qualities and needs. However, as regards the linguistic background and method of communication the diversity among the families taking part in this study is remarkable. Among the families a variety of methods of communication are utilised. Five families stated that they use only Sign Language in communication with the deaf child. Two families use Sign Language and signed Swedish/Finnish. One family uses Sign Language, Signed Finnish and spoken Swedish/Finnish. One family uses Sign Language and spoken Swedish. One family uses only Signed Swedish. Three families use signed Swedish and spoken Swedish (or Finnish). Four families only communicate in spoken Swedish/Finnish. In addition, one family uses spoken Swedish combined with Cued Speech (see Section 3.2 for a definition of Cued Speech). See Table 2 for an overview of the methods of communication used in the families taking part in this study.

As is evident from this sample of families with children who are deaf or hearing-impaired, the linguistic variability is enormous. This only shows how extremely complex the issue of language and education for deaf children is. It is not possible to consider all deaf and hearing-impaired children as having identical language backgrounds.

An interesting observation concerning the communication methods is that two families reported using both Finnish Sign Language and spoken Swedish or Finnish. As was mentioned in Section 3.2, speech and a natural Sign Language cannot be used simultaneously – one of the languages suffers. If speech and Sign are used at the same time the word order usually follows that of the spoken language (Kyle & Woll, 1985). One can thus assume that the signing in the two families at least occasionally follows the syntax of the spoken language and cannot be considered a natural Sign Language.

Table 2. Method of communication among the eighteen families

Method of communication	Number of families
Sign Language	5
Sign Language and signed Swedish/Finnish	2
Sign Language, signed Finnish and spoken Swedish/Finnish	1
Sign Language and spoken Swedish	1
Signed Swedish	1
Signed Swedish and spoken Swedish/Finnish	3
Spoken Swedish/Finnish	4
Spoken Swedish and Cued Speech	1

As can be seen in Table 2 altogether thirteen families state that they use Sign in some form in communication with the deaf or hearing-impaired child. The remaining five families reported using only oral communication, one family in combination with Cued Speech. However, three of the families who reported using some form of manual communication only occasionally do so and these parents view spoken Swedish (and/or Finnish) to be their child's primary language. For this reason these three families are included in the spoken Swedish group. That is, ten families belong to the signed communication group and eight to the spoken language group. The results on choice of communication method of the families using Sign Language will be reported on first, then the results from the families using spoken Swedish and/or Finnish.

8.2.1 Families using manual communication

The ten families who have opted for signed communication (Finnish Sign Language, Finland-Swedish Sign Language or a signed representation of Swedish or Finnish) as the first language for their deaf child are all convinced that this means of communication is the only correct one for deaf children. These parents – who did not have any significant background knowledge on deafness or Sign Language – all feel Sign Language to be the natural and only appropriate means of communication with deaf children. The initial sorrow of learning that their child is deaf was more difficult than having to adjust to signed communication. These parents all stressed the need to view deafness from the child's point of view. According to them excluding Sign Language is egoistic on the part of the parents. The main concern for these parents – who mentioned the difficulty, or lack of time to learn Sign Language – was not whether they were happy with the choice of communication method, but whether their child was happy.

Choosing Sign Language

Parents in this category view Sign Language as a necessity for a deaf child's normal cognitive and psychosocial behaviour. They believe that a full communication with a deaf child is only possible through the medium of Sign. When asked why they chose Sign Language the parents could not specify why, they did not

consider it a choice for them to make. Following are the responses to the question on why the parents began communicating in Sign Language:

(1)

Completely natural, there were simply no other choices, there were no other choices. It is not something I have chosen, one cannot choose, choose between this or that, there was only one possibility. It is completely clear-cut... My child was the first deaf person I met so I knew nothing [about deafness or Sign Language] but it was still completely obvious that with a deaf person you use Sign Language.

(2)

I think that as soon as we started thinking about it, or when we found out that he is deaf it was completely clear. I remember how we were in the car and talked with our other children that we will definitely start using Sign Language.

(3)

Personally I feel that those who choose anything else are in fact rather egoistic. They choose only for themselves when it actually is the child who is at focus... And one knows that Sign Language is the language of deaf people, yes there was no question about it.

(4)

It felt like we had to, in order to get contact with your child.

(5)

It just turned out that way, in order to get contact with her we sign. We sign because, I don't know if it is something we chose, it just happened. It happened so naturally, it is the only thing she reacts to.

(6)

It was obvious. It was not a choice, it was absolutely, I have NEVER considered starting with any oralism or something like that. That has never been a train of thought for me.

(7)

Father: When we think about our child, he has to be the starting point and that also concerns which language he should get. The situation is easy for deaf children with deaf parents, they, they don't have to think. We cannot start with ourselves, what language we want him to have; we have to consider what language he should have. We cannot satisfy our own needs, it's his needs that have to be satisfied.

Mother: We did not choose language from our point of view but from the child's. It was natural and obvious and, and logic. But, but my God, if you are a logically thinking human being you choose Sign Language, if you are sensible then.

For the families quoted in (1), (2) and (6) there seems to be no significant process of decision-making relating to the choice of communication method, that is, the parents did not consider different options. Despite no prior experience of deafness or Sign Language these parents categorically reacted negatively to the use of spoken language with a deaf child. The reasons for this choice are similar to those given by the parents quoted in (3) and (7), that is, an altruistic and child-centred argumentation. However, the parents in quotations (3) and (7) mention the child and his or her needs whereas the parents in quotations (1), (2) and (6) do not. The parents in quotations (4) and (5) mention the parent-child interaction as the main motive for choosing Sign Language.

Learning Sign Language

Parents reported some difficulty in learning Sign Language and how it initially was arduous to get accustomed to manual communication. One mother found it difficult to actually free her hands for communication:

(8)

Well, I think, I don't seem to get my hands to suffice for everything because I constantly, from morning to evening, have something in my hands that, so I think it is such an impractical language. You need both hands free but they say that gradually you get so used that you don't notice how you talk and sign at the same time.

Despite the initial difficulties learning Sign Language themselves the parents pointed out that giving their child a language and establishing a functional communication with their child was their main priority. The next quotation is from an interview with the parents of a deaf school-aged child.

(9)

Mother: I am happy with Sign Language but maybe you [the father] would have considered (uncompleted sentence)... But choosing a spoken language is also difficult, then you have to work so much harder.

Father: It is not important if she [the mother] is content or if I am content, it is the child who is in question.

The time between the diagnosis of the hearing loss and the introduction and learning of signed communication was very difficult for the families. Not being able to communicate was extremely stressful for both the parents and the children. When Sign Language was introduced, the children themselves showed less frustration, aggression and anger. In addition, the more relaxed parent-child interaction can be influenced by the parents' gradual transition into and acceptance of their new role as parents of a deaf or hearing-impaired child.

(10)

Perhaps she became a little, when our communication emerged she was indeed calmer. She became calmer because it is clear that as long as we didn't have any way of communicating it didn't work.

(11)

Yes, she became calmer, much calmer when we had a language to communicate in... right in the beginning before we got started with the communication she was often frustrated, very angry quite often. It was very difficult, but now we notice, now it is much easier... her fits of rage have greatly decreased.

Prior to the final diagnosis of the hearing loss the mother in the latter quotation decided to test the influence her signing had on her hearing-impaired child who benefits from using hearing aids. One day she signed with her child who then was calm and content. The following day when the mother did not sign at all, the child was cranky and upset. On the third day when Sign again was used, the child was happy. The mother said:

(12)

Before we found out that she is hearing-impaired I took a course in Sign Language. I thought I would try one day, or I kept signing a little for several days and then she was satisfied. One day I decided to test her and not sign at all. That day she just cried. The following day I continued to sign and then things were fine again.

This child's behaviour can of course be attributed to many factors but for the mother this "test" clarified the need of Sign Language for her child. According to the mother, having learned Sign Language this child's knowledge of both written and spoken Swedish has greatly improved. A development that both the parents and the child's day-care teacher firmly believe is due to the child's enhanced awareness of language, which in turn, is due to improved signing abilities.

In another interview a mother of a school-aged deaf child reported a similar improvement of child's Swedish language coinciding with an increasing fluency and flexibility of Sign Language. In one case, because of a lack of a Swedish-speaking speech therapist and Sign Language instruction at home for the parents, the deaf child had to wait six months for any structured communication to begin. The parents remembered the six-month period of non-existent communication as horrifying. As a part of the early habilitation during this period the parents were recommended play therapy for their child. But once Sign Language instruction and communication had started, the child was diagnosed as developing normally, and in no need of therapy. The parents of this child consider Sign Language an absolute necessity in the communication with deaf children. Communicating with deaf people solely through speech and lip-reading is, according to them, an indication of wishful thinking on the part of the hearing people. The significance of Sign Language for the psychosocial development of their child was also obvious for these parents, and according to them, growing up – and attending school – in a signing environment is essential for the development of a strong deaf identity and self-awareness.

The parents who have chosen Sign Language as the main method of communication for their children emphasise the need for a signing environment and interaction with many other deaf children. Some parents also commented that they themselves wish for more interactions with deaf adults:

(13)

Mother: And for me, that there would be more deaf adults, that's what I'm looking for.

Researcher: What role does deaf adults have for you?

Mother: Language models for me, like behaviour, how you behave in Sign Language. And for me to practise my skills and not only sign with children and talk about child-stuff but about adult-issues.

Experienced attitudes

The attitudes in society towards deafness and hearing-impairments and the use of Sign Language were issues raised by some of the parents during the interviews. The first quotation (14) is from the parents of a hearing-impaired pre-school child communicating both in Sign Language and Swedish and the second quotation (15) from the father of a school-aged deaf child.

(14)

Mother: Yes, people think we don't set limits to her. People feel sorry for her because she is hearing-impaired. That's what they do.

Father: Yes, absolutely, yes. We notice that all the time, yes that people feel sorry for her because she has a hearing loss. Yes, we see that all that time. Poor child when you have to use sign with her. They do feel sorry for her. And you could say that she is ahead of children her age in almost all other areas, she only lags behind with her speech.

(15)

Or that if you're deaf you're an idiot, comments like that, they are of course rare but they have occurred.

The parents felt that other people often are ignorant of deafness and Sign Language and that using Sign Language is often viewed as a burden for both parent and child. Moreover the parents commented that the child's hearing loss seems to be the one characteristic that (hearing) people focus on, not acknowledging that the child is making excellent progress in other areas. The parents view their child as any other child and do not wish people to feel sorry for the fact that the child has a hearing loss.

8.2.2 Families using oral communication

This second category consists of eight families with children who have hearing losses ranging from mild to profound. Three of the eight children have a cochlear implant. Of these three families, one family reported using Signed Swedish and speech and one family reported using speech combined with, if necessary, Cued Speech (see Section 3.2); the third family uses only spoken language. The other five families communicate only through spoken language and have opted, for the time being, not to use Finland-Swedish (or Finnish) Sign Language. Still, in addition to the two families (with a child with a cochlear implant) using some signed communication, the six other families reported occasionally using a few signs to

support or emphasise, a spoken utterance. In quotation (36) in Section 8.2.3, the mother of a severely hearing-impaired child strongly emphasises the benefits of having used signs during the child's early speech development.

Degree of hearing loss and choice of communication method

Included in this group are families whose children's loss of hearing are so mild that they perform rather well in both school and other social settings. Nevertheless the families emphasised the need for support services and/or a personal school assistant. Common to all these eight families is the opinion that since the hearing loss is not severe, or because the child is learning a spoken language or has received a cochlear implant, communication through speech is sufficient and there is no need for Sign Language. They stressed the need for speech training and the need to teach the child to listen. This was especially evident for parents of the three children who have cochlear implants.

For five of the eight families in this category the fact that the child's hearing loss was not profound turned out to be the decisive factor when choosing spoken Swedish (or Swedish/Finnish in bilingual families). The hearing losses (in these five children) ranged from mild to severe and had in four cases been diagnosed when the child was four to five years of age and in one case (a severe hearing-impairment) at the age of one. At the time of the diagnosis the children's development of speech had already emerged and the parents therefore did not consider their child to benefit from Sign Language. The following are responses from three families to the question on why they chose spoken language communication:

(16)

We haven't really needed it because he hears quite well. It was more talk about hearing aids and things like that.

(17)

Mother: It was the natural thing because his hearing loss is so mild. Sign Language wasn't an issue at all.

Father: With hearing aid her comprehension of speech is near perfect and in a calm environment, like home, without a hearing aid. So there was no, there was no need for Sign Language then.

(18)

Because he had hearing, so much hearing that he could say, we have on video, a film of him when he, on his first birthday, says mommy. And I know that if you can say mommy you can say anything. And then we COMPLETELY went in for that, because he had some hearing. Because when he was little we noticed how happy he was when he was allowed to turn up the radio to maximum volume, that he heard some sounds. We completely went in for this, I haven't had a thought that he would start with Sign Language.

For these families the choice of a spoken language is more connected to the child's degree of hearing loss and capability of producing speech than to a choice dominated by issues such as language and cultural belonging.

Hearing society, family and friends

For the parents of children with a severe to profound hearing loss diagnosed early in life Sign Language would have been an option but for reasons outlined below the parents chose not to communicate in Sign Language with their child. The main reason for this choice is that (according to parents) since this is a hearing world with few hearing people knowing Sign Language the deaf child has to adapt to the surrounding environment. The parents felt that a hearing-impaired child who can only communicate in Sign Language is at risk of being isolated. Therefore, also hearing siblings and relatives to a great extent influence the parents' choice of communication method:

(19)

The fact that she has a hearing sibling is also contributing factor to why we have decided to use spoken language.

(20)

Well, there were probably many reasons. One was simply that the environment she grows up in is a very speaking environment with rather old relatives, both from my and my husband's side... so it's not like we could just say, hey couldn't you start learning Sign Language... certainly some of them would have learned it quite well, but they wouldn't have, on the whole, I know I'm so persistent that if I had started with it, I surely would have learned it. But most others wouldn't have. And my mother was so desperate when she didn't learn how to sign that she just cried. She said that this is awful, I'm never going to be able to speak with my grandchild... It is a nice thought that everyone will learn Sign Language and speak with her but they're not going to do it.

(21)

Father: But Sign Language is, according to me, rightly or wrongly, it's a little, maybe it symbolises a stagnation known in Finland and that can be observed in Finland. It's sort of like, well, I view it as isolation for deaf people.

Mother: Particularly for us Finland Swedes who already are a minority within a minority, for us it is even a bigger thing, the fact that you perhaps, well that you decide to only use Sign Language. It would only be a few of our friends who would be able to sign. It would feel like a very burdensome alternative. And then we think that our child is so clever that Sign Language certainly wouldn't be a problem for him. We can see that he learns Sign Language anyway. He will, we do of course leave the door open in case it doesn't work out and we realise he will, so to say, be without a language, then it certainly is Sign Language. We don't want to exclude it.

(22)

Yes, well then the two of us have also discussed the fact that Sign Language will never be our mother tongue.

Two other families with severely hearing-impaired children also commented that although they now use spoken language, they have not completely excluded Sign Language. The parents commented that Sign Language may be useful in the future:

(23)

I then took a Sign Language course myself, no one told me to go there, rather I thought, well, because it's constantly there, how will it be with her hearing, will it go completely. There is so little left and at HYKS they say that it might even disappear. So I have thought about real Sign Language, that it could be good, we are not, not against it but it has just been too tough dealing with so much at once, we were so busy teaching her to talk.

(24)

He has been to Folkhälsan⁴² and he is very interested [in Sign Language] and he has now so many times asked if I would come to a course with him. And I have also promised that. When he so badly wants me to so, well, yes I thought. And it's so useful, I mean, when he still hears quite well and then you'd have Sign Language and also the spoken language. One could perhaps be of help sometime and get a profession through that.⁴³

Even though the family mentioned in the following quotation does not need Sign Language in their daily communication the mother commented on her plans to learn some support signs that can be used when it is not possible for her child to wear a hearing aid:

(25)

Signs as support, that's not really the same as Sign Language, because it's something that I've thought about a little, I'm actually going to take a course this spring. Because it can be useful in some situation, when it's a little noisy, and when you're swimming and he can't wear them [the hearing aids]. I have thought that then it would be good to use some signs and now here he has become so interested. Well, like when he sees the ladies talk with their hands here he is very interested. But it's nothing we need in our daily life, he hears, he gets along with his hearing aids.

⁴² Folkhälsan is a non-governmental organisation, representing the Third Sector, offering welfare and health services in the same manner that local governments do. The services offered by Folkhälsan include child welfare, neuropediatric examination and habilitation for disabled children.

⁴³ As was previously noted, it is common in Swedish to you use the indefinite pronoun "man" (ENG: one) when talking about oneself. Although the mother may appear to be speaking about herself in the last sentence of this quotation, she is in fact referring to her child.

The parents of children with a severe or profound hearing-impairment are aware that the method of communication they have chosen initially may be difficult and demanding for both the child and the whole family. The parents of a pre-school child with a cochlear implant said that they encourage their child to use speech:

(26)

Mother: Of course it's tougher for her, at the moment it's tougher for the child when we demand, try to demand that she speaks.. I mean we don't make a problem out of it for her, because if she doesn't want to then she can be quiet. But we try, we try to encourage her.

Father: We have never prohibited her from signing.

Mother: No, absolutely no, we haven't done that.

The families hope, that in the end, their choice of communication method will turn out to be rewarding, and allow the child to function in a hearing world on equal terms as hearing people, that is, allow the child to be able to interact freely with everyone. The mother of a school-aged severely hearing-impaired child with a cochlear implant reported:

(27)

And then I realised that she will make friends with children from our neighbourhood. Will they really learn [Sign Language]? Yes, they will be able to say "let's go cycling or out to play or should we go for ice cream" or something like that, but they will not be able to communicate. I don't believe it. And then I figured, okay, she is the one who will have to adjust to the environment. I will handle the problems when she is young and she will have to work like crazy, but then she'll get a grip of this. At least, so far this has proven to be the case.

(28)

Father: Well, it's like this, of course, now it's like. It's obvious that anyone who has a deaf child, that doesn't have a deaf child cannot understand that, the euphoric feeling when you realise that this child, that you get contact with it, you can talk to it. That the child is listening to you and that you can. We always used to tell our friends that in the shop you can shout to her. She turns around and has this look, that what is it.

Mother: Not even shout but say.

Father: Say. It sounds completely ridiculous. It's an enormous feeling. That you get contact.

Another factor that influenced the choice of a spoken language over Sign Language was that the parents wanted their child to be able to attend a nearby school for hearing children together with children from the neighbourhood. The parents view the decision process as balancing between the child's capability to understand and produce spoken language, the child's future needs and options as well as immediate hearing family.

Choosing a cochlear implant

Three of the eight families in this category had chosen a cochlear implant for their child. For the other five families a cochlear implant had never been an alternative and they could not see the benefits of it for their children. When asked if they had thought about a cochlear implant for their severely hearing-impaired child one mother replied:

(29)

NEVER IN MY LIFE, it destroys her hearing.⁴⁴

Deciding to give their child a cochlear implant was remembered as a difficult process forcing the parents themselves to be active and find as much information as possible about the implant and its possibilities and consequences for children born deaf or hearing-impaired. The parents of a severely hearing-impaired pre-school child with a cochlear implant replied as follows:

(30)

Father: So in my opinion, well, for me it was quite decisive, when I see how isolated deaf people otherwise are, particularly in today's world with Sign Language...Well, obviously, it makes you wonder what there is, like, is this really the right way? But then of course we have these other ways [Sign Language] but when you look at the results that we at that time saw in Switzerland and Germany and so, it's like fascinating. I have to say that like, to go this way was indeed a difficult decision for us and above all to then do this implant [cochlea implant]. But after six months of feeling bad then, well when you start to notice results, after that we haven't had any regrets.

Mother: We are content.

Father: And even if it only would be half as good as what we saw in Sweden or in Switzerland, well then one has to be content.

Although the parents (of children with a cochlear implant) reported over all having received very good care at the University Hospital of Helsinki (HUCS) they mentioned the lack of information and guidance from the professionals specifically regarding cochlear implants:

(31)

But what I do admit is that at times it has been very arduous, for the first that you have an implanted child, you're not. Well, like you're not used to it. We haven't received any guidance from Finland... In a way they [HYKS] have been fantastic to us but they haven't really, they haven't had that professional

⁴⁴ As a result of a cochlear implant surgery, possible residual hearing is destroyed, thus eliminating future use of conventional hearing aids should the cochlear implant prove to be unsuccessful.

touch. Well, so to say, you know that you would have expected. I wouldn't say they've done everything wrong. Quite the opposite, I think many things are fine but.

Parents of children with cochlear implants had anticipated a demanding and at times difficult period of speech training and frequent visits to the Auditory Unit but the reactions and comments from other people were something that surprised the parents. One family had been particularly subjected to criticism, the mother said:

(32)

No, I received so to say, no, I have received support, shall we say, I have had a very good support group behind me but for very long I had this that people thought I was crazy when I said I was going to teach my child to speak. But that has changed now, because now the implants are here [in Finland] as well and one knows that it is possible. It really is possible... I experienced that people thought what the hell is she doing, she destroys her child and that is the worst thing you can say to a mother, that you think of yourself and that you don't think of your child. Really, there is nothing as cruel, every mother knows that, when someone comes and blames you and says that you think of yourself and not at all of your child, well then it's like you think. What if it really is like this and deep down you know that it is my child that I think of, because it is only very few, it really is, most think of, no matter the decisions they make they, like, always think of what's best for this child. All parents want the best for their children, generally it really is like that and that is why I experienced it, well like, when I was criticised by others that what I'm doing is wrong, then it was quite brutal.

To conclude this discussion on choosing a cochlear implant, it is fair to say that the parents reacted strongly to this issue. Some parents were firmly against it whereas the parents who had chosen this alternative for their child were pleased although the process at times had been arduous and the reactions from other people occasionally had been very negative and upsetting. The main reason for choosing the cochlear implant was to give the deaf child as many opportunities as possible, to enable the child to participate more actively in the hearing society.

Social behaviour

Among the families communicating in spoken Swedish (or Swedish/Finnish) are those with children who can (with conventional hearing aids) produce and comprehend speech and who attend schools for normally hearing children. Nevertheless, their parents reported how they have gradually realised, as the child gets older, that hearing is arduous and demanding for the child, mainly in larger social settings, but occasionally also in one-to-one communication. The parents of these two children were concerned about the children's ability to function in groups and how the accessibility – or lack of accessibility – to instruction at school influences the children's intellectual development. The parents stated that the more demand-

ing social settings (larger peer and educational groups) and cognitive assignments (such as foreign language learning) have made them realise that even a mild to moderate or moderately severe hearing loss does influence the child's behaviour and development.

One parent reported how the child's loss of hearing (moderately severe, diagnosed at the age of four) now, at the age of eight has started to affect the child's social behaviour. The boy gets cross about not hearing and does not have many social contacts at school:

(33)

I do notice that he very often asks "what". And then he becomes cross, like, he gets cross with us when he doesn't hear although he actually surely gets cross with himself. But he reacts, like always takes it out on us, yes. But in school he does have it [the hearing aid] all the time and they think he manages fairly well. Or they say that with the social part he has trouble, absolutely not with his learning ability. But he is perhaps, well, quite reserved and well, he doesn't have, he doesn't have many friends there.

This boy also avoids social situations where attention may focus on him. Situations where strangers may communicate with him are stressful. The boy does not have confidence in his own hearing and looks at his mother for reassurance when talking with people he does not know. Twice the child may ask another person to repeat an utterance, but if he still has not grasped the sentence he pretends the message was understood. This child has also asked his mother to attend Sign Language courses with him. Furthermore, foreign language learning in school has become increasingly strenuous due to difficulty in lip-reading and perceiving foreign words. The parent was concerned about the child's recent social development and although the child currently performs rather well in school his mother was concerned about how the loss of hearing in the future will affect the boy's performance and attainment at school. Another family also mentioned similar experiences concerning their child's slightly avoiding social behaviour and lack of self-confidence in academic subjects.

(34)

She is very good at sports but when she had a presentation [in school] nothing came out of it. She is so unsure of herself.

8.2.3 Early habilitation and the choice of communication method

Another issue relating to choice of communication method is whether the information received in the early habilitation influenced the parents' choice. The results (from both the questionnaire and the interviews) referring to the parents' conception of the early habilitation are outlined in Section 8.4. For the sake of clarity, however, the specific topic concerning the early habilitation and choice of communication method is examined here.

The families using Finland-Swedish or Finnish Sign Language considered this mode of communication to be the natural and only language for children who are deaf. For these families the information received during early habilitation did not to a great extent influence their choice. Although the home guidance counsellor to some extent was influential the decision seems to be more founded in the parents' already developed beliefs or conceptions of communication and deafness, and thus to be rather independent of the early information received during the first stages of habilitation. This is supported by the fact that the parents emphasised that they felt the information to be very orally influenced, focusing more on speech training, hearing aids, and audiograms than on Sign Language and a cultural perspective on deafness.

The parents of signing children are, however, unanimous in their opinion that for parents who do not intuitively choose Sign Language, the information received during the early intervention probably influences to a large degree the choice of communication method. They commented that parents who have not fully understood the impact of deafness on a child, and have not had time to reflect on the consequences for the child, are naturally very sensitive to information suggesting that the child can learn to hear and speak. One father expressed it like this:

(35)

Yes, and parents who don't know anything or who have not yet processed the fact [that the child is deaf], and if someone then comes and says that I can fix your child then I do think that influences you. During that stage you are fairly susceptible, especially if it's your first child, you're young and know nothing, you certainly catch at every straw you can.

The parents of children with a moderate hearing-loss who are able, with conventional hearing aids, to perceive and produce spoken language also received information on Sign Language but figured it did not concern them. Most children belonging to this group were diagnosed late, around the age of four, when speech development was delayed but nevertheless had emerged. Having noticed this initial development of speech the parents did not consider Sign Language to be of any benefit for them. As has previously been mentioned, some of these families do, however, occasionally use single signs or the hand alphabet to support the spoken language. One family was offered the alternative of using the hand alphabet in order to facilitate the formation of spoken words but in the end never used this method. Another family of a severely hearing-impaired boy had in the beginning used both gestures and signs to communicate with the child. The significance of the family's early use of signs for their child's development of speech was something the mother repeatedly commented on during the interview. The mother also commented that if they had received more information on the benefits of using signs with hearing-impaired children (and not only with profoundly deaf children) they would, in all likelihood, have used even more support signs. As it now was she discovered this for herself:

(36)

Well, these support signs were of GREAT HELP then. Because we were given a book with all animals, the most common, these pictures. We looked at a picture and then showed the sign for them, the signs were down here, how you sign them and then there was a large picture, so we both looked at it, signed and said it using many different voices, not just mine. The support signs were of great help...Possibly yes [had we used more support signs if we had received more information about it] because I don't know if we received any information. I myself just discovered how important, how, how much better I could communicate with him, how much closer we came and how he was less frustrated when we had a way of expressing ourselves, and he, he could only talk because he understood my signs and he could make signs himself although he was so young. So particularly through the, although he couldn't hear he had a channel, so he didn't, he didn't turn into one of them that lay on the floor and kicked and shouted and he wasn't aggressive against others. We could see that in these, when we were in these groups, a week or ten days then there were these kids that ran around and hit the other in the head with something and well, I was frightened to death for this when we were there. The other children had this aggressiveness and then I had this, I thought it must be because they have, they cannot express themselves. So through these signs, it was of an UNBELIEVABLE help, without them, we wouldn't have had the language to express ourselves if we hadn't had those signs.

[- - -]

So to say, I don't know how we would have managed that period of time without the signs. So, they also provided more language, both the signs in addition to that real thing, like when you also experienced it.

Another mother also mentioned that if, early in the child's habilitation, she had received information on the possibilities and benefits (for hearing-impaired children) of using signs to support the spoken language she and her husband most likely would have done so.

One family, which has opted for a cochlear implant for their child, uses both speech and Sign. In this case, the home Sign Language instructor has influenced the family's view on the benefits of using Sign Language with their deaf child. Also, the parents' observation on the child's signing abilities and parallel development of Sign and speech has confirmed that the child's speech development will benefit from the use of Sign Language.

Regardless of the final choice of communication mode, all parents stressed both the significance of receiving up-to-date expert information as well as emotional support from other parents who have similar experiences.

(37)

It was very important, yes... You received the most information at these, at the courses. Because there were other parents and then, well, there you could discuss all possible things. They were of great help. Those were, what was the best at that time was to be in contact with others and to hear.

Moreover, with the exception of one family, the need for interaction with children and adults using the same means of communication (spoken or signed) and similar technical aids – such as hearing aids or cochlear implants – was stated by all parents regardless of method of communication or degree of hearing loss. A father of a child with a cochlear implant replied:

(38)

It was extremely important, partly because it was important for our child to see an adult with an implant and partly it was important for us to get a little, well, what this [to have an implant] means.

The one family who had a deviating opinion regarding this matter said it was because the child herself did not want to interact with other hearing-impaired children. The primary school-aged girl wants to be like everyone else and does not want to be reminded that she is hearing-impaired and needs a hearing aid. If the mother occasionally signs with the girl she gets upset and tells her mother to stop signing and according to the mother the girl quickly and angrily says:

(39)

I hear, don't, don't sign. I can hear, she's angry with me, I'm not allowed to sign. Not outside when others can hear or see. She says that I have a hearing aid, don't stand there and sign something when others can see. I want to be like everyone else, she says.

Despite the child's current behaviour this family is very active in finding information about hearing-impairments and meeting other parents with hearing-impaired children and are highly involved in their child's habilitation and education.

It seems natural that the very first contact or information received to some extent influences the families' choice of communication mode. However, the parents' view on deafness and communication (i.e. the medical or the socio-cultural perspective, see Section 2.1) and their reflections on their own and their child's cultural and social belonging, seem to be of greater importance in the decision than the information received in the early habilitation programme⁴⁵. This result has implications for the kind of information that should be offered to the parents. The parents themselves make their choices but they obviously need somebody with whom they can reflect on different perspectives, advantages and disadvantages in order to reach a solution.

In the following quotation a mother explains her process of choosing a particular communication method (spoken Swedish) for her severely hearing-impaired child. However, many other issues are also brought to attention in this quotation. To begin with the mother talks about the time dimension: only as a result of a long

⁴⁵ In this study the parents' level of education was not taken into consideration, a factor that has been linked to the selection of communication mode in families with deaf and hearing-impaired children (Kluwin & Gonter Gaustad, 1987).

and gradual process did the parents choose not to introduce Sign Language to their child although this form of communication was recommended at the University Hospital (HYKS). The mother also talks about how the information given as part of the early habilitation should cover the whole spectrum of communication methods and programmes. Then the mother speaks about parental beliefs and how the parent him/herself has to believe in a specific communication method in order to be able to pass it on to the child.

(40)

I didn't exclude Sign Language, or like, this wasn't a thing I, I thought when she was born that now I will exclude Sign Language. I didn't do that. It's, well, nothing that has happened, how I came to this has been like a long process, nothing has happened in one day or one week or one month, instead it has like actually been a very long period of time. They [HYKS] did suggest Sign Language for her because she is severely hearing-impaired. So I did get that. Or they said that Sign Language and home Sign Language instruction and something like that... The thing is that this information should cover everything, you know the different alternatives, what there is and different programmes that exist. So I think the information ought to be the kind of information that covers everything, you know, and what I still believe is that all parents should be entitled to choose for themselves and choose themselves because I don't believe in, if you choose something that someone else told you to do like this, because if you don't believe in it you're never going to do it. You will never learn Sign Language if you don't believe in it yourself. If you do not really believe that this is what I want to give to my child, I want to communicate in Sign Language, then you will never learn it. The same goes for spoken language. If you do not truly want to give the spoken language to your child then you're not going to get your child to speak or use a hearing aid or implant. You have to believe in it yourself.

To summarise, many different factors influence the parents' selection of language for their deaf or hearing-impaired child. The child's degree of hearing loss is a significant factor. Parents whose child has a mild or moderate hearing loss are very likely to choose spoken language communication but for parents with deaf or severely hearing-impaired children the choice is not as straightforward. Choosing a method of communication can be difficult, the parents have both to juggle and combine a range of different aspects and factors, including the differing perspectives on deafness and controversy within deaf education. Some factors, such as knowledge about deafness and educational options for deaf children are (at the time of the decision) completely new and unknown to the parents and it requires much time and effort to become acquainted with this field. Other factors influencing the choice demand reflection on issues such as cultural and linguistic identity of both child and parent. Parents choosing Sign Language want their child to have a totally accessible mode of communication and parents choosing spoken Swedish feel a child with spoken language skills have equal opportunities (as hearing children) and a better ability to participate in the Finland-Swedish community. The choice of communication method is conjoined with the educational options available for deaf children and this is discussed in the following section.

8.3 Educational decision-making

The different educational opportunities for Finland-Swedish deaf children are accounted for in Section 5.5. Analysed here are the educational problems facing a deaf or hearing-impaired child from the Swedish minority in Finland as well as factors influencing the hearing parents' educational decision-making process (that is, the process of choosing a school for their deaf or hearing-impaired child). The results presented in this section thus answer the third research question (How do hearing parents with deaf children experience the educational decision-making when there is no straightforward choice of school that provides the compulsory basic education for their deaf child who belong to a minority within a minority?).

The fact that the education of their deaf or hearing-impaired child is a difficult problem for the parents is evident. All seventeen families, regardless of the child's hearing status and primary mode of communication, or the family's place of residence, agreed that the educational situation for this group of children is beneath contempt. The parents more or less have given up hope of any improvement particularly concerning the educational situation for deaf signing children.

(41)

It is the way it is, although these school issues constantly are dealt with there is nothing you can do. How is it supposed to work out?

(42)

There is nothing you can do about the situation, it is miserable. There is nothing you can do, nothing is going to improve, what is there to do?... There are no educational opportunities, society doesn't take responsibility for the education of Finland-Swedish deaf children. They CANNOT EVEN arrange primary education.

The following two sections (Section 8.3.1 and 8.3.2) delineate the results from the questionnaire relating to the parental educational decision-making. That is, how the parents arrive at their decision on which school their deaf or hearing-impaired child will attend. First (Section 8.3.1) the parents' views on factors influencing their choice of educational placement are outlined, followed by the parents' views on the educational options currently available for deaf or hearing-impaired children (Section 8.3.2).

8.3.1 Choosing a school

The educational choices for parents of a deaf or hearing-impaired child from the Swedish minority in Finland are very limited, particularly for families with deaf signing children as there is no Finland-Swedish deaf school. Thus the parents find themselves in a situation with no straightforward solution as to where their children should be educated. As previously mentioned these parents (particularly parents of deaf or severely hearing-impaired children) are therefore thrown into a difficult decision-process and have to take many things into considerations. The results to question number 15 in the survey on factors influencing the choice of

school are presented in Table 3. The number in parenthesis indicates the number of responses. It is important to remember that the responses in the last section “children who had not yet started school or day-care”, are from parents of children with hearing losses ranging from mild to profound.

Table 3. Factors influencing the parents choice of school for their deaf or hearing-impaired child. The number of responses is given in parenthesis.

Current educational placement	Factors influencing parental educational decision-making
Mainstreamed in a hearing school(six children)	<ul style="list-style-type: none"> (2) Friends from hearing nursery (2) Close to home (1) Teacher’s readiness to integrate a deaf child in the class (1) The Swedish language (1) Possibility of receiving a personal school assistant (1) Other members of the family
Deaf school (four children)	<ul style="list-style-type: none"> (2) Instruction in Sign Language (2) Mainstreaming did not work (1) Finding deaf friends (1) Deaf adults (1) Finnish deaf school to avoid the former Swedish deaf school and its bad reputation and to enable the child to live at home (1) Absolutely necessary, no educational opportunities in Finland (1) Deaf school in Sweden to maintain the Swedish Language
Children who had not yet started school or day-care (eight children)	<ul style="list-style-type: none"> (1) Snäckan close to our home (1) Technical aids, signing teachers and children at Ytteresse (2) Future educational opportunities, possibility of finding an educational peer group (1) Deaf friends (1) The child’s language development (1) Possibility for parents to maintain the Swedish language. (1) Current place of residence (1) Parents’ chances of finding a job in new school area (1) Possibility to receive instruction in Finland-Swedish Sign Language (1) The municipality’s desire to co-operate (1) For the good of the child

As can be seen from the Table above, there is a recurrent pattern in that parents of children who had not yet started school reported similar influencing factors as parents of children who had already started school. These factors are further outlined in the following section.

8.3.2 Parents' views on the different educational options

Questions 16–18 in the survey explored the parents' conception of (1) a Finnish deaf school, (2) a deaf school in Sweden, and (3) inclusion in a school for normally hearing children. To some extent the answers to these questions overlap the answers presented in the previous section and the responses given in the interviews and which are presented in Sections 8.3.3–8.3.6.

(1) A Finnish deaf school

Five families were able to consider a Finnish deaf school for their child. Of the children of these five families, two attend a Finnish deaf school, one is attending a deaf school in Sweden, whereas the other two have not yet started school. For those families who could not consider a Finnish school the two main reasons are the Swedish language and the degree of hearing loss.

Of major concern for the parents who answered yes is the fact that the possibility of further education (in Finland) greatly depends on knowledge of Finnish, and this affects the parents' choices. According to these parents, a Finnish deaf school is the best alternative in Finland for a deaf child.

Among the no-responses are two families who want their child in a deaf school, but not a Finnish deaf school, two families who want their deaf children to attend a hearing school because of the social contacts with hearing friends and relatives. In addition, there are three families whose children (because of mild to a moderate hearing losses) use hearing aids and get along in schools for normally hearing children.

Regardless of the child's hearing status or current method of communication, seven families stated that they are Swedish-speaking and thus want their children to attend a Swedish school. The responses are presented in Table 4. As some families have stated more than one reason, the sum of the number of responses given in parenthesis does not equal the total number of *yes* (5) or *no* (13) responses.

Table 4. The responses to question 16 in the questionnaire.

Is a Finnish deaf school an alternative for your child?	
Yes. Five families	(2) Best alternative in Finland (1) If suitable group for my child (for hearing-impaired children or for children with cochlear implants) (1) No further educational options available in Swedish (in Finland) (1) To avoid moving to another country (1) Enables our child to live at home
No. Thirteen families	(7) We are Finland-Swedish and want to maintain the Swedish language (3) Child can hear (with hearing aids) and speak (1) Different culture (1) Social contacts with hearing family/friends (1) Hope that another solution will emerge (1) Will try mainstreaming first

(2) A deaf school in Sweden

Not surprisingly, moving to Sweden is not the solution for all families. Eleven of the participating families do not even consider education in Sweden as a possibility. The reasons for this are mostly family matters such as hearing siblings, relatives and the parents' occupational situation. For the families in favour of moving to Sweden the prospect of a signing environment and instruction in Sign Language are important. The families also view this as the best possibility for a Finland-Swedish signing deaf child. The responses are presented in Table 5. As some families have stated more than one reason, the sum of the number of responses given in parenthesis is higher than the total number of *yes* (7) or *no* (11) responses.

Table 5. The responses to question 17 in the questionnaire.

Is a deaf school in Sweden an alternative for your child?		
Yes.	(2)	Currently the only possible alternative
Seven families	(1)	To maintain the Swedish language
	(1)	Social contacts
	(1)	Good education
	(1)	Eventually the school in Örebro
	(1)	The child's future in Sweden because of no Swedish deaf school in Finland
	(1)	Yes, if it is the only possibility
No.	(4)	Child can hear (with hearing aids) and speaks
Eleven families	(2)	Do not want to move to Sweden
	(1)	Social contacts with hearing family and friends
	(1)	Too much signing in Swedish deaf schools
	(1)	No connection to Sweden
	(1)	Not of current interest
	(1)	Family situation, hearing siblings
	(1)	Parents' employment

(3) Inclusion

Eleven of the families find inclusive education in a hearing school the best alternative for their deaf or hearing-impaired child. Bearing in mind that nine of the children are profoundly deaf and seven hearing-impaired who get along with hearing aids, it is of no surprise that mainstreaming is such a popular alternative. However, whilst only four families considered mainstreaming to be an unsatisfactory alternative, some parents with profoundly deaf children want their child to be integrated in a school for normally hearing children. Possible reasons for this are further discussed in Section 8.3.6. Here it will suffice to say that the determining factors for inclusive education are the school's vicinity to the home as well as communication and interaction with hearing friends and relatives.

The parents who do not favour mainstreaming are unanimous in their opinions; integrating a deaf child in a hearing school is linguistically, socially and culturally devastating for the child. Two families with deaf children tried inclusion for a couple of years but when this did not work, placed the children in deaf schools in Sweden. Both these families now consider this to be the only appropriate alternative for a Finland-Swedish deaf child. The answers to this question are presented in Table 6. As some families have stated more than one reason, the sum of the number of responses given in parenthesis does not equal the total number of *yes* (12) or *no* (6) responses.

Table 6. The responses to question 18 in the questionnaire.

Is inclusion in a hearing school an alternative for your child?	
Yes. Twelve families.	(5) More convenient, close to our home. (4) The child's hearing loss mild to moderate, can hear and speak. (2) Interaction with hearing family and friends. (1) If no other more suitable educational programme is available. (1) The child has a personal assistant. (1) Signing teachers and other deaf children at Ytteresse school. (1) With a Sign Language interpreter, depends on the child's development but we think it will be difficult.
No. Six families	(2) No signing friends and no signing environment in school. (2) Have tried it but it did not work. (1) Deaf children have the right to receive their own language and culture in school. (1) Risk of isolation. (1) Stupid question ⁴⁶ .

From the responses to questions 15–18 in the questionnaire it becomes clear that four factors are recurrent. These factors are further elucidated in the parental interviews and will thus be presented in the forthcoming sections, 8.3.3–8.3.6. Here, however a brief conclusion on the parents' views (on a Finnish deaf school, a deaf school in Sweden and mainstreaming in a school for normally hearing children) and on factors influencing their choice of schooling as delineated from the questionnaire will suffice.

Not surprisingly, the first and major factor is the child's **degree of hearing loss**; a child with a mild hearing loss can attend a school for hearing children and since these children do not learn Sign Language, a deaf school is not an alternative.

The second factor is **the Swedish language**: regardless of the family's method of communication or the child's degree of hearing loss the parents feel strongly about maintaining the Swedish language. However, for parents of deaf signing

⁴⁶ This family strongly believes in Sign Language for deaf children and therefore considered this to be an unnecessary question.

children particularly from the greater Helsinki area the child's possibility of receiving education in Sign Language (in a Finnish deaf school) proved to be more important than explicitly receiving it in a Finland-Swedish context. This said, it does not at all mean, however, that the parents are satisfied with the current educational situation for their deaf children.

The third major factor is **social contacts**. Parents of deaf signing children value a signing environment and are therefore not in favour of mainstreaming. Whether the deaf school is in Finland or Sweden can then be attributed to many other factors such as family situation and ties to the Finland-Swedish language and culture. (These factors are discussed in forthcoming sections). For parents of deaf and hearing-impaired children using spoken language communication the social contacts with hearing family are very important.

The fourth factor is the **school's proximity** to home, but again, this was primarily an issue for parents of children with mild to moderate hearing losses. The parents of deaf signing children listed other factors (primarily instruction and social interaction) as being more important than the school's proximity to home in their educational decision-making. Again, this said, (and as will be outlined in the forthcoming sections) it does not indicate that the parents were happy about having to move or having to send their child to a school far from home.

Although the questionnaire does give a clear picture of the great range of difficulties facing the parents, it does not, however, provide us with the more detailed and in-depth information needed to comprehend fully the complexity of the educational choices the parents are confronted with. In the following sections a more in-depth analysis of the educational problems and factors influencing the educational choices is presented. These are naturally linked to the child's current educational situation and therefore there is some overlap between the findings set forth in this section and the analysis in the following sections.

Again, the results from the interviews are presented according to the two groups of communication mode. The results from the families using Sign Language will be reported first, then the results from the families using spoken Swedish and/or Finnish. Of the ten families using Sign Language only, or Sign Language combined with speech or signed Swedish/Finnish, four children attend school, the other six nursery school or pre-school.

The different factors, although interdependent, will, for the sake of clarity, be discussed separately. Parents belonging to the Sign Language group formulated far more factors influencing the choice. For the parents in the spoken Swedish group, the decision was not one that demanded as much effort as for parents of signing children. Since the children only communicate in spoken Swedish it remained obvious that the child will attend a Swedish-speaking school.

8.3.3 Educational problems facing families with signing children

Finland-Swedish Deaf signing children do not have equal educational opportunities as hearing children or as deaf signing children from the Finnish-speaking population. As previously mentioned several times, the educational situation for this particular group of children has, for a long time been poor. Since the closing in

1993 of the only school for Finland-Swedish deaf children the situation has, however, been indefensible. Not surprisingly, parents of signing children were dissatisfied and upset with the current educational opportunities for their deaf children. In the interviews with the parents who use Sign Language, six major problems could be discerned, problems that are partly dependent on each other but will, for clarity, be discussed separately.

The six problems are as follows:

1. *No Finland-Swedish deaf school*
2. *Small number of Finland-Swedish deaf children*
3. *Long school journeys*
4. *The Swedish language and the Swedish deaf and hearing cultures*
5. *Moving to Sweden not possible*
6. *The Finnish language and the Finnish deaf and hearing cultures*

1) *No Finland-Swedish deaf school*

Not surprisingly, of main concern for the families using Sign Language is the lack of a school with Finland-Swedish Sign Language as the language of instruction and teaching material in Swedish. However, as the parents point out, even if there were a school for these children not all problems would be solved. The families with deaf children are scattered all over Swedish Finland, which means that, regardless of the location of the school, some children would have to travel long distances. However, the option being between a good deaf school in Finland, and a deaf school in Sweden, the parents all responded that they would choose a school in Finland. The reasons for this are further outlined in items 4–6 below. However, as several parents mentioned, the possibility of ever re-opening a Swedish school for the deaf gradually diminishes as more and more parents opt for alternative solutions such as inclusion in hearing schools with an interpreter, or not introducing the child to Sign Language at all. One mother felt very strongly that families who do not choose Sign Language for deaf children contribute to the difficult situation for signing Deaf people:

(43)

They stand in our way, absolutely. Away with them, they keep us back, they keep us back, the development. Those parents who do not choose Sign Language do not understand that it is the only alternative for the [deaf] child, well they are sort of doing everybody else a disservice.

All families commented on the poor educational situation and one family was prepared to take legal action:

(44)

Father: It doesn't say in the law that you have to integrate deaf children... Could one take this to the EU tribunal in some way, this that Finland-Swedish deaf children are so badly treated, that they don't get the chance for equal educa-

tion. They pursue individual issues quite a lot in the EU, perhaps it would work. One needs to get a precedent on this.

Researcher: Would you have the strength to do that?

Father: I have the strength to do anything.

Mother: Yes, but it's a question of going under or not, to survive.

2) *Small number of Finland-Swedish deaf children*

The small number of Finland-Swedish children who are deaf is an issue that parents view as unfortunate, a larger group would naturally provide for more possibilities.

(45)

That is exactly how it is felt, they are only resorted to each other. So I don't know, I don't think there is anything else. In today's situation I don't think that there is another alternative [to a deaf school in Sweden]. If there were enough Finland-Swedish deaf then something would come out of this, what they have planned, this signing school. But when there isn't.

(46)

There are no educational opportunities for Finland-Swedish deaf children, they are all too few. It doesn't constitute a uniform group, they are all too few.

(47)

That they are all too few, that is the first thing that we're looking for, that there would be more deaf children. That is the most important thing.

All parents want the children to have the opportunity to interact with a larger peer group, to be able to choose friends and to be able to communicate freely with all children in the school, and not only with a few other mainstreamed deaf children. Several parents mentioned the fact that their child simply is not aware that larger groups of deaf signing children exist. The children are accustomed to a limited social group. One mother mentioned the feeling of both happiness and sorrow when watching her child during an adjustment course and observing how the child all of sudden realised that communication in Sign was possible with everyone present. The mother was happy that the child finally realised the true meaning of social interaction with both children and adults, but sad that this was only temporary and that back home this kind of social interaction was not possible. Her experience strongly influenced this particular family in their decision that the child needs to receive education in a deaf school with a rich signing environment.

(48)

Interviewer: How is it at the day-care?

Mother: Hm, yes it does work. He has been there two years now and this second year it has worked out better. Not, we have participated in a course at Malminharju now in June. And before that I thought, well the day-care is good. They sign there and the other children, or it's my child and one other hearing-

impaired child and hearing children and I thought that well he has a friend there and I know he rarely communicates with the other children. A little, but after this week in Malminharju [adjustment course for families with deaf/hearing-impaired children], there he could communicate freely with anyone so I thought that, no, we have to go somewhere straight away, it's useless to be here. I have thought that we would stay here for another year and then we move somewhere.

Many other families had experienced the same thing, and observing their child, for example, during a visit to a Finnish or Swedish (in Sweden) deaf school had made it clear that this was the place for their child.

Here, a geographical division is evident. The fact that deaf children who are from Swedish-speaking homes are so few was more often mentioned in the interviews with parents from Ostrobothnia (which is more Swedish-speaking) than in the interviews with the parents from Southern Finland (which is more Finnish dominated). The parents in Southern Finland also emphasised the Swedish language and culture but mentioned that the main issue is to gather a large enough group of deaf signing children, from both Finnish and Swedish-speaking homes, to ensure a rich linguistic (signing) and social environment.

3) Long school journeys

Long school journeys constitute reality for most deaf children and their families. The parents are well aware of the reason for this (that is, few deaf children) and have accepted this, as long as the education then received is of a high standard. Starting at the age of five, one of the children travels eightyfive kilometres (one way) to a Finnish deaf school. Although this is fairly common for deaf children in many countries it surely is not common for other children living in Finland. Not many parents of hearing children can even imagine having to send a child this young this far to receive the compulsory basic education. In this sense the parents view the situation for their children as problematic and unfair compared to other children living in Finland. Nevertheless, according to parents of signing children, the long distances to school are by far outweighed by the social and linguistic advantages of having larger educational and peer groups. Due to the family situation or the parents' employment, moving closer to a Finnish deaf school was not considered feasible for all families:

(49)

No, because we are self-employed and it is not possible to start from the beginning. Take our livelihood and move it somewhere, it doesn't work.

For another family moving to another town is feasible and to some extent desirable but still not voluntary:

(50)

Yes, [it's difficult] but it's still fairly easy for me. He is our only child, we don't own a house, have no business, it's quite easy for us to move and I think

our life-situation would improve if we moved...but it's not that voluntarily. If you think, what will I do then. Will you get friends and things like that.

As one mother pointed out, even in Sweden, where the educational opportunities are very good for deaf children, there are only a few deaf schools and the problem of long school journeys also exists there.

4) The Swedish language and the Swedish deaf and hearing cultures

The parents in the Sign Language group are very concerned about the child's risk of missing out, above all, on the Swedish language, but also on the Finland-Swedish deaf and hearing cultures. (This was also evident from the questionnaires, see Sections 8.3.1–8.3.2). Parents whose children already attend a Finnish deaf school, or parents who plan to place their child in a Finnish deaf school, are aware that their own native language (Swedish) will be – or already is – the child's third language. However, the parents, especially families from Southern Finland (which is more Finnish dominated) typically mention that since they live in a bilingual society they do not view this as negative. This statement correlates with the parents' own account of their knowledge of Finnish as well as their contacts with Finnish-speaking people. One family living in a Swedish-speaking area nevertheless decided on a Finnish deaf school, determined to manage, somehow, the Finnish language well enough to help the child with homework. In order to facilitate the child's schooling some families (usually one parent) have switched from Swedish to Finnish in communication with the child, that is, from Finnish Sign Language using Swedish articulation to Finnish Sign Language using Finnish articulation. (This was also mentioned in Section 5.5 in the discussion on Finnish Deaf schools). The two families who have done so find it necessary and therefore not so remarkable. Even so, these families are sad that the Swedish Language plays a minor role for their child and certainly view this as a gap in the education of Finland-Swedish deaf children. On this point the other families agree but cannot, under any circumstances, consider changing the home language to Finnish Sign Language combined with spoken Finnish. One family who had considered a Finnish deaf school and also a change of home language from Swedish to Finnish now strongly oppose this. Forcing siblings to change to Finnish in order for the deaf family member to receive education in Finland is wrong, the father said:

(51)

A Finnish deaf school, no, because then siblings have to learn Finnish and it's wrong that siblings now have to learn Finnish because the sister is deaf.

Furthermore, the Finland-Swedish culture is regarded as highly important for many of the families. The parents want their child to be part of the Finland-Swedish community and culture and, for this reason, they do not want the child to attend a Finnish school.

5) *Not possible to move to Sweden*

Of the nine families in the Sign Language group, the children of two families attend a deaf school in Sweden. Of the other seven families, three could consider this an alternative and four families could not. Nevertheless, all nine families stressed the financial burden of moving to Sweden, or to maintain one home in each country. One family strongly pointed out the lack of responsibility and support from the home city and the local Board of Education concerning the school situation for Finland-Swedish deaf children.

(52)

Mother: Society doesn't want our children to get an education, they don't care, they're pleased if we move to Sweden. Then they'll get rid of the problem

Father: There is no investment in Finland-Swedish deaf children, none at all
[- - -]

Father: There the instruction is good, then he would be on the same level as everyone else, in the case of friends, on a level with what the siblings now have. But this with economic resources, society does not want Finland-Swedish deaf children to get an education, the state should go in and finance so families with deaf children could afford to move to Sweden. Should we sell our house, should we buy a new house in Sweden, where would we get the extra money needed for our child's education, an extra 500 000 FIM. We have to invest so much in our child's schooling but the neighbour doesn't have to invest one penny. The municipality does pay if our child lives and goes to school in Sweden and comes home at the weekends but nothing if we move there.

The mother of a deaf pre-school child considered moving to Sweden but nevertheless thought it was absurd having to move to another country:

(53)

Yes, Sweden is indeed an alternative if I want to keep the Swedish [language] and make it easier for myself so I could think in Swedish. I have asked some well-informed people who have said that even if we move to Helsinki and my child would go to a Finnish school where he'll learn Finnish, to read and write in Finnish, I can still continue to articulate in Swedish. But well, I really don't know which to choose, at the moment I'm inclined towards Helsinki but I haven't made my mind up yet.

[- - -]

Yes, if you think about this with the school, it has to be a big group in order for something to come out of it. There isn't any. It's crazy, it's a crazy thought that you have to change country, those who travel over and move, it's crazy.

Few families have the financial, occupational or practical possibilities of moving to another country in order for their child to receive an education. The impact that moving to Sweden would have (or has) on family life was also frequently mentioned by the parents.

One family with a child who attends a deaf school in Sweden has arranged things so that one parent lives with the child in Sweden while the other parent has remained in Finland. The family is united during holidays and occasional weekends. This certainly does not allow for a normal family life, and it also affects the signing abilities of the parent remaining in Finland. This, in turn, has an impact on the parent-child communication and interaction. This situation is of course extra troublesome for families with older hearing siblings who have already started their schooling in Finland, and who therefore may not be so keen on moving to Sweden.

6) The Finnish language and the Finnish deaf and hearing cultures

Alienation from the Finnish language and the Finnish deaf and hearing culture, suffered by children receiving their education in Sweden, is seen as a problem for several parents. That is, in addition to missing out on the Finland-Swedish culture, these children also miss out on the Finnish language and Finnish culture since Finnish is not taught as a foreign language in schools in Sweden.⁴⁷ Pupils who want to continue their vocational training or studies (usually with a Sign Language interpreter), or find a job in Finland are naturally much better off, if they have some knowledge of written and spoken Finnish. Unfortunately, the majority of deaf pupils from Finland who move to Sweden remain there. The parents do, however, see the lack of opportunities for further studies as partly being the reason for the reluctance, on the part of deaf adolescents, to move back to Finland.

8.3.4 Factors influencing parents' choice of school for signing children

In the interviews factors influencing the parents' selection of school were further investigated and in analysing the data from the interviews four major factors were detected. These are:

- 1. Instruction in Sign Language and the social environment in a deaf school*
- 2. Inclusion unsuccessful*
- 3. The wish to maintain the Swedish language and the Finland-Swedish culture*
- 4. No possibility of moving to Sweden*

1) Instruction in Sign Language and the social environment in a deaf school

As the parents in this group are very strong in their opinions on Sign Language as the primary language for deaf people, it is not surprising that the possibility (for the child) of receiving instruction in Sign Language is the main priority when choosing school. Allowing their child to grow up in a signing and/or bilingual environment is considered a high priority by the parents. Therefore, the parents

⁴⁷ In Sweden, children with a native language other than Swedish do receive native language instruction in their home language, but this naturally does not cover the teaching of Finnish to deaf pupils from Finland with Swedish-speaking parents.

believe that only a deaf school with signing peers and signing teachers can provide a rich linguistic and social environment, as well as accessible instruction. This is not to say that all parents were happy with all experiences of deaf schools. For example, one child has attended two different schools for the deaf, and the parents were unsatisfied with the standard of education in one of the schools. The parents are nevertheless convinced that a deaf school (with instruction given in Sign Language) is the one and only choice. Ytteresse School is considered a good alternative but not the best one. In the long run the linguistic or social environment at Ytteresse is not sufficient for deaf children and can, according to some parents, be compared to mainstreaming. This has to a great extent influenced the parents' choice and as a result some families from Ostrobothnia are looking for other alternatives. The families in question stated that although this is very unfortunate for the small group of Swedish deaf children, one has to act in the best interest of every individual child and every family. The families mentioned an initial feeling of guilt and group pressure in looking for other alternatives but concluded that in the long run it is nevertheless very difficult to keep this small group of deaf children together.

For some families integrating their deaf child with hearing children was not considered a satisfactory solution. One family who initially mainstreamed their deaf child soon realised that being integrated with hearing children did not satisfy their child's need for social interaction with other deaf signing children and responded:

(54)

We had put a lot of effort in her leisure time, giving her the possibility to meet deaf people as she was the only deaf child at her pre-school. We have been taking part in summer-meetings, winter-meetings, she has had deaf friends over at our house, deaf friends and so on so we have tried to give it [contact with Sign Language and deaf people] outside of school. But then we realised that only that wasn't enough. And that's why we then chose a deaf school. We tried to give her so much, so much Sign Language and deaf people as possible and we thought that would be enough.

Another family with a deaf pre-school child was strongly against mainstreaming and the father concluded that:

(55)

If we place him in a hearing class we don't understand his situation...No one can understand, imagine going to school and no one else, the interpreter, no not even that, no one speaks your language, the interpreter speaks adult-language and the child child-language. There is NO ONE that is equal to you. No one could, no one can understand what it's like to be placed in a school where you don't understand, and, and it cannot be compared to hearing children going to school in another language.

Two families, whose children attend deaf schools in Sweden concluded that this alternative is the best one for their child: the children receive a good education through the medium of Sign, can maintain the Swedish language and interact in a fairly large peer group. In addition, some parents mentioned that the attitudes towards Sign Language and deaf people at large are more positive in Sweden than in Finland.

(56)

I do not yet have a very long experience from Sweden. That I don't have but there is a more positive attitude to Sign Language and all that. I don't know if it is, are they more used to it there or, no, I don't know, do they have more experience. I don't know but, well, these programmes. If you think about TV-programmes and things like that, even only the children's programmes. Teckenlådan [a children's tv-programme in Swedish Sign Language] is amazingly done. You don't find stuff like that here.

2) *Inclusion unsuccessful*

A few families tried mainstreaming in a hearing school during the child's first schoolyears, the reason for the inclusion mainly being the easy practical arrangements of having the child's school near the home. After some time the parents, however, realised that a hearing school could not satisfy the needs of their child, and consequently started investigating different deaf schools. The decision to transfer the child to a deaf school has had a large impact on the families, for example by entailing long school journeys for the children and other difficult practical problems for the parents. Nevertheless, the parents – and above all, the children – are more than happy with the transfer and do not in any respect regret the decision.

The mother of one family who first tried mainstreaming and then transferred their child to a deaf school responded as follows:

(57)

At first we thought about mainstreaming. And we believed in it ourselves. But when we realised it wasn't working, or we had planned mainstreaming for a couple of years and knew that sooner or later we would transfer him to a deaf school but it took place earlier than we perhaps first had planned. The first and second years he had an interpreter. He got on well, everything was new and exciting and it worked out fine. But it was during his second year that we realised how the social part was left out, and also the learning. It just doesn't work.

And when asked about the current school situation the parent continued by saying:

(58)

He is pleased, very pleased with the school, he wouldn't even want to change back one single day

For some parents of pre-school signing children the mere thought of mainstreaming was very upsetting, one parent replied:

(59)

Mainstreaming? A totally impossible thought, no possibility at all. A child needs a native language.

3) The wish to maintain the Swedish language and the Finland-Swedish culture

Unfortunately, the decision that the child will attend a school with Sign Language as the medium of instruction does not solve the educational problems for Finland-Swedish signing children. If the child attends a Finnish deaf school yet another language question arises: whether the child's second language will be Finnish or Swedish. As was discussed in the previous section the parents' wish to maintain the Swedish language and the Finland-Swedish culture is strong.

This dilemma is an issue that greatly influences the parents' choice of school. Here, the parents' own connection to Sweden and knowledge of Finnish (as well as knowledge of Swedish for Finnish-speaking parents) are crucial. The thought of placing their child in a Finnish deaf school did not appeal to some families. The mother of a school-aged signing child replied as follows when asked if they had considered a Finnish deaf school.

(60)

No, it wasn't, no, no, it wasn't. No, because we had moved to a town in the Swedish part of Ostrobothnia and I'm Swedish and our other children, so all my relatives are Swedish and we had moved and it was too Swedish for me to consider placing the girl, and like I knew I wanted the habilitation part that, that concerns the mother I wanted. And I knew I couldn't manage that in Finnish so it never really was an alternative. And because I didn't even know which school would have come in question, Jyväskylä, Uleåborg. Seinäjoki probably wouldn't even have been an alternative. I didn't want to send her to Jyväskylä and I didn't want to send her to Oulu either. It was even more alien to me to send her to something Finnish when I didn't want to send her away in the first place. So then at least I wanted to keep the Swedish as the last straw.

However, although the Swedish language and Finland-Swedish culture are important issues, the reality is that practical matters, combined with a wish to remain in their home country, in the end determine whether the deaf school will be in Finland or Sweden. This issue is discussed below.

4) No possibility of moving to Sweden

The question of whether deaf pupils shall be referred to schools in Sweden or not, is an issue that, regardless of their specific opinion for or against, engaged the parents very strongly. In essence the parents consider the prospect of having to move to another country as absurd. They are well aware of the high standard of deaf education in Sweden and many families have visited one or two Swedish deaf schools. Nevertheless, even though the parents want to provide their child with a good education, many families simply have no possibility of moving to Sweden.

The reasons most frequently mentioned were the parents' occupation and difficulty finding a job in Sweden, the financial burden of relocating and hearing siblings reluctant to move.

In addition, the cultural and Finnish language issues discussed earlier influenced the choice of school. When asked if they had considered a deaf school in Sweden one family replied:

(61)

Mother: No, we have NEVER thought about it, no, no.

Father: We have particularly thought that since we are such a big family that.

Mother: With jobs.

Father: With jobs and so. Those are things you have to think about. You cannot move there just like that and think you'll get a job. And I don't think the other children would have wanted to move either.

Mother: No, but we have never, we have never thought about it.

For other parents the thought of moving to Sweden was not as alien but even so the process of deciding whether to place the child in a deaf school in Sweden was stressful and difficult. When visiting a deaf school in Sweden the children and parents reacted very differently. According to the parents the children immediately "felt at home" but the parents themselves did not initially feel very comfortable in the new environment. It was a feeling, however, that already on the second visit had often turned into a positive one.

(62)

But if you are not ready for it then it doesn't work. And we were not, in a sense we were not yet, the first time we were there [a deaf school in Sweden] and saw it then, well yes it probably was a very good school but no, no, it did not feel good. But then the second time, well this is right. Then it felt right... Before we were, the year before [the move] we visited [the deaf school] and then he was in the classroom. Before he started we did two visits and he also received a letter and something else that his classmates had written and sent to him. And already the second time we were there we did not, then we didn't go to the classroom. He wanted to be left alone in the class, and take part in the instruction and we spent more time looking at housing and work and things like that. And I don't at all feel like, at first I was a little worried, because he has this Finland-Swedish Sign Language and to have to change to the Swedish one. And of course, in the beginning it was a little difficult, surely they didn't understand him 100%, or surely there were misunderstandings in the beginning. But it didn't take long until he had grasped it. And then I do think that the sooner you go the easier and better it is. Because at first I realised that, as they say, that if you are deaf and mainstreamed then you will easily be patronised in some way. But now, now it really is like, we are here on the same conditions and everything. When they come up and say why do you look like that and things like that, then at first he was hurt. It's like he understood that not everybody is equally nice.

8.3.5 Educational problems facing families with hearing-impaired children using spoken language

The parents of deaf children who use spoken Swedish (or Swedish and Finnish), and whose children already attend – or will attend – a school for hearing children did not state nearly as many different educational problems as the parents in the previous group. The fact that several of the children belonging to this group have mild to moderate hearing losses, and thus are capable of attending a school for normally hearing children naturally facilitates the child's education. Nevertheless, even the parents of children with mild hearing losses reported many difficulties with their child's schooling. The problems can be grouped as follows:

1. *General lack of knowledge and resources*
2. *Difficulty getting a personal school assistant*

1) *General lack of knowledge and resources*

Teachers' lack of knowledge and experience of children who are deaf or hearing-impaired is an issue that, according to the parents, affects the education of mainstreamed children. Among other things, the teachers need to be aware of the factors influencing the accessibility of the instruction for the deaf child, such as the child's place in the classroom and the necessity of the teachers to speak so that the child, if needed, has a chance to lip-read. Still, the classroom situation is tiring for many hearing-impaired children. The reality is that even children with a mild to moderate hearing-loss must constantly concentrate and be very attentive in order to follow the instruction. Needless to say, this is very tiresome and at the end of the schooldays these pupils are often exhausted.

(63)

He cannot concentrate on speech for too long, he gets in a bad mood if there is lots of noise, he wants to get away. The teacher often says that he is the only one who says I don't understand anything...Because he doesn't hear well he constantly demands support.

(64)

Researcher: What does she think of the situation in the classroom? Does she feel she misses out on information, for example, things that are said behind her?

Mother: Yes, I think, yes there are similar problems, yes but now she doesn't complain so much.

Father: Not any longer, but still in year five and six it was, when it was disorder in the class, a lot of talking, unnecessary talking and then, then we had to talk to the teacher about that as well. That it was too unsettled in the class, too much talking and too much scratching and so but it hasn't been so much about that now, not anymore in secondary school. But maybe you work in a different way.

Moreover the (possible) benefit of using an FM system⁴⁸ must be clarified for the teachers. One family did, however, comment on the difficulty of using an FM system in secondary school when the child has so many different teachers.

(65)

Father: Then we also, we tried an FM system for some time and it worked out fine, fine for some time. But then when, now in secondary school when you don't have, it's not the same teachers and well, it turned out to be too complicated.

Mother: Yes, it's a little complicated.

Father: Still in year five and six but then in secondary school it doesn't work.

Included in the home guidance counsellor's job is a requirement to visit schools with mainstreamed hearing-impaired children and inform the teachers and other staff working with the child about technical aids and the special needs of a hearing-impaired child. The parents did mention the significance of the home guidance counsellor (see also Section 8.4.2) but the experiences of how the school accommodated the child's needs varied greatly. Some parents felt that the schools do not act according to the information received, while other parents (see quotations 68 and 74) were very content with the schools' efforts to facilitate the deaf or hearing-impaired child's learning environment.

For example the benefit that deaf and hearing-impaired children can draw from working in small groups as well as their need for a well-structured class-schedule are issues the schools are not always aware of (again, an exception is found in quotation 74). Some families were upset by the schools' reluctance to arrange the schedule so that the cognitively more demanding subjects like mathematics and foreign languages would be covered in the morning and subjects like physical education and arts in the afternoon. The frequent change of teachers which unfortunately is reality in many schools today is extra troublesome for hearing-impaired children:

(66)

Constantly new substitute teachers and that has indeed been troublesome for her... If she doesn't hear the third time she doesn't ask anymore. And then, when they don't know that she doesn't hear some substitute teachers refuse to say it again. At home she will ask until she hears but not with unfamiliar people.

⁴⁸ The FM system can improve listening conditions for pupils who are deaf or hard-of-hearing and is the most common technical aid in schools with hearing-impaired children (Asumaa, 2000). It consists of a microphone and a transmitter worn by the teacher and a receiver (which is connected to the hearing aid) worn by the hearing-impaired pupil (Asumaa, 2000). The FM system, (FM is an abbreviation for "frequency modulated") improves the quality of the speaker's voice by reducing background noise and the effect of distance between speaker and listener (Queensland Government, 2003, [www-document](#)). The system is also called RT, an abbreviation for "radio frequency".

One must however bear in mind that the parents not only report negative experiences:

(67)

Yes, and indeed, they [the teachers] have been very efficient there, yes, yes, I can only recommend it [the school]. I have to say that I have been very, well, I think they've been very nice, really very nice.

(68)

Researcher: Have any isolation boards or [induction] loop systems been placed in the classroom?

Father: Yes, no not loop systems but the classes are softened with these boards following the material-description given by the home guidance counsellor. No problems at all, it has been taken care of. The school is benevolent in that.

Other adults working in the school can also be very significant for the hearing-impaired child:

(69)

Mother: But there is a pupil counsellor [SWE: skolkurator] who plays a very important role and the counsellor is very active and efficient in this matter and she is very involved in our daughter and very like this, a good fighter.

Father: Yes, in her opinion our daughter isn't, that she is unintelligent, it's only because of her disability that she doesn't have, she doesn't have the same opportunities as others to perceive abstract subjects, unknown words in history or so and especially foreign languages that are very difficult because we are still working on building her own language.

Finally, for many parents it is very upsetting that their child's education suffers because of a lack of information or knowledge about the special needs of hearing-impaired or deaf children. Also distressing is the fact that there sometimes are not enough financial resources to provide the extra support the child may need in order to achieve at school.

(70)

Mother: But it is just this with the school authorities, I think that that one should. The parents should receive information about the rights relating to the child's schooling, the rights for an assistant and, and support teaching and then who, who is then, who has the competence to decide about this. Is it the economic resources of the city or district that determines this or is it actually the needs of the child. It, it is really terrible that you keep referring to this that we can't afford it because it's going to cost so much more if you don't invest well in time.

Father: Yes, and it's things you can't measure in money, we're talking about a person's future and so, so it doesn't, if it costs 50,000 [FIM] or 70,000 per year then you cannot say. Saying that we can't afford it is no argument.

Mother: You can't measure a human being with, like this in money, a human being has value in herself.

The lack of enough resources to provide for the extra support in the classroom is salient when looking at the problems with finding and keeping a suitable personal school assistant for those hearing-impaired or deaf children who either are entitled to this one-to-one support or would benefit from it.

2) *Difficulty getting a personal school assistant*

The majority of the children using spoken language who already attend school have a personal school assistant. These parents mentioned the struggle to find and keep a good assistant as a major problem. The problems here are the low salary and the poor working conditions for an assistant. An assistant is paid on an hourly basis and during school holidays no salary is received. This naturally leads to difficulties finding an assistant in the first place.

(71)

Father: One ought to get an assistant...

Mother: Better conditions for the assistants, if it is [incomplete sentence]

Father: First, availability of assistants.

Mother: Well, availability of assistants, yes. But it is a vicious circle, the availability would surely be totally different if there would be better conditions for them.

(72)

Sometimes an assistant would be good... writing is very difficult, she would need help with that.

One family who had been lucky getting a good assistant for their son still commented on the poor working conditions for personal school assistants:

(73)

Mother: But because of that [the child attended a mixed class consisting of years 1 and 2] the assistant that was hired when he started school is of great help.

Researcher: So is the assistant hired for him, is it his personal assistant?

Mother: Well, yes.

Father: Yes, hired for him, yes, on paper but it is more like she sometimes works with the whole class and the teacher can concentrate on him and vice versa.

[- - -]

Researcher: Was it difficult finding an assistant?

Father: It wasn't really difficult, it was a little older person, with life experience... she has no schooling for it but.

Mother: A good way with children

Father: A good way with children and I think it's important that it is a person who is a little older, than if someone who is eighteen, nineteen appears. It may not have the same effect at all, I find that difficult to believe. It has worked out fine.

Researcher: So is it easy finding an assistant in your hometown?

Mother: No, it.

Father: Generally it is not easy but in this case, I believe, there happened to be three who applied.

Mother: But otherwise one has heard that, well, that it is difficult and they say that it is very much this with the salary.

Father: VERY MUCH

Mother: Very much that, that influences, and then when they, isn't it so that the employment ceases for the summer?

Father: And for Christmas.

Mother: And that they, all these benefits, no benefits.

Moreover, personal school assistants often transfer to other better-paid positions if given the chance. Parents view continuity in the relationship between the assistant and child as necessary for successful learning. This problem is accentuated for children who are timid and shy, characteristics several parents used when talking about their child. Another possible disadvantage that was reported by a couple families is that the child may develop a strong dependency on the personal school assistant.

Parents feel that they have little power to influence the situation with assistants. The parents feel powerless and point out that although the school may be accommodating towards the needs of pupils who are deaf or hard-of-hearing, the poor resources and support services available for these children cause a constant struggle. The following long quotation from the interview with the parents of a child with a mild hearing loss clearly summarises the problems reported by the parents of hearing-impaired or deaf children who use spoken language communication. It shows the difficulty of finding an assistant and also how active the parents themselves have to be, even when the headmaster and school are very accommodating towards the hearing-impaired child. Another reason for including such a long quotation is that it clearly points out several difficulties that arise once a hearing-impaired child enters secondary school. These are difficulties not mentioned in many of the other parental interviews as few parents included in this study have children who attend secondary school. In this quotation the parents thus talk about many of issues discussed throughout this work: the need for knowledge of the special needs of hearing-impaired children, the need for a personal school assistant and the difficulties relating to both finding and keeping an assistant. The parents also mention the lack of resources required within the educational system to consider the special needs of hearing-impaired children. Finally the parents talk about their own feelings and struggle to provide their child with equal learning opportunities.

(74)

Mother: Seventeen pupils [in the class], pretty good because the school has been accommodating towards this because they have tried to make up a class of somewhat calmer pupils and more able pupils and pupils that, that can do teamwork and maybe keep a little more quiet and also that there are fewer pupils.

Researcher: Did anyone inform the school on the special needs of hearing-impaired children?

Mother: The home guidance councillor.

Father: During primary school Folkhälsan did and they also arranged a, a course during the summer for primary school teachers and then she was lucky and had a, a primary school teacher that was very emphatic and interested and took the course and like, found out what having a hearing-impaired child is about. That was fine. Then when she moved on from year one and year two she lost her.

Mother: Year three and four

Father: Well, yes then she lost her and got another teacher and then things changed a little again and now in secondary school there's a little of the same empathy as in year one and two but...but we have also fought hard, not the least my wife has fought hard for assistants and support teachers. And sometimes it's worked better and sometimes not so good.

Researcher: To what extent does she need learning support or an assistant?

Mother: Fairly, she would need an assistant but when they, so to say, it's up to the assistant's personality and commitment and knowledge and skills so it hasn't worked now in secondary school. It worked very well in primary school.

Researcher: So she had an assistant in primary school?

Mother: She had, was it starting from year five and six, yes.

Father: One point here in this context is that it is very difficult to, well like, oneself act because the salary for these assistants is **DESPICABLE** so the one, the one who is willing to take the job, well then you just have to say thank you and well, like that. But we have had trouble finding, finding the right person to get along with our girl. And it's like this, if it doesn't work, it doesn't work and she doesn't get this contact. There is a special needs teacher in secondary school, a teacher that she likes very much and that she gets along fine with but she [the teacher] doesn't have time to only concentrate on her. But, but she is with her a couple hours a week and that is very good. A few subjects are particularly critical and for them she is entirely dependent on support of some kind. This concerns foreign languages and mathematics.

Researcher: What has been incorporated in the tasks of the assistant?

Mother: Well, it would be to help her during the lessons so she understands what the teacher is saying. She didn't want to co-operate with the assistant she had last year so it, the assistant became the class assistant instead so the teacher then perhaps particularly explained, well it was then cut off, it was a little like this.

Father: It was a little bothersome.

Mother: And then the assistant changed and is a little, well, who is a little unsure. And, and we don't blame this assistant but this **SYSTEM**. You see, we had asked for extra support lessons from the school authorities but they had thanked, said no and instead referred to an assistant. Perhaps it is cheaper (laughing). And now she needs more learning support and, and she has asked for it but when she says she doesn't get enough now and it is once again to be decided Do we have to call the school **AGAIN**, we've had lots of contacts and meetings and such.

Father: So if, if there is anything one can in any way emphasise here then it's exactly this. What we experience as the most difficult thing right now is the accommodating, or should we say, the school wants to but there are no resources for it. So, that is, the accommodating of children with different disabilities in the educational system. Well, concretely we only know of this but it is very arduous that the parents have to call and toil and call the school, the Education Department and inquire and be active because we have, we don't know how the Education Department works and what kind of decision process they have and what level of competence one should have on the learning support. And we cannot influence the situation with the salary for assistants and well, we can, we have a limited possibility to regularly, every week, check how it's going. If you then compare with the accommodating attitude at Folkhälsan or the Auditory Unit then, then the educational system is light-years from that. And the higher, the higher in the comprehensive school you get then it only gets far worse, at the same time the level and demands increases, the accommodating from the educational system simply gets worse. Even though the school and headmaster readily want to. So that's one thing that I personally would like to emphasise and that makes me both upset and, and disappointed. Mother: Mm, because it still is, so to say, about a child's future. Secondary school is crucial.

Father: Precisely between primary school and upper secondary school or further education, upper secondary, that is, secondary school is crucial.

Mother: It was like this, the contact we had with the Education Department during primary school, the school had asked for more support or so for her schooling from the Education Department and then the Education Department said that, no they can't afford it. Flatly refused. But then we called, then we started to call, how is this possible, her achievements at school are declining and what is she to do if she doesn't manage. Then I called the Education Department and with this inspector [SWE: inspektör] who is in charge of these matters and said that, he, she said that we must absolutely get. And then I called the Education Department again and the headmaster and then it all started with assistants. But now it looks like I have to start with this again, yes. There are so many teachers in secondary school, it is so much easier to collaborate with the primary school and class teachers. It is quite different in secondary school.

[- - -]

Mother: Yes, the schooling in many subjects is still very difficult.

Not only parents whose children already attend school mentioned the poor working conditions for the assistants. Parents of children under school-age also commented on this, and mentioned this inadequate state of affairs as one of their main concerns concerning their child's future education.

For one family the child's schooling initially proved to be very difficult with problems in many areas and the child was transferred to another school and now the child is doing well and has had the fortune of having the same personal school assistant for many years:

(75)

He has transferred to another school, among other things because of long school journeys, no friends. Now he has teachers who are well-informed and a school assistant, the same school assistant he has had since year one. And we are going to have her the whole time, we're not going to give her up. In that sense we are fortunate.

8.3.6 Factors influencing parents' choice of school for hearing-impaired children using spoken language

When analysing the interviews of the parents who use spoken Swedish in communication with their child who is deaf or hearing-impaired, three major factors that influenced the decision in choosing a school for normally hearing children were discerned. These three factors are interdependent and also, although not specifically discussed here, it must be pointed out that the choice of school to a large degree depends on, and is also partly the reason for, the choice of oral communication.

For the parents of children with mild to moderate hearing losses the choice of both communication method and hearing versus deaf school the choice was fairly obvious and unconfused. However, for the parents of severely hearing-impaired children in this category the choice was not as easy. One could say that these parents have chosen spoken language communication in an attempt to avoid the problems accounted for by the parents using manual communication (in the previous section). One parent said that due to the bad reputation the Swedish deaf school had (especially during its last years) they never would have sent their child to that particular school. A school has to be a secure and friendly place, and as the parents did not regard this to be the case they felt they had to look for other alternatives.

(76)

I knew about Borgå deaf school, I would never have sent her there because I knew that, well like, I don't send my child to a school with internal oppositions. In my opinion a school should be a secure and nice environment with a good atmosphere. If it doesn't have that then it's to hell with that and they don't learn a thing but they go there because someone has said that they have to go to school 190 days.

Thus, related to the fundamental question of choice of communication method, the following three factors that influenced the parents' choice of school are:

- 1. The possibility of attending a school near the home*
- 2. The ability to participate in activities with hearing children*
- 3. Social isolation and limited educational opportunities for signing children*

1) The possibility of attending a school near the home

The parents in this group highly value the fact that the child is (or will be) able to attend a Swedish-speaking school near the home. These children all attend (or

have attended) day-care together with hearing children, and the parents view it as very important for the child's social development and feeling of security to continue going to school with the same group of children.

(77)

Father: It is quite natural in other ways as well that you hope and try with it [mainstreaming].

Mother: And also it would be a natural environment for him, he goes to an ordinary hearing day-care and the same children are from this area, so many will start the same school so for him it would be to be torn apart from this social environment.

Moreover, the opinion was that it is emotionally and physically too demanding for young children to be sent to schools far from home. Also, importantly, as was mentioned earlier, given that the family had chosen spoken Swedish, the choice of school naturally was a hearing school. For the parents of children with a mild hearing loss too, the neighbourhood school was considered the best alternative.

(78)

Researcher: Did you visit different schools when he started school?

Mother: No.

Father: No.

Mother: No, the one that was closest.

Father: Closest, it had a good reputation and nice environment and so.

Mother: And then the fact that his big brother went to the same school. It was familiar to us in a totally different manner.

When discussing the importance of the school's proximity to home also the parents of children with mild to moderate hearing losses mentioned the possibility moving to Sweden if inclusion fails to meet the needs of their child. Not surprisingly the parents mentioned the same problems with this alternative as parents of signing children.

(79)

She was interested in Örebro [deaf school in Sweden] although she didn't see very much... But it is not an alternative, no, it really is not, it would still be such a big change. It would perhaps be different if one would notice that she really doesn't do well then I do think one would be prepared to make a move. But of course, with work and you don't move just like that, expensive and then, then it's not only a question of money, perhaps you want a job you're happy with. And if the rest of the family are unhappy then I don't think that the hearing-impaired child will do fine either.

One parent described how during a more difficult period their hearing-impaired son had inquired whether there was a suitable deaf school for him:

(80)

It was last year that was difficult, it was, last year was very difficult for our boy. It was everything, he entered puberty and things didn't go well and the assistant was no good, and yes (sorry, laughing) ... well, yes for, for our boy and then he several times asked if there is a deaf school that he could attend instead... and he came back to this several times during the school-year. And he, he actually asked for that particular model [the system in Kristinaskolan in Härnösand with separate classes for deaf and hearing-impaired children]... that was brought up several times but there is, there probably aren't any such alternatives in Swedish in Finland, at least not in the vicinity.

2) The ability to participate in activities with hearing children

The ability to participate in activities with hearing children from the neighbourhood is another factor parents view as important.

(81)

Father: Well, one does notice that. It was during the weekend when we were out in the park, in the toboggan run and similar things. So, it really is important for him that he knows all those children. Isn't it? It is still his social environment. And that they know who he is. Like, it is fairly natural for them. Those who know that he has an implant and that he is deaf so it's like just completely natural for them. That's him and he lives there and one knows, well, like it turns out to be like a togetherness. Yes, and if he would go to a signing day care then it would be quite an adjustment, they go to Hertonäs [a district in eastern Helsinki]. It's a completely different environment, and besides it is in Finnish.

The parents want their children to have the same opportunities as hearing children, not only in relation to the instruction, but also in relation to leisure activities. According to the parents, this is not a possibility for children attending deaf schools far from home. In such cases, the school taxi waiting to drive the child home restricts playing with friends and taking part in after-school activities.

However, all parents belonging to this group point out the need for the children to meet and interact with other children who are deaf or hearing-impaired. The parents do not want their child to be completely shut out from that particular peer group. Nevertheless, one child did not herself want to interact with other hearing-impaired children, on the contrary, instead of attending summer camps for hearing-impaired children she wanted to go to camps with hearing children. The other parents reported that their children enjoyed meeting other hearing-impaired or deaf children during summer camps and other social gatherings.

3) Social isolation and limited educational opportunities for signing children

This third factor is strongly linked to the two previous factors, and naturally also to the initial choice of communication method. In addition to the reasons men-

tioned above the parents using spoken language do so out of a fear of isolating a child communicating in Sign Language. The parents naturally want their children to become independent individuals with complete control of their life, but view this as incompatible with the use of Sign as the primary language. According to the parents, signing children with poor speech are too dependent on a Sign Language interpreter. The parents want their children to function in society without having to turn to an interpreter. Moreover, all these children are born into hearing families with no knowledge of Sign Language. Therefore, the parents want the deaf children to be able to communicate in a spoken language with friends and relatives and also to attend the same school as hearing siblings.

(82)

I don't want him to have the only link to an interpreter, an interpreter who interprets with friends and teachers and such because then he would be isolated. But it was like, the family and this that I didn't want him to be isolated from his relatives and the environment he has here, and the school, that he would learn to live and adapt himself to the environment... I remember a long time ago at the Light House I saw, then I was there and I looked. My child was very young and then I was there and they had drawn these, deaf children had drawn maps of their relatives. And then they had drawn a dot, with red dots the people who knew Sign Language. And it was terrible. They didn't, there were some siblings who speak a little, the father usually knew, not even perfectly but it was the mother who usually knew. The dad sort of knew, could sign a little and then there was, the siblings also knew but a cousin could perhaps some signs. But it always ended there and that too told me something. These were also issues that it's not just like that, like hey, now we have a deaf child in the family and now we'll all learn Sign Language

The fact that few hearing people learn Sign Language is confirmed by the mother of a deaf signing child in quotation (90).

For some parents the concepts of deafness, Sign Language and the Deaf community remained unclear even after the early habilitation. This uncertainty about the Deaf community added to the parents' feeling of the Deaf and signing community as being very different and isolated from the world of both hearing-impaired and hearing people.

(83)

No one signed with my deaf relative. I spoke with him, it wasn't a problem. And then young deaf people today, well, no, nothing, you cannot, they don't lip-read and if you don't know Sign Language you're totally out.

(84)

I was aware of the deaf school in Borgå but there was NEVER any questions about anything like that since my child isn't a signing child. Anyhow, since she, because we went in for speech. So for us it wasn't any loss when they took away the deaf school in Borgå. It has never, we were told, at these lectures

there was someone who talked about this, someone who has been a teacher at the deaf school. She was there on this course at the Light House...She told us about the difference between these Deaf and hearing-impaired, how deaf people do not approve of hearing aids and the hearing-impaired. That they are in a world of their own, that they so to say. This conception, this is the conception I formed of, because I don't know anything about the Deaf. We've had so much with finding about the hard-of-hearing, we haven't had time or strength to in any way get acquainted with the Deaf world. Nothing, I know, I have to say that I know very little about that, only what she then said, that they, that they, like only want to, how they sign and that many don't even want hearing aids. It was a, I understood that it was a separate world and something quite, a totally different system with the Deaf. How did she phrase it, well, in any case my memory of that is that it is a world of its own.

(85)

It becomes a group within a group and they have very little contact with the outside world.

Linked to the choice of communication mode for their deaf child is the parents' belief that children learning Finland-Swedish or Finnish Sign Language and attending a deaf school will not acquire high reading and writing skills, and that signing children academically and professionally will be behind hearing age-mates.

(86)

There is also another reason, with, then books. I love books. That is something that is extremely difficult for signing children. That has been proved.

Some parents view the occupational situation for a deaf signing individual to be extremely limited. The parents' hope is that inclusive education will provide the child with more opportunities for further studies and a rewarding placement in the workforce.

Summary

To summarise, parents choosing oral communication do so with the hope of providing the child with the possibility of participating in society on equal terms with hearing people. In the view of these parents, a deaf signing individual has fewer educational and occupational opportunities and is also at risk of social isolation. The parents are all aware of the possibility of using Sign Language and do acknowledge that they have received information on this mode of communication, but for the reasons previously mentioned, opt for oral communication.

Parents choosing Sign Language, on the other hand, do so because of a strong personal conviction that full communication with a deaf person is only possible through the medium of Sign.

According to these results it thus seems that two different views are at hand. Parents choosing oral communication for their deaf or severely hearing-impaired

child⁴⁹ tend to focus on factors such as educational and occupational opportunities and ability to function in a hearing world. Parents choosing manual communication focus on factors such as the child's prerequisites of communication and social as well as personality development.

8.4 Early habilitation

The fourth and final research question reads: What are the parents' experiences of the early habilitation for their deaf or hearing-impaired child? The results to this research question are presented in this section. As hearing parents rarely have any experience or background knowledge of deafness or different methods of communication, it may initially be difficult for them to understand fully the impact a loss of hearing has on the child's linguistic, cognitive and psychosocial development. Diversified information on deafness and communication is thus very important. A family with a deaf or hearing-impaired child visits many different institutions during the early intervention.

The questionnaire gives a general view of the quality and quantity of the information received by the eighteen Swedish-speaking (or bilingual Swedish and Finnish) families with deaf or hard-of-hearing children during the early habilitation. The answers from the questionnaire (which are set forth in Section 8.4.1) clearly indicate an inconsistency and diversity in the procedures and content of information given to the different families. This difference is evident both between families from different parts of Finland as well as between families from the same regions; that is, parents from the Helsinki area, for instance, did not even receive comparable guidance.

An issue dealt with in the interviews is whether the parents (independent of the communication mode they use with their child) are content with the information and support they received during the early intervention. These are issues that engaged the parents very strongly, and the outcome of these discussions is outlined in Section 8.4.

8.4.1 Receiving information on deafness

A great diversity in the responses is typical for the questions in the inquiry that address the views and conceptions of early habilitation. Despite habilitation plans there does not always seem to exist a consistent procedure to be followed when a child is suspected of having a hearing loss. In Finland all children attend a child health clinic on a regular basis (for example to receive vaccinations); these clinics are considered to be very influential in child-care issues. However, the actions undertaken in cases of a hearing loss bear witness to a lack (on the part of the

⁴⁹ For parents of children with mild to moderate hearing losses the choice of communication method (spoken language) and the local hearing school is more or less straightforward.

nurses at the child health clinics) of both experience and knowledge on how to treat families with deaf or hearing-impaired children. This includes knowledge on what further actions need to be taken. Some exceptions were evident; for example, families in one part of Helsinki were very content with the treatment received at a particular child health clinic. At this point one should bear in mind that the nurses at the child health clinics meet all children; obviously the nurses cannot possibly be experts on every disability or all special needs of the children that they may encounter. As the frequency of deafness or hearing-impairment is low, some nurses meet no or, at the most, one or two children with a hearing loss during their active work-years. These nurses thus have no possibility of gaining experience of treating children with a hearing loss. Even so, the parents expect a more coherent course of action once the hearing loss is diagnosed.

Actions taken at the child health clinics when the hearing loss was diagnosed

Eight families reported that no actions had been taken when the hearing loss was diagnosed. The ten other families stated a variety of different responses. For example, at their own demand they received an admission note to the Auditory Unit (SWE: hörselcentral, FI: kuulokeskus) at the university hospitals, or an admission note to a paediatric and then further to a university hospital. The consequences of a wrong or delayed action can be devastating. Above all, time spent on wrong procedures can be costly for developing adequate communication with the child. One family with a severely hearing-impaired child was directed to the wrong place. The mother recounted the events as follows:

(87)

Yes, she [the health visitor at the child clinic] said that she will send a referral, a referral to Kuulonhuoltoliitto⁵⁰. And we got an appointment to go there, we went for his one-year check-up in November, went to Kuulonhuoltoliitto in December and they said how have you come here, you're not supposed to come to us, you should go to HYKS. Well, how are we supposed to know where we're supposed to go, and there we stood and would have wanted, every DAY was important then when he was a year old and we knew he now needs to quickly get help. And he was one year old and we should get hearing aids. And then I had talked to someone who had said make sure you get two right away because you're not supposed to have to fight in order to get two hearing aids. That they shouldn't even try to offer one and then, and then it took SO LONG. We didn't come to HYKS until the end of January and that was, that was the worst period of time for me. This that we knew that he had, did not hear and meanwhile we let him slam on all pot lids and ringed on everything and we shouted in his ear and when he wanted we had all the radios turned up as high as he wanted, so he would receive these sounds anyway.

⁵⁰ In Swedish: Hörselvårdsförbundet, in English: The Finnish Federation of Hard-of-hearing.

Because we knew it is, that it is like, that he enjoyed being able to hear. And then we also had, we immediately started and tried with our hands. It was the worst and it shouldn't be like that.

The adjustment courses offered to families with deaf children are very important because it allows parents to meet other families with similar worries and questions. A Swedish adjustment course is arranged once a year. So in the worst case, Swedish-speaking families may have to wait almost a year after the hearing loss is diagnosed until they can participate in an adjustment course. This happened to one of the families in this study. In December 1997 this family learned that their two-year-old child had a severe hearing loss and not until December 1998 did they participate in an adjustment course. Needless to say, one year is a long period of time for a young child waiting for accessible communication, as well as for parents waiting to learn more about the specific needs of their child.

As was mentioned above, the answer to the second part of research problem cannot be discerned solely from the questionnaires, this is a theme more thoroughly discussed in the interviews. The questionnaire does, however, provide the sources, and briefly the content, of the information received in the early habilitation.

Receiving information on Sign Language and deafness/hearing-impairments

The parents received information on Sign Language from five different sources (the number of responses is given in parenthesis):

- * Home guidance counsellor (10),
- * Habilitation counsellor (2),
- * Folkhälsan⁵¹ (2),
- * University Central Hospitals (4),
- * Other parents (1).

Information on the deaf and hearing-impaired children's development was obtained from thirteen different sources altogether. Many families had stated more than one informant. Four major sources of information were, however, distinguished:

- * adjustment course (4),
- * other parents with deaf or hearing-impaired children (4),
- * home-guidance counsellor (4),
- * have gathered the information themselves (4).

⁵¹ Folkhälsan is a non-governmental organisation, representing the Third Sector, offering welfare and health services in the same manner that local governments do. The services offered by Folkhälsan include child welfare, neuropsychiatric examination and habilitation for disabled children.

Of the other nine sources all but two were only mentioned once, thus showing a great variation in sources of information. Among these nine are, for example, The Finnish Association of the Deaf, The John Tracy Clinic (in the US), and DHBS (The organisation for Finland-Swedish parents with deaf and hearing-impaired children).

Regarding both the quality and quantity of information given during the early intervention, on deaf children's specific abilities and needs, on information on Deaf culture, on deaf interest groups and parental organisations, the parents again reported many different informants. The most frequent response was: from other parents (5), and by DHBS⁵² (5), followed by deaf people (4), and the home guidance counsellor (4). Here it is only possible to draw attention to the diversity of the responses; a discussion of the parents' conception of the content of the information is omitted. This topic was discussed extensively during the interviews, and will be dealt with in Section 8.4.2.

The answers to questions 10–12 in the inquiry, which also deal with the information received – on hearing aids, cochlear implants and the possibility of receiving Sign Language education in the home – follow the same pattern as the answers to the previous questions; a great variability and many inconsistencies are evident. The Helsinki University hospital was the major source of information concerning hearing aids (thirteen responses).

8.4.2 Parents' conceptions of early habilitation

Regardless of the child's hearing status, the method of communication or the families' place of residence, the parents had quite a few negative experiences of the treatment received during early habilitation. In addition, they wished to improve many procedures as well as the information given in the habilitation. The bottom line in the parents' criticism is that the expertise and professionals working with children who are deaf or hard-of-hearing are polite and well-meaning but do not have enough knowledge of deafness, hearing-impairment, cochlear implants and different means of communication, to satisfy their needs. The direction of the criticism varies according to the families' choice of communication mode. Even though many of the families have had unpleasant or bad experiences of the treatment – especially at the Auditory Units – during the early habilitation, this was not the case in all families. The degree of criticism and dissatisfaction was linked to the child's degree of hearing loss and this will be discussed below.

The themes to be discussed here are: (1) Attitudes vary with degree of hearing loss, (2) receiving early habilitation in Swedish, (3) the need for diversified information and emotional support, (4) the timing of information, (5) support families, (6) habilitation programmes, (7) home guidance counsellor, and (8) Sign Language instruction as well as (9) the parents' own role.

⁵² The organisation for Swedish-speaking parents with deaf or hearing-impaired children.

1. Attitudes vary with degree of hearing loss

A common response, both among parents who use Sign Language and those who use oral communication, is a feeling of resignation. Both groups of parents have, by now, come to the conclusion that they do not receive all the necessary information from the professionals, and do not even expect it anymore. Instead, they look for support elsewhere, often from other parents and in a few cases from experts on deafness, cochlear implants or speech training programmes in other countries.

Here, a variation is, however, evident. The tendency appears to be that the milder the degree of hearing loss, the more positive the parents' attitudes towards early habilitation is. Parents of children with a mild to moderate hearing loss comment on the well-adjusted, supportive and accurate information they have received.

Parents of children with severe to profound hearing losses are not as satisfied. They do comment that although they have not been treated badly, they feel that the experts' level of knowledge is not enough. Interestingly, this applies both to parents who have opted for oral as well as to those who have opted for manual communication. The Auditory Unit at the University hospitals, the Finnish Association of the Deaf and Folkhälsan are mentioned as the only ones to know anything about deafness or hearing-impairments. However, the variation is enormous, for whereas some families are very content with the treatment received, for example, at Folkhälsan, other families are not and comment that Folkhälsan focuses too much on speech training and speech therapy.

Although most families using oral communication feel they have been well encountered, they do state that there exist deficits in early intervention. The parents feel they have to wait unreasonably long to receive some specific information, to proceed to the next stage in the habilitation, or for the child to receive adequate hearing aids (see quotation 87). The parents also want more information based on scientific research on the latest technology such as advanced hearing aids and cochlear implants. They feel that the attitudes towards deafness are negative. One father expressed these attitudes as follows:

(88)

Oh, so you have a deaf child, well, there's nothing to do about it. You'll just have to live with it.

At this point, it must be remembered that this is not a common opinion among all parents, parents of children with a mild hearing loss describe the personnel at the Auditory Unit as being of great support for both the parents themselves and their children.

Parents of signing children, however, comment on different things. These parents miss a more holistic approach towards the child. The parents' conception is that focus is only on the child's ear and they visit the Auditory Unit more out of a moral obligation, than a need to receive information or support concerning their child's development. One parent commented:

(89)

We simply felt it was useless to go there [the Auditory Unit], when we knew that he has to sit there again, and is again supposed to listen to all that and they sit there and write their small curves, curves which all look the same. And then we come to the doctor who says that now they will, how about a hearing aid and so on, we knew the marching order and simply thought it was a wasted day.

The parents feel that people working with deaf children but who do not sign cannot completely understand a deaf child or how a deaf child functions. One mother of a deaf signing child said that, perhaps because of a fear and uncertainty of deafness and how to interact with deaf people, professionals cannot see the whole (deaf) person. The mother further reasons that as a consequence the professionals are not able understand the deaf child. Although this is the conception they have, the parent realises that few hearing people sign and for this particular reason they are no longer very disappointed, rather they are indifferent, towards the experts involved in their child's early habilitation. The mother replied:

(90)

Hm, but I think that everyone who doesn't themselves sign feels a kind of distance, or everyone who doesn't sign cannot either understand how a deaf child functions. They are perhaps scared and like that, hm, and then they cannot see the wholeness, they can't see his wholeness. Those who do not sign cannot see his wholeness because they don't understand him. So it goes without saying then that they are not able to...No, but you're still so used to it and you understand that, if they don't sign themselves then they can't understand him and that's how it is, and you're so used to it, that, that's the way it works, it's constantly like that. It's only a few people that sign, if you think in the family, among friends and relatives. It's still quite rare that you bump into people that can sign so that's what's normal, that they, that people don't sign and you have to take the role of an interpreter.

Another parent who had similar experiences does not, however, accept similar attitudes towards her deaf signing child and explained:

(91)

The staff is fixated on the fact that he is deaf, that he cannot hear. I experience it as if they cannot see the whole child, rather they are fixated on the injury. What we do is, when, when the doctor cannot communicate or when doctors or health care personnel complain that they cannot communicate with the boy. When that situation comes when turn it all around and ridicule, or do the opposite so to say and the health care personnel react with oh, well no, you I can't sign and no, see I can't, what am I supposed to do now. So instead of letting the doctor sit and moan over the fact that the child cannot hear we make sure the doctor feels that here I [with emphasis on the word I and referring to the doctor] am the one who is disabled because I cannot now, I can't sign, I, I do not dare use gestures or show facial expression in order to start. We want to

show the health care personnel how it feels when they cannot communicate with him. And then, then when they've said, or well yes, admitted that they can't. Then it's okay, then we start from zero and we can start to discuss the child's overall situation.

2. Receiving early habilitation in Swedish

Opinions on receiving early habilitation in Swedish vary greatly. Some families feel they have been mistreated because of the language, some families commented that they never had any feeling of being treated any different than Finnish-speaking families. One family felt they had received better treatment because they were Swedish-speaking.

(92)

Every time he [the doctor] has apologised for his poor Swedish but I think he speaks perfectly.

An incident frequently mentioned by the parents who felt the language was an issue, is a hearing test administered in the Finnish language. The parents mentioned that even if the child had heard the questions asked, the child probably would not have reacted in any way because of no knowledge of Finnish. This procedure had caused great emotional stress and frustration particularly for the parents but also for some of the children who had taken part in this hearing test.

One source of dissatisfaction with the early intervention is the difficulty of immediately receiving speech therapy in Swedish. One family reported having to wait up to six months for speech therapy to begin, and that, that had been a very difficult time for the entire family.

3. Need for diversified information and emotional support

Not surprisingly, the parents want high-standard, objective information on deafness, deaf children's development and special needs. One mother puts it as following:

(93)

Yes, they should have straightforward, straightforward information. Not just blah, blah, blah it will be okay and this and that but knowledge, facts, a theory, this is how it is.

All parents state that they have – at least to some extent – received information on both oral and manual communication for deaf children, but parents using oral communication, more than parents using manual communication, emphasise the need for diversified information on different methods of communication. A common factor to the seventeen families – once the decision of communication mode is made – is the need to receive support and further guidance. As explained by one mother in quotation (32), there is nothing worse than to hear that you have chosen the wrong approach with your deaf child and that you are thinking more about yourself than about your child.

One mother points out that although the professionals' feeling of insecurity when encountering deaf children is one of the reasons for the dissatisfaction (among the parents) with the early habilitation, a major reason is also the professionals' inability to handle the parents' grief at having a deaf child. Many families turned to other parents of deaf or hearing-impaired children in order to receive the emotional support not provided by the professionals.

Parents using manual communication said that in the beginning they thought they would receive information on what they felt were important issues such as Sign Language and deaf children's development from the Auditory Units. Later on, however, they realised that this is not the case; from the Auditory Units you only receive so-called technical information. Answers to the more important issues you receive from other parents, from family programmes (such as summer camps for deaf children), from adjustment courses and from deaf people. Parents of signing children point out that they have therefore stopped asking for this kind of information during visits to the Centre for hearing, to audiologists, audiological assistants and child health clinics.

(94)

Well, so to speak, in the beginning you perhaps didn't realise this, the part that the hospital gives and stands for, because you perhaps. But now I have a clear line, that's what you get from there and then you get this Sign Language, the important part from DHBS' camps, meetings and the like. But in the beginning one perhaps thought that the doctors would give both and give all this information. But now one knows so you don't even try to demand anything like that either, that the doctors would given any of that.

4. Timing of information

The timing of the information given to the parents was also an issue that they feel is very important. For the majority of the parents, the time right after the diagnosis of the child's hearing loss was a period of shock and grief. Therefore they naturally were not susceptible to all information given to them. The parents view as gradual the process of accepting the fact that their child is deaf and the implications. The information in the early intervention needs to be accommodated to the parents' current stage in this process and, if necessary, the information should be given repeatedly and gradually more in-depth.

(95)

One is in a somewhat, should I say strange phase, in a way you become frozen, because the whole situation is frightening and then you can't take in the information. So you have to receive it in the beginning and you have to, like, be encouraged to do something yourself and find your way out of this frozen condition and get started.

(96)

Mother: Right when we found out that he was deaf there was so much information that it was too much to handle. There was, like, everything.

Father: And then it was about those hearing aids, it was such a fuss about those hearing aids at HYKS. How important it was that he immediately received hearing aids.

Mother: Yes, everything they could help with was given at the same time as the deafness was diagnosed so you thought you were in a different world. In that sense it was completely wasted.

One mother did, however, report a differing opinion: she would have wanted even more information and felt she couldn't get enough. The mother did reflect that this strong need for information was partly due to the fact that she herself had gradually begun to suspect that the child had a hearing loss:

(97)

No, I would have wanted even more...I think so, that since it [a suspicion that child has a hearing-loss] has been there since the beginning. It has developed during a longer period of time and it's not something that all of a sudden came and bang, loads of information. No, in the beginning I lacked information and I absorbed everything I received from all directions.

5. Support family

The parents view the contact with and support of other families with deaf or hearing-impaired children as very important for both the parents and the children.

(98)

We were five families. It was very important, yes...the most information you got from these, from these courses. Because there were other families and then, then well, there you could air all kinds of things. They were of enormous help. It was them, that was the best then, to be in contact with others and to hear.

(99)

Yes, sometimes you really feel like you're way over your head, simply to have a chance to talk to someone who has the same experiences.

However, one significant issue, which the parents miss in the early habilitation, is the possibility of receiving information on other families in similar situations. Because of rules prohibiting disclosure of identity, the personnel at the university hospitals, for example, are not allowed to distribute contact information to other parents. The parents are thus not aware of other families with children who are deaf or hard-of-hearing. This was widely criticised by most parents.

(100)

Yes, but I keep thinking that it's terrible, they are not allowed to give any [phone]numbers, they are not allowed to give. That you can't say that there are others. And although I think that you do tell them that they are allowed to give out, then it's still like, it doesn't work. I think there ought to be a system, even

a, only a note with name and age of the children in the family and that child is deaf, has been deafened or was born deaf or has undergone an operation with that hearing aid, what's it called, cochlear implant. So you have a chance to choose, or that the child uses spoken language and not Sign Language.

In addition, the parents expressed the wish that a support family using the same mode of communication should be appointed as soon as possible. As much of the information on practical and day-to-day issues is learned from other parents, a support family right from the beginning would facilitate the adjustment process for both the child and the parents. Parents of signing children asked for a project (for Finland-Swedish families) similar to "a good future for deaf children" undertaken by The Finnish Association of the Deaf (FI: *Hyvä tulevaisuus kuuroille lapselle*). The aim with this five-year project (which started in 1994) was to enrich the signing environment for small deaf children growing up in hearing families (Takala, Kuusela & Takala, 2000). Through a project of this kind, the hearing parents would come in contact with deaf adults, something the parents mentioned as being very important for them but which unfortunately rarely happens.

6. Habilitation programmes

Parents using oral communication emphasise the need for information on different habilitation programmes (and modes of communication) for deaf children. Only if various methods are presented can the parents select the mode of communication and educational programme that best suits the family. The parents of signing children, on the other hand, are not interested in information on oral communication or technical equipment, but rather in information on deaf children's overall development and special needs. Parents of signing children want the professionals to view the whole child and not as one parent expressed:

(101)

Well, it is, well that she is deaf and that she really should talk.

The professionals often fail to see and comment, for example, on the child's excellent Sign Language development, or the development of motor skills. The parents also need to hear that this child will be just fine. Here, it must be pointed out that this concerns the personnel more at the Auditory Units than at the child clinics, failure to view the child's total development specifically concerns the Auditory Units and not the child clinics. A mother and father describe their experiences as follows:

(102)

Mother: At times you also got a little cross because this [the fact that the child was deaf and did not speak] was so important. They didn't see anything else, how, she was in fact very good at signing but that wasn't important. At times that made us a little irritated.

Father: Yes, exactly. When oneself had, or shall we say it like this, when one had calmed down a little and started to accommodate and accept the situation, we viewed this from a different perspective. Then it was just that one thought that, well perhaps they should think about other things and not only on those hearing aids and all that...She sat there and someone said [in Finnish] “where is mum, where is mum?” and she was supposed to sit there and pretend to hear, press a button.

Many parents expressed the opinion that the professionals focus too much on the child’s hearing aids and speech development without commenting on his good signing skills and development in other areas. Even so, the families did not report any negative comments from the professionals concerning the families’ choice of language for their deaf child.

(103)

At the child clinic they have only been positive about me using Sign Language. Yes, that’s what they have been. At the child clinic they are only happy when you sign, that you at least have a communication.

(104)

No, he [the doctor] hasn’t been negative in any way, he hasn’t been that, but like neutral and asks how it goes and like that. And at one time he asked if we had thought about a cochlear implant and then I said no and then he didn’t say any more about that.

7. Home guidance counsellor

In addition, parents of signing children want more information on the Finnish Association of the Deaf, parental organisations for deaf children, parent-child programmes etc. All seventeen parents mentioned the home guidance counsellor as being an important person since this person usually is the first contact with Sign Language and the deaf world. However, the impression of the families who have chosen manual communication is that the home guidance counsellor has much more to offer families with hearing-impaired children and families who use oral communication than parents of deaf signing children. Parents of deaf signing children feel that the home guidance counsellor needs to be more proficient in Deaf culture and Sign Language communication in order to be able to give signing families the support they desperately need. In order to get this kind of information and support some parents said that a deaf home guidance counsellor would be the best alternative. A deaf home guidance counsellor would act as a linguistic role model for both the deaf child and the hearing parents.

For many families with children who have mild to moderate hearing losses the home guidance counsellor did play an important role, both when the hearing loss was first diagnosed and in the child’s different developmental stages, typically prior to the transition to a new educational setting.

(105)

Mother: The home guidance counsellor has also been there and informed, as early as last spring before he started school. He has started this autumn. She was there in May, when he was there visiting one day. Then she was also there and informed the whole class and everyone could try on the [hearing]aids.

Father: She came to the nursery as well and gave information and those friends are in the same class now so it has worked out fine.

[- - -]

Researcher: What was the teacher's attitude like?

Father: Yes, we were a little sceptical with that...we figured there may be problems with that but we owe very much to the home guidance counsellor, she informed us in a very good way.

The parents of a child with a mild hearing loss said that the home guidance counsellor had been of much help when their child experienced a difficult time at school and with her own identity and plans for the future.

(106)

Mother: How many lessons of learning support she would receive? What are her future prospects? She has thought much about that.

Father: Yes, a small identity crisis. But then, then we put, then, she had on her own responsibility and probably a very good conversation that we don't know anything about with, with the home guidance counsellor. The two of them went for hamburgers and then she had the chance to talk through everything with her.

Families who have received part of the early habilitation in other countries (mainly in connection with the child receiving a cochlear implant) also mention the benefit of the audiologist, physician, technicians and speech therapist working in a team.

8. Sign Language instruction and adjustment courses

The parents were content with the Sign Language instruction in the home. The only negative comment regarding this service was that the instruction ended too soon. Another service the families were very satisfied with is the adjustment courses offered to all families with children who are deaf or hearing-impaired. The courses clarified many things concerning deafness, deaf children and communication. In addition, during the courses the parents were free to discuss challenges and experiences with parents in similar situations, and also, the children were given the chance to interact with other deaf or hearing-impaired children. The courses are often deemed important in that they clarify – for the parents – what they need help with in the future. The parents would gladly participate in these types of courses more often but, at the same time, realise that it is not realistic to ask for more frequent adjustment courses in Swedish.

(107)

It took nearly a year after we received the diagnosis before we could go to the Light House⁵³. And that was almost too long because, I feel, there at the Light House we found out the most, we were there for ten days. It was the best we have been to. I would have appreciated getting that as soon as possible because there you could talk about the feelings you had inside. There they understood you. You talked about how it is and how it has been... Surely, given the chance one would want to go more often but it's okay. You have to face the facts that there are so few of these children in the Swedish parts of Finland. So you cannot expect too much ... It is much easier now since we have been at the Light House.

9. The parents' own role

The active role of the parents themselves in the early habilitation was frequently mentioned during the interviews. Regarding this particular issue, there was no variation among parents using different methods of communication. The parents have come to realise that they need to be active in order to gather necessary information and in order to come in contact with other parents of deaf or hearing-impaired children. In previous sections the parents' role particularly in relation to the child's schooling has been outlined.

Here some other issues relating to the role of the parents are presented. Demanding better service or more information is difficult for many parents. The situation is even more difficult for parents who themselves suspect that their child is hearing-impaired but are not initially taken seriously. In the following quotation this issue is raised as well as the need for early communication and early habilitation given by the experts in the field:

(108)

Father: We noticed these symptoms, symptoms of a hearing loss quite early. So we had begun observing him fairly early in order to find out if his hearing really is impaired and what we can do. But what I want to say here at once while I still remember. The most important thing is, here in the beginning the most important thing is to quickly, quickly, that you quickly get started with the early habilitation. One year sounds like a short time but in the beginning it is a long time...

Mother: Well, we thought, when he was about a year old we discovered that he might be hearing-impaired. But it wasn't until he was over two years old that they did the [hearing]test.

Father: And there, there.

Mother: And we had suspected it for so long but it was only then they started taking us seriously, that now we have to go and take the test.

⁵³ The centre in Helsinki owned by the Finnish Association of the Deaf, Finnish Federation of the Hard-of-hearing and Service Foundation for the Deaf.

Researcher: Had you asked for the test to be done earlier, as soon as you suspected?

Mother and Father: Yes, yes (simultaneously).

Mother: Yes, but then summer came so we had to wait.

Researcher: Were you not taken seriously?

Father: No, and then also at, well at these different, what's it called where you do the first check. One should be able to skip that one fast and at, what is it called, at the health care centres one ought to be able to quickly as fast as possible skip that one. Because they can, they don't know anything about this, one ought to come to the experts right away. To the highest level, HYKS, to HYKS right away.

Mother: We went to the city of xx (a city near the family's hometown) for a first.

Father: Yes, but they cannot either. In my opinion one ought to come to HYKS straight away. We then went to the xx-city and she was just busy with her bells behind the ears.

Mother: First we went to one check.

Father: And she knew nothing about what she was doing.

Mother: Then they sent us home so we had to wait AGAIN before we could go for the check and only then was it confirmed.

Father: So one ought to get to HYKS straight away, where the highest expertise is so one gets started either with Sign Language or anything. But this first communication must get started fast, Because otherwise the problem is that one cannot communicate with a child who doesn't either have. The child cannot hear, it doesn't know Sign Language. Then conflicts arise. And that could be avoided, this one year of quarrel if you would get started more quickly....

Researcher: So it was you parents, you yourselves that suspected this. Although you requested it not very much happened?

Mother and Father: No (simultaneously).

Father: So there one could of course, if one like that, afterwards, if one had known one would have exerted more pressure and demanded it.

Mother: Yes.

Father: But one didn't either know and one thought that it will come.

Mother: Yes, and usually one trusts these so-called authorities, that they do know and perhaps it is difficult to process everything that is happening.

As was mentioned earlier the parents expressed the opinion that because of the initial shock of learning that the child is deaf all relevant information should not be offered at one single occasion. The parents want the information to come repeatedly and, if possible, from more than one source. Even so, the entire group of parents who participated in the interviews emphasised the need for their own active role in finding information and being involved in school issues. The need to be engaged and to find more information on a variety of issues such as Sign Language classes, parental organisations, cochlear implants, auditory-verbal therapy is, according to the parents, at times very demanding and time-consuming. According to one father of a child with a cochlear implant the lack of specific infor-

mation for Swedish-speaking parents and a straightforward educational path forced them to look for additional information and other solutions:

(109)

I do believe that, well I think that if there were a well-functioning infrastructure then you surely would choose, if you had a true choice, well, in Finland-Swedish. That's the reason so many decide to move to Sweden, for that specific reason [that there is no Finland-Swedish Deaf school]. Your choice stands between moving to Sweden or to mainstream... if there had been, well, so to say, a strong tube saying that now you go in here and then we move on, like this you know. Then who says we wouldn't have chosen that. That is particularly the reason we did these long break outs. If there had been...if there had been a, well, a stop in front of one of the doors at HYKS, and if there had been a sign that says Swedish-speaking parents of deaf children who enter this door will have an infrastructure that takes it [the habilitation] in a certain direction. If that had been the case then I think it would have been closer at hand to go that way. But now it wasn't there and that's why we started looking. And then we found the implant. We had to look in order to find it. The infrastructure wasn't there either.

The parents of deaf signing children are not always satisfied with the treatment received during the early habilitation. In the parents' opinion, the information and habilitation resources undoubtedly concentrate more on the medical view of deafness, as opposed to the socio-cultural view. In connection to this topic the parents of a deaf child exclaimed:

(110)

Father: And then, there is one word here that I DETEST, do you get this on tape now, one word that I detest and that is, do you know which one, it is

Mother: Is it handicapped?

Father: RESIDUAL HEARING

Mother: (simultaneously) Residual hearing.

Father: No, but what the hell, if you don't hear you don't hear. What do you do with residual hearing if you don't hear speech but a nuclear bomb. Yes, I can't hear speech but a nuclear bomb, but really, what is that?

Throughout this chapter it has frequently been pointed out that regardless of communication method the deaf or hearing-impaired child's schooling demands a major input and involvement from the parents. In addition, parents wanting more specific information on different aspects of deafness or hearing-impairments all emphasised that the only way to gather information was to be active and to seek it on their own. One mother felt that she had to be very committed to her child's early habilitation in order to give her child the best possible start in life, a start that will lead to an independent life for both child and mother:

(111)

Researcher: So, as a parent, do feel that you have to be very active yourself?

Mother: UNBELIEVABLY.

Researcher: Do you feel that as a parent maybe you shouldn't need to be that?

Mother: Yes, well in this case, I thought that, that. At least for me I think that really it is at any rate obvious that she should get the best start possible in life and in order to someday become independent, that, that, maybe it is, hm, (pause) in the end, maybe I have thought mostly about myself when I have done this for her. Selfishly that I want to manage, that she'll manage and that I will be, not be needed any longer, that she'll receive as much as possible. And well on time. Fast.

In Section 4.4 the significance of a strong relationship between the parents for coping with the demands of having a deaf or hearing-impaired child was discussed. In connection with the parents' own role in the habilitation this was also occasionally mentioned during the interviews, as one mother commented:

(112)

Yes, and then it's very much this that it's not only the mother, but the father who wholeheartedly supports this and joins in and that everything works within the family. I think it's very much this, when we, I had so much support, for example, Dad came along to every single course, every visit to the health clinic, every single one. So it wasn't all left to me, if I had struggled on my own I don't think I would have managed, had the strength, but we were so together, and no one ever blamed the other, that it's your fault that the kid is hearing-impaired. We worked for it, we made the best out of it, every time when we went to HYKS in the autumn, in the spring and to Folkhälsan, all of these when we drove to Helsinki, then, when we had been there the boy knew that now we're going to McDonalds. We took it like this, we'll make it a positive thing so it's just not that now we'll go there... I don't think I would have managed it on my own, least of all with a father who would have pushed it away from himself. Then I wouldn't have coped, have had the strength like this, now I almost took it as my mission in life, I left my job and stayed at home, economically also unbelievable, a kid with a hearing loss that severe that he cannot be left to his own devices, you have to take part in the homework, you have to be there, it's extra hard with foreign languages.

Lastly, during the interviews several parents mentioned more general attitudes towards hearing-impairments, deafness and the use of Sign Language. The following quotation from the father of a child with a mild hearing loss describes exactly what many parents feel.

(113)

Yes it concerns the entire view within the educational system on, on children who are different, or that is, on children with a disability. Now I don't know the situation with other types of disabilities and so, but, but it has been, partic-

ularly at secondary school level it has been miserable. And, so, it is only a result of this view... you shouldn't need to demand it [learning support], it should be taken for granted. Shall we say like this, I think it goes without saying that different children should have equal opportunities. But that's not the case today, instead it's that different children, different children need to have, have like parents that are differently active and have, have a hell of luck with his or her school, that, that you choose the right school and the right district perhaps and so.

8.5 Reliability and validity

The relationship between reliability and validity can be unclear but in essence reliability attempts to answer concerns about the consistency of the collected data and validity focuses on the truth and accuracy of the interpretations of the collected data. The credibility of a qualitative inquiry is especially dependent on the credibility of the researcher because the researcher is the instrument of the data collection and the centre of the analytic process. A credible qualitative study, therefore, needs to address the techniques and methods used to ensure the integrity, validity and accuracy of the findings; the researcher's qualifications, experience, and perspective as well as the paradigm orientation and assumptions influencing the study (Patton, 1990).

Reliability

The specific techniques used for the data-collection are central when discussing both reliability and validity in qualitative studies. According to Peräkylä (1997) research based on tapes and transcripts provides the researcher with accuracy not possible in, for example, field notes. Of course, reliability is not guaranteed merely by having audiorecorded and transcribed an interview. One principal criticism of analyses of interviews is that the reader does not have access to the complete original material. The reader therefore has to rely on the researcher's selection and interpretation of the interview texts (Kvale, 1997). Kvale describes two possible methods to control the analysis of interviews: multiple analysts or a description of the course of action during the analysis. The latter option is used in this study. The steps of the analysis process are described in Section 7.4. In addition, the reader can him- or herself get a picture and feeling of the interviews through the numerous quotations from the parental interviews included in the previous chapter.⁵⁴ For reasons of confidentiality entire interviews cannot be included in this report.

Another crucial aspect regarding the reliability of a qualitative study is the communication between the researcher and the informants (Peräkylä, 1997; Ruth, 1991). Is there a common idea of the world allowing for communication, and if not, can the researcher using his or her intuition, self-examination and empathy, approach an unfamiliar world conception and yet allow for a dialogue about the

⁵⁴ A total of 113 quotations from the parental interviews are included in Chapter 8.

phenomenon to be studied (Eneroth, 1984)? At this point, the issue of the researcher's preconception enters. Even though I am not a member of the Deaf community I am familiar with the field of deafness and deaf education and have thus developed a preconception of both the domains of language and deafness, and that of education and deafness. Besides, it is worth pointing out that my previous encounters with these fields are quite diversified. Thus, it is fair to state that the prerequisites for a fruitful dialogue were present in the case of this study.

Through an increased knowledge of the different perspectives on deafness and by entering the parents' lifeworlds the objective has been to deepen the understanding of the communicational and educational decision processes among hearing parents of deaf children. Although the socio-cultural perspective on deafness has dominated the approach of this study, I have, specifically in order to understand the issue of oral communication for deaf children, participated in seminars on cochlear implants and auditory-verbal therapy for deaf children. These encounters have been extremely important in understanding the complexity regarding the habilitation of deaf children. Above all they have been crucial in helping me to understand the effect of information given to parents of deaf or hearing-impaired children and subsequently to understand and interpret parents' reactions and conceptions of the early intervention.

An open communication and a feeling of a common understanding between the informants and researcher (see Section 7.4) marked the interviews. The aim was specifically to enter the interview and treat the informants with an open mind and, naturally, not to make any evaluations or attempts to make the interview follow a path serving the researcher's own conception of the phenomenon. These are features which are essential in order to achieve a new structure or deeper understanding of the phenomenon.

Although the focus of the empirical part is placed on the interviews with the parents, the other sources of information – the questionnaire, the interviews with the experts and the visits to the deaf schools – have provided additional and informative data. These sources of information have strengthened the reliability of this study. The interviews with the experts and the visits to the deaf schools have allowed for a critical scrutiny and a deeper understanding of the facts put forward in the literature on deafness and deaf education, and of the accounts provided by the parents in the interviews.

The questionnaire was pilot-tested, and a few minor changes were done before administering it to the group of parents participating in this study. The findings from the interviews and questionnaire were cross-checked and compared for consistency, a procedure called triangulation of sources⁵⁵ (Patton, 1990). The results of the questionnaire are supported by the interviews; in no case is there a discrepancy between the parents' answers in the questionnaire and their portrayals in the interviews.

⁵⁵ Patton (1990) describes four types of triangulation: (1) methods triangulation, (2) triangulation of sources, (3) analyst triangulation and (4) theory/perspective triangulation.

Validity

Throughout the entire research process the researcher constantly has to keep an open and critical mind towards both the field of research and the methods (Kvale, 1997). In this sense validity is not a control undertaken in the final stages of the research process, rather validity refers to the continuous control of the trustworthiness, reliability, inclusiveness and reasonableness of the findings of the study (Kvale, 1997). Validity also includes the notion that the subjects' reflections, comments and opinions are correctly and accurately understood and reported. The issue of subjectivity of the researcher in qualitative research is frequently mentioned (Patton, 1990). It is therefore of great importance for the researcher to examine critically all stages of the analysis and interpretation of the empirical data. Kvale (1997) points out that in hermeneutical research the questions posed to the texts are very important. As mentioned several times before, my preconceptions and previous experience of the phenomenon at hand have influenced the approach for this study. In the analysis much effort has been placed on critically examining and questioning every step when approaching the interview texts and consequently classifying and interpreting the results. Frequently I examined my own conception of deafness, the nature of communication and language, parenting and social interaction and education in order to understand the parents' view and conceptions of the phenomenon studied here. Given the fundamentally differing views on deafness and language for deaf children, it was inevitable that I encountered this discussion in the interviews with the parents. This issue gave rise to frequent debates with myself, specifically concerning my ethical and moral responsibility towards the families. All families openly discussed the habilitation and choice of language and educational programme for their deaf child; analysing and classifying their choices was not an easy task.⁵⁶

Kvale (1997) further points out that validity is not only a question of research method as also theoretical inquiries concerning the nature of the studied phenomenon arise. In order to determine whether a method truly reflects the problems that the study attempts to examine the researcher needs a theoretical assumption of the phenomenon at hand. In other words, the findings from a study are valid if the theoretical explanations match the data; that is, to verify interpretations is in fact largely to create a theory (Kvale, 1997). Based on the theoretical framework of this work an understanding of the challenges facing hearing parents with deaf or hearing-impaired children certainly emerges. With this theoretical assumption of hearing parents' communicative and educational reasoning as a point of departure the results obtained in this study must be seen as reasonable, credible and valid but also new and thus contributing to a deeper understanding of the phenomenon in question. The reason is partly that some issues are marked and amplified in a minority population: in some areas the findings from this particular population of parents point to an even more complex situation than accounted for in the theoretical part.

⁵⁶ On a few occasions during the interviews a parent requested that something he or she was about to tell should not be included in the study and in all these cases I respected the parent's wish.

The issue of validity in qualitative studies is frequently called in question (Patton, 1990). Nevertheless, according to Kvale the difficulties relating to validity in qualitative studies need not point to an inferior position of this type of research, instead it may well indicate its excellent ability to portray and question the complex reality and social constructions of life (Kvale, 1997). Moreover, it is not beneficial for the research process to view validity as a very difficult and mystified concept; that may be counterproductive, as Kvale (1997) writes. The main task for the researcher should instead be to let the data and findings speak for themselves, however while constantly bearing in mind that the researcher him/herself is the main tool and that the abilities of the researcher reflect the validity of the research (Kvale, 1997).

Generalisations

A main difference between qualitative and quantitative research is the possibility of applying the findings to a broader population. Generalisations are considered one of the strengths of quantitative studies, and are traditionally not recommended in qualitative studies. Yet, generalisation in a qualitative study is to a certain degree appropriate, though the studied phenomenon needs to be theoretically deeply rooted (Peräkylä, 1997; Ruth, 1991). The results in all qualitative studies cannot consistently be generalised as such; in some cases the results should be viewed as descriptions of how individuals *can react* or what they *may do* under certain conditions, and not as rigorous descriptions of what they actually do (Peräkylä, 1997, 216). A richly described qualitative empirical material may also well reveal a deeper and diversified picture of the phenomenon at hand and therefore allow for generalisations in addition to the possibility of understanding or interpreting the world in a new fashion.

This study focuses on the conceptions and experiences of the early intervention for Finland-Swedish deaf children. However, it seems reasonable to believe that the conceptions and experiences of the parents may partly be applied in general to other populations of hearing parents with deaf or hearing-impaired children. Assumedly also Finnish-speaking parents of deaf children who select Sign Language as the main mode of communication are dissatisfied with the experts' medical approach to deafness. Furthermore, assumedly also those Finnish-speaking parents selecting oral communication and cochlear implants are, to a certain extent, dissatisfied with the information and treatment received. Above all, one may assume that many Finnish-speaking parents miss the emotional support regarding the early intervention of the child, and also encouragement concerning the child's overall development and everyday issues. On the other hand, the questions concerning educational opportunities are very specific to the population of Finland-Swedish parents. Certainly, concerns such as long school journeys, the quality of deaf education and the lack of personal school assistants for mainstreamed children are present among other groups of hearing parents with deaf or hearing-impaired children. Nevertheless, as has frequently been mentioned, the situation for deaf children from the Finland-Swedish minority is one step more complicated than for Finnish deaf pupils. Therefore, the findings of research problem (3) should not be generalised to cover the experiences of all hearing parents of deaf or hearing-impaired children in Finland.

Finally, one may ask why a study on the communication, education and habilitation of deaf and hearing-impaired children does not include the voices of deaf people themselves. Examining any aspect of deafness in this fashion may be hazardous, and not benefit Deaf people in any way, something that has often been undertaken throughout history. At this point it must be clarified that although no structured interviews with Deaf individuals have been conducted, the aim has been to bear the educational and linguistic rights of deaf people in mind. The theoretical part includes research conducted by both deaf and hearing-impaired individuals. Also, as mentioned earlier, my multiple encounters with deaf education have shaped my conceptual framework and my understanding of the problems and challenges of deaf education and the early habilitation of deaf children. However, the main reason for not having included deaf people in the empirical part is that this study examines the educational choices made by hearing parents of deaf or hearing-impaired children and in particular Finland-Swedish parents because there is no straightforward educational path for their children. The main target group for this study has thus been hearing parents of deaf or hard-of-hearing children.

9 Discussion

Children of a language minority often have more limited educational options than children belonging to a language majority. For children belonging to a minority within a minority the situation can be even more troublesome and this is the case for deaf or (severely) hearing-impaired children from the Swedish minority in Finland. The educational situation for these children cannot be considered satisfactory; there is no Finland-Swedish deaf school and there are no educational programmes specifically aimed for hearing-impaired children. Hence there is no straightforward answer to where and how to educate deaf children from the Finland-Swedish minority, and consequently at a time when the parents themselves still are learning about deafness or hearing-impairments they are forced to make difficult choices concerning their child's linguistic, cultural and educational path.

The aim of this study was to elucidate and deepen the understanding of the communicative and educational choices among hearing parents of deaf or hearing-impaired children. The theoretical framework is grounded in the phenomenological and hermeneutical traditions with the concept of lifeworld as a point of departure. This framework allowed me to enter the lifeworlds of the parents and gain insight into the complexity of educational choices for deaf and hearing-impaired children growing up in a bilingual society that does not offer them a straightforward option of schooling.

The current situation

The fact that the communication mode, the linguistic input and the type of educational programme show great variation among a population of deaf individuals is widely recognised, and is also supported by this study. A study of hearing Finland-Swedish families clearly demonstrates the many possible variations relating to linguistic and educational background within a group of deaf and hearing-impaired children. The situation for many hearing families with deaf children is (initially) difficult and growing up deaf or hearing-impaired in a linguistic minority adds yet another dimension to the challenge of receiving a good education. The population chosen for this study shows the complex circumstances of parenting a deaf child, and in particular parenting a Deaf signing child from a linguistic minority.

In order to receive education through the medium of Sign, a Finland-Swedish child has to attend a Finnish deaf school or move to a deaf school in Sweden. Both these alternatives can be considered fairly radical in a country guaranteeing a free compulsory and equal nine-year basic education to all children living in Finland.

One may think a Finnish deaf school is not such a remarkable solution for a Finland-Swedish Deaf signing child since the Finland-Swedish and Finnish signed languages are so closely related. First, however, is the fact that the teaching material is in Finnish, which is an additional language for most Finland-Swedish children. Secondly, choosing a Finnish school means missing out on the Swedish Language and the Finland-Swedish culture. Choosing a Finnish deaf school sometimes leads to one parent changing his or her home language to Finnish in order to facilitate the child's language development, that is, not only to Sign Language,

which naturally is done by all parents of deaf signing children, but to Finnish Sign Language accompanied by Finnish and not Swedish articulation.

Moving to a deaf school in Sweden, on the other hand, guarantees a good education in Swedish Sign Language with teaching material in Swedish. Even though this is a good alternative for the deaf or hearing-impaired child it obviously has far-reaching implications for the entire family life, affecting, for example, hearing siblings, parents' occupation and financial burden of moving to another country. The difficult rearrangements relating to employment, schooling for hearing siblings and place of residence for families with deaf children have been documented in previous studies and is also supported by the findings in this particular group of parents.

Choosing a method of communication

Not surprisingly, the interviews with hearing parents of deaf or hearing-impaired children showed that regardless of selection of communication method, the parents acted in what they considered to be the best interest of their child. Given that the parents rarely had any experience of deafness and that the early habilitation given to families is more or less identical, the interesting question is how the parents reason when choosing communication method and educational placement. Parents who want their child to be signing do so in order for the child to grow up in an environment that allows for fully accessible linguistic, cognitive and psychosocial interactions. They want the child to participate according to its own communication prerequisite, to communicate freely with parents and siblings, and to interact with friends on equal terms, and also to attend a school for the Deaf where the instruction (in Sign Language) is totally accessible. These parents emphasised internal factors such as the significance of Sign Language for a deaf child's personality and social development.

Parents using spoken Swedish and/or Finnish have chosen this means of communication with the same goal in mind, that is, interaction and communication with family and peers as well as access to education. However, these parents seem to focus more on external factors such as the availability of schools and the fact that the rest of the family is hearing. According to these parents, a child who is deaf but has learned to communicate in a spoken language grows up in an environment allowing for a normal cognitive and psychosocial development. The parents are aware of the extra training needed for the child to learn spoken language skills but the parents hope that the hard work and speech training early in the child's life is beneficial. They believe spoken language skills will enable the child to participate fully in family discussions and to interact freely with hearing friends and relatives as well as have equal educational and professional opportunities as hearing individuals. Spoken language skills enable the child to attend a school for the normally hearing which the parents view as highly desirable. One must, however, bear in mind that for children with a mild to moderate hearing loss spoken language communication is the most likely method of communication. Parents of these children are therefore not faced with as many and as complex decisions relating specifically to choice of communication method and education as parents of deaf or severely hearing-impaired children.

Educational opportunities for deaf/hearing-impaired children

The questionnaire and the in-depth interviews with parents of deaf children clearly demonstrate the dissatisfaction with the lack of educational opportunities for Finland-Swedish deaf or hearing-impaired children. The main educational problems among the families using signed communication are:

1. No Finland-Swedish deaf school.
2. Small number of Finland-Swedish deaf children.
3. Long school journeys.
4. Maintaining the Swedish language and the Swedish deaf and hearing cultures.
5. Moving to Sweden not possible.
6. Maintaining the Finnish language and the Finnish deaf and hearing cultures.

Several factors influenced the parents' choice of school for their deaf signing child, the main factors being:

1. Instruction in Sign Language and the social environment in a deaf school.
2. Inclusion unsuccessful.
3. The wish to maintain the Swedish language and the Finland-Swedish culture.
4. No possibility of moving to Sweden.

For the families using oral communication, the main issues of concern are the lack of personal school assistants and the lack of knowledge of deafness and hearing-impairment among teachers and school administrators. The factors that influenced the choice of school for these families are:

1. The possibility of attending a school near the home
2. The ability to participate in activities with hearing children
3. Social isolation and limited educational opportunities for signing children

Cultural identity

One main finding of this study was the strong sense of being Finland-Swedish and consequently the wish to maintain the Swedish language and culture. Every single parent included in this study at some point during the interview commented that "because we are Swedish-speaking" and emphasised their Finland-Swedish identity. Although practical matters were also very significant in the educational-decision making process, this strong cultural identity influenced the choice of school for their child. For some parents the wish to live in a Swedish environment and the hopes of their child receiving a good education (in Sign Language) while still learning Swedish is so strong that they see no other solution but to move to Sweden. Here we can recall the difficult solution of the family with one parent living and working in Finland while the deaf child and other parent live in Sweden.

Parents who had moved to Sweden responded that although not being able to remain in the home country this solution at least allows them to use Swedish in their daily lives while providing a high standard of schooling in Sign Language for their child.

Parents who had remained in Finland and chosen a Finnish Deaf school also had a strong sense of being Finland-Swedish but, mostly due to family matters, concluded that moving to Sweden was not feasible or desirable and that education in a Finnish deaf school was therefore the best alternative. While this educational alternative does not allow the child to have a strong connection to the Swedish Language the family can nevertheless live in Finland and naturally still be part of the Finland-Swedish community. Another advantage is that the child will learn Finnish, which is necessary for further education and employment in Finland.

Parents of children with mild to moderate hearing losses also talked about their Finland-Swedish identity but as their children can attend Finland-Swedish schools for normally hearing children the educational choice was fairly straightforward. Also parents of mainstreamed deaf or severely hearing-impaired children emphasised the Finland-Swedish identity and particularly the strong desire for their child to be able to interact with Swedish-speaking peers in the neighbourhood and thus to be part of that community. Parents of this group of children did, however, mention that if there were a Finland-Swedish Deaf school they might well have chosen that educational path.

Implications for future education

The findings of this study clearly indicate that the current situation for Finland-Swedish deaf and hearing-impaired children is not satisfactory. Action should be taken to guarantee Finland-Swedish deaf and hearing-impaired children adequate education in their home country and to this end the results of this study are important. The challenges are, however, numerous, mainly due to the small number of Finland-Swedish deaf children and to the non-existence of certified deaf teachers fluent in both Sign Language and Swedish. The resources of deaf education in Finland must therefore be concentrated; groups of Swedish deaf pupils could be included in the Finnish deaf schools. This would provide the pupils with a larger signing environment and the possibility of having shared instruction in many subjects.

However, exactly like parents of other linguistic or cultural groups Finland-Swedish parents of deaf or hearing-impaired children want their children to be educated in a context supporting the family's linguistic and cultural background. The added element here is of course that the parents want this to take place in a deaf school which strongly supports the deaf child's primary language and Deaf identity. So, in order for a Finnish Deaf school to be a reasonable and more approachable alternative for Finland-Swedish families there needs to be an element of Finland-Swedish culture and tradition as well as a chance for second language instruction in Swedish in the school.

Placing their child in a Finnish deaf school or in a Swedish deaf school (in Sweden) does not indicate that the parents are giving up on the Finland-Swedish culture as a part of their child's cultural identity. The parents simply feel that they

do not have any other alternatives and therefore have to compromise and to a certain extent leave out their own culture and language while allowing their child to receive accessible instruction and to participate fully in the Deaf community. However, having had the choice the parents would all have chosen a Finland-Swedish Deaf school. Nevertheless, it must be brought to our attention that a Swedish deaf school in Finland would not solve all problems with education for Finland-Swedish deaf or hearing-impaired children. Many children would still have a long school journey, which is also reported as being one major problem with deaf education in both Finland and other countries.

Parents of both deaf and hearing-impaired children have been included in this study. As the results presented in Chapter eight reveal, the two categories of parents partly differ in their choices of communication method and education. One major conclusion of this study is thus that hearing-impaired and deaf children should not be considered one group with similar educational and communicative needs. However, as the findings of this study indicate, the educational needs partly relate to the child's primary method of communication and not merely on the child's degree of hearing loss. That is, whether deaf or hearing-impaired, signing Finland-Swedish children encounter specific educational problems and deaf and hearing-impaired children using spoken language communication encounter other difficulties.

Experiences of the early habilitation

Turning now to the parents' experiences of the early habilitation, the results of this study indicate that the information received in the early intervention do not significantly influence the parents' selection of language for their deaf or hearing-impaired child. Signing parents do not view the information on and support for choosing Sign Language as sufficient. The selection of a particular mode of communication is more dependent on the parents' cultural identity, personal experiences and conceptions of communication and deafness as well as on their basic outlook concerning children and importantly also of the degree of the child's hearing loss. Nevertheless, parents of signing children agree that someone who has not yet come to terms with their child's deafness is certainly influenced by information suggesting that deaf children can learn to hear and speak.

The parents' conceptions and experiences of the early habilitation support services provided are not all positive. Regardless of the child's hearing status or the family's method of communication, the parents report negative experiences and a lack of expert knowledge on deafness, hearing-impairment, cochlear implants, Sign Language and deaf children's needs and abilities. Parents of children with a mild hearing-loss are, however, fairly content with the services and information received. Parents of signing children strongly point out the near total lack of information on Sign Language and the benefits of manual communication for children who are deaf, as well as the shortage of information on other aspects of deafness such as Deaf culture and deaf education. These parents are not happy with the more medical view on deafness present in the early habilitation. They demand a more positive attitude towards Sign Language and a total acceptance of deafness among the home guidance counsellors, who, the parents feel, are more proficient

in providing services for families with children who are hearing-impaired. Parents of signing children report receiving the essential and much needed emotional support from other parents with deaf children. In addition they have been forced to seek information and advice elsewhere themselves as the information provided by the home guidance counsellors and others involved in the habilitation process has not always been sufficient.

Given the results previously accounted for, one may expect the parents who have chosen spoken language communication to be satisfied with the services provided. This is, however, not always the case. On the other hand it must at this point be recollected that parents of children with a mild hearing loss are content with the early intervention provided while the parents of deaf or severely hearing-impaired children wish for more expert and topical knowledge on deafness, hearing-impairments and cochlear implants. As a result of this dissatisfaction a few families have turned to other countries in order to receive the early habilitation. In particular, this was done to receive more information on oral communication with deaf children, and for the child to receive both the cochlear implant and post-surgical habilitation abroad. These parents also miss the necessary emotional support and have, by analogy with parents of signing children, to a high degree turned to other parents of hearing-impaired children for encouragement and emotional support. In addition, the parents have themselves gathered information on different aspects of deafness and hearing-impairment as well as on educational opportunities.

Parents (from both the manual and oral communication groups) feel that the law prohibiting people involved in the early habilitation from revealing the names of other families with deaf or hearing-impaired children is not beneficial. On the contrary, the parents desperately want to come in contact with other families in similar situations. Once contact has been established, the parents are very active, organising meetings, seminars, summer-camps and also founding new parental organisations with the aim of providing support and information for “new” parents and for schools with integrated deaf or hearing-impaired pupils.

Given that the majority of deaf children are born into hearing families with no previous encounters with the language or the culture of the Deaf community, early habilitation is very important. Similar to other studies showing the significance of emotional support and multifaceted information the parents in this study report that the support, information and interaction with other parents of deaf or hearing-impaired children are indispensable for the coping process. Another important finding of this study is that the parents need more emotional support than they presently receive. The results of this study suggest that the quality of the early habilitation particularly for families with deaf or severely hearing-impaired children in Finland needs to be modified, improved and more individualised. Moreover, the parents want support families early on or persons encouraging and supporting the kinds of decisions made concerning everyday life with a deaf child. Parents of signing children also want more contact with deaf adults, for the above mentioned reasons. In addition, the parents want deaf people to function as linguistic role models both for the parents themselves and for their children.

Therefore, professionals highly competent in various aspects of deafness and signed communication should be involved and provide information to the fami-

lies. Different methods of habilitation and alternative communication approaches can be included in the early intervention, but the habilitation should under no circumstances exclude the socio-cultural perspective of deafness and the notion of bilingualism in deaf people. The critical period for language acquisition concerns deaf children as well. A strong body of research indicates that Sign Language does not form an obstacle to the acquisition of reading and writing skills or of speech; on the contrary Sign Language provides the path to bilingualism. In addition, the review of the literature, the expert interviews and the visits to schools for deaf children, point to the significance and need of Sign Language for deaf children's cognitive and psychosocial development. In fact, in Sweden the discussion is not whether deaf children should receive Sign Language or not, rather the resources are directed at improving and developing the services and education for deaf individuals. As the benefits from early exposure to a signed language are well documented, the habilitation needs to focus more on issues encouraging the use of Sign Language in families with deaf children. Again, given the complexity and variety among the population of deaf children (and their families) the need to individualise the early habilitation is evident.

Sign Language and bilingualism

A variety of studies have shown that signed languages are natural languages, that native signers code and store information in Sign, and that deaf children exposed to Sign Language early in life acquire it much like hearing children acquire their native language. Even so, being deaf means that phonetic cues are not readily available when learning to read and therefore deaf children often do not learn to read and write as easily as most hearing children. Deaf signing children's tendency to perform poorly in these areas may have encouraged the oralist movement, and the belief that Sign inhibits the acquisition of a spoken language.

The new movement in deaf education, bilingual education, has, especially in Sweden and Denmark, proven very successful in promoting deaf children's literacy skills and decreasing the knowledge gap traditionally present between deaf and hearing pupils. Furthermore, the review of the literature as well as the expert interviews clearly indicates that oral educational programmes for deaf children have not produced academically high-performing pupils anymore than have manual educational programmes. Moreover, oral training programmes have not considered the child's psychosocial or emotional development. For example, findings demonstrating the poor quality of play for hearing-impaired kindergarten children in an oral programme, compared to children in a programme using total communication, imply that speech alone does not provide deaf children with the necessary tool required for an uninhibited social interaction and development. A large number of studies on cognitive, linguistic, and psychosocial functioning in deaf children as well as the expert interviews conducted for this study suggest that the primary method for providing a rich and unconstrained development is a communication method on the terms of the deaf child. That is, a mode of communication that does not require constant training or total concentration from the child. The only mode of communication that can provide this is a signed language. We must acknowledge signed languages as languages with the same qualifications and possibilities

as spoken languages and with the advantage that a natural Sign Language meets the needs of and provides the resources for people who cannot hear. Despite extensive research proving this, the issues of language and education for deaf children seem to be issues of never-ending controversy.

As previously mentioned the population of deaf individuals is a very heterogeneous group regarding, for example, linguistic and cultural background. Although the issue of bilingualism is essential in the discussion of habilitation, language and education of the deaf child and may initially seem similar to bilingualism or the minority-majority polemic among hearing linguistic and cultural minorities, the discussions follow a somewhat different path. The Deaf minority encounters many challenges typical for linguistic or cultural minorities but additionally there are features and dimensions not present in spoken language minorities. The most salient feature is perhaps the fact that the common definitions of bilingualism are not directly applicable to deaf people, as they do not have the full prerequisites of learning a language based on aural-oral communication. Nonetheless, deaf children are fully capable of achieving bilingualism, the national Sign Language and good reading and writing skills of the national language(s). Rarely, if ever, is bilingualism considered negative in hearing people, and the same should hold true for deaf people. Knowledge of Sign Language does not isolate a deaf child, it promotes the deaf child's linguistic, cognitive, social and personality development; in essence fluency in Sign Language provides the child with more possibilities in the future.

Concluding remarks

Today there is a growing acceptance of minorities and an increasing readiness for inclusive education for disabled children and for providing the support and services required by individuals with special needs and to which, indeed, they have the right to. In addition, Sign Language is more present in society than a decade or two ago. For example, news in Finnish Sign Language is broadcast daily, some TV-programmes are close captioned, research on Sign Language is being conducted and many educational institutions now offer courses in Sign Language. Furthermore, as outlined in the literature review, there are studies providing evidence of the benefits of early Sign Language exposure for many areas of the deaf or severely hearing-impaired child's development (such as play behaviour, linguistic and cognitive development). This includes the pioneering work in Sweden on bilingual deaf education demonstrating the importance of deaf children growing up bilingual (with proficiency in the national signed and spoken languages).

Yet in spite of all the research and growing recognition of deafness and Sign Language one may ponder why more hearing parents of deaf and severely hearing-impaired children still do not readily choose Sign Language. Is the growing tendency towards oral communication and mainstreaming in a school for normally hearing children a result of no available deaf school or is it due to the increased availability of technical devices such as improved hearing aids and cochlear implants? The answer is not simple. Every parent has the right to choose a method of communication and has the right, and indeed a responsibility, to choose appropriate schooling for his or her child. It does, however, on the basis of the interviews seem reasonable to conclude that the increasing tendency for spoken language

communication and mainstreaming is forced upon many Finland-Swedish deaf children through the lack of any deaf school. With no straightforward educational placement Finland-Swedish parents have to look for other alternatives and then mainstreaming often seems to be the most convenient alternative, the alternative that requires the least rearrangements for the family. It is a vicious circle where the lack of a Finland-Swedish deaf school turns some parents away from Sign Language and into both oral communication and schooling and as a result there are not many Finland-Swedish Deaf children left needing instruction in Finland-Swedish Sign Language. Furthermore, on the whole it seems like it is particularly difficult (for hearing people) to view Deaf people as a linguistic and cultural minority – as opposed to spoken language minorities. It is evident that some parents who have chosen oral communication have not received multifaceted information on the significance of Sign Language and the Deaf Community for Deaf people as misconceptions about Sign Language and the Deaf Community are fairly common.

The number of children receiving cochlear implants is rising both in Finland and elsewhere. However, not all implanted children will develop good hearing and speaking skills. This is something both parents and the educational system have to be aware of and prepared for. Therefore, the deaf schools need to arrange education for the special group of children who to some degree benefit from spoken language input but may still be dependent on signed communication in more demanding social and cognitive settings, such as in the classroom. In order to make an informed decision hearing parents must (as part of early habilitation) receive extensive and multifaceted background information. This should include information on different aspects of having a cochlear implant, the benefits of using Sign Language and achieving bilingualism and also of possible difficulties facing mainstreamed deaf or severely hearing-impaired children, particularly in secondary education when the demands are increasing and the child has multiple subject teachers.

There is no reason why one should have lower expectations of deaf or hearing-impaired children; they should be given the chance to develop their full potentials. Therefore the objective of the early habilitation and all levels of education of deaf and hearing-impaired children need to be grade-level achievement, full participation in society, including fluency in the national spoken and signed languages⁵⁷. It is thus absolutely necessary that the national language is considered a second language for deaf individuals and taught accordingly. By this approach, the deaf children's mastery of the written language and ability to read is promoted and encouraged. Moreover, as was discussed in the literature review, only a signing environment with both deaf adults and deaf peers can provide the deaf child with the necessary components for a fully-fledged linguistic, cognitive and social development. For hearing-impaired children and for children with a cochlear implant it is equally important to meet other hard-of-hearing people of all ages.

⁵⁷ Fluency in Sign Language primarily concerns deaf or severely hearing-impaired children.

For a change to the approach and expectations of deaf or hearing-impaired children, attitudes towards Sign Language and the understanding of deafness among hearing educators and professionals working with deaf children need to switch from a more dominantly medical to a more socio-cultural perspective on deafness. The critical question is whether the hearing society enables the deaf or hearing-impaired child to develop according to his or her full potential. Although it is true that having a hearing loss affects many aspects of an individual's life, it does not mean that the quality of life needs to be affected. It seems that the hearing majority sometimes is unable to see beyond the hearing-impairment. Hearing people tend to concentrate on the deaf child's inability to hear; forgetting that deaf and hearing-impaired children have exactly the same range of personalities, emotions, skills, ambitions, needs and potentials as hearing children. In fact, many parents in this study reported having experienced ignorant attitudes towards deafness, hearing-impairments or signing children.

To conclude, in line with previous findings the present study clearly demonstrates that regardless of final choice of communication method and type of school all hearing parents need emotional support and objective information concerning their deaf or hearing-impaired child. In no case and regardless of type of school and communication method is it beneficial for a young, deaf or hearing-impaired child if his or her parents are left without the information and support needed for positively tending to the child's development. Nevertheless, despite rapid development and progress within the field of audiology and technical hearing aids, Sign Language and the objective of bilingualism must receive a more central role in the early habilitation, early education and fostering of deaf and severely hearing-impaired children. Studies in Sweden explicitly show that through Sign Language, deaf and severely hearing-impaired children can achieve bilingualism that hinders social isolation and allows for personal, social, educational and occupational achievement. Finally, similar to other linguistic minorities, Deaf people must have the right to use their own language, receive education in Sign Language and to maintain their own culture.

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APPENDICES

Appendix 1

The quotations from Chapter 8 as originally transcribed in Swedish.

8.2.1 Families using manual communication

(1)

Helt naturligt, inte fanns det ju några andra val heller, inte fanns det ju några andra val. Inte har jag valt, inte har man valt det, valt mellan det eller det, utan det fanns ju bara en möjlighet. Det är ju helt självklart... Mitt barn var den första döva jag träffade så jag visste ju ingenting [om döva eller teckenspråk] men ändå var det ju en självklarhet att med en döv så använder man teckenspråk

(2)

Jag tror att så fort vi ens börja tänka på, eller då vi fick veta att han var döv så var det helt klart. Jag kommer ihåg att vi satt i bilen och pratade med våra andra barn att absolut så börjar vi använda teckenspråk.

(3)

Personligen har jag tänkt att de som väljer något annat så de är ju egentligen ganska egoistiska. De väljer ju bara för sig själva och det är ju ändå det där barnet det som det är frågan om... Och nu visste man ju att teckenspråk är dövas språk, ja inte var det nån fråga om det.

(4)

Det kändes som ett måste nästan, för att man ska få kontakt med sitt barn

(5)

Det har bara blivit så, för att vi på något sätt skall få kontakt med henne så är det så att vi tecknar. Tecknar för att det blir, inte vet jag om vi valde det, det blev bara. Det gick så naturligt. Det är ju det enda hon reagerar på.

(6)

Det var en självklarhet, det var inget val, det var absolut, jag har ALDRIG stått inför det att jag skulle börja med något oralism eller något sånt. Det har aldrig varit nån tankegång för mig.

(7)

Pappan: Att när vi funderar på vårt barn måste vi utgå från honom, det gäller också vilket språk han ska få. Situationen är lätt för döva barn till döva föräldrar, de, de behöver inte fundera. Vi kan inte utgå från oss själva vilket språk vi vill

att han ska ha utan att vi måste utgå från det språk han ska ha. Vi kan inte tillfredsställa våra egna behov, det är ju hans behov vi ska tillfredsställa.

Mamman: Vi valde inte språk utgående från oss utan från barnet. Det var naturligt och självklart och, och logiskt. Men, men herrejess är man en logiskt tänkande människa så väljer man teckenspråk, att har man förstånd så.

(8)

Nu tycker jag ju, jag får ju inte händerna mina att liksom räcka till, för jag har jämt nating i händerna från morgon till kväll det, så det är det som jag tycker, det är ett sånt opraktiskt språk. Att man skall ju ha händerna lediga men de säger att då man småningom blir van så hoksar man inte på att man tecknar och talas medsamma.

(9)

Mamman: Jag är nog nöjd [med teckenspråk] men kanske du [pappan] skulle ha tyckt... (ofullständig mening). Men nog är det ju tungt att satsa på ett tal-språk också, nog får du jobba mycket mera.

Pappan: Inte är det det viktigaste om hon [mamman] eller jag är nöjd, det är ju barnet som det är frågan om.

(10)

Hon kanske blev lite, då kommunikationen började funka så blev hon ju lugnare. Hon blev lugnare för det är klart att så länge vi inte hade någon kommunikation så funka det inte.

(11)

Jo, hon blev lugnare, mycket lugnare då vi fick ett kommunikationsspråk...just i början före vi fick igång den här kommunikationen blev hon oftare frustrerad, väldigt arg, nu som då. Det var väldigt jobbigt, men nu märker man, nu har det blivit lättare... hennes raseriutbrott har ju blivit mycket mindre.

(12)

Före vi hade fått reda på att hon var hörselskadad så hade jag ju gått på tecken-språksskurs. Jag tänkte att jag sku försöka en dag, eller jag höll på flera dagar och teckna lite med henne och då var hon nöjd. En dag tänkte jag att den här dagen tecknar jag inte alls, nu ska jag testa henne, då grät hon bara den dagen. Följande dag fortsatte jag att teckna, då var det bra igen.

(13)

Mamman:Och sen för mig att det skulle finnas mera döva vuxna är jag ute efter.

Forskaren: Vilken roll spelar döva vuxna för dig?

Mamman: Språkliga förebilder för mig, som beteende, hur man betar sig på teckenspråk. Och för mig att träna min förmåga och inte bara med barn teckna, prata om barn-saker utan om vuxnas.

(14)

Mamman: Jå, folk tror att man inte har gränser åt henne. Man tycker synd om henne för att hon är hörselskadad, det gör man ju.

Pappan: Jo absolut, jo. Det märker man hela tiden jo. Att folk tycker synd om henne för att hon hör dåligt. Jo, det märker man nog hela tiden. Att stackars barn som ni måste teckan med. Nu tycker de synd om henne. Och hon är före barn i sin ålder i nästan allt annat kan man säga, bara talet som hon är efter med.

(15)

Eller att när du är döv så är du idiot, ungefär sådana här kommentarer, de är förstås sällsynta men sådana har nog funnits.

8.2.2 Families using oral communication

(16)

Vi har inte riktigt haft behov av det genom att han hör såpass bra som han gör. Det var nog mera prat om hörapparater och sånt.

(17)

M: Det var så naturligt för hörselskadan var så lindrig. Teckenspråk var inte alls aktuellt.

P: Hon uppfattar talspråk nästan perfekt med hjälp av hörapparat och också i lugn miljö, tex hemma utan hörapparat. Så det var inget, det fanns inget sånt behov då av teckenspråk.

(18)

Därför att han hade hörsel, så mycket hörsel att han kunde säga. Vi har på video, film på honom när han på ett-årsdan säger mamma. Och då vet jag att kan man säga mamma kan man säga vad som helst annat. Och då gick vi in HELT för det, när han hade hörsel kvar. För vi såg ju när han var liten hur glad han blev när han fick sätta radion, på max, att han hörde något ljud... Vi gick in helt och hållet för det här, jag har inte haft en tanke på att han skulle börja med teckenspråk.

(19)

Det är också en bidragande orsak när hon har ett hörande syskon det här att vi har gått in för talade språk

(20)

Ja, och så har vi ju diskuterat sinsemellan också det att för oss så blir teckenspråket aldrig vårt modersmål.

(21)

Nå, det fanns säkert hemskt många orsaker. En var helt enkelt det att den miljö hon växer upp i är en fruktansvärt talande miljö med relativt gammal släkt, både från min och min mans sida...så det är inte bara att säga hej att skulle ni kunna sätta er ner och lära er teckenspråk...visserligen skulle då säkert några ha

lärt sig någotlunda teckenspråk men de skulle inte ha, i det stora hela så visste jag att jag är så pass sinnikäs att jag sku säkert ha lärt mig det om jag sku ha satt igång med det. Men de flesta andra sku inte ha lärt sig det. Och min mamma var så förtvivlad över att hon inte lärde sig teckenspråk att hon grät. Hon sa att det här är alldeles hemskt, jag kommer aldrig att kunna prata med mitt barnbarn... Det är liksom en vacker tanke att alla ska lära sig teckenspråk och prata med henne men de kommer inte att göra det.

(22)

Pappan: Men teckenspråket är för mig liksom, rätt eller fel, det är litet ändå, kanske symboliserar en stagnation som är känd i Finland och som ses i Finland. Det är liksom en isolation bland döva som jag jag upplever det.

Mamman: Speciellt för oss som redan är en minoritet som finlandssvenskar så är det ju en ännu större grej, det att gå in kanske, liksom om man skulle gå in för att bara teckna. Det är så få av våra bekanta som skulle kunna teckna. Det skulle kännas som ett hemskt tungt alternativ... Och sen tänker vi också att vårt barn är så pass fiffig att vi är helt säkra på att tecken[språk] är inget problem för honom. Det märker vi ju ändå att han lär sig. Han kommer att, det är klart vi lämnar ju dörren öppen också att är det så att det inte funkar, och vi märker att han så att säga skulle bli utan språk, så är det ju klart teckenspråk. Vi vill ju inte utesluta det.

(23)

Jag har ju sedan själv gått med på teckenspråkskurs, att det var ingen som sade att jag ska dit inte, utan jag tänkte nu, för det finns ju hela tiden det där i, att hur blir hennes hörsel, att far den helt bort, hon har så lite kvar att när dom säger ju på HYKS att det kan liksom försvinna också. Att jag har nog funderat på det här med riktigt teckenspråk också, att det sku kunna vara bra, vi är inte, inte på det sättet emot det men det har bara varit för kämpigt att ta så mycket på en gång, för vi hade fullt upp med att lära henne att tala.

(24)

Han har varit på folkhälsan och hon är jätteintresserad [av teckenspråk] att han har nu så bett mig många gånger att jag sku komma med honom på en kurs. Och jag har lovat det också. När han vill så hemskt gärna att jag sku komma med på den så nu har jag tänkt. Det är ju också jättenyttigt, alltså att när han hör ändå någotlunda och sen sku man ha ännu teckenspråket och ännu det där talspråket. Man sku ju kanske också kunna vara till hjälp nångång också och bli något yrke genom det.

(25)

Tecken som stöd, det är ju inte riktigt samma som teckenspråk, för det är ju sånt där som jag nu har lite tänkt, jag ska faktiskt nu gå en kurs i vår. För det kan ibland vara bra i vissa situationer, när det är lite stojigare, och när man är och simma och han inte kan ha dem [hörapparaterna]. Då har jag tänkt att det kan vara bra kanske till visa lite såndant och nu har han ju blivit själv int-

ressererad här när han ser liksom här att tanterna pratar med händerna så är han hemskt intresserad. Men det är ju ingenting som vi behöver i dagliga livet heller, han hör ju, han klarar sig med sina hörapparater.

(26)

Mamman: Naturligtvis är det ju tuffare för henne, det är tuffare för barnet just nu det där att vi kräver, försöker kräva av henne att tala... jag menar vi gör ju det inte till ett problem för henne för att vill hon inte, då får hon vara tyst. Men vi försöker, vi försöker uppmuntra henne.

Pappan: Inte har vi nånsin förbjudit henne att teckna.

Mamman: Nej, absolut inte, det har vi ju inte

(27)

Och så tänkte jag att i den omgivningen vi bor i, att det är ju där hon får sina vänner och sånt här. Kommer de verkligen att lära sig? Jo, de kommer att säga skall vi gå och cykla eller ska vi gå ut och leka eller ska vi äta glass eller något sånt här, men inte kommer de heller att kunna prata. Jag tror inte på det. Och så tänkte jag att OK, det är hon som får anpassa sig till miljön. Att jag tar problemen när han är ung och han kommer att få jobba som fan, men så har hon liksom kommit in i det här. I alla fall har det visat sig att det gick så.

(28)

Pappan: Att liksom det här, förstås, nu är det där liksom. Det är klart att ingen som har ett dövt barn, som inte har ett dövt barn förstår det där, euforiska känslan då du märker liksom att det här barnet, att du får kontakt med det, du kan tala med det. Att det lyssnar på dig och att liksom du kan. Vi brukar alltid säga åt våra vänner förut att du i butiken kan ropa på henne. Hon vänder sig om och tittar att vad,

Mamman: Inte ens ropa men säga.

Pappan: Säga. Det låter ju helt löjligt. Det är en enorm känsla. Att du får liksom kontakt.

(29)

ALDRIG I LIVET, det förstör ju hennes hörsel.

(30)

Pappan: Så jag tycker liksom, det var för mig ganska utslagsgivande, då jag ser hur isolerade döva annars är, framförallt i dagens värld med teckenspråk... Det är klart, det liksom sätter dig att tänka att vad finns det liksom, att är det här faktiskt rätt sätt? Men sedan har vi förstås de här andra vägarna [teckenspråk] men när du tittar på resultat som vi då såg i Schweiz och i Tyskland och så, det är liksom begeistrande. Jag måste säga att det liksom, visst var det ett svårt beslut för oss att gå den här vägen och framförallt sedan då att göra den här implanteringen [cochlea implantat], men efter sex månaders liksom morkkis så, när man började se liksom resultat, så inte har vi ju efter det haft några regrets.

Mamman: Vi är nöjda.

Pappan: Och skulle det ens bli hälften så bra som det som vi har sett i Sverige och i Schweiz, så då får man liksom vara nöjd.

(31)

Men det som jag nog måste medge är att nog har det varit väldigt tungt tidvis men det här är ju första att du har ett inplanterat barn, man är inte. Man är inte van vid det alltså. Vi har inte fått någon som helst guidance från Finland...Nog har dom [HYKS] ju varit jättestoriska emot oss ändå på sitt sätt men dom har liksom inte, dom har inte haft den där professionella touchen. Liksom den där som du, du vet som du skulle ha väntat dig. Jag skulle inte säga att dom har gjort allt åt fanders inte. Tvärtom, jag tycker många saker är bra men.

(32)

Nej, utan jag fick liksom, nej nog har jag fått stöd, skall vi säga, jag har haft en hemskt bra tukijoukko bakom mig men jag hade hemskt länge nog att människor tyckte att jag är galen som säger att jag tänker lära mitt barn att tala. Men det har ändrats nu, för nu är implantaten här [i Finland] också och man vet att det är möjligt, det är verkligen möjligt.... Jag upplevde att människor upplevde att vad i helsike är det hon gör, hon förstör sitt barn och det där och det är det värsta man kan säga åt en mamma att du tänker på dig själv och du tänker inte på ditt barn. Alltså det finns ingenting grymmare, det kan vilken mamma som helst veta att när någon kommer och klandrar och säger att du tänker på dig själv och inte alls på ditt barn så är det liksom, man tänker att sedan att tänk om det verkligen är såhär och man vet ändå innerst inne att det är ju mitt barn jag tänker på. För det är nog hemskt få, det finns säkert såna som tänker på sig själv men det är nog hemskt få mammor, Utan det är nog verkligen, de flesta tänker på, de beslut de än tar så tänker de på att vad är liksom bäst för det här barnet. Alla föräldrar vill sina barns bästa, det är verkligen så i allmänhet och det är därför som jag upplevde det liksom, när jag fick kritik från annat håll att jag gör fel, så var det nog liksom ganska brutalt.

(33)

Nu märker jag ju såhär att han hemskt ofta frågar det där ”va”. Och så blir han ju arg, liksom han blir arg på oss när han inte hör, fast han egentligen säkert blir på sig själv. Men han reagerar, liksom avreagerar sig alltid på oss sen ja. Men att det där i skolan har han ju haft den [hörapparaten]hela tiden och de tycker att han nog någotlunda klarar sig. Alltså de säger att han med det där sociala har han svårt, absolut inte något på den här inlärningsförmågan. Men han är nog såndän kanske sådär ganska slutet och det där, inte har han, hemskt mycket kompisar har han inte där.

(34)

I idrott är hon hemskt modig, men när hon sku ha föredrag [i skolan] blev det nog ingenting. Hon är så osäker på sig själv.

8.2.3 Early habilitation and the choice of communication method

(35)

Jo, och föräldrar som inte vet något eller inte ännu hunnit bearbeta det och om någon då säger att jag kan fixa ditt barn så tror jag nog det påverkar. I det stadiet är man nog ganska mottaglig synnerhet om det är ditt första barn och du är ung och du vet ingenting, så då tar du nog nästan varje halmstrå du kan få.

(36)

Att dom här hjälptecknena var till MYCKET NYTTA då. För att vi fick en sån hän bok med alla djur, dom här vanligaste, dom här bilderna. Vi såg på en bild och så visa tecknet för dom, tecknena fanns här nere hur man tecknar dem och så var det en stor bild, att vi både såg på det, teckna och sa det och i flera olika röster, inte bara min. Stödtecken var till otroligt stor nytta... Eventuellt jo [hade vi använt mera stödtecken om vi hade fått information om det] för att jag vet inte om vi fick nån information, jag bara själv upptäckte hur viktigt, hur, hur mycket bättre jag kunde kommunicera med honom, hur närmare vi kom och hur mindre frustrerad han var, att när vi hade ett medel att liksom uttrycka sig, att, han, han kunde säga bara för att han förstod mina tecken och han kunde själv göra tecken fast han var så liten. Så just via dom, så fast han inte hörde så hade han en kanal, att han blev inte, han blev inte den som låg på golvet och sparkade och skrek och han blev inte aggressiv mot andra. Att det såg vi ju i dom här, när vi var i dom här grupperna, en vecka eller tio dagarna så det fanns ju dom här ungarna som sprang omkring och slog den andra i huvudet med nånting och det där jag var livrädd för det här jag när vi var. Dom andra barnen hade det här aggressiva så hade jag den, jag tänkte att det kommer säkert för att dom har, dom kan inte uttrycka sig. Att via dom här teckena så, det var en OTROLIG hjälp, utan dom, vi sku inte ha haft språket att uttrycka oss om vi inte sku ha haft dom där tecknena... Alltså utan tecken förstår inte jag hur vi skulle ha klarat den tiden, att det gav också mera språk, att både tecken ihop med det där verkliga, att du fick liksom uppleva det också.

(37)

Det var mycket viktigt, jo... Mest information fick man ut från dom, från dom här kurserna. För att det var andra föräldrar och så, då det där, där kunde man ventilerat allt möjligt. Dom hjälpte nog otroligt. Det var nog dom, det som var det bästa då, att ha kontakt med andra att få höra.

(38)

Det var otroligt viktigt, dels var det viktigt för vårt barn att se en vuxen med implantat och dels var det viktigt för oss att få litet, det där att vad betyder det här [att ha ett implantat]

(39)

Jag hör ju, du får inte, du får inte teckna. Jag hör ju, hon är arg på mig, jag får inte teckna. Inte ute när andra hör eller ser, hon säger att jag har ju hörapparat,

du ska inte stå dit och teckna något när andra ser. Jag vill vara som andra säger hon.

(40)

Jag valde inte bort teckenspråk, alltså det här var inte en sak så här att jag jag tänkte då hon föddes att nu väljer jag bort teckenspråk. Det gjorde jag ju inte. Alltså ingenting som har hänt, hur jag har kommit till det här har varit frågan om en liksom lång process, inte har någonting gått på en dag eller en vecka eller en månad utan det här är liksom också fråga om egentligen en jättelång tid. Alltså de [HUCS] föreslog ju för henne teckenspråk, för hon är ju så gravt hörselskadad. Så det fick jag nog. Eller de sa att teckenspråk och teckenspråk-sundervisning och något sånt här... Det är ju det att den här informationen borde gälla allting, att du vet de olika alternativen vad som finns och olika programme som finns. Alltså jag tycker ju att informationen skall vara en information som skulle gälla allting förstår du, och vad jag fortfarande tror är att alla föräldrar skall få välja själva och välja själva för jag tror inte på, om du väljer någonting som någon annan har sagt åt dig att gör det här, för om du inte tror på det här så gör du det aldrig. Du kommer aldrig att lära dig teckenspråk om du inte tror på det själv. Om du inte verkligen tror att det är det här som jag vill ge åt mitt barn, jag vill kommunicera med teckenspråk, kommer du aldrig att lära dig det. Samma sak gäller talat språk. Om inte du liksom verkligen vill ge det talade språket åt ditt barn så kommer du inte att få ditt barn att tala eller använda sina hörapparater eller implantat. Du måste tro på det själv.

8.3 Educational decision-making

(41)

Det är ju som det är, fast de här skolfrågorna hela tiden är på tapeten så inte går det ju att göra något. På vilket sätt skall de gå?

(42)

Man kan inte göra något för situationen, den är eländig, man kan inte göra något, ingenting kommer att förbättras, vad finns det att göra?... Det finns inte något utbildningsmöjligheter, samhället tar inte ansvar för finlandssvenska döva barns utbildning. INTE ENS lågstadiet utbildning kan de ordna.

8.3.3 Educational problems facing families with signing children

(43)

De står i vår väg, absolut. Bort med dem, dom bromsar oss, dom bromsar oss, utvecklingen. De föräldrar som inte väljer teckenspråk inte förstår det, att det är det enda alternativet för [det döva] barnet så de gör liksom alla andra en stor björntjänst.

(44)

Pappan: Det står inte i lagen att man måste integrera döva barn...Kunde man föra det här till EU domstol på något sätt det här att finlandssvenska döva barn blir så undermåligt behandlade, att de inte får chans till likvärdig utbildning? De driver ju mycket individuellas sak i EU, det skulle kanske gå. Man borde få ett, ett prejudikat på det här.

Forskaren: Skulle ni orka med det?

Pappan: Jag orkar vad som helst.

Mamman. Ja men, det är ju frågan om att gå under eller inte, att överleva.

(45)

Det är just det som känns då de är för få, de är liksom hänvisade bara till varandra. Så inte vet jag, inte tycker jag det finns liksom något annat. Jag tycker inte i dagens läge att det finns något annat alternativ [än dövskola i Sverige] heller. Om det skulle vara tillräckligt många finlandssvenska döva så skulle det nog bli något med det här som de hade tänkt, med den här tecken-språksskolan. Men då det inte finns.

(46)

Det finns inga utbildningsmöjligheter för finlandssvenska döva barn, de är för få. Det blir inte en enhetlig grupp, de är för få.

(47)

Att de är så få, det är som det första vi är ute efter, att det ska finnas många döva barn, det är det viktigaste.

(48)

Intervjuaren: Hur fungerar det på dagis?

Mamman: Hm, ja nu funkar det. Han har varit två år nu och det här andra året har det funkade bättre. Inte, vi har ju varit på en kurs nu i Malminharju [anpassningskurs för familjer med döva/hörselskadade barn] nu i juni. Och tidigare tänkte jag som nu är dagis bra, de tecknar ju där och de andra barnen, eller det är ju mitt barn och ett annat hörselskadat barn och hörande barn, och jag tänkte att han har ju en kompis där och de andra barnen vet jag att han inte just kommunicerar med. Lite då men efter den här veckan i Malminharju så han kunde kommunicera fritt med vem som helst så tänkte jag att nej, vi får nog genast någonstans, att det är onödigt att vara här. Jag har tänkt att vi ska vara här ett år till och sen ska vi flytta någonstans.

(49)

Nej, för att vi är privatföretagare och vi har inte möjlighet att börja om. Ta med vårt bröd och flytta det någonstans, det går liksom inte.

(50)

Ja, men jag har det ändå ganska lätt. Han är enda barnet, vi äger inget hus, har ingen firma, det är ganska lätt för oss att flytta och jag tror vår livssituation blir bättre av att flytta...men det är ju inte så frivilligt. Om man tänker att vad ska jag göra då? Får man vänner och sånt?

(51)

Finsk dövskola, nej för då måste syskon lära sig finska och det är fel att syskon måste lära sig finska nu för att brodern är döv.

(52)

Mamman: Samhället vill inte att våra barn ska få utbildning, de bryr sig inte om, de är nöjda om vi flyttar till Sverige. Då slipper de problemet.

Pappan: Man satsar inte på finlandssvenska döva barn, inte alls.

[- - -]

Pappan: Där har de god undervisning, då skulle han vara på samma nivå som alla andra, jämställd det som syskonen nu får i fråga om kamrater. Men det här med ekonomiska resurser, samhället vill inte att finlandssvenska döva barn ska få utbildning, staten borde gå in och finansiera så att familjer med döva barn ska ha råd att flytta till Sverige. Ska vi sälja vårt hus är, ska vi köpa nytt i Sverige, varifrån får vi de extra pengarna som behövs för vårt barns skolgång, extra 500 000 mk. Vi måste satsa så mycket på vårt barns skolgång men granen behöver inte satsa ett penni. Kommunen betalar nog om vårt barn bor och går i skola i Sverige och kommer hem till veckosluten men ingenting om vi flyttar dit.

(53)

Ja, Sverige är ju ett alternativ om jag vill behålla svenskan och det, göra det lättare för mig själv så att jag får tänka på svenska. Jag har frågat vissa insatta som har sagt att även om vi flyttar till Helsingfors och mitt barn börjar gå i finsk skola där han lär sig finska, att läsa och skriva på finska, kan jag ändå fortsätta artikulera på svenska. Men ja, jag vet faktiskt inte vilket jag skall välja, för tillfället lutar det åt Helsingfors men jag har inte ännu bestämt mig

[- - -]

Ja, om man tänker på det här med skola, det måste ju vara en stor grupp för att det ska bli till nånting. Det finns ju inte. Det är knäppt, det är en knasig tanke att man ska byta land, de här som far över och flyttar, det är knasigt.

8.3.4 Factors influencing parents' choice of school for signing children

(54)

Vi satsa ganska mycket på fritiden, att hon skulle få träffa döva då eftersom hon var ensam döv i förskolan, vi har varit med på läger, sommandagar, vinterdagar och hon har haft kompisar hemma, döva kompisar osv. så att man liksom försöker ge det [kontakt med teckenspråk och döva] på fritiden. Men vi kom ju till att det inte räcker med det. Inte ju bara, då blev det att vi valde

dövskolan. VI försökte ge så mycket, så mycket teckenspråk och döva som möjligt som vi trodde att det skulle räcka med.

(55)

Sätter vi honom i hörande klass förstår vi inte hans situation...Ingen kan ju förstå, tänk att gå i skola och aldrig förstå nån annan, ingen annan, tolken, nej inte ens det, ingen annan talar ditt språk, tolken talar vuxenspråk och barnet barnspråk. Det finns INGEN som är jämlik dig. Ingen skulle, ingen kan förstå hur det är att sättas i en skola där du inte förstår, och, och det går inte att jämföra med hörande barn i ett annat språks skola.

(56)

Jag har ju inte så lång erfarenhet från Sverige ännu inte. Det har jag ju inte men där kanske nog är positivare attityd till teckenspråk och allt sånt. Jag vet inte då att är det, är de mera vana vid det där eller nej, jag vet inte, har de de längre erfarenhet? Jag vet inte men liksom sådana programme. Om man tänker på TV-programme och sånt, att redan bara de här barnprogrammerna. Teckenlådan är otroligt gjort. Sånt finns ju inte alls här.

(57)

Först tänkte vi ju på integrering. Och trodde på det själva. Men då vi märkte att det inte funka, eller vi planera integrering i några år och visste att det så småningom blir dövskola men det blev tidigare än vad vi kanske tänkte från början. Han gick första och andra klassen med tolk. Själv trivdes han ju bra, allt var ju nytt och allt var liksom spännande och det funka bra. Men andra året så då, inte vantrivdes han inte men vi märkte att han blev, den sociala biten bara blev, och inlärningen också förstås. Inte funkar det ju.

(58)

Han är nöjd, han är jättenöjd med skolan, han skulle ju inte byta tillbaka inte en dag heller.

(59)

Integrering? Fullständigt omöjlig tanke, ingen möjlighet alls. Ett barn behöver ett modersmål

(60)

Nej, det var det inte, nej, nej det var det inte. Nä, för att vi hade flyttat till en ort i svenska Österbotten och jag är svensk, och våra andra barn, så hela min släkt är svensk och vi hade flyttat och det var för svenskt för jag skulle kunna tänka mig att sätta flickan, och jag visste liksom att jag ville ha den här habiliteringsbiten som, vad mamman gäller ville jag ha. Och jag visste att jag inte klarar av det på finska så det var nog aldrig ett alternativ. Och därför jag visste inte ens heller vilken skola som skulle ha kommit i åtanke, Jyväskylä, Ul-eåborg. Seinäjoki skulle väl kanske inte ha varit ett alternativ heller inte. Inte vill jag skicka henne till Jyväskylä och inte ville jag skicka henne till Oulu

heller. Att det var ännu mer främmande för mig att tänka att jag sku ha skicka henne till något finskt då när jag inte ville skicka bort henne överhuvudtget så jag ville nu åtminstone hålla kvar det där med svenska som halmstrået då.

(61)

Mamman: Nej, det har vi ALDRIG tänkt på, nej, nej

Pappan: Det har vi reflekterat över just för att vi är en stor familj så att

Mamman: med jobb

Pappan: Med jobb och så där. Det måste man ju tänka på. Det är ju inte sådär bara att flytta dit och tänka att man får jobb. Och inte tror jag att de andra barnen skulle ha velat flytta dit heller.

Mamman: Nä, men det har vi aldrig, det har vi aldrig tänkt på.

(62)

Vi var ju före, året före var vi och se och då var han ju inne i klassen. Vi var på två besök före han började plus att han då fick något brev och sånt där som klasskompisarna hade skrivit och skickat åt honom. Och redan andra gången vi var dit såvar vi ju inte alls, så var vi inte med i klassen. Han ville bli lämnad ensam i klassen då och med på undervisningen och vi var mera och se på bostäder och sånt och jobb osv. Och jag tycker inte alls, först var jag lite liksom orolig för att han hade ju de här finlandssvenska teckenspråket då och att ändra då till svenska. Och klart att det kanske var lite jobbigt till att börja med, att inte förstod de väl honom till 100% eller säkert blev det lite missförstånd där i början. Men inte räckte det så länge innan han var in i det. Och så tror jag nog det att ju förr man far, desto lättare och bättre är det. För att första tiden liksom märkte jag som de sa att är man döv och integrerad så blir man beskyddad på något sätt nog. Att men nu är det verkligen liksom att här är vi på samma villkor och allt. När de kommer och säger att hur ser du ut sådär och sånt där, så nog blev han sårad av det först nog. Han liksom fatta att alla inte är lika snälla.

8.3.5 Educational problems facing families with hearing-impaired children using spoken language

(63)

Han orkar inte koncentrera sig för länge på prat, blir på dåligt humör om det är mycket ljud så vill han bort. Läraren säger ofta att han är den som säger jag förstår ingenting...Han fordrar det där stödet hela tiden när han inte hör ordentligt.

(64)

Forskaren: Hur tycker hon att själva klassrumssituationen är? Upplever hon att hon gå miste om information, sådant som sägs bakom henne till exempel?

Mamman: Jo, jag tror, ja såna problem finns ännu, jo, men hon klagat inte så mycket nu.

Pappan: Inte numera, men ännu då på femman sexan så var det, när det var oroligt i klassen, mycket prat, onödigt prat och då, då måste vi säga till åt läraren om det också. Att det är för oroligt, för mycket prat och för mycket skrap och så här men det har inte varit så mycket om det nu tycker jag, i högstadiet mera. Men man kanske jobbar på ett annat sätt.

(65)

Pappan: Sen har vi också, vi har provat FM apparat en tid och det gick ju bra, bra en tid. Men sedan nu när, på högstadiet när man inte har, det är inte samma lärare och så här, så det blev för krångligt.

Mamman: Jo, det är lite jobbigt.

Pappan: Femman och sexan så fortfarande men sen på högstadiet går det inte.

(66)

Hela tiden nya vikarier och nya lärare och det har nog varit jobbigt för henne... När hon tredje gången inte hör så frågar hon inte mera. Och sen, några vikarie lärare vägrar säga på nytt när de inte vet att hon inte hör. Hemma frågar hon nog tills hon hör men inte av främmande.

(67)

Jå och de [lärarna] har varit hemskt duktiga där nog alltså, ja, ja, jag rekommenderar bara [skolan], jag måste säga att jag har varit alldeles liksom, jag tycker de har varit jättekivoga, jättekivoga verkligen.

(68)

Forskaren: Har det i klassen satts in isoleringsskivor eller [tele]slingor?

Pappan: Jo, nej inte slingor men klasserna är dämpade med såna här skivor efter material-beskrivning som hemvägledaren haft dit. Det är nog inga problem alls, det är gjort. Skolan var välvillig till det.

(69)

Mamman: Men där finns ju kurator sen som spelar mycket stor roll och kuratorn är mycket aktiv och bra i den här frågan och mycket engagerad i vår dotter och är väldigt så här, bra kämpare där.

Pappan: Jå, hon anser ju att vår dotter inte är, att hon inte är dum utan det är bara det att hon har ett handikapp som gör att hon inte har, hon har inte samma chanser som andra att uppfatta abstrakta ämnen, främmande ord i historia eller så här och just då i främmande språk som är mycket jobbiga i och med att vi fortfarande håller på att bygga på hennes eget språk.

(70)

Mamman: Men det är just med skolmyndigheterna att tycker jag att, att man borde. Föräldrarna borde få information om rättigheterna när det gäller barnens skolgång, rättigheterna till biträde och, och stödundervisningen och sen att vem, vem som sen är, har, vem har kompetens att bedöma om det här. Är det stadens eller kommunens ekonomiska resurser som avgör det här eller är

det liksom själva det här barnets behov. Att, det, det är hemskt tycker jag om man hänvisar till det här att man inte har råd för det kommer att kosta oerhört mycket mera sen om man inte satsar i god tid.

Pappan: Jo, och det är sånt som inte går att mäta i pengar liksom, det är frågan om en persons framtid och så här så det går liksom inte, om det kostar 50 000 eller om det kostar 70 000 per år så det går inte att säga. Det är inget argument att vi inte har råd.

Mamman: Man kan inte mäta en människa med, såhär i pengar, en människa har värde för sig.

(71)

Pappan: Assistent borde man ju få...

Mamman: Bättre villkor för assistenterna, att om det är [ofullständig mening]

Pappan: För det första, tillgång till assistent.

Mamman: Nå, tillgång till assistent, ja. Nog är det ju en ond cirkel att tillgången skulle ju säkert vara en helt annan om det skulle vara bättre villkor för dem.

(72)

Assistent sku nångång vara bra...att skriva är mycket svårt, där sku hon behöva hjälp.

(73)

Men därför [banet gick på en sammansatt klass med två årskurser] så är det ju mycket stor hjälp av assistenten som anställdes när han började skolan.

Forskaren: Så är assistenten anställd för honom, är det hans personliga assistent.

Mamman. Ja, liksom

Pappan: Ja, anställd till honom jo på pappens men det fungerar ju nog så att hon liksom är för hela klassen ibland och läraren kanske kan koncentrera sig på honom och vice versa.

[- - -]

Forskaren: Var det svårt att få assistent?

Pappan: Det var väl inte så svårt egentligen, det var en lite äldre person med livserfaren... hon har ingen utbildning på det men

Mamman: Bra med barn.

Pappan: Bra hand med barn och det tror jag är viktigt att det är en lite äldre person, tror jag, än att det kommer en som är 18,19 år, det kanske inte alls har samma effekt, jag har svårt till tro det. Det är lyckat.

Forskaren: Så är det lätt att få assistent på er hemort?

Mamman: Nej, det.

Pappan: Det är nog inte lätt annars men i det här fallet råkade det vara tre tror jag som sökte.

Mamman: Men annars har man ju hört det liksom svårt och mycket nog den här lönen säger dom

Pappan: VÄLDIGT mycket

Mamman: Mycket det som och när dom sen och är det inte så att som, anställningen upphör typ till sommaren?

Pappan: Och till julen.

Mamman: Och att dom har alla dom här förmånerna, inga förmåner.

(74)

Mamman: Sjutton elever [i klassen], ganska bra för att skolan har ju kommit till mötes på det viset att dom har försökt bygga upp en klass med lite lugnare elever och duktiga elever och som, som kan samarbeta och håller lite tystare kanske plus att det är mindre antal elever.

Forskaren: Informerade någon skolan om hörselskadade barns behov?

Mamman: Hemvägledaren.

Pappan: Folkhälsan på lågstadiet och det var också dom som ordnade med, med kurs för lågstadielärare under sommaren och då hade hon turen att ha en, en lågstadie-lärare som var, som var mycket empatisk och intresserade och gick på kursen så här och tog reda på vad det handlar om att ha hörselskadade barn. Det var fint. Sen när hon kom upp ettan och tvåan så tappade hon henne

Mamman: trean och fyran

Pappan: ja, så tappade hon henne och fick en ny lärare och då ändra det lite igen och sen nu högstadiet så lite samma, samma empati som på ettan och tvåan men... men vi har ju kämpat hårt också, inte minst min fru har kämpat hårt med assistenter och stödlärare. Och det har ibland gått bättre och ibland mindre bättre.

Forskaren: I vilken utsträckning skulle hon behöva stödundervisning eller assistent?

Mamman: Ganska, assistent skulle hon behöva men när dom är alltså, det är upp till assistentens personlighet och engagemang och kunskap och förmåga så det har inte fungerat nu i högstadiet. Det fungerade mycket bra där i lågstadiet.

Forskaren: Så hon hade assistent i lågstadiet?

Mamman: Hon hade då, var det från femman och sexan, ja.

Pappan: En poäng i sammanhanget så det är det att det är mycket svårt att själv liksom agera där, där för liksom för att lönen för de här assistenterna är ju så ERMBARLIG så att den, den som liksom är villig att ta jobbet så måste man liksom bara tacka och så här. Men vi har haft problem med att hitta, hitta rätt person som skulle komma överens med flickan vår. Och det är så att om det inte fungerar så fungerar det inte liksom och hon får inte kontakt och så här. Där finns ju speciallärare på högstadiet som hon, som hon gillar mycket och som hon kommer mycket bra överens med och som hon har mycket bra kontakt med men hon har ju inte tid att koncentrerar sig på henne enbart. Men, men hon är ju med henne några timmar i veckan och det är mycket bra. Det är ju vissa ämnen som det är speciellt kritiskt, där hon är helt beroende av stöd i någon form. Det är då främmande språk och matematiken.

Forskaren: Vad har hört till assistentens uppgifter?

Mamman: Nå, det skulle vara att hjälpa henne på lektionerna att hon skulle förstå vad läraren säger. Hon ville inte samarbeta med den assistent hon hade förra året så det, assistenten blev istället klassassistent så läraren kanske förklarade speciellt, nå det bröts nu sedan, det var lite så här

Pappan. Det var lite jobbigt

Mamman: Och det byttes assistent som nu är lite så här, som är lite osäker. Och, och vi anklagar liksom inte den här assistenten men det här SYSTEMET. Vi hade begärt nämligen extra stödtimmar från skolmyndigheterna men dom har tackat, sagt nej och hänvisat en assistent istället. Det är kanske billigare [skratt]. Och nu behöver hon mera stödundervisning och, och hon har begärt men när hon säger att hon inte får tillräckligt nu och det är lite öppet nu igen. Måste vi nu IGEN ringa till skolan, det är mycket kontakter och möten och sånt vi har haft.

Pappan. Så om, om man på något sätt kan poängtera någonting i samband med det här så är det just det här. Att det är det som vi upplever som svårast just nu så det är tillmötesgående, eller vi säga skolan vill nog men det finns inga resurser för det. Så det vill säga tillmötesgående i skolväsendet till barn med, med, med olika slags handikapp. Vi känner nu bara konkret till det här men det är väldigt jobbigt att föräldrarna måste ringa och slita och ringa till skol, till skolverket och höra och vara aktiva för vi har ju, vi vet ju inte hur skolverket fungerar och vilken beslutsprocess dom har och vilken kompetensnivå man måste ha på stödundervisningen. Och vi kan inte påverka löneläget för assistenterna så här och vi kan, vi har ju, vi har ju begränsad möjlighet att regelbundet kolla varje vecka hur det går. Om man då jämför med tillmötesgåendet hos folkhäl-san och hörcentralen så, så är ju skolväsendet ljusår från det och ju högre, högre upp man kommer i grundskolan så blir det bara sämre och sämre samtidigt då som nivån och kraven växer så blir liksom tillmötesgåendet sämre och sämre från skolväsendet. Även om skolan i sig och rektor gärna vill. Så det är en sak som jag själv sku vilja poängtera som gör mig faktiskt både lite upprörd och, och besviken.

Mamman: Mm, för att det är liksom ändå ett barns framtid det handlar om. Högstadiet det är ju kritiskt.

Pappan. Just mellan lågstadiet och gymnasiet eller fortsatt utbildning så är ju gymnasiet, alltså högstadet kritiskt.

Mamman: Det var så här, kontakten som vi hade med skolverket det var på på lågstadiet så skolan hade begärt mera stöd eller så här från skolverket här för hennes skolgång så sade skolverket att nej dom har inte råd. Helt blankt. Men sen ringde vi, sen började vi ringa, att hur är detta möjligt, att skolan går neråt för henne och vad ska hon göra i skolan om hon inte klarar av det. Sen ringde jag till skolstyrelsen och med en sån här inspektör som tar hand om såna här frågor och sa att, att han, hon sade att vi måste absolut liksom få. Och då ringde jag igen till skolverket och rektorn och då liksom först sattes det igång med assistenter. Men nu ser det att liksom ut att vi igen måste sätta igång, ja. I högstadiet är det så många lärare, det går mycket lättare att samarbeta med skolan då när det lågstadiet och klasslärare, på högstadiet är det lite annorlunda.

[—]

Mamman: jo, skolgången är nog ännu mycket svår i många ämnen.

(75)

Han har ju bytt skola pga svårigheter, bland annat på grund av lång skolväg, inga kompisar i skolan. Nu har han lärare som är insatta och skolgångsbiträde, samma skolgångsbiträde som han hade från första klassen. Och vi tänker ha henne hela tiden, inte tänker vi ge upp henne. På det sättet är vi nog lyckliga.

8.3.6 Factors influencing parents' choice of school for hearing-impaired children using spoken language

(76)

Jag visste om Borgå dövskola, jag sku aldrig ha skickat dit henne för jag visste att den var liksom, jag skickar inte mitt barn till en skola som har inre stridigheter. Jag anser att en skola skall vara en trygg och kiva miljö med en bra atmosfär. Har den inte det så är det liksom åt helvete och de lär sig ingenting utan de går där för att någon ha sagt att de skall gå 190 dagar i skolan.

(77)

Pappan: Det är ju ganska naturligt annars också att man hoppas och försöker på det [integrering].

Mamman: Plus att det skulle vara en naturlig omgivning för honom, för han går i en vanlig hörande lekis och dom samma barnen är från det här området, så många kommer att börja i samma skola så för honom liksom att inte rivas ut ur den sociala.

(78)

Forskaren: Tittade ni på olika skolor när han skulle börja skolan?

Mamman: Nej.

Pappan: Nej.

Mamman: Nej, den som var närmast.

Pappan: Närmaste, den har gott rykte och fin miljö och så här.

Mamman: Och sen att storebror gick i samma skola, det var bekant för oss också på ett helt annat sätt.

(79)

Hon var nog intresserad av Örebro fast hon inte såg så mycket... Men det är nog inte ett alternativ, nä, det är det nog inte, det är nog ändå en så stor förändring. Det är ju sen annat kanske om man sku märka att hon verkligen inte klarar sig så nu tror jag att man sku vara beredd att bryta upp. Men det är ju klart det där med arbetsplats och det är inte bara att flytta, dyrt, och sen att det är ju inte ens sen bara pengar man vill ju ha sen kanske ett jobb som man trivs med. Att inte tror jag att det där hörselskadade barnet sen heller det där om resten av familjen mår dåligt så har det bra.

(80)

Det var ju då i fjol som var jobbigt, det var, ifjol var mycket jobbigt då för vår pojke. Det var allt då, han kom in i puberteten och det gick dåligt och assistenten var bara skräp, och ja (förlåt, skrattar) ...Ja, alltså för, för vår pojke, ja då flera gånger så frågade han att om det inte finns en dövskola där han kunde gå istället... och det återkom flera gånger under läsåret det här just. Och han, han frågade faktiskt efter en såndän modell [systemet i Kristinaskolan i Härnösand med skilda klasser för hörselskadade och döva barn] ...det var på tapeten flera gånger men det finns, finns förmodligen inga sådana alternativ på svenska i Finland, åtminstone inte i närheten.

(81)

Pappan: Det märker man liksom nog. Det var på veckoslutet då vi var ute här i parken, i källbacken och liknande saker. Så nog är det liksom ändå viktigt för honom att han känner alla de där barnen. Eller hur? Att det är ju ändå hans sociala miljö. Och att dom vet vem han är. Det är ju ganska naturligt för dem liksom. Dom som inte vet att han har ett implantat och att han är döv så det är liksom helt naturligt för dom bara, det att det just är han och han bor ju där och man känner, liksom det blir liksom en gemenskap. Joo, och där är ju också en ganska stor omställning att skall han i teckenspråksdagis, så dom far till Her-tonäs. Det är liksom en helt annan miljö, och dessutom på finska.

(82)

Jag vill inte att han skall ha den enda länken till en tolk, en tolk som tolkar med vänner och lärare och sånt här för att då kommer han att bli isolerad. Men det var liksom familjen och det här att jag inte ville att han skulle vara isolerad från släkten och den omgivning han har här, och att skolan, att han skulle lära sig leva, och anpassa honom till miljön... Jag kommer ihåg för länge sedan såg jag på Ljusa Huset, så var jag och titta. Mitt barn var hemskt litet och så gick jag där och de hade ritat upp såna där, döva barn hade ritat upp kartor över släkt. Och så hade de ritat punkter, med röda punkter de människorna som kunde teckenspråk. Alltså det var ju förfärligt. Inte kunde ju, det var något syskon som kunde prata lite, pappan bruka kunna, inte ens liksom perfekt utan det var mamman som bruka kunna. Pappan kunde sådär att kunde liksom tecken och så fanns det, syskonen kunde också men nån kusin kanske kunde eventuellt kunna några tecken. Men det sluta alltid där och det sa mig något också. Det här var också sådana saker att det är inte så där bara, att hej nu har vi ett dövt barn i släkten och nu lär vi oss alla teckenspråk.

(83)

Inte var det någon som teckna med min döva släkting. Jag tala med honom, inte var det något problem. Och sedan unga döva i dag så, no, ingenting, du kan liksom inte, dom läser inte läppar och kan du inte teckenspråk så då är du helt out.

(84)

Sen visste jag ju nog om den här dövskolan i Borgå men det var ALDRIG fråga om något sånt när mitt barn inte var ett teckenbarn. När hon ändå, när vi satsa på det här med talet. Så var inte det nån förlust för oss att de tog bort dövskolan i Borgå. Det har aldrig, vi fick höra, vi hade ju med, på dom här föreläsningarna så var det någon som berättade där om det, som har varit lärare på dövskolan. Hon var där på ljusa huset på den där kursen... Att hon berättade då hur skillnaden var mellan dom här döva och hörselskadade, att döva godkände inte hörapparater och inte hörselskadade. Att dom var i en egen värld, att dom liksom. Den uppfattningen, så har jag liksom bilda mig sånhän uppfattning om att, för jag känner ingenting till om dom döva. Vi har haft så fullt upp med att ta reda på dom hörselskadade, vi har inte haft tid och ork att sätta oss in överhuvudtaget i döv världen. Ingenting, jag vet, jag måste säga att jag vet hemskt lite om det, bara vad hon sade då att hur dom, hur dom liksom bara vill, tecknar och många alls inte sku ha hörapparater. Att det var en, jag förstod att det var en skild värld och en helt annan, ett helt annat system med dom döva. Hur sade hon nu det, men i alla fall blev minnet att det är en helt egen värld.

(85)

Det blir en grupp i en grupp och har ändå hemskt litet kontakt sedan med yttervärlden.

(86)

Där är en annan orsak också, med, sedan böcker. Jag älskar böcker. Det är en sak som blir hemskt svårt för ett teckenspråksbarn. Man har ju konstaterat det.

8.4.1 Receiving information on deafness

(87)

Jo, hon [hälsovårdaren på rådgivningen] sade att hon skickar remiss, remiss till Kuulonhuoltoliitto (Hörselvårdsförbundet) och vi fick tid dit, vi var på hans ett-årsgranskning i november, kom i december till Kuulonhuoltoliitto och de sade att hur har ni kommit hit, att inte ska ni ju hit till oss, att ni ska ju till HYKSen. Nå, vad vet vi vart vi ska, och där stod vi och vi sku villa, varje DAG var viktig då när han var ett år och vi visste att han borde få hjälp nu hastigt. Och han var ju ett år då och vi ska ha hörapparater. Och så hade jag pratat med någon som sa att se till sen att du får två genast för att det där, att man ska inte behöva kämpa för att få två hörapparater. Han hör dåligt på båda öronen så se till att du får två från början. Att dom ska inte alls komma och försöka bjuda ut en och det där, och då räckte det SÅ LÄNGE. Vi slapp ju först i slutet på januari till Hyksen, och det var, det var det värsta tiden i min period. Det här att vi visste att han hade, hörde inte och under tiden då så så lät vi honom slå i alla kastrullock och vi klinga i allt och vi skrek i hans öra och vi hade alla radion då när han ville hur högt, att han sku få dom här ljudena ändå. För vi visste att det är, det som är, att han njöt när han fick höra. Och då hade

vi också, vi börja genast då, och försökte med händerna. Det var värst och så får det inte ske.

8.4.2 Parents' conceptions of early habilitation

(88)

Aj, du har ett dövt barn, nå inte kan man göra något åt det. Du måste lära dig leva med det”

(89)

Vi tyckte att det var lite meningslöst att fara till dit [hörselcentralen] helt enkelt när man visste att hon sitter där och ska igen höra på de där, där sitter de och skriver sina små kurvor och kurvorna ser likadana ut och så kommer man till läkaren som säger att nu ska de, hur är det med hörapparat och såhär så att man visste den tågordningen, och tyckte det var en bortkastad dag helt enkelt.

(90)

Hm, men jag tror att alla som själva inte tecknar så känner ett slags avstånd, eller alla som inte själva tecknar så kan inte förstå som heller hur ett dövt barn fungerar. Att de kanske är rädda och sådär så hm, så då kan de inte se helheten, de kan inte se hans helhet. De som inte tecknar kan inte se hans helhet för de kan inte förstå honom. Så det säger väl sig självt då att de inte kan... Nej, men man är ändå så van och man förstår det där, att om inte de själva kan teckna så kan de ju inte förstå honom och så är det då, och så är man så van med det att det är så det fungerar, så är det ju jämt. Det är ju bara några få människor som kan teckna om man tänker på i familj, släktingar och vänner. Det är ju sällan ändå man stöter på människor som kan teckna så att det är ju som det normala att dom, att folk inte tecknar och att man fungerar som tolk.

(91)

Personalen är fixerad vid att han är döv, att han inte kan höra. Jag upplever nog att de inte kan se barnet som helhet, utan de är fixerade på skadan. Vad vi gör är, att, att när läkare inte det där kan kommunicera eller när läkare och vårdpersonal beklagar sig att de inte kan kommunicera med pojken. När situationen kommer så vänder vi på det hela och förlöjligar, så att säga gör det motsatta och vårdepersonalens reaktion nej men att oj, sidu, jag kan ju inte teckna, och nej, att jag kan ju inte, hur ska jag nu göra. Så istället för att låta läkaren sitta och voja sig över att barnet inte hör så ser vi till att läkaren får känna efter att det är ju JAG som är handikappad här för att jag kan inte nu, jag kan inte teckna, jag, jag vågar inte göra gester eller visa miner för att få igång. Utan vi vill visa vårdpersonalen hur det känns när dom inte kan kommunicera med honom. Och sen, sen när de sagt, eller ja erkänt att de inte kan. Då är det okay, då börjar nollläget och då kan vi börja diskutera barnens situation i sin helhet.

(92)

Han [läkaren] har varje gång ursäktat sig för sin dåliga svenska men jag tycker han pratar perfekt.

(93)

Ja alltså de borde ha direkt, direkt alltså kunskap. Inte bara liksom pälä, pälä, pälä, det blir nog bra och det ena och det andra, utan kunskap, alltså fakta, teori så här är det.

(94)

Alltså i början kanske man inte fatta det här, den sidan som sjukhuset ger och står för, för man kanske trodde. Alltså nu har jag som klar gräns att det är ju det som man får därifrån och sen får man det här teckenspråket, den här viktiga biten från DHBS läger och träffar och sånt. Men till en början kanske man trodde att läkarna sku ge båda då och berätta all den här informationen. Men nu så vet man ju så man försöker inte kräva något då heller, att läkarna ska ge sånt.

(95)

Man är i ett ganska sånt här, skall vi säga underligt skede, du blir liksom frusen på sätt och vis, för det är skrämmande hela situationen och då tar du inte heller emot information. Så du måste få den i olika liksom, du måste få den i början och du måste liksom bli sporrad till att kunna själv göra något och bygga dig ur det här frusna tillståndet och komma till att börja.

(96)

Mamman: Det kom så mycket information just då vi fått reda på att han var döv att det var alldeles för mycket. Det kom liksom allt.

Pappan: Det var sen också om de där hörapparaterna, det var sånt liv om de där hörapparaterna på HYKSen. Hur viktigt det var att han skulle få hörapparater genast.

Mamman: Jo, överhuvudtaget allt de kunde hjälpa med kom samtidigt som dövheten konstaterades så man trodde man var i en helt annan värld. Det var helt bortkastat på det viset.

(97)

Nä, jag skulle ha vilja ha haft ännu mera jag... Jag tror det, att det [misstanken om en hörselskada] har varit med från början. Det har liksom under en längre tid mognat och det inte något som kom plötsligt här, pang massor med information. Nej, utan jag sakna information i början och jag sög i mig allt som jag fick från alla håll och kanter.

(98)

Vi var ju fem familjer. Det var mycket viktigt, jo... Mest information fick man ut från dom, från dom här kurserna. För att det var andra föräldrar och så, då

det där, där kunde man ventilera allt möjligt. Dom hjälpte nog otroligt. Det var nog dom det som var det bästa då, att ha kontakt med andra att få höra.

(99)

Jo, man känner sig nog på sju famnars vatten emellanåt, bara det där att få prata med någon som har samma upplevelser.

(100)

Jå, men jag tycker att det är ju så hemskt hela tiden, dom får inte ge några numror, dom får inte ge. Att man kan inte säga att det finns andra. Och fast jag tycker att man uppger där att dom får ge ut, så ändå är det så att dom inte, det funkar inte. Jag tycker att det skall vara ett system då, fast en lapp där det skulle vara namn och vilka ålders barn det finns i familjen och det barnet är dövt, har blivit döv eller fötts döv eller har blivit opererad med den där hörapparat, vad heter den cochlea implantat. Att man har möjlighet att välja, eller just att det barnet sysslar med tal och inte med teckenspråk.

(101)

Nå, nu är det ju det att hon är döv och att hon egentligen borde tala.

(102)

Mamman: Man blev lite arg emellanåt också just för att det var så viktigt det här [att hon var döv och inte kunde tala]. De såg inte så hemskt mycket annat, hur, faktiskt hon kunde ju hemskt bra teckenspråk men det var inte så viktigt det inte. Man kunde nog bli lite irriterad emellanåt.

Pappan: Jo just det, när kan just själv hade, ska vi säga så här när man själv lite hade lugnat ner sig och börjat acceptera situationen så då såg man ju på det här med andra ögon. Då blev det just så här att man tyckte att kanske de sku kunna tänka på annat och inte bara på de där hörapparaterna och hela faderullan... Hon satt där och nån sa att "missä äiti, missä äiti?" och hon sku sen sitta där och låtsas höra, trycka på nån knapp.

(103)

På rådgivningen har dom bara varit positiva till att jag använder teckenspråk. Jo, det har dom varit. Nu är dom bara glada där på rådgivningen när man tecknar, att man har en kommunikation i alla fall.

(104)

Nå, inte har han [läkaren] varit negativt inställd på något vis, det har inte varit, men som neutral och frågar hur det går och så. Och nån gång fråga han om vi har tänkt på cochlea implantat och så sa jag nå och inte sa han sen något mera om det.

(105)

Mamman: Hemvägledaren har varit där och informerat också, redan i våras före han börja skolan. Han har börjat nu på hösten. Hon var där i maj hon, när han var där på en besöksdag så var hon med och informera hela klassen och alla fick prova [hör]apparater.

Pappan: Hon var ju på dagis också och informera och dom kompisarna är ju med i skolan nu på samma klass så att det har gått bra.

[- - -]

Forskaren: Och hur var lärarens inställning?

Pappan: Jo, vi var lite skeptiska där ...vi tänkte att det kan bli problem där men det är nog mycket hemvägledarens förtjänst, hon informerade på ett mycket bra sätt.

(106)

Mamman: Hur många stödtimmar skulle hon få? Vilka framtidsmöjligheter hon har. Det har hon grubblat på mycket.

Pappan: Ja, en, en liten personlighetskris. Men där, där också då så ställde vi, då också, hon hade ju på eget bevåg och förmodligen ett mycket bra samtal som vi inte vet någonting om med, med hemvägledaren på hörcentralen. På tumanhand gick de och åt hamburgare och då fick hon prata ut med henne.

(107)

Det tog ju ändå nästan ett år innan vi fick åka till Ljusa huset [Dövas Förbunds anpassningskurs] efter att vi hade fått det här beskedet. Och det var nästan för länge för där i Ljusa huset tyckte jag, det var det ställe där vi fick reda på mest, vi var ju tio dagar där. Det var det bästa vi har varit på. Jag skulle gärna villan få det så fort som möjligt för där fick man prata om de här känslorna som fanns inom en. Där förstod de det. Man fick prata om hur man har det och hur det varit ...Visst sku man gå oftare om man sku ha möjlighet men det är ju okay. Man måste ju se det som ett faktum att det är såpass få av de här barnen i Svenskfinland. Så inte kan man kräva för mycket heller... Det är mycket lättare sen när man har varit på ljusa huset.

(108)

Pappan: Vi såg de här symptomen, hörselnedsättningssymptomen ganska tidigt. Så vi hade börjat iaktta honom ganska snabbt för att få reda på om han faktiskt hör dåligt och vad vi kan göra. Men det skulle jag vilja säga här med detsamma medan jag kommer ihåg. Det viktigaste är, det viktigaste här i början är att man får en snabb, en snabb, att man snabbt kommer igång med habiliteringen. Ett år låter som en kort tid men det är en lång tid i början...

Mamman: Nå, vi tyckte, ungefär där vid ett år upptäckte vi att han kanske är hörselskadad. Men det dröjde ju ända tills han var över två år då de gjorde det [hörsel]testet.

Pappan: Och där, där.

Mamman: Och vi hade misstänkt det så länge men då först började de ta oss på allvar, att nu måste vi fara och testa.

Forskaren: Hade ni bett om att testet skulle göras tidigare, så fort ni misstänkte?

Mamman och Pappan: Jo, jo (samtidigt).

Mamman: Jo, men det blev ju sommar så vi måste vänta.

Forskaren: Blev ni inte tagna på allvar?

Pappan: Nej, och sen också på, ja på de här olika, vad heter det där man gör

den första kontrollen, den borde man kunna hoppa över fort och på vad heter det, på hälsvårdscentralerna borde man kunna hoppa över så fort som möjligt. För de kan, de vet inte någonting om det här inte, man borde komma till experterna med detsamma. Till högsta nivån, HYKSen, till HYKSen med detsamma. Mamman: Vi var ju till XX-staden (en stad nära familjens hemort) på den här första.

Pappan: Ja, men inte kan de heller. Jag anser att man borde få komma till HYKSen med detsamma. Vi kom sen till XX-staden och hon höll på med sina klockor där bakom öronen.

Mamman: Vi var först på en kontroll.

Pappan: Och hon visste inte nånting om vad hon höll på med.

Mamman: Sedan så skickade dom hem oss så vi vänta IGEN förrän vi fick fara på nästa kontroll och då först fick vi bekräftat.

Pappan: Så man borde få komma till HYKSen med detsamma, där den högsta expertisen finns så man kommer igång med antingen teckenspråk eller vad som helst. Men den här första kommunikationen måste man komma igång med snabbt. För annars är det det problemet att man inte kan kommunicera med ett barn som inte har varken. Barnet hör inte, det har inte hörapparater, det kan inte teckenspråk. DÅ blir det konflikter och det skulle man slippa. Det här ett år av gräl om man skulle komma snabbare igång...

Forskaren: Då var det ni föräldrar, ni själva som misstänkte det här? Fast ni bad om det så hände inte så mycket?

Mamman och Pappan: Nej (samtidigt).

Pappan: Så där skulle man förstås, skulle man sådär i efterskott, skulle man ha veta om det skulle man ha tryckt på och krävt det.

Mamman: Jå.

Pappan: Men man visste ju heller inte och man tänkte att nu kommer det.

Mamman: Jå, och nu litar man ju oftast på de här s.k. auktoriteterna, att de vet nog, och det är ju ganska svårt att bearbeta allt som händer.

(109)

Jag tror nog att, nog tror jag, om det skulle finnas liksom en fungerande infrastruktur så skulle du nog säkert välja, om man skulle ha ett äkta val så att säga på finlandssvenska. Därför tar ju så många och fattar det beslutet att flytta till Sverige just av den orsaken [att det inte finns en finlandssvensk dövskola]. Ditt val är då emellan att flytta til Sverige eller att integrera...skulle det ha funnits liksom en så att säga, en stark putki som skulle ha sagt att nu går du in här och så kör du så här va. Så vem säger att vi inte skulle ha valt det. Det var just därför som vi gjorde långa liksom brytnader. Att skulle det ha funnits... Skulle det ha funnits liksom en, ett stopp framför HYKS:ens dörr och det skulle ha stått en lapp där att finlandssvenska dövas föräldrar som går in här, så skulle ha haft en infrastruktur som kör det [habiliteringen] åt ett visst håll. Nog tror jag att det skulle ha legat betydligt närmare att gå den vägen om det skulle ha funnits det. Nu fanns den inte, därför började vi söka. Och så hittade vi då implantatet. Vi måste ju söka för att hitta det. Det fanns ju inte den här infrastrukturen heller.

(110)

Pappan. Och sen, det finns, det finns ett ord här som jag AVSKYR, får ni nu med det här på bandet, ett ord som jag avskyr och det är, vet ni, det är

Mamman: Är det handikappad?

Pappan: HÖRSELRESTER

Mamman: (samtidigt) hörselrester

Pappan: Nä men vad fan, hör man inte så hör man inte. Vad gör man med hörselrester om man inte hör tal men en atombomb. Jo, jag hör inte tal men en atombomb, ja men vad är nu det?

(111)

Forskaren: Så, som förälder, upplever du att man måste vara mycket aktiv själv?

Mamman: OTROLIGT

Forskaren: Tycker du att man som förälder kanske inte borde behöva vara det?

Mamman: Jo, nå i det är fallet så, så tyckte jag att, att. För mig åtminstone så tycker jag det är riktigt åtminstone en självklarhet att hon ska få en så god start i livet för att någån gång kunna bli självständig att, att det är ju kanske, hm (paus) kanske jag sist och slutligen har tänkt mest på mig själv när jag har gjort det här för henne. Att egoistiskt det att jag vill klara, att hon ska klara det, att jag ska bli, inte behövas sen mera utan hon ska få så mycket som möjligt. Och i god tid. Fort.

(112)

Jo, sen är det ju mycket det här att det inte bara är mamman, utan pappan som helhjärtat stöder det här och går med och det funkar inom familjen. Jag tror att det är mycket här, att när vi liksom, att jag hade ju så stort stöd att tex pappa var ju med på varenda en kurs, varenda rådgivning, varenda en. Att det var inte alls utlämnat åt mig det här, att sku jag ensam ha kämpat tror jag inte att jag sku ha klarat det, orkat heller, men vi var nog så tillsammans, ingen heller skyllde nånsin på den andra, att det är ditt fel att ungen är hörselskadad. Vi jobba för det, vi, vi tog det bästa ut av det, varje gång man sku till Hyksen på hösten, på våren och till Folkhälsan, alla dom här när vi sku köra till H:fors så, så det där efter när vi hade varit så visste pojken att nu far vi till McDonalds. Vi tar det sen så här, vi gör det till en positiv grej att det inte bara är att nu far vi dit...Jag tror inte att jag skulle ha klarat det ensam, allra minst med en, en pappa som skulle ha skjutit det ifrån sig. Då skulle jag inte ha stått ut, orka på det här sättet inte, nu tog jag det nästan som en livsuppgift, jag lämna helt mitt jobb och blev hemma...ekonomiskt också otroligt, en unge med så grav hörselskada kan inte lämnas åt sitt öde, du måste vara med i läxorna, du måste vara med, det är extra jobbigt med främmande språk.

(113)

Jo där det gäller hela liksom synen inom skolväsendet på, på avvikande barn, eller det vill säga på barn med handikapp. Nu vet jag inte hur det sedan är med andra slags handikapp och så här men, men det har varit, just på högstadienivå

har det varit ganska beklämmande. Och, så att, det är ju bara ett resultat av den här inställningen...man ska inte behöva kräva det [stödundervisning], då skall det vara en självklarhet. Ska vi säga så här att jag tycker att det borde vara en självklarhet att olika barn ska ha lika möjligheter. Men det är det ju inte i dag, utan det är olika barn, olika barn måste ha, ha liksom olika aktiva föräldrar och ha, ha en jäkla tur med sin skola, att, att man väljer rätt skola och rätt kommun kanske och så här.

Appendix 2

The questionnaire

THE EARLY HABILITATION OF DEAF AND HEARING-IMPAIRED CHILDREN FROM SWEDISH-SPEAKING HOMES

1. At what age was the child's hearing loss diagnosed?

2. The sex of the child: ____ girl ____ boy

3. How old is the child now? _____

4. What mode of communication do you, at the moment, use with your child? Tick the correct alternative(s).

____ Sign Language ____ signed Swedish/Finnish

____ spoken language ____ Cued Speech

____ other, what _____

5. Did you know anything about Sign Language, deafness and hearing-impairments before your child's hearing loss was diagnosed?

6. What actions were taken at the child health clinic when the hearing loss was diagnosed?

In questions 7–12, please indicate if you have not received any information.

7. When, and from whom, did you receive information about Sign Language?

8. When, and from whom, did you receive information about deaf and hearing-impaired children's development?

9. When, and from whom, did you receive information about Deaf culture, deaf organisations and parental organisations?

10. When, and from whom, did you receive information about hearing aids?

11. When, and from whom, did you receive information about cochlear implants?

12. When, and from whom, did you receive information about the possibility to receive Sign Language instruction at home?

13. Did you receive enough home Sign Language instruction?

14. Did you receive enough information about the early habilitation of deaf and hearing-impaired children? (Tick the correct alternative)

___ yes

___ no, what was missing?

The following questions concern your child's present or future education.

15. What factors influenced the choice of school for your child?

16. Is a Finnish deaf school an alternative for your child?

___ Yes, why?

___ No, why not?

17. Is a deaf school in Sweden an alternative for your child and your family?

___ Yes, why?

___ No, why not?

18. Is mainstreaming in a hearing school an alternative for your child?

___ Yes, why?

___ No, why not?

19. Do you have any requests concerning your child's education?

Thank you for your cooperation!

FRÅGEFORMULÄRET

FINLANDSSVENSKA HÖRSELSKADADE OCH DÖVA BARNNS TIDIGA HABILITERING

1. Vid vilken ålder diagnosticerades ert barns hörselskada?

2. Barnets kön: _____ flicka _____ pojke

3. Hur gammalt är barnet nu?

4. Vilket kommunikationssätt använder ni för tillfället med barnet?
(kryssa för rätt alternativ)

_____ teckenspråk _____ tecknad svenska/finska
_____ talspråk _____ Cued Speech
_____ annat, vad _____

5. Visste ni något om teckenspråk, dövhet och hörselskador innan barnets hörselskada upptäcktes?

6. Vilka åtgärder vidtogs på rådgivningen då hörselskadan upptäckts?

Vid fråga 7–12, om ni inte erhållit någon information vänligen ange även det.

7. När och av vem erhöll ni information om teckenspråk?

8. När och av vem erhöll ni information om hörselskadade och döva barns utveckling?

9. När och av vem erhöll ni information om dövkultur, dövas intresseorganisationer, föräldraorganisationer?

10. När och av vem erhöll ni information om hörapparater?

11. När och av vem erhöll ni information om cochlea implantat?

12. När och av vem erhöll ni information om möjlighet till hemundervisning i teckenspråk?

13. Erhöll ni tillräcklig hemundervisning i teckenspråk?

14. Erhöll ni tillräcklig information om döva och hörselskadade barns tidiga habilitering? (kryssa för lämpligt alternativ.)

_____ ja
_____ nej, vad saknades

Följande frågor gäller ert barns framtida/nuvarande skolgång.

15. Vilka faktorer påverkar/påverkade valet av skolgång för ert barn?

16. Är finsk dövskola är ett alternativ för ert barn?

___ Ja, varför

___ Nej, varför inte

17. Är dövskola i Sverige ett alternativ för ert barn och er familj?

___ Ja, varför

___ Nej, varför inte

18. Är integrering i hörande skola ett alternativ för ert barn?

___ Ja, varför

___ Nej, varför inte

19. Har ni önskemål i fråga om barnets skolgång och utbildning?

Tack för besväret!