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ABSTRACT

This thesis explores parental perspectives on hearing-screening of children, and the importance of the time of detection of a congenital hearing impairment for the child's development. A qualitative approach based mainly on interviews was employed, and the results were analyzed according to three different methods-empirical phenomenology, grounded theory, and case-study. The thesis is based on four Swedish studies. The first study describes parental experiences and opinions regarding neonatal hearing screening. The second study describes parental reactions to late confirmation of a congenital hearing impairment. In the third study, the parents' experiences in early and late confirmation are compared. The fourth study focuses the importance of early or late confirmation of a congenital hearing impairment for linguistic and social development. Results indicate early detection of a congenital hearing impairment facilitates understanding of the child's needs and promotes better interaction within the family. Parents clearly preferred early knowledge of whether their child had a hearing impairment or not. A late detection was associated with much uncertainty, anxiety, and frustration. Results also show the importance of early sign language acquisition for infants with a profound congenital hearing impairment, not only for language development, but also for social development. (Contains 108 references.) (CR)

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and

The Importance of Early Language Acquisition

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To my Family

Infinite possibilities by finite means

ORIGINAL PAPERS

The present thesis is based on the following four studies, referred to in the text as Study I through IV.

Study I. Magnuson, M., & Hergils, L. (1999). The Parents' View on Hearing Screening in New-borns. Feelings, Thoughts and Opinions on OAE-screening. *Scandinavian Audiology, 28(1),* 47-56.

Study II. Magnuson, M., & Hergils, L. (in press). Late Diagnosis of Congenital Hearing Impairment in Children. The Parents´ Experiences and Opinions. *Patient Education and Counseling.*

Study III. Magnuson, M., Hergils, L., & Dahlgren, L. O. (submitted). Hearing Screening of Infants. Parents Prefer Early Confirmation of Congenital Hearing Impairment.

Study IV. Magnuson, M. (2000). Infants with Congenital Deafness; on the importance of early sign language acquisition. *American Annals of the Deaf, 145(1)*, 6-14.

CONTENTS

I. INTRODUCTION

All children do not begin to speak at the same age, and it may take some time until a delayed speech development becomes obvious. Parents eventually start wondering what might possibly be wrong; why does the child not begin to talk at the age when this is expected to occur? A delay of speech development can be caused by a number of factors, and parents often fear that something might be wrong with the mind or the brain. However, it is well known that a hearing impairment of sufficient degree can lead to delay or absence of speech development with a subsequent delay of the linguistic development. Such disturbances may lead to a disability having a severe impact on the ability to communicate during all of childhood and adult life. Therefore, detection of a hearing impairment early enough to give the child appropriate support is utterly important.

The conventional tests that have been used for hearing screening in infants are difficult to standardise and to interpret (for details, See Chapter V). Even a pronounced hearing impairment may sometimes remain undetected for a long time; two or three years may elapse until the hearing impairment is confirmed. New methods are now available for detecting a hearing impairment already in newborn infants and it is assumed that these methods, when commonly available and practised, will minimise a delay of the linguistic development and speech caused by congenital hearing impairment. The habilitation for facilitating the child's development can thus be started once the impairment is confirmed.

Outline of thesis

Universal hearing screening of new-born children with the aid of otoacoustic emissions (OAE) was started in Linköping University Hospital in September 1995. The aim of the present studies was to learn about the parent's perspective on the screening activity. Interviews were carried out with a number of parents whose children had gone through hearing screening shortly after birth, both in cases where the child had normal hearing, and in cases where a hearing impairment was found. The interviews were focused on the parents' own expectations, feelings, experiences and opinions with regard to the test procedure and the result. For comparison, a number of parents were interviewed where the children had gone through conventional screening tests without detection of the hearing impairment.

The detailed results were accounted for in separate articles (Study I and II), and the overall comparison in a third one (Study III). A fourth study describes the benefit of early detection of a hearing impairment by a case study focusing on two boys. In one of them a profound congenital hearing impairment was detected the day after birth; in the other boy the detection of the hearing impairment was delayed. A study of their progress with regard to linguistic and social development, using observations and interviews with parents and teachers, was presented in a separate article (Study IV).

The present account begins with a brief description of the importance of communication and language, and proceeds with describing the developmental process in infants. There is also a description of WHO´s classification of disability and classification of hearing impairments. The account proceeds with methods for data collection and analysis used in the four studies that are included in the present investigation. Each study is then summarised with regard to its design and results. Finally, the results and conclusions of the whole investigation are discussed.

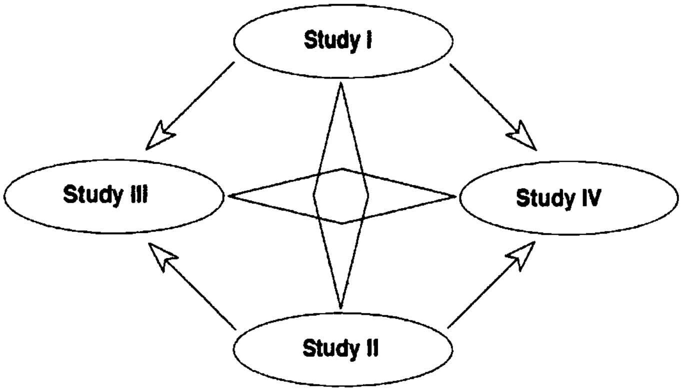

Figure 1. The four studies and their relationships. In study I the original question was addressed; the experiences of parents whose children had been involved in the new OAE hearing screening programme. Study II focused the opposite situation, namely, the experiences of parents whose children had been subject to traditional hearing screening, and where the hearing impairment had escaped detection. The two different situations were then compared in Studies III and IV. The results of the first two studies were compared with the purpose of finding differences or similarities in Study III, and in Study IV the different preconditions for linguistic development in early and late detection of a hearing impairment were examined.

II. SENSES FOR LANGUAGE

The senses of smell, taste, and touch are used both for communication and orientation by many different species, but the senses for hearing and sight are special. Hearing and sight are the two senses that are decisive for our human communication by language. The special characteristics that distinguish them from the other senses is that the ears and the eyes are able to pick up information from a distance. Sound and light are energy forms suited for transmission of linguistic information by having sufficient range and bandwidth to transfer complex messages carried in a signal that varies comparatively rapidly in time. With spoken language there is a direct feedback between speech and hearing. A major difficulty is encountered when this feedback is not operative: When a child cannot hear other people speaking, and cannot hear its own voice, it does not spontaneously acquire any ability to speak and, maybe, not even a language. A complete development of linguistic competence is still possible, provided the child is exposed to sign language so the sense of sight can take over.

On the possibilities of language

Communication by language is the basis for the human development, socially, culturally, and technically. The fully developed languages are distinguished by their unlimited capacity of expression and variation. In principle, a language can include an infinite number of words - any kind of phenomenon can be given its unique name, and new words can be created by combining different word elements, and by derivation from existing words. All spoken words are composed by a few dozen phonemes that are combined to form meaningful word parts and full words. The words are combined within a syntactic structure to form word groups and sentences, where the function of words within the sentence are marked out by the word order, suffixes, and small grammatical indicator words (Linell, 1982; Strömqvist, 1992). The language makes possible an exchange of messages, feelings, and moods between individuals. This can be accomplished with immediate result in time and space, like when somebody makes a request, or cries out a warning. But maybe the most unique aspect of language is the action at a distance in time, which makes it possible to convey a message through the time dimension, thereby passing on social patterns, imaginations, experiences, and knowledge to future generations (Humboldt, 1836). For a substantial part of our history this was accomplished only by oral tradition and, later, with the aid of the technical innovation of writing down the message (Ong, 1990). It is clear how language in contemporary society has been operational in amplifying itself in a steeply increasing exchange of information. The development of new techniques has increased the working range of language both in time and space. The techniques for printing, telegraphy, telephone, radio broadcast, television, computers, communication satellites, and the Internet – all these techniques exercise an important influence on language proficiency and, subsequently, this means a profound impact on the possibilities and lifestyles for all humans of today.

Our inborn linguistic ability

Language development begins already in early infancy when the child listens to and learns to recognise different speech sounds (Steinberg & Belsky, Ch. 6, 1991). The first recognisable expression of this early linguistic development is babbling, which is an imitation and a play with different speech sounds and intonations. Whether the parents speak French, English, or Swedish, the characteristic sounds of the spoken language dominate, and the babbling vocalisations are thus coloured by the linguistic environment (Levitt & Utman, 1992). Vocal babbling has been seen as a phenomenon based on the maturation of the vocal organs responsible for production of spoken language, but manual babbling is also observed in deaf children who are exposed to sign language. As a first step in the development of a mature semantic system, phonetic elements and units are produced by deaf and hearing children alike. Babbling is connected with the abstract nature of language and the child's expressive ability. Babbling is an expression of a non-modal, brain-based function connected with the expressive ability to produce vocalisations and signs (Petitto & Marentette, 1991). Non-modal means that the linguistic ability is not limited to vocal communication but can be expressed in different ways, for example, as sign language.

Human language thus seems to be founded on a unitary linguistic ability. In the development of spoken language as well as sign language there are similarities as regards the time course and structure (Stokoe, 1960). In analogy with other parts of developmental biology, linguistic ability seems to be both constrained and flexible. Linguistic ability is internally constrained with regard to the specific structures that may develop (phonetic and syllabic structures), but it still is flexible as concerns development of different expressive modes, such as speech and signs (Petitto & Marentette, 1991). Vocal and manual modalities are both used in vocal language since gestures are integral parts of the speech. People who use sign language also make use of accompanying gestures, and "gesture" is not synonymous with "sign". Sign language is commonly called a "gestural language" but, in addition to words, different gestures are thus also used to emphasise and clarify the meaning (Mc Neill, 1992). In analogy with vocal language, sign language should therefore be denoted manual language.

Colloquial communication

Linguistic communication (vocal or signed) can work both as a bridge and as a barrier between people. Social boundaries can be crossed or eliminated by those who recognise each other's signals and interpret them correctly. However, incompatible norms for language and communication can draw social boundaries between individuals (Nilsson & Waldemarson, 1995).

The preconditions and details in the interaction during colloquial conversation with spoken language using auditory signals described below are almost identical for sign language, which relies on visual signals. With spoken language the acoustic signal ends momentarily, permitting very limited overview. Long and complex sentence structures are difficult to overview, and casual verbal expressions therefore tend to be brief and simple, and not as grammatically correct as in written language. However, interaction during a conversation requires much attention on the part of both the speaker and the listener, and understanding speech puts great demands on short-term memory and the decoding ability of the listener. Speech is characterised by a high degree of redundancy, which facilitates the decoding process (Linell, 1982). Redundancy means that some aspects of an expression can be predicted by other characteristics of expression, or from variables associated with the circumstances of the conversation and the specific situation.

In a well working conversation the partners establish a psychological relation to each other, a reciprocal relationship where the speaker and listener can envision each other's situations. A conversation is associated with a situation that often means shared experiences, which form a tacit basis for the communication. The language does not need to be complete because comprehension is possible even with minor hints accompanied by body language. For example, eye contact, mimics, hand movements, pointing, and body posture are used to complement the speech. The listener reacts by the same means with small sounds or body language when expressing, for example, boredom, doubt, interest, expectation, or joy. The talker can continuously tune to the listener, repeating or elaborating on details if the message needs more explanation, or stopping when the listener seems already to know about the issue (Nilsson & Waldemarson, 1995). As mentioned, very nearly the same preconditions as outlined above for spoken language are valid for sign language as well.

Social life is based to a large extent on the spoken language. Therefore, anyone who has reduced hearing ability is more likely to have a problematic relationship with other people. The speech signal is blurred, which leads to frequent misunderstandings. One can hear that somebody is telling me something, but one cannot comprehend the meaning of what is being said. The ability to make oneself understood by other people may also meet with difficulty because one's own speech is poorly modulated and difficult to understand. One cannot participate in the small talk that is so important in the social interplay and this leads to a feeling of alienation (Nordén, Tvingstedt & Äng, 1990). The ability to hear also depends on external factors. A suitable physical environment with good acoustic conditions, and good light conditions for facilitating visual clues, is needed for the comprehension of speech. Also, the technique must be working in the area where the person is staying (the hearing aid, the audio-coil) (Lindholm, 1994).

Hearing impairment and linguistic development in children

Individual inborn factors together with the influence from the environment, most notably by the parents, provide the basis for language development (Apuzzo & Yoshinaga-Itano, 1995). Many children with a hearing impairment have little or no immediate contact with spoken or signed language (for details on the impact of different degrees of hearing impairment, see Chapter V). The hearing impairment excerts a negative influence on speech perception which, subsequently hinders the development of both the receptive and expressive functions. Because language (spoken or signed) is the fundament for the child's own development, a delay of language acquisition is a major obstacle for the development of other skills, namely, personal and social development, literacy and academic prospects (Marschark, 1993; Vaccari & Marschark, 1997; Diefendorf, 1999; Wilbur, 2000).

The development of language is seen best within a communication framework (interactive process) (Lacerda, 1998). From the start, spontaneous development proceeds in a close complimentary relation to other persons. The child's early behaviour is expressive, meaning that behaviour reflects emotional and physical states. The child's behaviour is also evocative and requires intervention by others who pay attention to and interpret the child's behaviour, and react to it. Eventually, the child's behaviour becomes socially obligatory as an interplay between the child and the social environment develops. This social obligation is based on mutual expectations of satisfaction of needs and emotional contact (Allwood, 1978).

Linguistic interaction; some features in the child s early communication

Most adult people cannot resist their strong instinct to make contact with small and helpless infants. It is a human trait to smile and speak in a soft baby-talk voice to the child, which invites the child to participate in a dialogue and also promotes the growth of social bonds (Snow & Ferguson, 1977; Baron, 1992). Developing a linguistic behaviour provides an interaction between child and caretaker. An isolated child does not experience any need for communication and does not develop language, or very poor language at best, despite the fact that it is born with a readiness for language development (Curtiss, 1977; de Villiers & de Villiers, 1979). Each time one responds to the child's efforts to make contact, it learns that somebody reacts and listens, and that it is profitable to communicate. Thus, the child is encouraged to continue the tentative contact seeking activity.

Children learn language first in the contact with the caregiver who uses the caregiver talk interaction pattern, "motherese" (Nelson, 1993). This process of interaction provides the child with important interpersonal experiences and knowledge of pragmatics, or social rules for communication, such as vocal turn taking, eye contact, and shared references. The interaction also indicates how words are placed in a meaningful relation (semantics), the use of suffixes (morphology), and the specific sound patterns of the own language (phonemics) (Bergen, Hutchinson & Johnston, 1994; Sachs, 1989).

It is now appreciated that the infant has a communicative competence far greater than previously believed (Jusczyk & Hohne, 1997; Trevarthen & Marwick, 1986). The ability to perceive language is present very early, and infants can perceive speech sounds and patterns and differentiate them from other sounds (Marcus, Vijayan , Bandi Rao & Vishton, 1999). A reduced input in connection with a hearing impairment leads to difficulty in developing language and social skills (Baron, 1992; Hindley & Parkes, 1999). Therefore, it is important to detect the hearing impairment early, so the difficulty can be mitigated (Robinshaw, 1995; Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). This emphasises the need for a reliable hearing test that is suitable for general screening of infants.

III. THE DEVELOPMENTAL PROCESS

The human species is characterised by its comparatively extended childhood. During their development and growth children depend on the help and protection provided by the caregiver (primarily the mother) over a long time period. In an evolutionary perspective this need for a close relationship with the caregiver may go back to previous epochs when humans were living in nature and were surrounded by a physically dangerous environment. This view is called the ethological theory, and refers to human evolution in its early stages when firm attachment to the mother was necessary for survival. Thus, the mother usually plays the central role when the child develops and socialises in interaction with her and other persons who are close to the child (Bowlby, 1969). By the interaction the child learns to understand the surrounding world and gains understanding of the self as a person in relation to others. It learns social patterns and behaviours, and the culture within the group and the society. The developmental process in children is the core in pedagogic work; one must be aware of how the process proceeds in individual children, and how different factors may influence development. Knowledge of the normal stages in development is a good point of departure but is not sufficient for understanding the dynamics of a child's development. While growing up the child's development is influenced by the people and experiences that the child meets in its contacts with the environment (Bronfenbrenner, 1979). The influencing factors are so many and so varied in different environments and from one child to another that it is impossible to envision a common pattern that is valid for all children. The process of development goes on all the time as the child's needs and skills develop and change, but it does not always proceed at a steady pace. Development is characterised by discontinuities; a child may seem to have come to a stand still, only to take a step forward when maturity and circumstances are right.

A world to explore for the infant

The infant explores its world in a systematic and purposeful manner. Already at birth the child recognises the mother's voice since, while still in the womb, it learned characteristic prosodic patterns of her voice (Kolota, 1984). After an initial state of "birth arousal", most children are somnolent and communication with the environment by sight and sound is sparse during the first two weeks. However, a newborn child can obviously imitate the caretaker by protruding the tongue, and when 12 to 21 days old it can imitate both facial and manual gestures (Meltzoff & Moore, 1977). The early interpersonal contact, the "primary inter-subjectivity", is a direct emotional exchange between mother and child characterised by face to face exchange of smiles and gentle sympathetic sounds and words. The brain mechanisms for perception go through a rapid anatomical and functional maturation, and at 5 to 6 weeks inter-subjective communication becomes more active. At the age of two months the child has formed an image of the mother, identifying her as a preferred communication partner. The exchange develops into genuine turn taking between the infant and the mother. The child rapidly learns to recognise her individual features, not only her voice and appearance, but also her personal manners of expression, and the infant's affective responses are distinctly different with strangers (Trevarthen & Marwick, 1986).

Between 4 and 6 months, as muscular strength and co-ordination improve, and as a result of maturation of the visual system, the child begins to discover things and events in the immediate environment. With increasing curiosity the child begins to grasp nearby objects. During the last part of the first year, around 9 months of age, the nature of communication changes in a way that is important for the development of the referential functions of language. The child's attention begins to alternate between interesting objects and the mother, and the child gradually begins to understand the mother's intentions as expressed by her gestures and vocalisations. This "secondary inter-subjectivity" is a process that prepares the way for learning how words refer to acts, objects, and events. It is known that utterances of infants 10 to 18 months of age serve well-intended communicative functions. Even before the child can express itself verbally the child already owns a rich repertoire of practical semantics (Trevarthen & Marwick, 1986). Thus, the child shares its experience of the world with the mother and likes to communicate about it, commenting on the surrounding world. The visual area of the brain and its motor region seem to mature before the auditory cortex and its motor region. Thus, at an age of 18 months a child who learns sign language commonly uses about 50 words, while a hearing child uses the same number of spoken words when 19 to 20 months old (Baron, 1992). In both cases, this is followed by a continuous and rapid development of the vocabulary (Rice, 1990).

Bonding and Attachment

The relationship between the child and the caretaker is of utmost importance for the infant in its future development. Bonding and attachment are concepts that stand for the emotional relation and mutual dependence between the mother and the child. It is assumed that there is a biological background for this mutual binding, but it is understood that the affective dimension in the interaction with the caretaker determines its quality.

Bonding

Bonding means the mother's binding to the infant. The process of bonding starts immediately after birth, or already before birth. Most mothers seem to have a natural inborn tendency to stay close to the child to protect it. Bonding is a natural and spontaneous process that develops when the child is healthy and the mother receives adequate support from her social environment. Stern (1995) argued that, before birth, the mother creates an image of her child but, if this view is not confirmed, and when circumstances are unfavourable, the bonding procedure and her mothering behaviour may be hindered or disturbed.

Attachment

Attachment refers to the child's relation to the mother. Bowlby (1969), developed the attachment theory, which views the infant as biologically predisposed for this attachment; every child needs to stay in close contact with the primary caretaker. For the development of attachment the primary caretaker (usually the mother) must be available and responsive to the child's needs and be able to give much attention and sensitive care throughout the period of infancy. Ainsworth (1973) defined attachment as "an affectional tie that one person forms to another specific person, binding them together in space and enduring over time".

By studying the behaviour of children in the so-called "strange situation", Ainsworth described how children differ with regard to the quality of the attachment. First the child and the mother are together in a room, the mother leaves the child with a stranger and, after a while, the mother returns. The child's reactions to the mother's leaving and returning were studied, and three different behavioural patterns were described, which relate to the child's attachment. If the mother is sensitive, empathic, and responsive, the child develops a "secure attachment" (group B). If the mother is insensitive and unresponsive, the child develops an "insecure attachment", which may be "anxious-avoidant" in which case the child seems indifferent to the mother's presence and ignores her (group A). An insecure attachment can also be "anxious-resistant", meaning that the child strives to remain close to the mother and shows anxiety when she leaves, but withdraws or shows anger when she comes back (group C) (Ainsworth, Blehar, Waters & Wall, 1978; Ainsworth, 1979). In addition to this scheme, one further group has been observed in traumatised children, an "insecurely attached disorganised/disoriented" reaction pattern (group D) (Main & Solomon, 1986).

Because the child usually develops an emotional relation with both parents, Belsky (1981) transformed the mother-infant dyad into a family system comprised of husband and wife, and including mother-infant as well as father-infant relationships. Most children thus develop a secure attachment to both mother and father (Hvang, 1981).

The caretaker's sensitivity to the child's signals and responses plays an important role. It is evident from modern attachment theory that ignoring the child's crying leads to more crying in a vicious circle (Ainsworth, 1979). If one is capable of listening to the child's signals and responses, the child learns to interact in a manner leading to synchronisation and turn taking between signals and responses given by the child and the caretaker. When this synchronisation fails to appear such an interaction does not develop. In extreme cases the child becomes helpless and ceases to respond. The child further learns that responses are meaningless and, since interaction is vital for further development of the communication, this may be detrimental for the child. Early knowledge of a child's hearing impairment makes it possible to compensate with the aid of other sensory modalities, touch and visual signals. In case of late detection of the hearing impairment the child is not deprived of emotional contact and interaction. The parents can build a well functioning interaction by eye contact, touch, and movements in a dialogue-like interplay (Stern, 1985, 1995; Trevarthen, 1996). However, a hearing impairment means that the auditive modality, which is an important means for communication, may be insufficient or totally absent.

A child with a disability

For many parents it is a traumatic experience to be confronted with the discovery that the child has a hearing impairment. It is well known that the sorrow and disappointment caused by the birth of a child with a disability and the practical problems that ensue can lead to a family crisis. Parents may silently accuse themselves or their partner of being the cause of the child's disability. When a parent already has a negative self-image, the child with a disability may be seen as a confirmation of this negative picture, which makes it more difficult for the parent to treat the child with warmth and love (Luterman, 1999).

Cullberg (1980) described four phases in the development of a crisis. The first acute phase is a state of shock, an emotional turmoil that can express itself very differently. In the second phase the emotional reactions are still strong and unstable, but the defence mechanisms are now recruited in a process of rearrangement of the whole psychic apparatus, which leads to a rational integration of reality. The third phase is characterised by processing, and is followed by the fourth phase with development of adaptation and orientation according to the new circumstances, which may ultimately lead to a complete recovery. Cullberg also stated that normal life crises, including the traumatic crisis, are preconditions for human growth and maturity. Maturity means a better insight with respect to basic conditions of life as well as knowledge of other persons' resources and limitations; a dialectic view on human development.

A traumatic event can lead to obstruction of communication between parents and child. If the mother goes through a short-lasting depression, it may have no lasting consequence but, when protracted, a depression may have negative influence on the mother-child interaction because the mother becomes insensitive to the child's signals. Teaching mothers to become more sensitive, and to realise if the child is under- or over-stimulated (interaction coaching), can reduce negative consequences (Dyregrov, 1997).

It is difficult for parents of children with a disability to create a clear picture of the child's present and future development, since the normal developmental scheme is not valid. When the presence and severity of a possible functional impairment are uncertain, parents cannot envision the future. This difficulty is accentuated if the parents have no frame of reference in which to place this new experience. Stern (1995) described this predicament by stating that a deficiency may arise concerning the ontogenesis of the parents' representation of the child. This situation is valid also for parents whose child has a single disability caused by, e.g. a hearing impairment. Yet if the child is accepted, having a child with a disability may sometimes add to the quality of mothering; a "loving more dimension" (Kalland, 1995).

When performing hearing screening in new-born children it is of great importance to observe the different reactions in parents so they can be given adequate support. One previous study on parental anxiety in connection with OAE screening was conducted in England (Watkin, Baldwin, Dixon & Beckman, 1998). The result of this study that was based on a questionnaire showed that only a few mothers experienced slight uneasiness. This uneasiness, was not seen as having been caused by the early test. Rather, the mothers were anxious because the child was taken from them when the test was done. In the Linköping screening programme one or both parents are always present during the test.

Health professionals are frequently criticised by parents of children with a disability. Negative factors for the future relation between parents and professionals must be avoided by ensuring that the diagnosis is not unduly delayed, and that the parents' knowledge and opinions are not ignored, or their ability disregarded. For avoiding a feeling of mistrust or intimidation one must emphasise that the professional care is not the only important but, rather, the parents will themselves play an important role for the continuous development of the child (Bergen & Wright, 1994).

IV. DISABILITY

World Health Organization (WHO), classification (ICIDH-2)

In the new classification from the World Health Organization (WHO) the concept of disability is used as an umbrella term for different impairments, activity limitations and participation restrictions (ICIDH-2 BETA-2 DRAFT, 1999). The ICIDH-2 stands for International Classification of Functioning and Disability, but the acronym ICIDH goes back to a former classification and is kept for historical reasons (International Classification of Impairments, Disabilities, and Handicaps). The new classification is focused on the social participation of the individual, and the concept "handicap" is replaced since the term reflects only negative aspects – a person's disadvantage with respects to the norms of society. It is stated that disability is a multidimensional phenomenon resulting from interaction between humans and the environment. ICIDH-2 does not deal only with disabilities; in fact it is about all people:

> "ICIDH-2 users must be reminded that ICIDH-2 is not a classification of persons at all. It is a classification of people's health characteristics within the context of their individual life situations and environmental impacts. It is the interaction of health characteristics and the contextual factors that produces disability. In short, it is important that individuals not be reduced to, or characterised solely in terms of their impairments, activity limitations or participation restrictions" (p. 195).

The classification according to ICIDH-2 (1999) encompasses three dimensions:
1) Body functions and structure;
2) Activities at the individual level;
3) Participation in society;

1) The body dimension comprises two classifications, one for functions of body systems, and one for the body structure. Body Functions are the physiological or psychological functions of body systems. Body Structures are anatomical parts of the body such as organs, limbs and their components. *Impairments* are problems in body function or structure as a significant deviation or loss.

2) The Activity dimension covers the complete range of activities performed by an individual. Activity is the performance of a task or action by an individual.
Activity Limitations are difficulties an individual may have in the performance of activities.
3) The participation dimension classifies areas of life in which an individual is involved, has access to societal opportunities, or faces barriers. Participation is the nature and extent of a person's involvement in the life situations in relationship to Impairment, Activities, Health Conditions and Contextual factors. *Participation restrictions* are problems an individual may have with the manner or extent of involvement in life situations.

Environmental factors have an impact on all three dimensions and are organised from the individual's most immediate environment to the general environment.
Contextual factors include both personal and environmental factors. Contextual factors represent the complete background of an individual's life and living. They include environmental factors and personal factors that may have an impact on the individual with a health condition and that individual's functional state.

Medical and social models

A disability can be seen from two different perspectives; the medical and the social models. ICIDH-2 applies an interactive, dialectic approach in trying to integrate the two perspectives. In the medical model a disability is seen as a personal problem caused by, e.g. disease or trauma. The disability is seen as a condition that requires medical intervention and treatment of the individual by professionals. According to the social model a disability is not an attribute of an individual but rather a result of a complex collection of conditions, many of which are created by the social environment. Since the disability is mainly a socially created problem, the management of the condition requires social action. It is a collective responsibility of society at large to make the necessary environmental modifications for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change. In short, disability becomes a political issue.

In general, a hearing impairment can be congenital or acquired – temporary or lasting – varying or progressive. The degree of impairment can be mild, moderate, severe or profound (uni- or bilateral). A congenital hearing impairment of a degree that requires habilitation in order to avoid negative consequences for the future development and prospects of the child is found in one or two per thousand newborn children. According to the WHO classification above with its three dimensions the poor hearing ability means an impairment of the function of the ear (the organ system for hearing, including the external ear canal, middle ear structures, inner ear, and its nervous connections). There is an activity limitation concerning the ability to hear, with implications for the ability to develop and use spoken language. There is further a participation restriction with regard to education and future professional and social life.

V. HEARING AND HEARING TESTS

Classification of hearing impairments

A hearing impairment is characterised by the difficulty of hearing that is experienced in daily life. This correlates fairly well with the result of a hearing test – the audiometrical hearing threshold for pure tones – even though pure tone audiometry involves a quite different listening situation. A person's hearing is tested with an audiometer with a number of discrete tones ranging in frequency from 125 to 8000 Hz (vibrations per second), where low frequencies denote base tones, and high frequencies are treble tones. The lowermost sound level that is required to hear a specific tone, the hearing threshold, is measured in decibel hearing level (dB HL). Zero dB HL is a very faint sound that can just barely be heard by a reference group representing the average young population with normal hearing. In a case of a hearing impairment the measured hearing threshold is higher, and the difference from the reference group indicates the hearing loss in dB. The hearing thresholds for each frequency are plotted as a series of points, which form a curve in a logarithmic diagram, the audiogram. In order to estimate the severity of the hearing impairment, the mean value is calculated for some of the frequencies that are judged to be of most importance when listening to and understanding speech. The mean of three discrete frequencies (0,5, 1 and 2 kHz) has generally been used, the pure tone average (PTA). Different ranges for PTA are defined for classifying the severity of the hearing impairment as mild, moderate, severe, or profound:

Table I: Classification of different degrees of hearing impairment

PTA, dB HL	CLASSIFICATION
< 35	mild
35 to 64	moderate
65 to 89	severe
≥ 90	profound

The values given above are used here when evaluating the degree of hearing impairment for the children under study. The classification is based on the hearing impairment in the child's best ear. In a number of EU projects the three conventional "speech frequencies" have been complimented by an additional fourth frequency (4 kHz), because it is known that this frequency does also contribute significantly to the understanding of speech, especially in background noise. In cases of hearing impairment the audiogram usually slopes rather steeply in the high frequency range, and the individual mean value as well as the intervals for PTA that are used for classification will be about 4 to 5 dB higher when calculated from the 4 frequencies, compared to values based on the three conventional ones. Accordingly, when the 4-frequency model is used, the interval from 40 to 69 dB HL is equivalent with a moderate hearing impairment.[1]

> A mild hearing impairment (< 35 dB) is associated with the practical difficulty that even though vowel sounds are heard clearly, voiceless consonants, short unstressed words, and faint speech cannot be perceived.
> A moderate hearing impairment (35 to 64 dB) means difficulty with normal speech. Most speech sounds at conversational levels are lost, but can be heard with amplification (a hearing aid). High frequency sounds, such as fricatives and short unstressed words, are not heard. The person may have difficulty learning abstract concepts, multiple word meanings, and to develop object classes.
> A severe hearing impairment (65 to 89 dB) means that a person can understand shouted or amplified speech without a hearing aid. Only loud environmental sounds and intense speech at close range can be heard. Vowel sounds and consonant group differences can be heard with amplification. Development of grammar rules and abstract meanings is delayed or missing.
> A profound hearing impairment (≥ 90 dB) means that not even intense speech sounds can be heard, and the person cannot understand amplified speech. In addition, the person is unable to hear his/her own speech production. Manual language (not vocal) plays a major role in language acquisition. A person with a profound hearing impairment may be a candidate for cochlear implantation.[1]

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[1] The information above was collected from different sources (Arlinger, 1991; Bergen et al., 1994; Lidén, 1985).

Traditional tests

Observation audiometry

Observation audiometry and play audiometry are audiometrical methods adapted for children based on watching the child's reactions to sound stimuli. In Sweden, the Boel test (Stensland Junker, 1972) is used in observation audiometry from 6 months to 1 1/2 years of age. The Boel test (Blicken Orienterar Efter Ljudet) was originally designed for testing a child with autism with respect to its communicative ability. This distraction test is still commonly used to test the hearing in children aged 7 to 9 months at well baby centres. After establishing eye contact with the child a small jingle bell is sounded behind the child's head, outside the field of view. If the child turns its head to localise the sound source, the hearing is judged to be normal. A negative response requires further hearing tests. The "Baby-test" is a similar method using a standardised sound source that emits a frequency modulated tone centred at 3000 Hz. The tone is presented at a distance of about 20 cm behind the child at a sound level of approximately 30 dB HL (Lidén, 1985; SAME, 1983; SAME, 1990).

Play audiometry

Play audiometry (Kankkunen, 1982) is a psychoacoustic test in which the child listens actively. The test is used in children aged 2 1/2 to 7 years. The hearing ability as a whole is tested, not only the function of the ear. In play audiometry the child is told to move e.g. a coloured play cube to indicate that the sound is heard. The child is not allowed to see when the investigator presents the sound stimulus via earphones, one ear at a time, by pressing a button. The tester must avoid falling into a certain rhythm, since the child can then easily learn to give responses in the same rhythm. The sound is presented with different tone frequency and sound level, and thus an estimate of the hearing threshold for different frequencies can be obtained (Barr, 1955). Presently, the test must be made by an experienced nurse or audiologist in order to obtain a reliable performance and judgement of the result. Play audiometry is an important test that is used for screening a majority of 4-year old children. The test will remain an important tool for detecting acquired hearing impairment as well as progressive forms of sensorineural hearing impairment in infants. Both the distraction and play audiometry tests can be developed further to improve their sensitivity and specificity.

Neonatal screening

Otoacoustic Emissions (OAE)

Hearing screening of newborn children can be universal, or targeted at high-risk children. The main issue is to have a method that, at low cost, can produce reliable results with a minimum of false positive and negative results. In practical use, the tests serve to identify children with a hearing impairment by sifting off the majority of those who have normal hearing. The tests that are best suited for screening of infants are Otoacoustic Emissions (OAE) and automated Auditory Brainstem Responses (aABR). In the present studies OAE was used for screening of newborns. This method was developed in the late 19-seventies by Kemp and collaborators (Kemp, 1993). The OAE test is a non-invasive and painless method where a small probe is fitted in the external ear canal (See Fig. 2).

The probe is connected to a mobile (laptop) computer which presents the stimulus and result. The OAE method is based on the fact that healthy sensory cells of the cochlea (the outer hair cells) actively emit a weak sound in response to external sound stimulation. The stimulus sound consists of short clicks that stimulate the cochlea over a wide frequency range, meaning that many hair cells are activated simultaneously. The response from the hair cells is picked up by a sensitive microphone lodged in the ear probe and, after some signal processing including averaging of the weak response signal, the emitted sound can be distinguished from external noise. Detection of a response from the inner ear requires that the hearing threshold be 30 dB or less, and that the middle ear function is normal (both the stimulus and the weak response sounds must travel over the middle ear transmission mechanism).

A clear response thus means that both the middle ear and the outer hair cells of the inner ear are functioning normally. If no response is detected, this may indicate a temporary disorder of the sound conduction that may exist during the first few days after birth owing to the presence of fetal fluid in the middle ear, or vernix in the external auditory canal. If a second OAE test does not give a positive result, an audiological assessment is done using an electrophysiological test, such as diagnostic ABR.

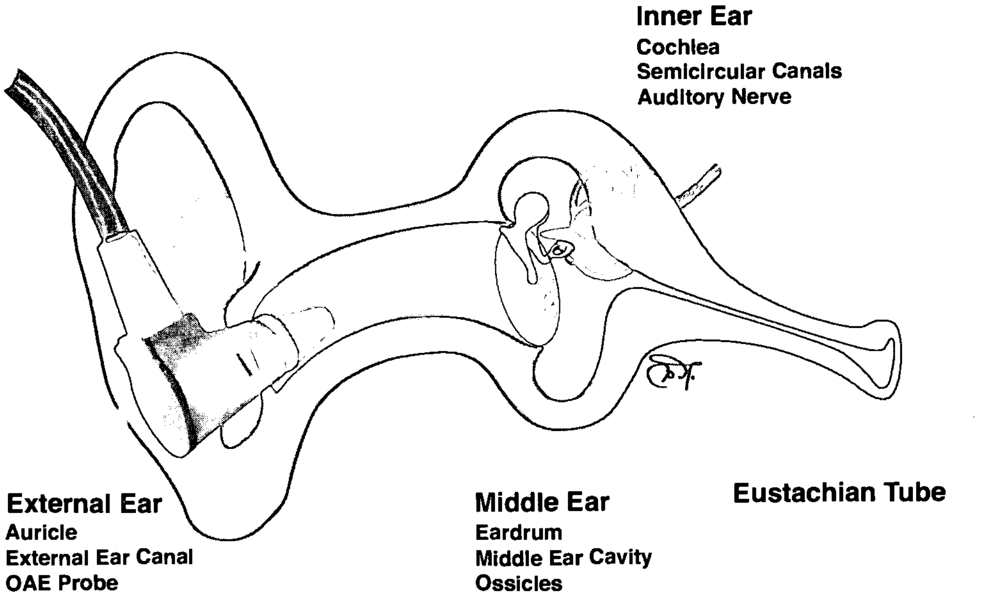

Figure 2. Schematic rendering of the external, middle, and inner ear. The OAE probe lodged in the external ear canal contains a small loudspeaker and a sensitive microphone. During an OAE test short click sounds are presented by the loudspeaker and transmitted over the eardrum and the three ossicles in the middle ear, setting up a wave motion of the basilar membrane located in the cochlea in the inner ear. The sensory hair cells that are distributed along the basilar membrane are stimulated by the wave motion, and respond by electrical impulses that travel over the auditory (cochlear) nerve to the central nervous system. The response also includes minute active vibratory movements by the hair cells. These movements are transferred backward through the ossicles and the eardrum, creating a weak echo sound in the ear canal. This sound is picked up by the microphone in the OAE probe.

In ABR the same kind of click sound as in OAE is most commonly used as auditory stimulus, and the weak electrical activity in the first relay stations in the nervous pathway (the cochlea, cochlear nerve, and brainstem) are picked up by skin electrodes. This is first tried as a screening or diagnostic test in natural rest and, if the result is inconclusive, the test is repeated in general anaesthesia. For minimising the risk of anaesthesia, this is done when the child's weight is above 5 kg. In the presence of a hearing impairment, the ABR test indicates the magnitude of the impairment. Habilitation measures can be started once the hearing impairment is confirmed.

Delayed confirmation

A differing behaviour with a poor or absent speech development is commonly the reason for suspecting the presence of a hearing impairment. One might imagine that children with congenital hearing impairment are detected at a much earlier age than is actually the case. In reality, many of these children are not detected with the aid of the conventional methods (distraction tests and play audiometry). Thus, confirmation is delayed, in some cases by one or more years. In Sweden, the average age for detection has varied from 16 to 41 months between communities. To give an idea of the magnitude of the problem I compiled data for all children from the county of Östergötland who were enrolled in the child habilitation group at the Department of Audiology, Linköping University Hospital over a period from 1990 through 1999. Tables II and III and Figure 3 present the number and age for confirmation for children with a need for intervention, and the distribution of the degree of hearing impairment. The high figures are influenced by the fact that the 4-year screening was abandoned for a period of time in part of the county. There were also four children who were born in a country other than Sweden.

Table II: Age at confirmation with regard to degree of hearing impairment, all children.

DEGREE OF IMPAIRMENT	n	MEAN AGE	MEDIAN AGE	RANGE
Profound	15	2 y	1 y 8 m	4 m — 6 y 3 m
Severe	16	2 y 7 m	2 y 3 m	10 m — 5 y 6 m
Mild-to-moderate	60	4 y	4 y 3 m	2 m — 6 y 5 m
All children	91	3 y 3 m	3 y 11 m	2 m — 6 y 5 m

Table III: Age at confirmation with regard to degree of hearing impairment, four children who were born in a country other than Sweden excluded.

DEGREE OF IMPAIRMENT	n	MEAN AGE	MEDIAN AGE	RANGE
Profound	12	1 y 4 m	1 y 6 m	4 m — 2 y 2 m
Severe	16	2 y 7 m	2 y 3 m	10 m — 5 y 6 m
Mild-to-moderate	59	4 y	4 y 3 m	2 m — 6 y 5 m
All children	87	3 y 2 m	3 y 9 m	2 m — 6 y 5 m

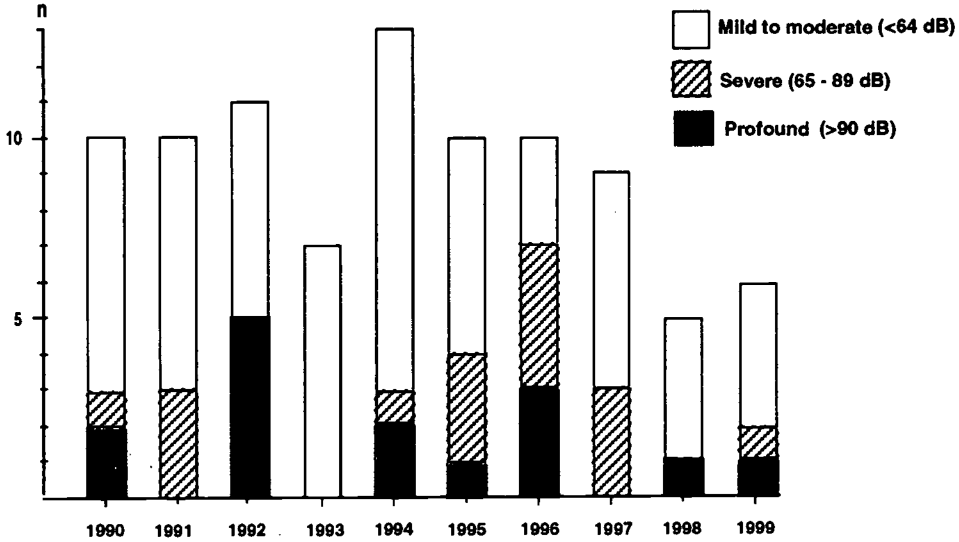

Figure 3. Number of new children who were enrolled in the habilitation group per year during the last 10 years. Classification based on the best ear.

VI. AIMS OF THE INVESTIGATION

In September 1995 universal hearing screening of newborns was introduced at the Department of Audiology, Linköping University Hospital. The early detection of hearing impaired children made possible by the test was expected to improve their future prospects by virtue of enabling an earlier start of the habilitation. Since few children are born with a hearing impairment one must thus pay attention to the fact that a large number of children with normal hearing will undergo the testing procedure. The present studies were undertaken with the aim to investigate possible consequences of the hearing screening for the involved families.

The following questions were addressed

1. How did parents experience the new OAE screening programme? What feelings, thoughts, or opinions were evoked by the screening? In the view of the parents, was their relationship with the child influenced in any way by the screening? Did parents find the new screening programme to be positive or negative?

2. What are the consequences of late detection of a child's hearing impairment as seen from the parents´perspective? What experiences, thoughts, and opinions did the parents have regarding late detection and confirmation of the child's hearing impairment? Would the parents have wanted hearing screening of their child at the maternity ward?

3. When comparing the parents' reactions with regard to different hearing screening programmes, what were the advantages and disadvantages? What experiences, thoughts, and opinions did the parents have regarding the different hearing screening programmes?

4. Are there any advantages for early detection of a hearing impairment for the child? In the parents' and teachers' perspectives, what advantages and disadvantages may be found with an early detection? This is illustrated by comparing the early language acquisition and social development in two boys, one whose bilateral profound hearing impairment was detected early and one whose impairment was detected late.

VII. METHODOLOGY

Point of departure for the present work

When the present investigation started there were two opposite views on hearing screening of newborns. One view focused on the great difficulty encountered when a child is found to have a hearing impairment, especially when the impairment is detected late. Universal OAE-screening of newborns promised to reveal the diagnosis soon after birth. This would make it possible to start habilitation very early, which would mean a great advantage for both the child and the parents. Another view was opposed to this prospect because of the fear that universal OAE-screening might result in unwanted disturbance of the parent-child relationship. After birth, and during early infancy, one should avoid performing tests and investigations that might give rise to anxiety and involve a risk of disturbing the development of this all-important relation.

This situation with the opposed views on OAE-screening was the point of departure for the present work. When the investigation was underway, the parents' experiences with regard to OAE-screening showed itself to be very positive, and the investigation developed within a pedagogic perspective. The parent's concern for providing the child with the best possibility for early language acquirement became the central theme in the present work.

When organising a screening programme like this it is important to achieve something genuinely positive for the parents and children. One must pay attention to different aspects, such as the technical and administrative aspects but, it is equally important to emphasise the parental perspective. The parents are the ones who have direct personal experience with the procedure, and they can tell others about it. It seemed natural, therefore, to ask the parents about their experience and to then compile and analyse their experiences and opinions in a systematic manner with the aid of qualitative research.

The research philosophy

In the following account, I will describe the methodology only as concerns the actual choices made in the present investigation. The choice of methods is motivated by the fact that the investigation deals with questions regarding the practical, empirical importance of hearing screening for parents and children. Given the present aim of investigating parental reactions and the intention of following up the answers – also the possible unexpected aspects that might be traced – with complimentary questions, I chose a qualitative approach based mainly on interviews. Qualitative research is often used when there is no theory, or because an existing theory does not adequately explain a specific phenomenon. Qualitative science applies an inductive research model, building abstractions and concepts that can be used to formulate new hypotheses or theories.

A qualitative research process is based on the assumption that knowledge of the world is changing, and that the individual builds up knowledge about this world with the aid of the senses and by social interaction; this is the philosophical (ontological) point of departure. The philosophy applied in the present investigation is focused on the experiential perspective; the conceptions, experiences, opinions, and ideas that are central and important for those who are attended. The aim is to describe their situation.

In the epistemological perspective one can gain knowledge about the world by investigating and describing it (Giorgi, 1985). Because a qualitative study is focused on processes, meanings, and understanding, the content must be rich enough to ensure that a correct and multidimensional description can be obtained. It is presumed here that meaning resides in people's experiences, opinions and statements, and that this meaning can be mediated and made comprehensible through observation and interpretation by the investigator.

> "The meeting with the issue of study is the start of the investigation, and the establishment of its qualities is the goal" (Eneroth, 1984, p. 81).

Context

The environment in which the object of investigation is enclosed is an aid for understanding and explaining the results. The environment is different as to time, place, and social interaction, and can never be neutral. The way of accounting for the relevant context is thus related to the ontology and the epistemological problem (Scharfstein, 1989).

Separate kinds of context that exist on different levels can be analysed and differentiated, as well as combinations of these (Säljö, 2000). The physical context pertains to the specific environment and activity. In the present work the home environment of the different families, and the sign pre-school was the physical context. The cognitive and communicative context were closely related in this case and applied to the specific experiences of the parents. In Study I the parents had experienced OAE screening and early detection of the child's hearing impairment, but had no experience of late detection. The opposite was true in Study II; the parents had experienced late detection of the child's hearing impairment, but had no knowledge of OAE-screening and early detection of the hearing impairment. In both cases, however, the historical context was similar. The interviews were carried out about a year after the confirmation of the hearing impairment. A majority of the parents had worked through their crisis and were able to describe their situation adequately, reflecting over and verbalising their experiences in great detail. In Study IV, the early versus late identification of children with hearing impairment was a new experience to the parents, but early detection was new also to the teachers at the sign pre-school, and to the auxiliary teachers from the Department of Audiology. Hearing screening of newborn babies was previously not possible, and to start habilitation in early infancy means that traditional routines no longer apply. The fact that OAE-screening was a new technique for all concerned can thus be referred to the cognitive and communicative contexts as well as to the historical context.

Design of the investigation

The persons who were selected for the present studies were recruited on a voluntary basis. The interview persons were first contacted by sending them a letter that described the aim of the study and the fact that taking part was fully optional. Acceptance was then confirmed by telephone. Most interviews with parents were performed in their own homes. The teachers were interviewed at the sign pre-school. All studies in the present investigation were approved by the ethics committee for research at the Linköping University Hospital.

A procedure of successive extension of the material was applied in the present investigation (see Figure 1). After interviewing certain groups of parents whose children had gone through OAE screening, and after analysing and publishing the results in Study I, there was a need to know more. With the aim of comparing the situation of the "OAE-families" with the situation experienced by parents whose child had a hearing impairment that was detected late, i.e., without the aid of OAE screening, a new group was investigated in Study II. New interviews were performed, and the data was analysed and published in Study II. When going out from the empirical phenomenology employed in Studies I and II, it was possible to proceed by studying the underlying structures in the category system. With access to both materials, the two different situations were compared in Study III, and for practical reasons, the comparison was accounted for in a separate article. However, there was still a need for a closer view on the family situation in early or late detection of a hearing impairment, and to describe the children's different preconditions for social and linguistic development. Two boys with bilateral profound sensorineural hearing impairment were studied in Study IV. This selection of subjects aided in facilitating a clear distinction, and in accomplishing contrast between the two different situations.

Research Procedures and Analysis

In the present investigation three research approaches were found to be suitable, mainly because they are all built on an empirical basis and can be used for qualitative analysis. Empirical phenomenology aims at studying phenomena within the individual perspective and was employed here in Studies I and II. Grounded theory includes the individual perspective but does also encompass the social dimension, and this method was used in Study III. Study IV was performed as a case-study.

Empirical phenomenology

As mentioned, Studies I and II were performed using empirical phenomenology. Phenomenology does not comprise a single delimited and uniform philosophy. The philosopher Husserl is often viewed as the "primary inventor" of phenomenology, but it can rather be defined as a manner of thinking that existed before being recognised as a philosophy (Merleau-Ponty, 1962). Husserl developed and argued for a scientific method within a philosophical and theoretical perspective, while Giorgi focused on the practical empirical level. Giorgi (1985) thus saw phenomenology mainly as a means of elaborating a method adapted to empirical issues. The object for phenomenologically grounded psychological investigations should be the world-as-experienced, and there is a strong emphasis on the inseparability of subject and world.

Going out from human experience and awareness, empirical phenomenology is a research strategy aimed at exploring the world by describing it (Giorgi, 1992). In the analysing process the researcher describes and understands the subject's concrete description, seeking to clarify the meaning of the lived experience. One can describe a generalised structure, but Giorgi means that one can describe as many structures as necessary and points out the separate steps in the procedure. The material is transcribed to yield an overview and wholeness of the matter. It is then divided into separate parts to form "meaning units". The object of the research is found in the reflected statements and opinions of the interviewed persons. The essence of the description is clarified by combining meaning units within descriptive categories (Giorgi, 1985, Alexandersson, 1981). According to Giorgi (1985) the essence is what is found to be constant within the variation, the invariate. The essential and invariate can be distinguished by describing and analysing the variation.

The aim is to discover the meaning enclosed in factual descriptions. Since reality can extend one's imaginative ability one must, as far as possible, avoid imposing any pre-formulated categories for ordering the data. Merleau-Ponty (1962) says that phenomenology should maintain a living dialectic relation between facts and possible interpretations. In order to get access to these possibilities one needs a rich supply of facts, and the study of the real empirical variation will increase our ability to understand possible variations. By actively looking for all possibilities, a structure in the relation between the subject and the world is discovered. The understanding of this meaning develops through a process of mutual exchange between the real lived experience and how it is actually described by the subject (Alexandersson, 1981).

Four concepts – description, reduction, essence, and intentionality – are central to phenomenology, and they can at the same time be used to distinguish between different phenomenological movements. In the present investigation these concepts are understood within the tradition of empirical phenomenology (Giorgi, 1985; 1994).

Description: It is assumed that the subject has actually experienced the described phenomenon, so that it can be localised to a specific time and place. The statement made by the subject describes what the subject considers to have happened, and what this means for the subject.

Reduction: The aim of reduction is to find an objective description in the set of possible variations. To understand the world of the subject, the investigator must enter this world as far as possible unbiased. Fidelity with respect to the phenomenon is essential. The analysis should be done without presumption and not go out from any specific hypothesis or theory. On a thematic level, theories can be tried to illuminate relationships in the material.

Essence: In the analysis, the desirable result of the reduction and the following reflection is to expose the essence. This essence is the fundamental or central characteristic of the experience.

Intentionality: The object towards which the consciousness of an individual is directed on a pre-reflective level, noema, can be understood in the various ways it presents itself in experiences. However, the individual is no passive receiver of sensory stimuli. Rather, the meaning of the object or event for the individual, noesis, is determined by previous experiences and knowledge. (The term intentionality has its origin in Brentano's philosophy). Intentionality is the reflected experience – how something is experienced by a real existing human being (Alexandersson, 1981; Giorgi, 1994). With this definition of consciousness and meaning as intentionality, it can be processed as fact.

Grounded theory

This method for comparative analysis was used in Study III in order to encompass the social dimension. When forming the concept of "Grounded Theory", Glaser and Strauss were inspired by the symbolic interactionism in their view of the characteristics of social life – how it works, and which aspects are meaningful to investigate in order to gain better understanding (Glaser & Strauss, 1967). Symbolic interactionism focuses on the meaning of events as experienced by individuals and the symbols that mediate the meaning (Mead, 1934). This meaning is continuously modified and developed through experience and interaction with others. The meaning is shared with other persons through the language and socialisation process. Grounded theory departs from the notion that the individual is born into and influenced by the complex reality of the social world, and the social usefulness stands out as the most important quality when determining what to study. The interest of the researcher is pragmatic and focused on practical human life, staying as close as possible to the practical empirical reality. In this scientific approach the social world and its phenomena are studied from the perspective of the actor and in the environment where the phenomenon is located. The method aims to illuminate human interaction, and to reveal the complex interaction between people and groups. A central feature of this analytic approach is "a general method of comparative analysis" (Glaser & Strauss, 1967, p. 1).

Glaser (1992) argues that the data must appear in the material and should not be pressed out of the material to accelerate the process. Glaser also emphasises the importance of avoiding pre-formed schemes and presumptions. This is fundamental to allowing concepts and patterns to emerge during the act of coding, when the researcher codes for indicators of phenomena; a process that ultimately leads to a core variable or a core process. Coding means that the researcher asks questions about the material: what do the data tell about the studied item, and what kind of event does this statement indicate? The aim is to find data that express something specific about social phenomena and processes (Glaser, 1978). Glaser & Strauss (1967) asserted the importance of a close relationship between data and daily realities: "a grounded theory that is faithful to everyday realities of a substantive area is one that has been carefully *induced* from diverse data" (p. 239).

The concrete analysis of the data can be described as occurring in different phases – substantive coding (including so called open coding and selective coding), and theoretical coding. These phases can be more or less interlaced during the procedure. In open coding, limited data segments are given substantive codes, and different concepts are defined. Comparing similarities and differences is done continuously, challenging the assumptions against the data. Selective coding means that one or more core categories are identified and described. Theoretical coding is a process characterised by a back-and forth interplay between data and assumptions of conceptual relationships. By using the substantive codes that have been created, and with the aid of theoretical codes, one tries to link the emerging concepts to core variables, which comprise the basis for the theory (Glaser, 1978).

The theories that are generated in the process may first be viewed on a conceptual level, and limited to a specific area or aspect of reality, describing how reality appears for the persons who are investigated and, specifically, the problems that are central to them (substantive theory). As the process goes on, a theory of a more general kind can be created (general theory; grounded formal theory). This is accomplished by the interplay between data collected in the actual research, and the theoretical analysis including formation of concepts, and statements of relationships between concepts. The procedure may lead to a theory with high conceptual density while maintaining meaningful variation (Glaser & Strauss, 1967; Strauss & Corbin, 1994). (See Figure 6, Chapter VIII).

Qualitative interviews

The present investigation was based on thoroughly planned qualitative interviews conducted with the aim of giving the desired information on the parent's experiences, feelings, and opinions with regard to OAE-screening, and the consequences for the child in early or late confirmation of the child's hearing impairment. The questions were constructed for the specific context. Going out from this planning with pre-defined interview questions and clarifying follow-up questions, all interviews in Studies I and II were semi-structured to permit an open dialogue with parents. All interviews were tape recorded. The recordings were typed verbatim directly after the interviews, and were complimented by notes made by the investigator during and/or immediately after each interview. Kvale states that the knowledge created by an interview is inter-relational, and points out that the data obtained is neither objective nor subjective, but inter-subjective (Kvale, 1996). By its open and non-standardised form this kind of interview is suited for gaining an in-depth qualitative material. The questions directed to the subjects were given a "Please, tell me about ..." -form to give the interviews a dialogue-like character with the intention to reach the subjects' genuine experiences, and rich and varied responses. At the beginning of the interviews the subjects were told that I wanted them to speak freely and to tell me their own experiences and opinions. The order of questions in the interview guide (see appendix) was thus not followed strictly from one point to the next since, during the early course of the interview, the subject could spontaneously take up items and give answers to questions that appear at the end of the guide, and vice versa. Further, subjects often took up questions of their own, issues that were not included in the lists.

Study I was thus based on semi-structured interviews with parents whose child had undergone OAE-screening in the newborn period. The questions covered different areas of interest: Information before the test, the test situation, the information about the result of the test, the parent's attitude towards the child, advantages and disadvantages with the screening test (see Interview guide in appendix).

Study II was conducted in the same manner. Like the first one it was based on semi-structured interviews, in this case with parents whose child had a hearing impairment that was detected late. The interviews aimed at illuminating different feelings, experiences, and opinions with respect to the confirmed hearing impairment. The areas of interest were: How and when, and by whom was the hearing impairment suspected, the parent's feelings, experiences and opinions regarding conventional hearing screening, and their attitude to hearing testing in the new-born period (see Interview guide in appendix).

Case-studies

Study IV was designed as a case-study, and the material was collected from three different sources: interviews, observations, and video recording, e.g. data triangulation. In a case study a specific phenomenon is investigated, e.g. a person, or an activity. Such a study can be a single- or multiple-case study. The cases attract interest because they are unique, or because it is of interest to find characteristic patterns by comparing them. A case-study is thus conducted to compare different acts or interaction patterns in terms of similarities and differences. The intention is to interpret, describe, and understand social phenomena, processes, and relationships (Merriam, 1998; Yin, 1994). In Study IV, I selected two individuals with the aim to investigate the linguistic and social development in early and late detection a congenital hearing impairment. The cases were first analysed and presented on an individual basis (within-case analysis) and, in a last phase the two cases were compared (cross-case analysis). (See Figure 7, Chapter VIII).

Data triangulation means that the results of a study are enriched by using different sources in the data collection when studying one and the same phenomenon to obtain a multi-faceted picture of their situations (Patton,1990). The intention was to illustrate similarities and differences in early and late detection of a profound hearing impairment by studying two real cases. The interviews formed the basis of the data collection, while observations and video recordings were used to support the analysis.

Interviews: In Study IV the interviews were semi-structured and took a dialogue-like form. An introductory first part in the interviews was structured in order to give background information on the communicative pattern in the family (see Interview guide in appendix).

Observation: Child observation is a way of getting information and knowledge about the individual child and the group, so as to be able to decide which level of development the child has reached within different areas of behaviour, and different patterns of interaction. When performing observations one must be aware of the relation to the observed person or group. Merriam (1998, p.100) describes Gold's classical typology as a spectrum of four possible standpoints, ranging from "complete participant" (member of the group being observed), over "participant as observer" and "observer as participant", to "complete observer" (unknown by the group). In Study IV my role can best be described as “observer as participant”, meaning that parents, teachers and children knew that I was observing them. In intervals, I made video recordings of the children's interaction with their mates, parents, and teachers. This was done with discretion in order not to disturb the children and the ongoing activities.

Video recording: Considering the communication between children, video recording is a means of catching details of the interaction, making it possible to focus on new aspects that were not documented during observation, and can also emphasise observed aspects. In Study IV the impression of the interpersonal dialogue was emphasised, and was subsequently given a more prominent place in the results. The result is an empirically based description of the development of the children's communication, their social and language skills.

Synthesis

Finding a basic coherence between the different phases of the research process was essential. The aim was to delimit and systematise the different phenomena pertaining to the parents' experiences of participating, or not participating, in OAE screening with their child.

Study I was done at the individual level as well as the group level by applying empirical phenomenology and using descriptive categories for analysis and description. Three groups were selected: parents whose child passed the OAE test at the first examination, parents whose child had to undergo one or more follow-up tests before passing, and parents whose child had a hearing impairment. A new constellation consisting of two groups crystallised in the process of analysis. One group comprised those who passed the first test, or passed after a single follow-up test. The parents whose child had to go through more than one follow-up test reacted differently and were referred to a second group (see Figure 4, Chapter VIII).

Study II also used empirical phenomenology and descriptive categories. The analysis was originally done at the individual level but, despite the fact that the children were of different age when the hearing impairment was confirmed, and despite that the degree of hearing impairment differed, a group level was established during the analysis (see Figure 5, Chapter VIII).

Study III followed from the empirical materials collected and analysed in Studies I and II, and the result was developed into a grounded theory. The theory becomes applicable by the fact that its main categories are founded on scrutinising empirical data for generalised relationships between concepts and descriptive categories (see Figure 6, Chapter VIII).

Study IV did not aim to compare the children as individuals but, rather, the consequences of early and late detection of the hearing impairment were compared. This was a case study, but the empirical phenomenology could be applied thanks to the fact that a large amount of data was collected. Characteristic differences between early and late detection were described using interviews with the parents and teachers, and by observations and video recording in the children's own environment, at home and in a specialised sign pre-school (see Figure 7, Chapter VIII).

Validity and Credibility

In the phenomenological approach the importance of the unique description, interpretation and explanation is emphasised, and the unique life experiences of individual persons. Phenomenology is the study of essences and also of existence and meaning. This implies that we must ask different questions and that questions are phrased differently when asking different individuals.

A researcher in qualitative science is obliged to maintain a methodical manner of work throughout the research procedure so the data collection and analysis is described in sufficient detail to permit others to judge the quality of the results. When judging the relevance of the interpretation, accuracy of the documentation is important as well as the understanding of the material and coherence in the report, i.e., that there is an internal consistency. Even though the validation is built into the whole research process in qualitative studies, it is the results that are primarily validated in the finished work (Kvale, 1996). Giorgi associates validity and reliability with the concept of essence and interpretational consciousness: "If the essential description truly captures the intuited essence, one has validity in a phenomenological sense" (Giorgi, 1988, p. 173). Kvale (1996) emphasises the communicative validity; the judgement of the communicative validity is based on how well the description is understood by the reader. Giorgi (1975, p. 96) states that the reader should "see what the researcher saw, whether or not he agrees with it".

Validity in terms of coherence or consistency means the judgement of whether the results are logically coherent or not. Larsson (1994) points out that the presence of internal logic should not be seen only as a criterion on validity but also as a more universal characteristic for judging the quality of the work as a whole. Kvale (1996) and Larsson (1994) both emphasise the importance of pragmatic validation, arguing that it goes beyond communicative validation. In the present investigation I tried to be as accurate as possible in describing the research procedure and when presenting the results, aiming to make the interpretational consciousness visible. Another aim was to show the pragmatic values of the work.

VIII. STUDIES I THROUGH IV

Summary of Study I

The aim of the study was to describe the OAE screening programme with regard to information and psychological support of parents, and if possible suggest improvements. In the parents´ view, was their relationship with the child influenced in any way by the screening? Did parents find the screening programme to be positive or negative? What feelings, thought or opinions were evoked by the screening?

The study was based on interviews, and in order to obtain an overview of different experiences and opinions, parents were recruited from 3 different well baby centres in the community. Three groups were selected: parents whose child passed the OAE test at the first examination, parents whose child had to undergo one or more follow-up-tests (re-tests) before passing, and parents whose child had a hearing impairment. In total 49 parents were interviewed, the parents of 26 children.

Results

The attitude expressed by a majority of parents was clearly positive with regard to the OAE test. The parents desire to help understand and help their child if a hearing impairment was found was a central theme expressed by all parents. They were anxious to know that the child's development would not be retarded. If they had another child, all of them would want to do the test again, even though some hesitation was expressed by parents whose child had a mild unilateral hearing impairment with no need for intervention.

The result of the study also showed that the parents' presence when the test was done promoted an attitude of reassurance and interest, due in part to the fact that they could see how the test was performed, and in part to the audiological assistant's (in Swedish: Audionom) explaining the procedure in a positive and informative manner. Much attention was paid to informing the parents and showing the test procedure at the time of the test, and informing about the probable reason when the child did not pass the test and a second test had to be done.

In the majority of parents the test caused very little anxiety. Parents whose child passed the test at the first try, or after one follow-up test, were very positive with regard to the test. However, anxiety was evoked if the child did not pass the first follow-up -test, and this reaction should be identified and appreciated. On the whole this applies only to a few parents, and it should be possible to improve counselling and communication between hospital professionals and parents. Prolonged anxiety was found in one case only, and it might have been possible to reduce this anxiety had better information and support been given.

The study showed that all parents of children who had to be tested more than twice needed support and complementary information, regardless of the final result. The anxiety diminished when parents were told the final result, when the parent-doctor contact had been established, and a plan for action could be outlined. The study also showed that parent reaction is individual and therefore it is not possible to know beforehand how much support is needed in individual cases. This depends on the individual's sensitivity to stress and capacity to comprehend information.

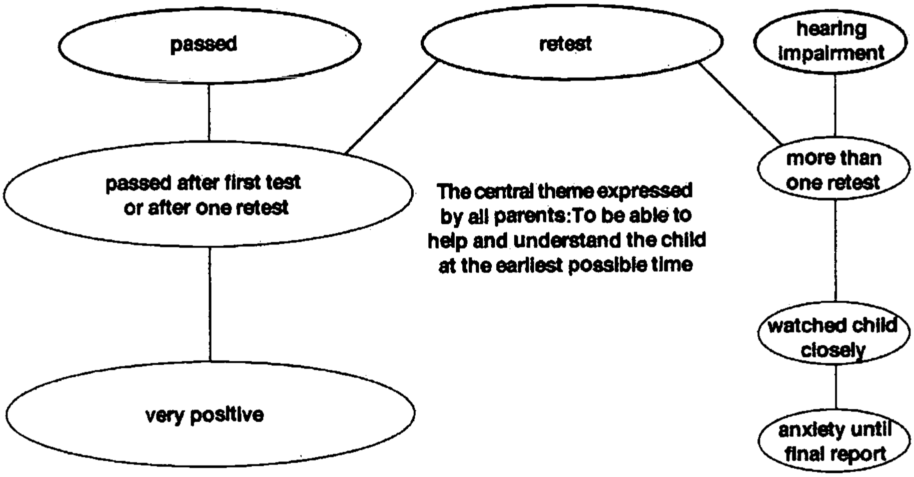

Figure 4. Analysis of the results for the different groups. The individuals included were selected with the explicit aim of describing different reactions; the reason for the three groups. Note that the proportions between groups are not representative of the whole population; among the total number of children enrolled in the OAE-screening programme, only a very small proportion was subject to follow-up testing (retest).

Conclusion and suggestions derived from the study: One practical result of the study was to improve the information to parents about the hearing screening of newborns given at the maternity ward, and to give the information earlier (at maternity welfare clinics).

Another suggestion was to improve the programme by identifying an audiological assistant (in Swedish: Audionom) to be responsible for information, for answering questions, and for serving as a contact person between parents and the department of audiology. Continuous access to professional information during the time for audiological assessment is needed to support parents and reduce anxiety.

A third aim of much importance for the parents is to shorten the waiting time for audiological evaluation for those children who do not pass a second OAE test.

Summary of Study II

This study was initiated to lend a perspective to the first study where the hearing impairment was detected in the new-born period. Study II aimed to learn about parents´ experiences, thoughts and opinions with regard to their child's hearing impairment having remained undetected for a long time. The interviews focused the following questions: How was the hearing impairment detected? What experiences and opinions did the parents have regarding the detection and confirmation of the hearing impairment? Would the parents have wanted hearing screening of their child at the maternity ward?

Ten persons were included in the study, the parents of 8 children with congenital sensorineural hearing impairment in need of habilitation. The severity of the impairment varied from mild to moderate, over severe, to profound. After a long time of uncertainty, the differing behaviour and the poor or absent speech initiated referral to the audiology department for hearing testing.

Results

The interviews showed that the parents pass through certain stages together with their child. Despite the fact that the severity of the hearing impairment varied, and despite that the impairment was detected at a different age from one child to another, the phases followed same order and time course in all. After birth there was first a calm period characterised by a feeling of security. When in contact with the caretaker and on visual contact the child babbled and reacted positively. The child appeared to thrive and the parents remained unaware of the hearing problem. Eventually the parents, usually the mother, began to suspect that something was wrong. The child did not begin to speak like other children, but had its own difficult-to-understand language, or no language at all. The child's behaviour was different from that of other children of the same age. Some of the children were very active and others were shy and, because of the difficulty in communicating verbally, the parents had many conflicts with their children. A suspicion grew that something was wrong; parents even wondered if there might be something wrong with the child's mind or brain. This phase was characterised by much uncertainty, anxiety, and frustration and lasted for a varying period of time in different families – from one year to more than two years.

Figure 5. The phases through which the parents pass together with their child.

In addition to the mandatory visits at the well baby centres, all children had been in contact with health care personnel several times before being referred to the Department of Audiology for hearing testing. As time passed, three of the eight children were treated with ventilation tubes repeatedly. In some cases the mothers had several appointments with medical care personnel because of fears that a hearing impairment might be present, without the suspicion being appreciated, and some of the parents were deeply disappointed with the medical care. All children had passed the conventional screening tests in spite of the fact that they had a hearing impairment. In one case the parents first were unwilling to believe the result of an additional hearing test because a physician at the well baby centre had primarily judged the child's hearing as being normal.

When the sensorineural hearing impairment was ultimately confirmed the parents felt relief over the fact that the child's poor speech and differing behaviour could be explained, but at the same time they felt sorrow over the child's hearing impairment.

When the hearing impairment was confirmed, all parents adapted to the new conditions, and they were now focused on helping their children. The time when habilitation measures were initiated was an important turning point both for the children and the parents.

When habilitation had been underway for some time, they noticed that the children made progress and were more joyful. The parents found that the language and social behaviour of the children improved markedly. All parents would have wished to participate in hearing screening in the newborn period, had the possibility been present.

Summary of Study III

This third study was planned with the intention of describing and comparing the consequences of early and late confirmation of a hearing impairment. However, the carrying through of the study was postponed (deliberately) until the results of the last study were present, since the empirical results in Study IV lend support to the theory that crystallised in Study III. In this manner all four studies combine to form a unit.

The aim of Study III was thus to describe and compare the parents' reactions with regard to the different hearing screening programs, using a qualitative-empirical approach based on interviews. All families were living in the same county, and the period that had elapsed from the time of detection was about the same, which provided a unique opportunity to compare the two different situations as experienced by the parents. The interviews were analysed in a two-step manner. First, descriptive categories had been defined in Study I and II. In a second step the analysis was extended here by defining core categories for the two studies; this ultimately led to common core categories.

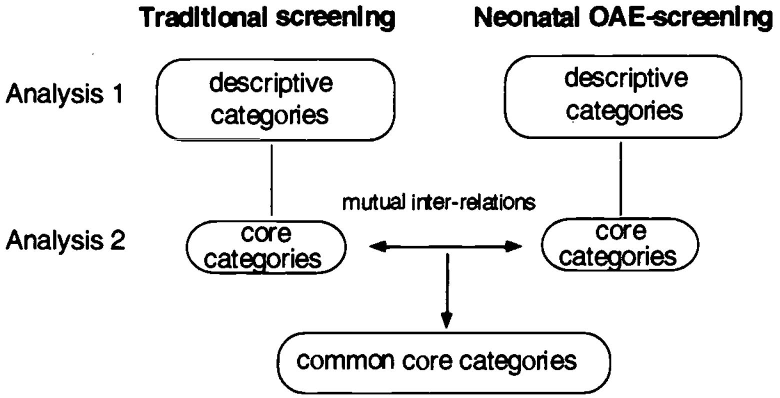

Figure 6: The two-step analysis and the final common core categories.

What similarities or differences could be found? What experiences and opinions did the parents have regarding hearing screening?

Results

The following four common core categories were discerned:

- Parents prefer early knowledge.
- Uncertainty creates anxiety.
- Information and individual counselling can reduce anxiety.
- Parents need a plan for the future.

Parents prefer early knowledge: The results show that anxiety was caused by the uncertainty of whether the child had a hearing impairment or not. From the parents' perspective, OAE- screening provides the benefit of being able to help and understand the child at the earliest possible time, should a hearing impairment be detected.

Uncertainty creates anxiety: Late detection of a child's hearing impairment obviously lead to a long and trying period characterised by uncertainty and anxiety and aggravated by recurrent conflicts between parents and child because of the disturbed communication. In cases of early detection, the anxiety experienced by the parents whose child had to undergo more than one follow-up -test with OAE was of relatively short duration and appeared while awaiting the final result of the audiological assessment.

Information and individual counselling can reduce anxiety: Both in late and early confirmation of a hearing impairment, the anxiety was relieved when a contact between the parents and professionals was established.

Parents need a plan for the future: All parents whose child was found to have a hearing impairment needed a plan for the future, regardless of whether the hearing impairment was confirmed early or late, and regardless of the degree of the impairment.

Conclusions: In early detection of the child's hearing impairment the parents can start habilitation at an early stage together with their child, and the uncertainty will be of comparatively short duration. It is important to make this period of uncertainty while awaiting the final result of the audiological assessment as short as possible, since the anxiety faded when parents were told the final result of the assessment. Early detection constitutes a considerable advantage for the child who can be given appropriate habilitation and start developing language, enabling the child to take active part in the social life within the family environment as well as outside.

Parents whose child is found to have a mild, unilateral hearing impairment also need a plan for the future. These families are not enrolled in any habilitation program, but the program could be made meaningful for this group also by establishing a parent-doctor contact and follow up. To establish a dialogue between parents and professionals, informing the parents of the degree of the hearing impairment and its consequences is a pedagogical responsibility. To optimise the potential benefit of OAE screening, the habilitation program should be adapted according to the new conditions that are present when hearing impaired infants are to be fitted with hearing aids and trained to communicate with sign language.

Summary of Study IV

Study IV aimed to describe and compare the development of linguistic and social skills related to early or late exposure to sign language. The study does not aim to compare individual children but, rather, the consequences of early and late detection of the hearing impairment are compared. The importance of an early language acquisition was illustrated by studying two boys who had a bilateral profound sensorineural hearing impairment. In one of them the hearing impairment was detected in the maternity ward with the aid of OAE. The other boy's impairment was not detected until 2 years of age. Figure 7 shows the different steps in the analysis.

Results

The early detection of the first boy's (Rasmus) hearing impairment meant that the habilitation could start at the age of 4 months, and he soon acquired sign language providing an effective two-way communication. When beginning in the sign preschool at 1 1/2 years he was thus already able to communicate, and his sign language showed continuous development. Rasmus' parents and his supervisors at the sign pre-school, including the auxiliary teachers from the audiological team, found his linguistic and social skills to be adequate and according to his age.

For the second boy (William), because of the late detection of his hearing impairment, a pre-lingual phase without words lasted more than two years. He developed his own way of communicating by pointing and pushing his parents to make them understand. William's family started sign language education when he was 2 1/2 years old, and the start was not at all easy since the old "private code" that had been developed within the family was of no use in the new environment at the sign pre-school. He had to learn new manners and an entirely new and unfamiliar language.

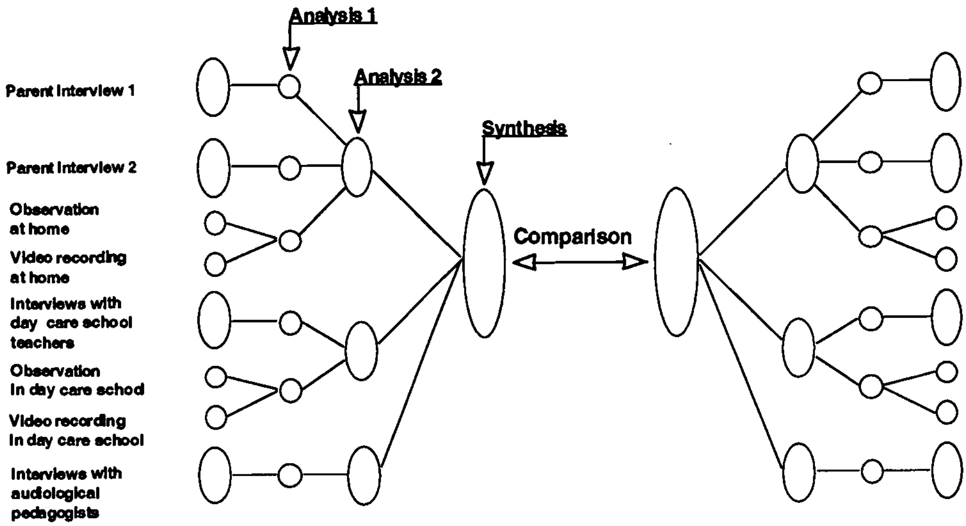

Figure 7: Scheme to show the different steps in the analysis.

The two examples demonstrated that a profound hearing impairment means a disadvantageous position for linguistic and social development, unless the impairment is detected early so linguistic stimulation can be afforded by fitting of hearing aids and sign language education. This early stimulation enables the child to gain confidence by currently knowing what is going on. The child learns where to look for visual cues, which makes communication meaningful and enables the child to feel that he/she participates in a social relationship.

Conclusions: Obvious differences could be observed between the two boys regarding their social and linguistic development related to the time of detection of the hearing impairment. This illuminates the importance of early detection and habilitation for avoiding an unwanted partitioning of individuals in different groups with differing social and academic prospects depending on good or poor linguistic stimulation during infancy.

Universal neonatal hearing-screening is the only means by which early detection and habilitation can be achieved. For a deaf child with hearing parents it is a matter of vital importance to make it possible for the child to start developing language by signing, even though the parents may eventually opt for cochlear implantation.

The specialised sign pre-school staffed by teachers skilled in sign language, and playmates, who also used sign language in their interaction, were very important for both children in gaining social and linguistic skills.

Summary of results

- Detection and confirmation of a hearing impairment using traditional methods was found to occur much later than previously assumed.
- From the parents´ perspective, OAE- screening provides the benefit of being able to help and understand the child at the earliest possible time, should a hearing impairment be detected.
- The anxiety in connection with OAE-screening reported by parents whose child had to undergo more than one follow-up -test with OAE was caused by the uncertainty of whether the child had a hearing impairment or not.
- In cases of early detection with the aid of OAE, this anxiety was of short duration and appeared while awaiting the final result of the audiological assessment.
- Late detection of a child's hearing impairment leads to a much longer and more trying period of uncertainty and anxiety with recurrent conflicts because of the disturbed communication.
- Both in early and late confirmation of the hearing impairment the anxiety was relieved when a contact between the parents and professionals was established.
- All parents whose child was found to have a hearing impairment needed a plan for the future, regardless of whether the hearing impairment was confirmed early or late, and regardless of the degree of the impairment.
- Obvious differences could be observed regarding the social and linguistic development relating to the time of detection of the hearing impairment, which illuminates the importance of early detection and habilitation in order to enable linguistic stimulation during infancy.
- Parents and teachers were all of the opinion that the specialised sign pre-school where the children were exposed to sign language was of much importance for the linguistic and social development of the children who had a profound hearing impairment.

IX. DISCUSSION

Methodological considerations

The primary purpose in the present investigation was to describe the parents' experiences and opinions, and to learn from them. Another purpose was to describe advantages and disadvantages for early detection of a hearing impairment for the child. The related issues taken up in the introduction and discussion, such as language development and habilitation of children, are included to give background information and to illuminate the problem more thoroughly. I used empirical phenomenology as the manner of working when analysing the situations as described by the parents (Giorgi, 1985). Bringing together the different studies by using grounded theory according to Glaser and Strauss (1967) was made possible by the fact that the results of the different studies were based on analysing descriptions given by the parents. Studies I, II, and IV were used to understand and describe how reality appeared for individuals. In study III, the investigation could be extended. The original descriptions formed the basis when building a theory of a more general character.

> Phenomenologists say that they describe "the intuitions that arise as a result of their perceiving the subjects express their relationships in situations, or else as a consequence of reading descriptive accounts of such situations. The intuitions so described may later cohere into categories or concepts". The grounded theorists describe "the scientific contribution as the forming of concepts to account for how subjects meaningfully relate to their situations" (Giorgi, 1994 p. 210).

For both, the foundation for the scientific labour is the same, even though the theoretical interpretation of the labour differs.

What is qualitative science about?

Behavioural science deals with increasing our comprehension of humans. Qualitative science is expected to give new understanding of the investigated phenomenon by virtue of the analysis and the arguments put forward in the presentation.

> ”A successful analysis results in a new way of seeing some aspect of reality; forming new categories and concepts for thinking, with the result that a phenomenon that was previously incomprehensible can be made plausible within a relationship that was previously unknown” (Larsson, 1994 p. 179 / my translation).

The interview form made it possible to display also the unexpected; issues not thought of before – knowledge that is not part of the concepts, thoughts, or opinions held within the medical or technical perspectives. When considering an issue that is à priori thought of as belonging to the medical and technical realms it seems to be relatively unusual to go out from the parents' perspective. That parents contribute their knowledge, and that the professionals listen to and apply this knowledge may be unusual, but parents of today want to take part, and to share the responsibilities that were once exclusively a matter for professionals. The results accounted for in Chapter VIII, and listed at the end of the chapter, were not expected. The majority of these points were revealed thanks to the interview method of data collection.

In Sweden, Otoacoustic Emissions (OAE) is a method that was previously untested for hearing screening in newborns, even though it had been used in several regions in the USA and in Europe. One previous study with favourable results had been performed in England by Watkin, Baldwin, Dixon and Beckman (1998). Mothers were followed over a nine-month period using a questionnaire. One recent study that also showed favourable results with regard to neonatal hearing screening was performed at well baby clinics in Linköping using a questionnaire (Hergils & Hergils, in press). The present investigation was initiated because it was important to extend the knowledge and to learn about the experiences and opinions of Swedish parents with regard to early OAE screening (Study I). With regard to the present investigation; was it successful in reaching new and better comprehension? Is universal neonatal hearing screening advantageous when seen from the parental perspective? Is it good for the child's linguistic and social development? Does it provide the child with better prospects concerning the linguistic and social development?

Through the interviews it was possible to find out about the positive and negative outcome of OAE screening, and whether the screening activity had given rise to parental anxiety. It was also possible to define areas where the hearing screening programme could be improved. Initially, it was hoped that when applying universal OAE hearing screening, the programme would bring something genuinely positive for parents and children, without any drawback in the form of new disquieting effects. One important point that evolved during the course of the present investigation was to study and describe the alternative possibility, i.e. to describe relevant characteristics of the traditional screening programme in the parental perspective (Study II). It was found that with the traditional program hearing impaired children were identified at a higher age than might be presumed. This is evident from Figure 3, and table II and III where I have given the time of confirmation in this county for different degrees of hearing impairment over the last 10-year period.

A critical comparison between the two possibilities showed a clear advantage for early screening in the perspective of the parents (Study III). But how about the children? The importance for the child was focused on by investigating and comparing early with late identification of bilateral profound sensorineural hearing impairment. This comparative study illuminated the benefit of early identification, and early start of habilitation, for the child's linguistic and social development (Study IV).

The practical usefulness of the present investigation thus seemed to be evident. However, Larsson (1994) states that improvement of theory is an important and integral part of qualitative research. Building a theory means "to find patterns or essential features from data" (p. 175). In this regard the research deals with systematising and delineating a specific area. The present thesis on OAE screening of infants is the first in Sweden, and the only one that is based on interviews. The work contributes by conceptualising and systematising the parents' experiences and opinions on neonatal hearing screening. The mapping and uncovering of the parent's views is seen most clearly when comparing the results of the different study groups and, additionally, by such comparison the total variation was maximised.

On the advantage of early detection

Some studies show that early detection at the age of six months or before is of great importance for the child's language development (Robinshaw, 1995; Yoshinaga-Itano, Sedey, Coulter & Mehl, 1998). These authors refer primarily to spoken language, but language development can be seen within a wider scope. In Sweden, the Swedish sign language is the official first language for the Deaf, and spoken or written Swedish is a second language (Lgr 80, 1983; Bergman, 1994). Study IV focused on the children's understanding and use of sign language in everyday situations. This study showed an obvious advantage of early detection of a congenital hearing impairment for the family and the child.

From the parents' perspective the main benefit of early detection of the hearing impairment was that the child's development would not be retarded. The results of the four studies in the present investigation show that parents want early knowledge of whether their child has a hearing impairment or not. The possibility of creating an early communication with the child by fitting of hearing aids and education in sign language was emphasised by the parents as something positive and desirable. The very positive attitudes with respect to OAE screening reported by parents in Study I do not come automatically. The best results are achieved by a well designed programme that is subject to continuous discussion, criticism, and improvement.

In cases where a hearing impairment is detected, the habilitation can start without delay; this is the primary advantage of hearing screening in the newborn period (Diefendorf, 1999). Because the degree of hearing impairment and linguistic ability varies so much between individual children, the supportive measures must be varied accordingly. Parents can be informed how to communicate with the child by using close eye contact and signs, and the infant can be fitted with hearing aids. The majority of children with hearing impairment belong to the group classified as mild-to-moderate, who can follow a normal course of development if identified and fitted with hearing aids at an early age (see Figure 3 and table II and III). In a case of severe hearing impairment, the child needs hearing aids and the family can be educated to use "sign as support". A child with a profound hearing impairment is also fitted with hearing aids, but amplification of sound is not sufficient for language development. Here, the adequate step is sign language education for the child and the whole family as early as possible, whereby the child may obtain a linguistic development according to its age (Study IV). This is important irrespective of whether the parents opt for cochlear implantation or not.

On the fear that neonatal hearing screening might create anxiety

OAE-screening is used to clear the majority of infants with normal hearing, and to identify those with a need for further assessment (Hergils, in press). Some of the parents in Study I, even though they would not chose to refrain from participating in the test, suggested that the screening would be performed later, perhaps when the child was 3 or 4 months old. The practical reason why the test is done in newborns is that one can reach all children and parents at the maternity ward. In the newborn period the child can usually sleep calmly while the test is being done, which facilitates the procedure to a high extent. At the age of 2 or 3 months the child reacts promptly on the touch and sound of the ear probe, and the child may not remain quiet, so the test tends to be much more difficult to carry out as a screening procedure. One further drawback with postponing the test is that, at this age, some children have already had their first otitis media with subsequent effusion of fluid in the middle ear. This would cause a negative effect on the screening activity since OAE does not differentiate a conductive hearing impairment from a sensorineural one. The resulting false alerts would lead to more follow-up-tests and, subsequently, more anxiety on behalf of the parents.

One motivation for the present investigation was awareness of the fear that OAE-screening of newborns might cause anxiety in the parents and disturb the early development of the parent-child relation (for details on bonding and attachment, see Chapter III). Studies related to screening for congenital hypothyroidism are often referred to in connection with psychological effects in parents (Fyrö & Bodegård, 1987; Tymstra, 1986). Parents who had received false positive results were interviewed, and many showed profound and lasting reactions, despite the fact that the final results were normal. The preconditions in the two studies on congenital hypothyroidism are thus not comparable with those of the present investigation. It might be feared, however, that similar feelings of anxiety might be released in some parents in connection with hearing screening. Study I showed that, in general, the test caused very little anxiety. Some anxiety appeared in parents whose child had to do more than one follow-up test before passing, but there was no indication of a disturbed parent-child relationship. Among the parents in Study I, prolonged anxiety was found in only one couple. When compared to the prolonged and often deep anxiety experienced by parents in cases of late detection described in Study II, the anxiety experienced in connection with OAE-screening was evidently of short duration, and in most cases this anxiety faded when parents were told the final result whether the child had a hearing impairment or not. To be anxious for the child when a hearing impairment is suspected is a natural reaction on the part of the parent. Eliminating all anxiety is impossible, but to minimise the anxiety that may arise in connection with OAE-screening must be an important goal.

The detection of a hearing impairment does not result in identical reactions in all parents, and does not necessarily lead to a crisis. There are different solutions. The mother can see her child as any other healthy child. Alternatively, she can accept that the child has a hearing impairment and tell her friends and relatives about it, which helps them to understand the difficulty. However, problems arise in cases in which the mother views the child as defective and decides to hide this fact, while continually looking for other possible defects that might affect the child (pathologising). Then, nobody can understand the mother's problem and nobody can give her support (Kalland, 1995). This difference – seeing a child with a defect, or a defective child – can maybe explain that in one case the presence of a mild hearing impairment can become a problem of larger magnitude than a profound hearing impairment in another case. The professionals involved in identification and habilitation of hearing impaired children must observe different parental reactions to be able to give adequate support; it is important to maintain an open attitude with regard to the individual need for support.

How to reduce anxiety?

One means of reducing anxiety would be to give information on the OAE screening procedure already at the maternity welfare clinic. The mother (often both parents) is present during the test according to the procedure applied in Linköping, which seems to have a positive effect by reducing anxiety. The parents could see that the child could sleep quietly while the test was being done, and that the test did not cause any pain. The positive attitude expressed by the audiological assistants (in Swedish: Audionom) and their willingness to inform parents about the test and to answer questions certainly contributed to the fact that parents did not experience anxiety when it was found that a first follow-up-test was necessary. A close contact between professionals and parents also seems important for minimising anxiety during the time for assessment of a hearing impairment, so parents can receive well informed and satisfactory answers to their questions. The final test result and the diagnosis should preferably be explained in the presence of both parents to help them understand. To receive the same information, and to share it while being together facilitates the parents' cognitive and emotional adaptation to the new circumstances.

One important point is to make the time for assessment of a hearing impairment as short as possible. The present investigation shows that uncertainty creates anxiety in the parents, both the relatively short-lasting anxiety in connection with

OAE-screening, and the more protracted anxiety that is associated with late detection of a hearing impairment. It was evident in Studies I through IV that parents want to learn as soon as possible if their child has a hearing impairment or not. It was also evident that parents with children who were found to have a hearing impairment need a plan for action in order to feel confident when facing the future. Parents want to share the responsibility and to take an active part in the habilitation process, and it is important to pay attention to them and help improve their competence. Parents whose children have a unilateral mild hearing impairment with no need for intervention need clear information that they will be offered follow-up examinations, so they understand that they are not going to be left alone, but will have opportunity to take up questions that may arise later.

Late detection means a difficult situation for children and parents

Studies II and IV focused on the difficulties encountered by children whose hearing impairment has been detected late. These children have grater difficulty in developing language and in grasping and adapting to social codes. Most of the parents had experienced much anxiety when wondering what might possibly be wrong with the children, and persevered in their efforts to find the cause. Some worried over the mental health of their child, fearing that brain damage might be the reason for the differing behaviour. Some of the children were extremely shy, while others were very active and demanding, and in some children the behaviour changed between extremes depending on the situation. There were frequent conflicts between child and parents and, seemingly, the conflicts were situation dependent and caused by poor communication and misunderstandings.

Not being able to hear or to make oneself understood means alienation for the child in its interaction and play with other children (Higginbotham, Baker, Neill, 1980). Whether this leads to social difficulties in the long time perspective for all the individual children in this investigation is unknown. However, several studies show that late detection of the hearing impairment leads to considerable delay of language acquisition and communication skills with consequent long term risk to educational achievement, mental health and quality of life (Davis, Bamford, Wilson, Ramkalawan, Forshaw & Wright, 1997; Vaccari & Marschark, 1997; Bamford, Davis, 1998).

Some of the children in Study II had difficulty adapting to their hearing aids and, according to the parents, this was in part a result of late detection. They were of the opinion that the child would have adapted more easily had the hearing impairment been detected earlier. Most of the children did however not have much difficulty adapting to their hearing aids, and in these cases the parents found that receiving the hearing aid was an important step that promoted the child's linguistic and social development.

When parents have to face the previously unknown fact that there is a hearing impairment in a child who is couple of years old, they also discover that this means a large change for the families, as shown in Study II. After a long period of worrying and many visits to doctors, the children were referred to the Department of Audiology where the diagnosis was assessed. When the parents finally knew the explanation for the differing behaviour, they felt relief, but at the same time some sense of sorrow for the hearing impairment of the child, and over the delay in identifying the impairment. The delay explains why some of the parents in Study II felt much disappointment and anger toward the medical care personnel in the home community, who had failed to detect the hearing impairment at an early age.

Why were not all children with a hearing impairment detected early?

How is it possible that the hearing impairment had not been detected earlier in the children in Study II, all of whom had repeatedly been in contact with health services? The explanation may be that traditional hearing screening tests are not sensitive enough to identify all children, in combination with a tendency to let the child pass, when in doubt, rather than taking on the burden of being ”a bearer of bad news” (Robertson, Aldridge, Jarman, Saunders, Poulakis & Oberklaid, 1995). The conventional hearing tests are obviously not sensitive enough, and a hearing impairment may seem a rather distant possibility, keeping in mind that congenital hearing impairments are relatively uncommon in the population (1 to 2 per 1000 newborn children). Another factor may be a conflict of interests between the time at disposal for the test and the child's need to adapt to the test situation. Still another factor may paradoxically reside within the child's special situation of having a hearing impairment. Because of poor hearing the child becomes more attentive to other sensory modalities. The child learns to use the peripheral visual fields more effectively (Neville, 1990), and also learns to use tactile stimuli that may occur during a hearing test (Öhngren, 1992). As a result of these compensatory mechanisms the child may appear to perceive and react to the auditory stimuli, while in fact responding to visual and tactile clues during the test. This ability to cope in the test situation is merely a reflection of the style of communication that develops within a family with a hearing impaired child. The parents subconsciously supply the child with a varied set of facial expressions, signs, and other visual clues to enable and improve understanding. Because the child responds to these clues the parents may remain unaware of the hearing impairment for a period of time. When helping the child communicate with others they translate the poor language to make it comprehensible (Bergen, Hutchinson & Johnston, 1994). Sometimes a sibling may help the child communicate (Dunn, 1993). With a poor voice quality and articulation, and even in the absence of speech, a child may still be able to communicate with the aid of a sibling who can perceive the message and serve as an interpreter between the hearing impaired child and the parents; such a case was described in Study II. However, as described in Study II and IV, there are problems outside the home environment, and when a hearing impaired child grows older.

Congenital hearing impairment as a disability

The National Institutes of Health (NIH) consensus statement (1993) and the European Consensus programme (1998) both clearly recommend hearing screening of newborns. The problems involved with late detection as well as the advantages with early detection of a hearing impairment are thus recognised at a high professional level (see scheme in Figure 8).

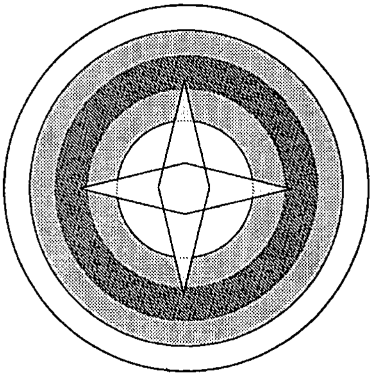

Figure 8. Scheme to illustrate the barriers in the society that affect the child with a hearing impairment. Even though the child's needs are appreciated both at the family level (inner circle) and at the high official level (outer circle), there are still many obstacles at intermediate levels in the society.

Communicative and linguistic uncertainty can lead to increased social, emotional and cognitive uncertainty (Antia & Kreimayer, 1992; Brown, Prescott, Rickards & Paterson, 1997). The negative consequences of a hearing impairment can be reduced or eliminated by medical, technical, and social means, and the view on disability benefits from integrating these different aspects. A child with a hearing impairment can be seen as belonging to a category of disabled people. This is a common but not very profitable view. It is more adequate to see an individual child among other children, a child with special needs. For a child with congenital hearing impairment, environmental as well as medical and technical factors have an impact on all three dimensions according to the WHO classification (ICIDH-2, 1999) – body functions and structure, activities at the individual level, participation in society.

The new ICIDH-2 classification with its comments can be interpreted as an ambition to let the individual have more independence and freedom with regard to the society and its institutions – a reconsidering of the subject-object relationship. According to the old view, the authority in question is the subject that decides and takes action when making an intervention, for example in a case of hearing impairment, while the individual (the patient) is the object. In the new view the relation between individual and society is more like a partnership, and the joint interest is emphasised. The individual has special needs that should be satisfied in order to facilitate his/her life and future development. To realise this is a shared interest. Access to diagnostic methods for detecting the hearing impairment as early as possible as well as access to professional help with habilitation are prerequisites for achieving an optimal development. Likewise, access to an appropriate school, further education, and working conditions will minimise the disability, i.e. the consequences of the hearing impairment.

In many of the American states there is now mandatory legislation for universal hearing screening of infants (presently 32 states, more pending). The competence that is being built up with continued education, in combination with the demand from parents, might lead to general introduction of hearing screening of newborns in Sweden. The present investigation confirms that parents want early knowledge of whether their child has a hearing impairment or not: Early identification of the impairment was clearly preferred to late detection, and this preference was expressed very distinctly. Some Swedish counties have now started up universal hearing screening programmes, and in some others there are now plans to do so.

Habilitation

One must pay attention to the fact that every child has a unique set of characteristics that will contribute to how development will proceed, and the child must be given individual support according to the conditions of its own. Thus, one important factor that will influence the development is the flexibility of the habilitation, and a program adapted to the continuous individual development can reduce the risk for a social and linguistic disability to a minimum (Apuzzo & Yoshinaga-Itano, 1995).

Speech training

In Sweden, speech training of children with hearing impairment is presently a highly controversial issue because of the fact that for a long time period a strictly applied oral method for speech training was previously enforced upon children with severe and profound hearing impairment (Bergman, & Nilsson, 1999; Nelfeldt, 1995). OAE-screening is a procedure meant for detecting children with a hearing impairment, and has no bearing on the choice of communication modality to be used. However, it seems that some people might look upon OAE-screening of newborns with reluctance or doubt because of a fear that this oral regimen will be taken up once again. Such a development does not seem probable. Rather than resorting to the old speech training according to the oral method, it seems much more probable and rational that early identification of hearing impaired children leads to a more natural language acquisition with less need for formal training. When parents become conscious of the fact that the child has a hearing impairment at a much earlier time, they will pay attention to the child's abilities and difficulties, which implies the possibility that the linguistic and social development may proceed in a natural manner in the daily interaction with the child, which was demonstrated in one of the cases described in Study IV. Early detection of a hearing impairment enables the development of a dialogue with natural turn taking.

A child has much to learn from the parents and other adults, as well as from mates (Steinberg & Belsky, Ch.7, 1991). The communication styles of the adults influence the child's ability in many ways, and the child with a hearing impairment of course needs some training, like all children do. Therefore, the non-linguistic and emotional expressions in the interaction must be integrated with the linguistic expressions. For promoting language development there is no reason to choose to follow a strict oral or manual method. Rather, one must respect the fact that the hearing as well as the cognitive abilities and separate kinds of context differ from one child to another, and to therefore use all favourable means for each individual child. An intervention departing from the mutual interest of facilitating the child's communicative ability, and based on co-operation with the parents and the child will have good opportunity to succeed. With appropriate technical aids, signing as support, or sign language, the child will have the possibility to understand what is going on and what is being said in the near environment, and will hopefully succeed in acquiring a language without too much formal training. Language acquisition means spontaneous linguistic development, while learning a language is linguistic development as a result of systematic instruction. Often, the first language is acquired and second language is learned, but recent educational trends favour a more child-centred kind of education in which the teacher's role is not so much seen as the "source for learning", but more as "a facilitator of acquisition" (Vonen, 2000).

Playing with words

Language acquisition occurs in a complex interplay between the child and the environment. Children also learn much in their interaction with other children, which is both positive and necessary for the development. Some of the parents interviewed in Study II were anxious that the poor speech of a child with a hearing impairment might cause alienation. However, the importance of fellowship with other children was also emphasised.

The course of linguistic improvement is often tested from the narrow viewpoint of the different rule systems of the language. In the long time perspective, when one tries to educate the child simply to understand and use the words correctly, this might possibly inhibit the understanding of language. The understanding of words must be permitted to carry over to different aspects in the environment. The child must have the freedom to fantasies, without too much respect for words in a ritualised sense, which can inhibit the child's development in the long run (Heath, 1986). Nursery rhymes and pun are closely related to playing, the natural expression of all children. This gives room for experimenting and for gaining linguistic consciousness without risk for failure, and this lust-filled interaction is thus important for the child (Aronsson, 1983; 1991). As concerns the sign language used by the Deaf, it is now known that it is an advanced language containing all shades of rhymes, pun, and slang expressions.

It was earlier believed that learning more than one language is deleterious for a child because the available room is restricted. Vonen (2000) states that the old ”container metaphor” is refuted by the well known fact that in many parts of the world children grow up to be bilingual or trilingual. It is utterly important to have access to one language to understand and to make oneself understood. Having two languages does not make it more difficult for the child. Rather, one language may facilitate the other, and despite the differences, spoken language and sign language can be used alternatively and support each other. A child with a profound hearing impairment, or a child with a cochlear implant, may thus benefit from being bilingual.

The sign pre-school

In Sweden there are a few special pre-schools for deaf children, but the majority of children with severe-to-profound hearing impairment are integrated in the common pre-school (as a group of hearing impaired children, or as individuals). Only a physical co-localisation does not automatically lead to integration between hearing and hearing impaired children. This does not happen spontaneously but demands conscious planning and management (Ellström, 1993). A supportive communicative style practised by the adults seems further to promote well-being and the communicative and social development of the children. The contents and quality of the interaction in combination with a positive attitude with regard to fantasy- and role-playing are factors that promote the development of the children (Preisler & Ahlström, 1997; Ahlstöm, 2000).

Study IV in the present investigation emphasised the importance of having access to the specialised sign pre-school where hearing impaired and hearing children are integrated. In the pre-school environment the children can interact and play with their mates. This is very important for all children, not least for children with a hearing impairment – and for some it is necessary for promoting language and social behaviour. A previous study in the integrated sign pre-school in Linköping showed that hearing impaired/deaf children preferred playing with their hearing impaired/deaf mates, but they also wished that the hearing children would learn sign language so they could communicate better. Likewise, even though the hearing children preferred playing with their hearing mates, they thought that it would be good to learn more sign language. Thus, according to the children, the language was of much importance for the choice of playmates (Magnuson, 1990). Educated pre-school teachers who are also proficient in sign language seem to be a prerequisite for children with profound hearing impairment to acquire the language in a playful and natural manner. In practising their supportive function, the preschool teachers are experts who must be able to read and understand the needs of the individual child, being aware of the importance of an impaired hearing, and knowing the degree of impairment for each individual child.

X. GENERAL CONCLUSION AND PRACTICAL IMPLICATIONS

It was evident that a late confirmation of a child's hearing impairment gives rise to considerable difficulty for both parents and children. Parents experienced prolonged anxiety while repeatedly trying to get help and to find an explanation for the child's differing behaviour and deficient speech. They did not only feel anxious about the child's delayed development, but they also felt much disappointment over the fact that the diagnosis had not been made earlier. Some had bad conscience over the many conflicts with the child, which arose because they could not understand the child's difficulty before the hearing impairment was confirmed.

A child's development is a process that is influenced by a large number of factors. However, there was nothing to indicate that neonatal OAE-screening had any negative influence on behalf of the child; rather, early detection and habilitation has a positive influence on the child's linguistic and social development. From the viewpoint of the parents it can be stated that early hearing screening is the preferable method. In the present investigation the parents' desire to help and understand their child as early as possible was the central point. This leads to the assumption that hearing screening in the newborn period can have positive consequences for the parent-child relation.

Parents were anxious when a child failed to pass a follow-up test, and before the final assessment of the hearing impairment was finished, The anxiety that appears in connection with early hearing screening and early detection of a hearing impairment occurs in a sensitive period for the mother. This anxiety seems to be of short duration, but there is good reason to try to minimise the anxiety by improving the screening programme and to be more sensitive to the different reactions of the parents. Once a contact with the doctor had been established it was possible to begin building a plan for the future, and more information and support was received in the contact with the habilitation team. For those of the children who had a profound hearing impairment the parents and teachers were all of the opinion that the specialised sign pre-school, where the children were exposed to sign language, was of much importance for the linguistic and social development of the children.

In the long time perspective, early detection and habilitation are important for avoiding an unwanted partitioning of individuals in different groups with differing social and academic prospects, depending on lack of early linguistic stimulation and consequent poor language acquisition. This applies in cases of bilateral hearing impairment, and especially when hearing parents have a child with bilateral profound hearing impairment. For a deaf child with hearing parents it is a matter of vital importance to provide the possibility for the child to start developing language by signing – and this applies also for children who will become candidates for cochlear implantation.

Future development — need for information

A new situation arises when universal neonatal hearing screening comes to be used commonly. The change will involve a new need for education – doctors, audiological assistants (in Swedish: Audionom), midwifes, nurses, child psychologists, pre-school teachers, and other groups, must increase their knowledge of the new preconditions that apply when hearing impairments are detected in infants at an age much younger than was previously possible. In the critical assessment period new questions from the parents arise all the time, and the professionals must have a comprehensible strategy and consensus with regard to the habilitation. The need for information, and the need for pedagogical and psychological support to the parents must be reconsidered, and the habilitation must be given new forms to be adapted to the young infants. It is also important that parents whose child is found to have a mild unilateral hearing impairment are clearly informed that the hearing will be followed up, so parents can understand that the early detection has favourable consequences for the child in the long time perspective. An acquired hearing impairment, of course, is not detected by neonatal screening and it is important to inform parents, teachers, district nurses, and school nurses how to detect an acute or progressive acquired hearing impairment. Since the hearing could previously not be tested accurately in newborns, some children who are now presumed to have congenital hearing impairment may in fact suffer from an acquired impairment. When universal hearing screening has been in effect in a population for some years it will eventually be possible to determine the real incidence of congenital hearing impairment.

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Little Fredrik, and Helena with Frida on her lap who are seen on the cover. The picture implies that the present thesis does not deal with the techniques for hearing screening; it is about people.

Bengt, my husband, and our children Martin and Karin were all in a hurry presenting theses of their own before me. Karin's foreword – ”I believe one can do everything as long as one finds joy in doing it” – has remained my lodestar.

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APPENDIX: Interview guides used in Studies I, II and IV

This interview guide is a set of to-do lists containing the different questions that I intended to ask. I had the guide available during the interviews in order not to forget any important aspects. With the intention to reach the subjects' genuine experiences, and rich and varied responses, the oral questions directed to the subjects were given in a Please, tell-me-about form to let the interviews take on dialogue-like character. At the beginning of the interviews the subjects were told that I wanted them to speak freely and to tell me their own experiences and opinions. The order of questions in the interview guide was thus not followed strictly from one point to the next. During the early course of the interview, the subjects could spontaneously take up items and give answers to questions that appear at the end of the guide, and vice versa. Further, subjects often took up questions of their own, issues that were not included in the lists. One exception to this freedom of speach is the guide on background information on linguistic stimulation at home (Study IV); this part of the interview was structured, and based on questions in the defined order.

1. Otoacoustic emissions screening: Children who passed the first test (Study I)

Child s name: **Mother** (age): **Father** (age):
Date of birth:
Siblings (number and age):

Information before the test
What is your opinion about the information regarding the test?
When did you receive information? Was the time right or should it bechanged?
Describe your own attitude with regard to the test before it was done!
Did you feel positive towards to the test? Did you have any fears with regard to the measuring instrument? Fears on behalf of the child?
The brochure explains that most children do not have impaired hearing. Did you appreciate this information?

Time of the test
Describe how you experienced the test!
When the test was done — how did you feel with regard to the child? Positive? Calm? Anxious?
How did you experience the test situation? Did you feel confident with regard to the audiologist? With regard to the measuring instrument?

Result of measurement
How were you informed about the result? How did you experience the result? Did you have any specific thoughts or feelings with regard to the child? How did you feel? (Were you glad? Anxious? Indifferent?) Please, tell me how you felt on the occasion! Tell me also how you think you would feel in case your child had not passed the test?

Attitude
If you were offered to participate in the test today, what would your answer be?
In your opinion, did the test cause you unnecessary anxiety about your child? Did the test change your attitude with regard to your child — any change of feelings or affection? To what effect? Please, tell me about your own experience!

Complimentary information
Would you take part in a hearing test already at the maternity ward in case you had a new baby?
What is your opinion about advantages and disadvantages with hearing screening?
Is there anything else you want to tell me?

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2. Otoacoustic emissions screening: Children who failed the first test (Study I)

Child s name: **Mother** (age): **Father** (age):
Date of birth:
Siblings (number and age):

Information before the test
What is your opinion about the information regarding the test?
When did you receive information? Was the time right or should it be changed?
Describe your own attitude with regard to the test before it was done!
Did you feel positive towards to the test? Did you have any fears with regard to the measuring instrument? Fears on behalf of the child?
The brochure explains that most children do not have impaired hearing. Did you appreciate this information?

Time of the test
Describe how you experienced the test!
When the test was done — how did you feel with regard to the child? Positive? Calm? Anxious?
How did you experience the test situation? Did you feel confident with regard to the audiologist? With regard to the measuring instrument?

Result of measurement
How were you informed about the result? Please, describe how you felt when you were told that a new test had to be done! How did you feel with regard to your child? (Nothing special? Anxiety? Anger?) How did you feel when waiting for the second test? Please, tell me how you felt on the occasion!
How did you experience the waiting time before the next test? Did you need to ask somebody or talk about the matter with somebody? With whom did you speak?
How did you experience the second test? (Like the first one? Did you feel more anxious?)

How did you feel when you were informed about the result of the second test? (Did you trust the result?)

Attitude

If you were offered to participate in the test today, what would your answer be?
In your opinion, did the test cause you unnecessary anxiety about your child? Did the test change your attitude with regard to your child — any change of feelings or affection? To what effect? Please, tell me about your own experience!

Complimentary information

Would you take part in a hearing test already at the maternity ward in case you had a new baby?
What is your opinion about advantages and disadvantages with hearing screening?
Is there anything else that you want to tell me?

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3. Otoacoustic emissions screening: Hearing impaired/deaf children (Study I)

Child s name: **Mother** (age): **Father** (age):
Date of birth:
Siblings (number and age):

Information before the test

What is your opinion about the information regarding the test?
When did you receive information? Was the time right or should it be changed?
Did you feel positive towards to the test? Did you have any fears with regard to the measuring instrument? Fears on behalf of the child?

Time of the test

When the test was done — how did you feel with regard to the child? Positive? Calm? Anxious?
How did you experience the test situation? Did you feel confident with regard to the audiologist? With regard to the measuring instrument?

Waiting time

How did you experience the waiting time before the next test? Did you need to ask somebody or talk about the matter with somebody? With whom did you speak?
How did you experience the second test? (Like the first one? Did you feel more anxious?)
How did you feel when you were informed about the result of the second test? (Did you trust the result?)

Result of measurement

When were you informed that your child has a hearing impairment? By whom? Did you feel that the information was given the right way? How did you experience the information?

Please, describe how you felt when you were told that your child has a hearing impairment! How did you feel with regard to your child? (Nothing special? Anxiety? Anger?) Please, tell me how you felt on the occasion!

Did you get any help or information from professionals what it means to have a child with a hearing impairment? (Who could you ask? Did you get the answers you needed?)

If you had the opportunity to choose — would you want to know about the hearing impairment early, or when the child is older? What would you choose? Please explain your opinion!

Attitude

If you were offered to participate in the test today, what would your answer be?

In your opinion, did the test cause you unnecessary anxiety about your child?

Did the test change your attitude with regard to your child — any change of feelings or affection? To what effect? Please, tell me about your own experience!

Complimentary information

Would you take part in a hearing test already at the maternity ward in case you had a new baby?

What is your opinion about advantages and disadvantages with hearing screening?

Is there anything else that you want to tell me?

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4. Late detection of hearing impairment (Study II)

Child s name: **Mother** (age): **Father** (age):

Date of birth:

Siblings (number and age):

Detection of hearing impairment

How did you find out that your child has a hearing impairment?

Was it detected at the well-baby centre? Did you detect it yourself?

Before contacting medical service and asking for help, did you think and wonder for yourself some time when trying to find out if he/she could hear?

Where did you seek contact, at the well-baby centre, or the department of Audiology?

How did it happen; were you contacted by the department of Audiology?

Was your child referred to the department of Audiology? At what age?

How was the hearing test performed?

When was the testing at the department of Audiology done? How was it done?

Were both of you present during the testing?

Report of hearing impairment

How did you think and feel when you were told that the child has a hearing impairment?
How did you react?
How did you feel about the fact that the impairment had not been detected earlier?
Were you anxious because the hearing impairment was detected so late?
How did you react? (Indifference? Anxiety? Sorrow? Desperation? Anger?)
What did you fear with regard to the child? (Speech and language development? Other fears?)
Was it all right to get the report at the time?
Would it be better to learn about it earlier; already at the maternity ward?
Tell me about your communication with the child! Between other persons in the family and the child!
Are you anxious about not being able to communicate with the child?
Have you received any help and support? How? Who supplied support? Tell me what kind of help?
What about your hopes and fears regarding your child s future?

Hearing tests in new-borns

Today the child's hearing is tested already at the maternity ward. Have you received any information about the fact that such a test is offered? Would you accept such a test in case you had another child?

Advantages or disadvantages

Do you think that it is good to detect the hearing impairment early? Do you consider it to be a disadvantage? Give me your opinion about advantages and disadvantages!
Is there anything else that you want to tell me?

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5. The communicative development: Interview with parents (Study IV)

Communication within the family

How do you regard the child's ability to understand, and to make itself understood?
How is the family members ability to understand the child and to make themselves understood?
Is there a difference in the communication between the child and the mother - father - other family members?
What seems to work well in the communication, and what does not? (Positive and negative reflections, difficulties).
Try to evaluate the child s communicative ability within the family, on a scale from 1 to 5 (To make itself understood, and to understand what the family members say). Motivate!

Communication with playmates

How does he/she do when together with mates? Is there a difference when together with children who are hearing impaired (and use sign language), as compared to hearing children?

Does the child take initiatives to contact other children to start playing? How does he/she manage?
Do other children take contact with your child?
Try to evaluate the child's communicative ability when together with other children, on a scale from 1 to 5. (To make itself understood, and to understand what other children say). Motivate!

Linguistic development

How do you evaluate the child's ability to speak (sign) in relation to its age? (Normal - early - late).
How do you estimate his/her linguistic development? Give me your impressions of his/her difficulties and progress.

Emotional reactions

How does the child react if he/she does not make him/herself understood? (Angry, sorry, withdrawn).
Do you regard the child's hearing impairment as a handicap?

Sign language - Cochlear implant

What do you think about sign language?
What do you think about cochlear implants? (Expectations?)
Have you received information on habilitation and cochlear implantation?

Future

How do you see the child's future?
What are your plans and hopes?

Interview with parents: Questions on linguistic stimulation at home (Study IV).

Do you tell or read fairy tales to the child?
Does he/she like to listen to fairy tales?
How often do you read to the child?
Who reads (mother, father, other relative?)
What kind of books do you read to him/her?
Does the child have a favourite book?
How many books of its own does the child have?
When you are reading; is the child sitting in your lap, or beside you?
Do you borrow books at the library? How often?
How many books do you borrow?
Do you read books yourselves? How often?
Do you usually explain words in fairy tales?
Does it happen that you stop reading to ask if the child understands the words and the narration of the story?
Do you connect the story to other things or events that the child has experienced?

Does the child have any records, audiotapes, or CD s?
Does the child have any favourite music?
Has the child learned any songs?
Does the child sing him/herself?
Do you or somebody else sing to the child? How often?

Does the child watch TV?
How often, and for how long?
What kind of programmes?
Does the child watch videotapes?
What kind of films?
Does the child watch alone, or is somebody else present?

What does the child like most to play or do?
Does the child like to play games? What kind of games?
Does the child take an interest in letters or numbers?
Does he/she know some letters?
How far can the child count?

Is the child enrolled in day care, pre-school, or a similar activity?
Does he/she like it?
Do you find it good or bad? Explain why!

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6. Interview with teachers at the sign preschool (Study IV)

Information on daily routines
Free play within the school
Half - structured play
Concept formation with hearing impaired children
Lunchtime and other meals
Free play in the schoolyard
How long have you been working as a teacher in the school?

Specific questions with regard to the two boys, R and W.
When did the child start school? How many days per week does the child attend school?
Did the child know any sign language at the beginning?
How was the child's linguistic development at the time (Sign language; early, normal, late for age)?

How is the child doing today? (performance of sign language).

Can the child sign so you understand? Can he express himself so that you can understand him? How well can you understand?
Does the child understand you? How do you make the child understand?

Tell me about his interaction when playing with his peers.
Is he able to make other children understand? How does he make them understand?
Does he understand other children? How do they make themselves understood?
How is the interaction when they are playing?
Does he take initiative to start playing?
Do other children take the initiative?
Is there a difference with regard to contact and interaction with children who can sign, compared to hearing children? What difference do you find?
What happens when other kids do not understand him? Tell me about his reaction!

How do you evaluate his linguistic development and his language today?
Try to evaluate the child s communicative ability with the teachers on a scale from 1 to 5. Motivate!
Try to evaluate the child s communicative ability with other children on a scale from 1 to 5. Motivate!
How do you evaluate the child s linguistic ability (Sign language; normal, early, late, very late for his/her age).
How does the child react when he does not manage to make him/herself understood? (Angry, sorry, withdrawn).
Do you notice any differences in the behaviour of the two children we have been talking about (With regard to the time of detection)? Please tell me about your observations!
Have there been any changes over time?
In your opinion, what do you think it means for the child to attend the sign pre-school? Tell me your own impressions!
Is it advantageous or disadvantageous to detect the hearing impairment early or late? What is your opinion?
Is there anything else that you think would be important to note here?

7. Interview with auxiliary teachers from the department of Audiology (Study IV)

What kind of work do you do?
How long have you worked with severely hearing impaired children?

Specific questions regarding the two boys R and W.
When did you first meet R/W and their parents?
How did they seem to react over the child's hearing impairment?

How do you evaluate the communication between R/W and their parents at the time, on a scale from 1 to 5? Motivate!

How do you think that the parents feel about the hearing impairment today?
Do the parents use sign language?
How would you judge the communication between R/W and their parents today on a scale from 1 to 5? Motivate!
From a linguistic perspective, is the development of R/W to be evaluated as early, normal, late, or very late for their age?

Can you understand what R/W is trying to communicate? How well can you understand?
Does the child understand you? How do you make the child understand?

You have also seen R/W together with their mates. How do you evaluate their communication on a scale from 1 to 5? Motivate!
Can R/W make other children understand? How do they make them understand?
Tell me about the interaction when they are playing!
Is there a difference in the interaction between R/W and children who use sign language compared to the interaction with hearing children?
Try to evaluate the communicative ability of R/W with respect to other children on a scale from 1 to 5. Motivate!
How does R/W react when he is not able to make himself understood (Angry, sorry, withdrawn).

In your opinion, what does it mean for R/W to attend the sign pre-school?
Do you see any difference in the behaviour of R/W with regard to the early or late detection of the hearing impairment? Tell me your opinion!
Has there been a change over time as regards their behaviour for as long as you have known R/W and their parents? What is your own impression?
Is there any marked difference in the parents' way of reasoning with regard to the child and its hearing impairment?
Do the parents see the hearing impairment as a handicap?

Is it advantageous or disadvantageous to detect the hearing impairment early or late? What is your opinion?
Is there anything else that you think would be important to note here?

Study I

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The parents' view on hearing screening in newborns

Feelings, thoughts and opinions on otoacoustic emissions screening

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KEY WORDS:
communication, hearing impairment, neonatal hearing screening, otoacoustic emissions, parental concern

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Since September 1995, universal hearing screening of newborns has been carried out at the Linköping University Hospital with the aid of otoacoustic emissions. The present study is based on interviews with parents in order to get their views on neonatal hearing screening. A total of 49 persons participated in the interviews, the parents of 26 children. A clearly positive attitude to the test was expressed by a majority of parents, and the screening seemed to cause very little anxiety. Parents whose child passed directly, or after one re-test, were very positive to hearing screening. The few parents whose children had to be tested more than twice took a more ambivalent view. Anxiety was evoked when the child did not pass the first re-test; this was a critical point. Another important point was when parents finally were given a definite answer as to whether the child had a hearing impairment or not; the anxiety then seemed to fade. These parents need individual counselling and support during the time of audiological assessment, and a plan for future action. From the parents' perspective the advantage of hearing screening is the potential to help and understand their child at the earliest possible time if a hearing impairment is detected.

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Introduction

Several studies show that early diagnosis of hearing impairment in children leads to obvious advantages with regard to habilitation (Greenstein et al., 1975; Markides, 1983; Greenberg, 1983; Ramkalawan & Davis, 1992; Mauk & Behrens, 1993; Apuzzo & Yoshinaga-Itano, 1995; Robinshaw, 1995). In September 1995 the Department of Audiology at the Linköping University Hospital introduced universal screening of hearing in newborns with the aid of otoacoustic emissions (OAEs). The programme was funded by national grants. The parents were offered the option of having OAE screening (without charge) as part of the general health screening at the maternity ward. They received an information brochure describing the purpose of the test and how it is performed. Parents were further informed by the maternity ward personnel and by the audiologist when the test was being performed at the ward, usually in the presence of both parents. A total of 2963 children were tested during the period from September 1995 to March 1997. During the time period, five children with different degrees of hearing impairment were identified; two had a unilateral, mild hearing impairment, one a mild hearing impairment, one a severe hearing loss, and one a profound hearing loss.

In order to reach all children, the testing was done at the hospital maternity ward. If the first test did not show normal results, a second OAE test was done as soon as possible, often when the mother and child were still in the maternity ward. As early discharge from the maternity ward (before 72h) is increasing, it was not always possible to offer OAE screening before discharge (e.g. at the weekend). These children were tested when they returned to the maternity ward for the general health screening 3 days post partum. Children who did not pass after two OAE tests were referred to the audiology department for ABR screening during rest/sleep, or diagnostic ABR under general anaesthesia. In a few children, repeated OAE testing was done in the neonatal period. The timing of complete audiological assessment was decided in consultation with the parents.

Aim of the study

The present study aims to evaluate and improve the present programme with regard to information and psychological support of parents. The study was performed as in-depth interviews to describe the parents' perspective on early hearing screening. In the view of the parents, was their relationship with the child influenced in any way by the screening? Do parents find the screening programme to be positive or negative? What feelings, thoughts or opinions were evoked by the screening?

Subjects

Parents of children belonging to three well-baby centres in Linköping were asked to participate in the interviews. The well-baby centres are situated in areas where people live in their own homes or in apartments, the socio-economics status ranging from single unemployed mothers to families where one or both parents had academic professions. The present investigation aimed to discover the views of 10 couples whose children passed the first test, and 10 couples whose children had to submit to a re-test before passing; those were chosen randomly. All parents whose children had a hearing impairment were asked to participate. Taking part in the interview was fully optional, as was the screening, but most parents who were asked did accept; only three couples were unwilling to participate.

The first group consisted of 11 mothers and 10 fathers whose child had passed the first test; in five cases the baby was their first. The second group comprised 11 mothers and 9 fathers whose child passed after re-testing, and in seven cases the baby was their first. Additionally, there were four couples whose child had a hearing impairment; two children had a unilateral, mild hearing impairment with no need for intervention, one child had mild hearing impairment and was supplied with a hearing aid, and one child had a profound hearing loss. In this third group, two of the babies were the parents' first. In total, 49 persons were interviewed, the parents of 26 children, ages ranging from 22 to 37 years for the mothers and from 24 to 45 years for the fathers. Fathers were asked to participate in the interviews because, in Sweden, fathers are generally engaged to a high degree in the birth and care of their children. Fathers are free from work for a 10-day period (paid) around the delivery to support the mother and share the joy over the newborn child. The individuals included in the present study were selected with the explicit aim of describing different reactions. It should be noted that the proportion of parents between groups is not representative of the whole population. Among the total number of children included in the OAE screening programme, only a very small proportion were subjected to re-testing.

Method, measuring instrument and analysis

This qualitative study based on interviews was designed to obtain an overview of the parents' concepts of OAE screening, both positive and negative. The results form a structure which is subsequently discussed in relation to the results of other investigations. Using qualitative methods the central issue is to encompass a wealth of content and meaning but, at the same time, good structure. A qualitative study should have heuristic value, i.e., the presentation should enable the reader to see some aspect of reality from a different angle (Larsson, 1994). To obtain an overview, the questions focused on different areas of interest, with complementary questions when needed. Specifically, the areas covered in the interviews were: information before the test, test situation, test report, parents' attitudes to the child, advantages and disadvantages of the hearing screening. The interviews were characterized by open dialogues with questions intended to find out different opinions and feelings. In most cases both parents were present during the interview. Parents were instructed that there was no need for the couple to share the same views. The important point was to speak openly about their individual experiences in connection with the screening test of the child.

To get an overview of the parents' reactions, the study was performed by the first author, who was not a member of the team involved in the screening procedure. The interviews took place 8 to 12 months after the screening test of the children and lasted between 30 and 60 min. All interviews were tape-recorded and then typed verbatim. The transcripts were done immediately after each interview and were supplemented by notes taken by the investigator. The analysis began with the collection of relevant quotes for the different areas, and units of meaning were defined. These served as a basis for analysis within each group of parents. The analysis includes both descriptions of conceptions and a study of their relationships. The analysis concerns the group level, comparison between groups, and the individual level. During the process of analysis new areas of interest were found and a new group constellation was formed.

Results

The results show that parents' views on the hearing screening test were similar on several points. The desire to understand and help their child if a hearing impairment was to be found was a central theme expressed by all parents. If they were to have another child, all would prefer to do the test again, even if some reluctance was found in parents whose children had a unilateral, mild hearing impairment with no need for intervention.

Experiences and opinions differed, however, when the larger group of parents, whose children passed after one or two tests (passed after the first or second test = 39 persons), were compared with the smaller group, whose children had to be re-tested more than once (more than one re-test = 10 persons). When the child passed after the first or second test the parents reacted very positively and were pleased to get confirmation that all was well. However, cases where the child did not pass the re-test aroused anxiety. The parents explained that they watched the child closely to find out if s/he could hear or not. Here, individual reactions concerning the test were present depending on how the parents experienced the treatment that was offered.

Information before the test

All parents. All 49 parents who were interviewed learned about the screening of newborns only on arrival at the maternity ward. Many of the parents (29 of 49) considered the hearing test to be part of the general check of the newborn baby and that it was appropriate to be given information shortly after delivery. Most of them had no memory of the information brochure that was given to them at the maternity ward, since "there were so many other things around". Only a few remembered the brochure, and only one person claimed to be able to understand the written information at the time. When reading the brochure at a later date, many found it informative and interesting. Several parents (20 persons) would have preferred to have been given information before the delivery, e.g., at the maternity welfare clinic. Many parents expressed great interest in learning how it is possible to test the hearing of newborns. The fathers took part to a large degree; 17 of the 26 fathers were present during the screening tests.

None of the interviewed had parents or siblings with congenital hearing impairment. A few of the mothers had had previous contact with hearing impaired or deaf persons at work or in private life. In advance of the hearing test, there did not seem to be any fear for the child regarding the measuring equipment.

Measuring procedure

Passed after the first or second test. All 39 parents in this group considered that the measurement was done quickly and smoothly. The information that was given at the time of measurement was found to be valuable. The audiologists demonstrated and explained, and the parents felt confident. Parents of children who passed the first test all found that the measurement caused no discomfort at all. These parents reacted positively; they felt very pleased that all was well with the child's hearing. Parents whose children failed the first test were informed by the audiologist that the presence of fetal fluid in the middle ear or vernix in the ear canal could be the reason; they were thus satisfied with the explanation as to why the child needed a re-test. Two of the mothers whose child was their first would have preferred to wait 2 weeks rather than doing the test when the child was only 1 or 2 days old.

More than one re-test. The 10 parents whose children had to be re-tested more than once expressed that they were anxious when their child did not pass the first re-test. The results also showed that these parents had experienced the hearing tests to be more problematic than other parents who were interviewed, and here there were individual experiences. The parents were unaware of the time required for a final evaluation of the hearing in infants, and had difficulty accepting the time delay. Since they found the time delay to be long, they would have preferred the test later on, when the child was about 1 month old. The parents whose child passed after several re-tests were contacted by telephone after the third test, and the audiologist gave more information which reassured them.

Parents' attitude to the child, positive and negative influence

Passed after the first or second test. For parents of children who passed after the first test, or after one re-test, their attitude towards the child did not seem at all influenced in a negative way. Rather, positive reactions were expressed by many: "I find this to be an excellent way of finding out if there is anything wrong at the earliest possible time and of being reassured knowing that everything is all right. That is what I think". None of the parents whose child passed after one re-test seemed to feel anxiety. "No, I don't think that it was disturbing at all."

More than one re-test. The couple whose child had to be re-tested several times before they learned that the child had normal hearing, and the parents of children in whom a hearing impairment was found, experienced a change of attitude; namely, they watched the child more closely. Could s/he hear or could s/he not? Ultimately, when the answer came after audiological evaluation, the parents felt assured, and adapted to the situation. They believed that they already knew the truth, and this seems to confirm that they observed the child in a way which they probably would not have done if the early screening not had been performed.

The mother of a child with normal hearing: "... to tell the truth, we found out that he reacted to sounds. As matters were, we wondered and watched, and so. I don't think I would otherwise have done that." In this case no prolonged anxiety can be traced after the mother learned that the child's hearing was normal: "I let it go, no that has certainly not left any such traces." The mother of a child with mild hearing impairment supplied with a hearing aid: "We tried out in the beginning, so we knew he reacted to sound." The mother of a child with profound hearing loss: "Yes, we understood because when we came home we were rebuilding (our home) and he didn't react. Now, we tried to find out, and were thinking so much, you know." In these cases, after getting the report on the hearing impairment, a positive influence could be seen as an effect of the parents' early knowledge of the hearing impairment. "He has not suffered in any way from it, not that we have been influenced in such a way, no I don't believe that"—"Yes, it is good that they find out so early, then. It is important, I can see that. It is important to get started as soon as possible, that's what I think."

The mother of a child with unilateral, mild hearing impairment with no need for intervention: "I didn't think she had bad hearing, I thought she could hear, I checked that she turned and such things." During the time interval that elapsed until the hearing assessment was done at the Audiology Department the parents experienced anxiety, but this was released when they were informed and had a plan for future action: "Not since I was there the last time.—Before, I was wondering more, but, after, I don't think I have worried any more."

In the present study there was only one case where the parents were still anxious, and this might have had a negative influence on the child. In this case a unilateral, mild hearing impairment with no need for intervention was found in the child, and the parents experienced all the hearing tests to be very trying. At the same time they compared the child with an older sibling and considered that the new baby's development was late. This couple were those most uncertain of the degree of the child's hearing impairment, and also the most uncertain regarding the follow-up. "Like I say, she is late. She is normal perhaps, but the first was so early in all respects." "No idea if there will be another follow up."

Advantage and disadvantage

Passed after the first or second test. The parents clearly expressed their views on the advantage of early screening and their willingness to help the child if something was "wrong". Parents seemed conscious of the fact that a hearing impairment can cause problems but, at the same time, many explained that there were handicaps of greater magnitude, and so had not given much thought to hearing problems. The attitude to the hearing screening itself was positive in all parents who were interviewed, i.e., all would like to do the test if they had another child. Most saw the screening as a measure of security. "I think, of course, when the possibility is there to test newborns, with that technique though, I think it would be terrible if one could not continue with this."

More than one re-test. Parents of children who had to do the test more than twice before passing and parents of children who had a hearing impairment took an ambivalent stand with regard to hearing screening. All expressed the opinion, however, that they were willing to have the test carried out if they had another child, but with some hesitation on the part of parents whose children had a unilateral, mild hearing impairment and where no need for intervention was present.

Parents could of course find advantages with the early screening, but the anxiety that was caused before the final result was known was a disadvantage. Parents of children subjected to more than one re-test before being passed saw the possibility offered by the test of obtaining early knowledge about the presence of a hearing problem as being the advantage. "If one does not know, one can be anxious when suspecting that something else is wrong with the child." Parents of a child who had a profound hearing loss seemed to feel that they got help and support, even though they had been impatient while waiting for the audiological evaluation. The parents of a child with mild hearing impairment supplied with a hearing aid also seemed to feel that they received good help. In contrast, parents whose children had a unilateral, mild hearing impairment without the need for intervention seemed to feel that although they had experienced hearing testing, nothing had changed.

Thoughts and opinions on hearing screening

Passed after the first or second test. Most parents spontaneously expressed their wish that the hearing screening should continue, and many were of the opinion that screening should be mandatory. At the end of the interview several parents used the following expression: "I hope this can continue!" Most parents also remarked that the test was done quickly and without any discomfort for the child. The language and the child's development and the ability to communicate with the child were subjects spontaneously touched upon by the parents. Many of them believed that late detection of a hearing impairment can cause anxiety, and many expressed the opinion that to offer universal hearing screening in newborns was good: "We were very glad when we were offered something like this, because if there had been some problem with her it would have been good to know from the beginning."

More than one re-test. The parents of the child subjected to more than one re-test before passing would not have chosen to do without the test. They expressed the view that the result could explain other behaviours that a child can develop. They were truly conscious of the aim of the test: "Yes, if one looks at what the aim is, it is to detect hearing loss as early as possible, and thus it is best to carry out such a test as early as possible to see if there is a hearing impairment."

The mother of a child with profound hearing loss had noted that the test was optional and first thought: "This is just another superfluous thing." Finally, however, the parents decided to let their child be given the test. Their presumption was unfounded when they became convinced of the importance of the hearing test: "It is important to start with sign language as early as possible; yes, what a problem for those who have to wait 2 years." Here, the whole family started to learn and use sign language when the child was 6 months, and this was pointed out to be very positive. "It is good that they do it early, so one can start up the language, so one can be in advance of the child regarding language, so one can understand one another, that is positive."

The parents whose child has a mild hearing loss, and had been supplied with a hearing aid, found that early hearing testing was important.

They were happy that their child was born in Linköping: "This is super. Now we have time to prepare ourselves, and it must be best for him to adapt to the aid and to be able to talk."

Parents whose children had a unilateral, mild hearing impairment with no need for intervention found the hearing screening to be problematic and would have liked to have been given more information. "Yes, if one had been told the reason and everything. They couldn't do anything at all, there was nothing to do. one knows that there is something wrong, but I know that anyhow."

Discussion

The present study was performed in order to get the views of parents on hearing screening in newborns and to evaluate and improve the screening programme. The use of a qualitative approach with open questions was valuable since some of the feelings, thoughts and opinions mentioned by the parents had not been detected using a questionnaire. one must be aware of the fact that the views of individual parents are formed by their individual underlying characteristics.

Is there good reason for carrying out early hearing screening, or do such programmes bring about unnecessary anxiety? Studies often referred to in connection with psychological effects in parents are related to screening for congenital hypothyroidism (Fyrö & Bodegård, 1987; Tymstra, 1986). In these a large number of parents who had received false-positive results were interviewed, and many parents showed very profound and lasting reactions, despite the fact that the final results were normal. The preconditions in the two studies on congenital hypothyroidism are thus not comparable with those of the present study. It might be feared, however, that similar feelings of anxiety could be released in some parents in connection with hearing screening. To motivate a programme for hearing screening, such psychological consequences must be minimized. In the hearing screening programme addressed here, there was a relatively small number of parents whose children had to be re-tested. These parents were well informed by the audiologists about the probable reason, and this possibly contributed to the favourable outcome. Among those who had to do the test more than twice in the present study, only one child had normal hearing; in the other cases the audiological assessment showed that there was a hearing impairment.

The results of the present study show that the hearing tests caused very little anxiety. Improvement of the information given to parents could possibly have reduced this even more. There was a small number of children who had undergone test and re-test without passing. This situation proved to be a critical point when parents became anxious. A second important point for these parents came after the audiological evaluation, when they knew the final result and had a defined action plan; this was the moment when parents felt relief from anxiety.

Information

It was obvious that the parents showed great interest in the test. Many were fascinated by the fact that it is possible to test the hearing in a newborn child and wanted to know more about how the test works. The parents were satisfied that their questions were answered by the audiologist at the time of the test, but new questions came up later.

Despite the fact that little more than half of the parents found that the right time for information was in direct connection with the test, many still felt ignorant concerning what had in fact been measured. Many of the parents did not notice or remember the information brochure that was given to them before the test. After delivery the mother is highly emotional, and this is probably not the most suitable time to give information. From a pedagogic–psychological point of view it would be better if parents were to learn about the test before delivery, as nearly half of them would have wished. one natural step would be to give information during visits to the mother-care centre, in connection with general information, with the aims of making parents more aware of language acquisition and of stimulating communication with the child. The information should be designed in accordance with the culture and norms of the own country.

Language—cooperation—communication—habilitation

Early detection of hearing loss is a very important step in the habilitation of hearing impaired children. An early intervention programme for hearing impaired children is favourable in the development of more mature communication, in association with less stress, and in a higher qualitative interaction within the family (Greenberg, 1983). Language acquisition in children is determined by the interplay between biological and physical constraints on the one hand, and social factors on the other (Strömquist, 1989). Generally, language development is seen as a continuous process where important components are founded in infancy. Several authors have studied the infant and its meeting with the environment from a neuro-psychological perspective (Trevarthen & Marwick, 1986). Such research has led to the view of the child as the "competent infant"; the competence is communicative to a large degree. By nature, a child is a social individual and early contact with the caretaker by means of language is important if development is not to be delayed. It has been shown that the ability of perceiving language begins far earlier than previously believed. Very early, infants can perceive sound patterns of words and discriminate them from other sounds (Juscyk & Hohne, 1997). It is thus important that a child with hearing impairment gets all the support it needs as early as possible; for example, by being supplied with a hearing aid.

The earlier the hearing impairment is identified, the better is the development of language skills. Early identification is a critical factor that concerns habilitation, regardless of whether the hearing loss is uni- or bilateral, sensorineural, mixed or purely conductive, mild, moderate, or profound (Mauk & Behrens, 1993). It is now recognized that early detection of hearing loss is essential if children are to be given the chance to reach their potential language skills (Bess, 1993). Unfortunately, in too many children the hearing impairment is not detected until the age of 2 to 3 years, which is much too late.

It has been shown that deaf infants babble with their hands, and that they pass through different stages of gesticual babbling like hearing infants do with their verbal babbling (Petitto & Marentette, 1991). The time course as well as the structure in gesticual and verbal language are similar, which implies that human language is founded on a common language ability. Knowledge of a child's hearing impairment is central if parents are to start learning sign language early enough. Specifically, this was what the parents of the child with profound hearing loss in the present investigation appreciated as the positive outcome of the screening test and the following audiological evaluation.

Vulnerability

Some investigators have questioned the rationale of early screening, in that such testing may give rise to unwanted emotional reactions on the part of the mother. Bess & Paradise (1994) claimed that there was no empirical study in support of the belief that early intervention (at 6 months) in cases of congenital hearing loss was more advantageous than intervention at a later time (18 months) and, thus, that the risk of causing emotional disturbance was not justified. Johnsen (1994) discussed ethical considerations, mainly the potential psychological risk associated with neonatal screening. Davis (1993) questioned whether it might be wise to abstain from identifying children with a mild or unilateral hearing loss, because not only would the shock and anger felt by parents faced with an unwanted diagnosis be minimized, but also the number of parents who receive false-positive results in a screening programme. And it would prevent obstacles obstructing important parent–child bonding. The present study shows that only a very small number of parents belong in such a risk group so long as their needs receive optimal attention from the beginning. The aims must be to identify this risk group and to improve the programme by providing good information and care for parents at the time of the screening as well as after it. Here, it is important to emphasize the parents' individual needs for support.

Attachment theory states that ignoring the child's signals leads to crying, which can give rise to a vicious circle with more crying (Ainsworth, 1979). When the signals are apprehended, the child learns the interplay between the signals and responses exchanged between child and caretaker, and a synchronization develops. When there is a lack of synchronization, the interplay does not develop and the child remains helpless. Early knowledge of a child's hearing loss is a prerequisite for compensating this loss with another sensory modality, exchanging auditory for visual clues in communication.

In a previous study of anxiety related to hearing screening using questionnaire by Watkin et al. (1998), mothers were followed over a 9-month period. Results showed that the majority felt no anxiety. In the few who were anxious, the uneasiness was slight and was not caused by the early testing. Several mothers remarked that they were anxious when the child was taken from them to have the hearing test (Watkin et al., 1998). In the Linköping screening programme, either one or both parents are always present during the test.

Feeling anxious for one's child when a hearing impairment is suspected is a natural reaction. As expressed by some parents: "This was no unnecessary anxiety, but we certainly felt anxious until we knew for sure." To eradicate all anxiety is impossible, so the aim must be to reduce it by focusing on the small group where more than one re-test was done. The present study shows that some of the parents whose child had to be subjected to more than one re-test would have benefited from more support. The parents of a child with a unilateral, mild hearing loss experienced a pronounced and lasting anxiety. Whether this anxiety has any negative influence on their relationship with the child cannot be determined because the interview instrument was not sensitive enough to this. In order to answer the question whether the hearing test had negative or positive influence in the short- or long-term perspective, one would need to observe the mother–father–child relationship over a long period of time. However, the analysis suggests that the central theme is the uneasy feeling of not knowing or understanding what the test and the result really mean.

Professional and parental perspectives

The parents in the present study were clearly positive with respect to early detection of hearing impairment, and emphasized their desire to be able to understand and help their child at the earliest possible time; this parental perspective on cost effectiveness was pointed out as the important advantage of early detection. They did not want a delay in the child's development as a result of late detection of a hearing impairment. This goal of the hearing screening programme was thus shared in common by the professionals and parents. However, it is inevitable that perspectives differ on some points.

The result of an American investigation on a large number of children showed that only 1% of the screened children needed audiological evaluation. It was concluded that universal screening was not only possible to carry out, but also very practical, with regard to the relatively low cost (Maxon et al., 1995). Experiences of OAE screening in Linköping were the same; very few children needed audiological evaluation. Confirmation of hearing impairment in children at the age of 3–4 months is judged to be reasonable, considering that ERA under anaesthesia must be used in some cases. Davis et al. (1997) reviewed different methods and combinations of methods for detecting hearing impairment in infants and found that the use of universal neonatal screening was the most cost-effective. one study focused on parents with hearing impaired children who had not been subject to neonatal screening, and who thus had no early knowledge of the hearing loss (Watkin et al., 1995). A large majority of these parents (89%) would have appreciated a neonatal screening test, allowing for earlier diagnosis and their subsequent adaptation to the needs of the child and understanding of why the child seemed to ignore them. The conclusion of the study was that, despite the fact that early diagnosis can result in emotional turmoil, it is favourable for the child.

The parents in the present study were clearly positive with regard to early detection but, at the same time, they had difficulty understanding the time needed for audio logical assessment of the hearing loss. In the individual parent's perspective, the present time is all important, and parents of children with a unilateral, mild hearing impairment with no need for intervention were left with a feeling of uncertainty. The child seemed to hear but apparently something was wrong. In the professional perspective, early detection is a valuable gain affording the opportunity of paying special attention to these children at follow-up consultations. In the individual perspective of the parent and child, early detection can thus mean a considerable gain for the future. However, at this time, parents of children with a unilateral, mild hearing loss with no need for intervention did not seem to appreciate this gain. With education and improved support, parents may be able to see the value of hearing screening and early detection.

Conclusion

The investigation shows that the desire to understand and help their child if hearing impairment is found is a central theme expressed by all parents. If they had another child, all of them would want to do the test again, even if some reluctance is found in parents whose children have a unilateral, mild hearing impairment with no need for intervention. The present results also show that parent presence during the test promotes an attitude of reassurance and interest with regard to it, due in part to the fact that they can see how the test is performed, and in part to the audiologist's explaining the procedure in a positive and informative manner. Much attention was paid to informing the parents at the time of the test. No anxiety seemed to be evoked in cases where a second test was necessary, because parents were reassured and informed about the reason. However, anxiety does occur in parents if the child does not pass the re-test, and this reaction must be identified and appreciated. on the whole, this applies only in the case of a few parents, and it should be possible to improve counselling and the communication between hospital professionals and parents. Prolonged anxiety was found in one case only, and it might have been possible to reduce this anxiety had better information and support been given. The investigation shows that all parents of children who had to be tested more than twice needed support and complementary information, *regardless* of the final result. The anxiety diminished when parents were told the final result, when the parent–doctor contact had been established, and when a plan for action could be outlined. The study also shows that parent reaction is individual and therefore that it is not possible to know beforehand how much support is needed in individual cases. This depends on the individual's sensitivity to stress and capacity to comprehend information.

The professionals should try to see things from the perspective of the parents. Parents generally know very little about a hearing handicap and have no knowledge of the extent of, and the time needed for, audiological evaluation. A few parents obviously had a feeling of uncertainty and many unanswered questions. With this in mind, the programme could be improved by identifying an audiologist to be responsible for information, for answering questions, and for serving as a contact person between parents and the department of audiology. Continuous access to professional information during the time f audiological assessment is needed to support parents and reduce anxiety; this should be given priority.

The positive response of parents regarding OAE screening was evident in the investigation; this is one reason why current plans for the universal screening service are being expanded to encompass the whole county. One result of the investigation is a desire of the maternity welfare clinic to improve the information given to parents and to give it earlier. Another aim is to shorten the waiting time for audiologic evaluation, and to facilitate closer contact between parents and professionals.

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Study II

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Late diagnosis of congenital hearing impairment in children
The parents' experiences and opinions

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Abstract

The purpose of the present investigation is to describe how parents experience a delayed identification of their child's hearing impairment. Ten parents of 8 children were interviewed. The impairment was confirmed when the children were between 2 years, and 5 years and 8 months. The results show that the parents and their child pass through a series of distinct phases: Unawareness, Suspicion, Confirmation and Habilitation. After the birth of the child there was first a calm period, which lasted until the possibility of a hearing impairment was suspected. Once the suspicion was raised, a time of much anxiety and frustration ensued. The parents described how defective communication and misunderstanding lead to frequent conflicts with their child. The differing behaviour of the child, in combination with poor language development, initiated referral to audiological assessment and confirmation of the hearing impairment. After confirmation, the parents felt relief but at the same time a sorrow. When hearing aids had been fitted and education in sign language was under way, the child's language and social behaviour improved. Supposedly, the late detection is explained by the combination of an insufficient test method that cannot detect all children with a hearing impairment and, in cases of uncertainty, a tendency to let the child pass rather than "bringing bad news". All parents in the present study would have wished to participate in a hearing screening program for new-borns, had the opportunity been present.

Keywords: Congenital hearing impairment; Late diagnosis; Parental opinion

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1. Introduction

Since September 1995, universal hearing screening of new-borns with the aid of otoacoustic emissions (OAE) is used at the Dept. of Otolaryngology, Linköping University Hospital (US). With the use of traditional methods for hearing screening a hearing impairment is detected too late in many children, which was the reason for introducing OAE. This is a non-invasive and painless method based on the fact that healthy sensory cells of the cochlea (the outer haircells) actively emit a weak sound in response to external stimulation by short click sounds [1]. If no response is present, other electrophysiological tests such as audit-

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ory brainstem response (ABR) are used to find out if the hearing is impaired, as well as the kind and degree of the impairment. In the Linköping community, after the first two years of neonatal OAE screening, the results showed 98.5% coverage of newborn children. Using only the OAE method, 97.1% of children showed normal results for both ears. Where further investigation was necessary, it took the form of ABR testing during natural rest, or under general anaesthesia. The advantage of neonatal OAE hearing screening is thus good coverage of the population and early detection of hearing impaired children.

At the time of the present study, US was the only hospital in Sweden where OAE was used for universal hearing-screening of new-borns. In other parts of the country the conventional methods for hearing screening were used. Observation audiometry like the Boel-test, or the Baby-test were both used for screening children aged 7 to 9 months [2,3]. Play audiometry, in which the child is listening and taking active part, was used for screening children between two and a half, and four years of age [4]. In play audiometry the procedure can be varied according to the child's age and development at the time of the test [3,5,6].

Hearing-screening using observation audiometry methods is performed at the well-baby centres. Play audiometry is used for the screening of 4-year-old children in most communities and is usually carried out by a trained nurse, also at the well-baby centres. Good knowledge of child development and experience in testing children, as well as good ability to manage children, is needed when performing the tests and interpreting the child's reactions. General practitioners are responsible for the well-baby centres and thus for referring the child for audiological assessment when a hearing impairment is suspected. Even though many children with congenital hearing impairment are detected with conventional screening, too many children with hearing impairment are not detected until later; the mean age for detection in Sweden varies at different centres from 16 to 41 months (≥ 40 dB HL, best ear).

1.1. Aim of study

A first study in a series of investigations to evaluate and improve the hearing screening program with regard to the pedagogical and psychological support of parents has been published recently [7]. The aim of the present study is to learn about parents' experiences, thoughts and opinions with regard to their child's hearing impairment having remained undetected for a long time. Paying attention to the parents' perspective is central to identifying unexpected aspects and, therefore, a qualitative-empirical approach was used in which the subjects were encouraged to express their thoughts and experiences.

How was the hearing impairment detected? What experiences and opinions do the parents have regarding the detection and confirmation of the hearing impairment? Would the parents have wanted hearing screening of their child at the maternity ward?

2. Method

2.1. Subjects

The parents recruited in this study had children with a hearing impairment supposed to be congenital, although it was not confirmed with the conventional methods. To enable a comparison with an earlier study of children detected by neonatal OAE screening [7], the interviews were carried out one to two years after the confirmation of the hearing impairment At the time of the present study (spring 1998) a total of 9 children filled this criterion. One was excluded because of the family's language difficulty, and thus 8 children were included. The 8 children had bilateral hearing impairment to an extent that needed habilitation. The children live in the county of Östergötland but were not born in Linköping and had thus not gone through neonatal hearing screening. Some of the families live in a community where the 4-year screening with play audiometry was no longer practised.

Taking part in the interview was fully optional. Both parents were asked to participate, but only in two cases both parents accepted. Two of the couples were divorced. In the present study 10 parents were interviewed (7 mothers and 3 fathers), aged 25 to 44 years. When the interviews were carried out the children were from 3 years and 5 months, to 7 years old. Two are single children, five have older siblings, and one has a younger sibling. The degree of hearing im-

Table 1
The degree of hearing impairment, the age of suspicion and confirmation, use of hearing aids and sign language for the eight children in the present study[a]

Degree of hearing impairment	Age at suspicion	Suspicion raised by	Age at confirmation	Use of hearing aid	Sign language
m. profound	1 yr	gen. pract.	2 yr	bilateral	sign l. + speech
f. severe	3 yr	mother	4 yr 7 mon	bilateral	signs as support
m. moderate	2 yr 6 mon	paediatrician	2 yr 10 mon	bilateral*	sign l. + speech
m. moderate	1 yr	mother	2 yr 10 mon	bilateral	signs as support
m. moderate	2 yr 6 mon	mother	4 yr 8 mon	bilateral	signs as support
f. moderate	3 yr	mother	5 yr 3 mon	bilateral	signs as support
m. moderate	4 yr	mother	5 yr 8 mon	bilateral	signs as support
f. light-moderate	4 yr 6 mon	mother	5 yr 8 mon	bilateral*	–

[a] m = male; f = female; * fitting of hearing aids in progress.

pairment, the age of suspicion and confirmation, use of hearing aids and sign language is seen in Table 1.

The time when the parents or the professionals first suspected that the child had a hearing impairment occurred between 1 year, and up to 4 years and 6 months of age. The impairment was confirmed when the children were between 2 years, and 5 years and 8 months. In the meantime all children with parents had been in touch with the medical service on several occasions. Three of the children had received tympanostomy tubes repeatedly. In one of them an untold risk factor was present, a half-brother with hearing impairment. Another risk factor was present in a second child who was born with severe jaundice.

2.2. Measuring instrument

The study was approved by the ethic committee for research at the US. The design of the study was based on in-depth, semi-structured interviews to obtain an overview of the parents' experiences with regard to the delayed confirmation of the child's hearing impairment. The interviews lasted 50 to 80 min and were characterised by dialogues with complementary questions when needed aimed at exposing different experiences, feelings and opinions with regard to how and when a hearing impairment was suspected and confirmed, and their attitudes towards hearing screening of new-borns; for example: How did you find out that your child has a hearing impairment? Tell me, how did you feel when you were informed that the child has a hearing impairment?

2.3. Analysis

All interviews were tape-recorded and transcribed verbatim immediately after each interview. The text was supplemented by notes made by the investigator. First, relevant quotes for different areas were collected, and units of meaning were defined. These served as the basis for analysis and to find similarities and differences. The analysis includes both descriptions of conceptions and scrutiny of their relationships. The analysis concerns the individual level with comparison on this level.

During the process of analysis of the whole material a number of descriptive categories emerged. These categories followed a characteristic temporal pattern, displaying four different phases of development. The phases are described by their descriptive categories, the number of which varies between phases depending on the diversity of concepts and amount of information given by the parents. The descriptive categories are illustrated by citations, and are subsequently discussed in relation to results of other investigations.

The quality of the study was scrutinized against criteria described by Kvale and Larsson [8,9]. Accordingly, the validation was not only an evaluation made after completion of the study. The validation procedure was performed throughout all the stages of the study and was thus built into the research process, involving continuous control with respect to the empirical material to make sense of the results. The results have thus withstood critical scrutiny while the study was carried out, the "discourse criterion".

When the presentation can enable the reader to see some part of reality from a different aspect, this is one further quality aspect, the "heuristic value". When the results have a practical value the study fills the "pragmatic criterion".

3. Results

The degree of hearing impairment and age at detection for the eight children is seen in Table 1. Despite the fact that individual characteristics differed significantly, the analysis showed that the development followed a similar course. The results show that all parents passed through four distinct phases together with their child. These phases with their description categories constitute the final result.

3.1. Unawareness

The first phase was a calm period lasting one or more years characterised by a feeling of security. During this first period none of the parents suspected the hearing impairment of their child. When in close contact with the caretaker and on visual contact the child babbled and reacted positively. The child appeared to thrive and the parents remained unaware of the hearing problem. "... we had no reference, nobody to compare with. Then we talked to him as usual because we were totally unaware that he could not hear".

3.2. Suspicion

The parents, usually first the mother, noticed that the child was different and wondered what could be wrong. A suspicion grew that the child suffered from a hearing impairment. A period of anxiety and frustration began, the length of which varied between families, until the hearing impairment was ultimately identified. In two families the mother explained that the father did not want to accept the possibility that the child did really have a hearing impairment.

3.2.1. Speech development did not start

The speech did not develop like in other children, but the child had its own difficult-to-understand language, or no language at all: "but the most evident was that he never began to talk." This constant wondering: "why is my child different?" remained with the parents during a period ranging from 1 year, to 2 years and 3 months, until the clear answer was at hand that the child's hearing was impaired. The time period from the appearance of suspicion until the final answer was present was a time of much anxiety and frustration for all parents. Some parents worried over the possibility of a brain damage or some other serious defect: "it was worrisome indeed and we did not know whether it was some damage to the brain, or what it really was about".

3.2.2. The child's behaviour

The three girls were all withdrawn and appeared silent and shy; they withdrew when several persons were present and did not respond when somebody spoke to them. The mother of a six-year-old girl: "then one did not know whether she was shy or, rather, one was not sure and did not know what was the matter, only that she was different from other children, I thought then". The five boys were described as being withdrawn or active depending on the circumstances. The parents found that these children were sometimes active to the extent that conflicts could not be avoided. The mother of a six-year-old boy: "he was not only running about, but he did not hear what I said". The mother of a four-year-old boy: "he has a strong will. He does whatever he wants to do and, yes this was difficult. He was so wilful and if he was not near enough we could not control him".

3.2.3. Conflicts and bad conscience

Most parents had recurrent conflicts with their children and some had a bad conscience when they learned about the hearing impairment: "then one had a bad conscience over the fact that one cried and shouted, and he did in fact not hear. I was forced to be angry every time". The conflict could be evoked by the child and parents not understanding each other: "but in the beginning not even I understood her. Then we had extreme conflicts, that is true". The children could feel lost regarding what was happening around them, and what intentions were valid for the moment: "if he does not understand all of it, like if one is changing something, then he is very angry". For children who had siblings, these often served as middlemen and interpreters between the hearing impaired child and the parents: "she had a big brother as an interpreter then, and she just pointed and he knew exactly then what she wanted".

3.2.4. Neglect and consolation

Six of the mothers and one of the fathers announced their suspicion of a hearing impairment to physicians, in some cases time after time, but were of the opinion that the professionals did not listen: "he did not listen to me as a parent". The parents found that both professionals and friends wanted to comfort them when they expressed their fears over their child's being late with speech development. In this situation they were eager to receive this comfort. All had a friend or a relative who had been late in starting to speak: "we should not be so anxious, and the child would eventually catch up with its language development. This was just what we wanted to hear".

3.2.5. Health service appointments

In two cases a hearing impairment was suspected at the one-year visit to the well baby clinic. Despite this fact, there were many visits to the doctor for these children, as well as for all other children, before the hearing impairment was confirmed: "we visited many doctors, this was a struggle. It was worrisome. Nobody believed me". On the other hand, the parents of a child with a profound hearing impairment first had difficulty understanding that the child had poor hearing: "one shook it off". In this case, after an early summary examination, the physician had judged the child as being of normal hearing, which supported the parents in their belief that the child had good hearing. Three of the children were repeatedly treated with tympanostomy tubes: "yes, she had tubes twice. Finally, they put in a kind of T-tubes so they should stay longer, since the tubes fell out each time". Two of the children were trained by a speech therapist since the delayed speech development was thought to be due to a language disturbance: "so, we had a speech therapist. We visited her for a time. It was difficult, he had to concentrate so hard". When children did not pass their hearing tests, the interpretation of the results was that they did not co-operate. During hearing tests some of the children performed in a way that led to the misinterpretation that they were able to hear: " she was pretty smart, though. She cheated those guys". These children did not develop their speech as expected, and they were ultimately referred to the Dept. of Audiology at the US, where the hearing impairment was identified.

3.2.6. Children at risk

Two children who can be characterised as "children at risk" also remained undetected for a long time (one was confirmed at the age of 2 years and 10 months, and the other at 4 years and 6 months). The first child had severe jaundice at birth, and the second had a half-brother with a hearing impairment. The hearing-impaired relative was not known to the health officials at the time, but the child with congenital jaundice was checked up regularly twice a year: "what I am thinking of is that others who happen to be in the same situation should at least be informed that this might be a problem. For us it is all over. It is too late now, isn't it? Others should have the possibility of being informed earlier".

3.3. Confirmation

When the hearing impairment was confirmed all parents received good help and adapted to the new preconditions. After confirmation the parents felt relief when they ultimately knew what distinguished their child from others, but at the same time they were worried over the hearing impairment.

3.3.1. Relief and worry

The parents were very disappointed over the long time that had elapsed from suspicion to confirmation: "for now one must do the best. We do not believe that it will all be well but anyhow we think that he is doing well". One couple felt so much anger over the delayed confirmation that they filed complaint to the medical authority: "yes, I reported it and my complaint was approved. If the impairment had been discovered two years earlier she would have been better off". The parents of the profoundly hearing impaired child took part of the blame for the delayed detection themselves. Despite all difficulties, they did not fully realise that it was all a matter of impaired hearing, since the child used to govern the parents in a very determined manner by, for example, pointing, pushing them, and pulling their arms: "sometimes all was chaos when he wanted to tell us something and we did not understand when he pointed. And we had to coax him to make him calm". By postponing an examination under general anaesthesia that was planned when the child was 1.5 years old, they were of the opinion that they had themselves delayed the confirmation of the child's hearing impairment until he was two years old. In this case the physician at the well baby clinic had primarily judged the child's hearing as being normal, which may have contributed to the delayed suspicion of hearing impairment: "and he clapped his hands, and the first time the boy heard and, after that, he did not care. It was already then".

3.4. Habilitation

The parents found that things became easier when the children had learned some sign language, or were supplied with hearing aids, or both. Several of the parents, usually the mothers, participated in sign language education to be able to better communicate with their children. All parents were now decided on trying to help their child in every respect. The time when habilitation measures were initiated by the Dept. of Audiology was an important turning point both for the children and the parents.

3.4.1. Better understanding and more cheerful children

After a while parents noted that the child began to make progress: the language started to develop and the behaviour became more social. Ultimately, they had learned why the child was different: "yes, she has become much more confident now that she has got a hearing aid and can keep up with things better". Most children use *signs as support*: "small and tall can sound the same and then one can make it clear with signs. So he can see what it is". Sign language training was taken up by the whole family of the child with profound hearing impairment, and the child learns sign language at a pre-school class for hearing impaired and deaf children: "yes, there is a difference. He just soaks up the signs. He learns fast. He takes delight in it. He can sit there alone, signing, while he is playing." When children were supplied with hearing aids they walked about listening to everyday sounds, and sometimes the stimulation was too intense, so they were tired in the afternoon: "yes, when he got the hearing aids he found out that he could hear the birds singing and things like that. Then I feel like crying, he had not heard birds! Yes, there are so many sounds in the house now and sometimes one understands that he becomes tired".

3.4.2. Progress

After the hearing impairment had been confirmed all parents were of the opinion that their children were well cared for regarding habilitation and support, e.g. fitting of hearing aids, education in sign language, help with referring the children to certain pre-school classes to promote their speech development: "yes, the hearing aids have been good. They have been an enormous help. It is like day and night". Two of the children had difficulty accepting their aids, but the children received extra help to adapt: "he is making progress. He is talking much more. Previously he hardly talked at all, but now he is talking much more". Two of the children with moderate hearing impairment and the child with profound impairment are going to different integrated pre-school classes: "he enjoys the class. He meets other children who use sign language".

3.4.3. On the future

All parents looked forward with confidence but, at the same time, they realised that the hearing impairment might give rise to problems, and they were anxious about problems that might come up: "sometimes she does not find the right words. Then, she is aware of her handicap". Some parents thought that it was a good thing that the children were conscious of their hearing handicap and that other children in the neighbourhood also knew, so they would not be stigmatized as stupid when they started school: "it is easy getting such a stigma, and people think one cannot understand anything, isn't it?" Some parents expressed anxiety over the possibility that the children would be subjected to mobbing in the future although, at present, there were no indications: "just imagine if he will be teased and all that!"

All parents, except the parents of the child with profound hearing impairment, are planning to place their child in an ordinary class. Education support and technical equipment will be supplied by the community. The parents want to try out if this setting is possible: "his social life is with his friends out here". However, the parents of the child with profound hearing impairment are planning to place their child in a school for the deaf where the education is carried out in sign language as a first language: "many decide to move to Örebro, and in the long term I believe it will be the best".

3.4.4. On OAE screening

All parents that were interviewed wanted to participate in neonatal hearing screening in case they would have another child: "yes, I would absolutely want it, one wants to know instead of waiting for years". Some of them said that they would probably be sorry to know about the hearing impairment, but for the child's sake, and thinking of all they had been through, they would not hesitate to participate in hearing screening in the neonatal period: "of course one feels very sorry, but to get to know it after a couple of years is certainly not better". All parents expressed their opinion that early knowledge is preferred: "I don't find such a message to be catastrophic but, rather, it is a help". Some parents had read about OAE screening in the paper or heard about it from friends, while others learned about it at the time of the interview: "to get to know about the hearing impairment late – that is the real damage, and then I realise the advantage of having the offer of the test done early".

4. Discussion

The use of a qualitative approach with open questions was valuable since some of the parents' experiences and opinions had not been detected using a questionnaire. The purpose of the present investigation was to describe how parents experience a delayed identification of their child's hearing impairment. The families who were enrolled in this study were living in districts without a neonatal hearing screening program. The children were referred for audiological assessment during a certain time period, and the mean age at confirmation of the hearing impairment in these districts was relatively high.

4.1. Cause for late detection

Why are causes other than hearing impairment first suspected for explaining a delayed speech development and a differing behaviour? The present study shows that conventional tests cannot detect all children with a hearing impairment and, once the suspicion is raised, it is difficult to obtain confirmation of the impairment. Observation tests in children have a built-in weakness, and consequently a built-in difficulty for the observer to judge the result.

Methods for observation- and play-audiometry are designed to provide evidence for a general judgement of the child's communication skills [2,4]. Since many different factors are involved it is difficult to obtain a uniform performance of the test and uniform judgement of the result. In lack of strict criteria, the child's reactions during the test may be interpreted differently. Parents naturally hope that the result will be good, and there may be a tendency from the side of the professionals to give a positive message. Failure to identify cases of hearing impairment may thus depend on a combination of a test method that is not capable of finding all the children and a preference on the part of the professionals, when in doubt, to let the child pass rather than being a "bearer of bad news". A desire to allay anxiety may be detrimental when parental fears are well founded [10]. The low incidence of congenital hearing impairment (1 or 2 in 1000) may also lead to insufficient alertness.

Three of the eight children in this study were supplied with tympanostomy tubes because a hearing impairment was suspected. This is a rational treatment when the hearing impairment is caused by effusion of fluid in the middle ear. However, there is a risk when a child with sensorineural hearing impairment is included in this large category of children with tympanostomy tubes, namely, that the check-up visits are primarily focused on the ventilation of the middle ear. The fact that many children with congenital hearing impairment are supplied with tympanostomy tubes was also commented by Robertson et al. [11].

4.2. Context; tactile and visual stimuli

In addition to the technique used when conducting the test, attention must be paid to the context in which the test is done. There may sometimes be a conflict of interests between giving enough time for the child to adapt to the investigator and the test situation, and the time schedule of the investigator.

In lack of auditory stimuli, hearing impaired and deaf children are able to develop an increased sensitivity to other sensory modalities, for example, tactile stimuli [12]. In the test situation the infant is usually seated in the mother's lap, which offers the opportunity of transferring tactile information, making the child respond as expected. It has also been shown that hearing impaired and deaf persons use their peripheral visual fields more effectively than the hearing, and that they are more able to observe what is going on "at the corner of the eye" [13].

4.3. The child's different behaviour and vulnerable social situation

It is terribly frustrating not being able to acquire the code to the language, and not being able to make oneself understood, or to understand what others try to convey in words [14]. In the present study there were children who were highly active but some were extremely shy, and in some of the children the behaviour changed depending on the situation. The parents described a number of conflicts with their children. The conflicts seemed to be situation oriented, that is, the conflict was evoked by defective communication leading to misunderstanding. In the asymmetrical relation between adult and child, the caretaker occupies the privileged position, which gives the child a feeling of inferiority and utter powerlessness in the conflict situation. Six of the children had siblings and in some cases the parents found that the sibling with normal hearing could best understand what the hearing impaired child wanted to say. In this way the brother or sister served as interpreter between the impaired child and the parents.

Some parents expressed their anxiety over the child's relation to other kids in the future because of communicative difficulty. The socialising of children is not just a consequence of what the adults think, organise and try to teach, but there is a parallel and independent socialising in the co-operation among children [15]. The lack of a rich and expressive language will hamper social contact and participation both in social play and fantasy play [16].

4.4. Practice implications

Watkin et al. [17] used a questionnaire to parents who had no early knowledge of the hearing impairment of their children. A significant majority of parents would have appreciated an early diagnosis. An interview study by Magnuson and Hergils [7] with parents of children who had OAE screening in the neonatal period showed a clearly positive attitude to the test. The study showed that parents want early knowledge if a hearing impairment is present or not, to be able to help and understand their child so its development will not be impeded; this was seen as the major benefit of the test.

Robinshaw [18] studied the communicative and linguistic behaviour in children with severe to profound hearing impairment who had been supplied with hearing aids at the age of 3 to 6 months. The results showed that children who were identified and given amplification at the age of 6 months acquired language and linguistic skills at an age similar to that of hearing children. A habilitation program based on the individual development can minimise the risk of a social and linguistic handicap. Yoshinaga-Itano et al. [19] who studied different predicting factors for a successful result with deaf and profoundly hearing impaired children with hearing parents reached the same conclusion: Identification of the hearing impairment at 6 months of age followed by an appropriate intervention is the most effective strategy for obtaining a normal linguistic development.

The present study shows that the habilitation was much appreciated by the families. The parents gained better understanding, and the children became more cheerful and started to make progress. This shows that a habilitation program designed for the individual child is of great importance for the linguistic and social development. The parents' explicit desire to obtain early knowledge of the hearing impairment of the child is thus legitimate. According to the opinion of the parents, the late confirmation caused the real damage.

Continued education of general practitioners, nurses and paediatricians is necessary to ensure that the parents' suspicion is taken seriously. Bess [20] finds that it is important to educate the professionals as well as the general public about the importance of early identification. He means that it is a well established fact that early identification of hearing impairment is crucial for hearing impaired children to reach their potential language skill. Davis et al. [21] states that late detection of hearing impairment leads to considerable delay of speech acquisition and communication skills with a consequent long term risk to educational achievement, mental health and quality of life. Parving [22] emphasises that better information to both professionals and non-professionals about the signs of a hearing disability, in combination with easy access to a professional audiological unit, could improve early detection of and intervention for children with a hearing impairment. With a well developed medical service, such as in Sweden, late confirmation of a hearing impairment is clearly a failure that is not acceptable. Seemingly, to make professionals as well as parents aware of how to detect a hearing impairment is a central pedagogic task. It must be noticed that OAE screening of new-borns detects congenital hearing impairment, not cases where the hearing impairment is acquired during childhood. In uncertain cases one audiologic assessment too many is preferable to too few.

5. Conclusion

The disadvantage of the late detection dominated the parents' feelings. Initially, a false evaluation from the professional side was present, a denial of the hearing impairment that in some cases was transferred to the parents. Some of them gratefully received the positive message, but most parents understood that something was wrong and had to spend much effort to reveal the reason why the child was different. The results of the present study show that parents pass through a distinct series of phases together with their child. After birth follows a calm period lasting one or more years until the suspicion of a hearing impairment arises. Once suspicion is aroused a period characterised by much anxiety and frustration follows; the length of this period varies between families. The children in this study were highly active or extremely shy and, because of the disturbed communication, there were frequent conflicts between parents and children. After the long period of uncertainty, the child's different behaviour and the poor language initiated referral to the Dept. of Audiology, where the hearing impairment was confirmed. When the hearing impairment was detected parents felt relief from understanding the reason why the child was different, but at the same time they worried over the confirmed hearing impairment. After fitting of hearing aids and training in sign language, the speech and social behaviour of the child improved. The parents observed how the child made progress and was more pleased and joyful, and parents were now better prepared to help their child. A habilitation program designed for the individual child supports the family and is of great importance for the child's development. All parents would have preferred to participate in an early hearing screening, had this possibility been present. Seemingly, to make professionals as well as parents aware of how to detect a hearing impairment is a central pedagogic task. With the individual child in focus, the present study shows that when in doubt, one referral too many is certainly better than too few. The parent's anxiety and concerns should be taken seriously.

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Study III

HEARING SCREENING OF INFANTS

Parents Prefer Early Confirmation of Congenital Hearing Impairment

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The purpose of the present investigation was to compare the results of two different samples on early and late detection of congenital hearing impairment in children with regard to the parents′ reactions. The studies emerged from a qualitative-empirical approach. Four main categories emerged. 1. Parents prefer early knowledge, i.e., they were urgently concerned that the child′s linguistic and social development would not be delayed. 2. Uncertainty of whether the child had a hearing impairment or not was a primary cause of anxiety, as well as uncertainty regarding the degree of the impairment and the future consequences for the development of the child. 3. Information and counselling can evidently serve to reduce this anxiety. Since the parent′s reaction is individual, the profession must be prepared to provide individual support. 4. Parents need a plan for the future and found security in the habilitation. Conclusion: The early diagnosis of a hearing impairment made possible by otoacoustic emission screening involves new demands for audiological assessment and subsequent habilitation of very young children, including fitting of hearing aids and sign language education for the infant and the family.

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1. Introduction

The traditional methods that have been practiced for hearing screening of infants, e.g. distraction tests and play audiometry, have a built-in weakness because the judgement is strongly depending on the experience of the investigator. In Sweden these tests are performed at well-baby centers; observation audiometry at 7 to 10 months of age, and play audiometry at 4 years. Many children have passed such tests despite having a hearing loss, and have been judged as having normal hearing, which leads to a considerable delay until the correct diagnosis is made.

The mean age for detection of a hearing impairment in need of habilitation varies from 16 to 41 months in Swedish communities. A late detection of a hearing impairment often leads to a protracted anxiety on behalf the parents because of the uncertainty of what may be wrong with their child (Magnuson & Hergils, 2000 (in press). In cases where the hearing impairment is not detected at an early age the language development meets with difficulty, resulting in a retarded or absent development of speech, which may also influence the development of social skills.

Play audiometry is a psychoacoustic test where the hearing ability is tested as a whole, not only the physiology of the ear. This test may be subject to further development to improve its sensitivity and specificity and will remain an important tool for detecting acquired hearing impairment as well as progressive forms of sensorineural hearing impairment in infants. However, there is an obvious need for a reliable test to make possible an early diagnosis of congenital hearing impairment. Measurement of otoacoustic emissions (OAE) is a computerized method for investigating the physiology of the ear. The procedure is non-invasive, painless, and yields an objective measure of the function of the middle and inner ear. Since no co-operation is needed, the method is suitable for hearing screening in newborn children (Kempt & Ryan, 1993; Davis & Bamford & Wilson & Ramkalawan & Forshaw & Wright, 1997). In a National Institutes of Health (NIH) consensus statement (NIH, 1993) universal neonatal hearing screening was recommended, and the European Consensus Programme (1998), also recommends universal neonatal hearing screening. Universal OAE screening of newborns is now practiced in several centers both in the United States and in Europe. In Sweden, universal OAE screening of newborns was first introduced at the Linköping University Hospital (US) in 1995, and is now being introduced in some other Swedish communities.

When organizing a program for hearing screening of infants it is important to recognize different aspects of the program, such as the technical and administrative aspects and, not least, the parents′ perspective. Hearing screening of newborns might have negative consequences, since the mother is highly emotional at the time of birth. Paying attention to the parents′ perspective is central to improving the final outcome of the screening program; the habilitation of the children and the care of the parents. Thus, it is of utmost importance that something genuinely positive is achieved, and that any negative factors be minimized. At the Dept. of Audiology, US, the parental perspective has been focused, studying how parents experience different screening programs. Two interview studies have been carried out describing parents′ experiences, attitudes and opinions. One study focused a sample of children who had gone through hearing screening with traditional methods, which led to a delay in detection of the hearing impairment (Magnuson & Hergils, 2000, in press) and another study focused a number of children who had gone through neonatal OAE screening with early detection (Magnuson & Hergils, 1999).

1.1. Aims of the Study

The aim was to study and compare the parent′s reactions with regard to the different hearing screening programs, using a qualitative-empirical approach based on in-depth interviews. All families were living in the same county, and the period that had elapsed from the time of detection was about the same, which provided a unique opportunity to compare the two different situations as experienced by the parents. What similarities or differences can be found? What experiences and opinions do the parents have regarding hearing screening?

The two parent groups included in the present investigation have previously been studied separately (Magnuson & Hergils, 2000 in press; Magnuson & Hergils, 1999). The present comparative study is interesting from several aspects. When the results are compared it is possible to make a number of observations of a more general significance that can extend the theoretical understanding of the parents′ different situations and their reactions. This knowledge can serve as a guideline for the organizing of a screening program, and thus the comparison also has a direct pragmatic purport. In addition, the study can promote better understanding among parents regarding hearing, hearing impairment, and the purpose of hearing screening in infants. One can assume that early detection of a hearing impairment is a crucial step in the habilitation of hearing impaired infants and, hence, to improve and spread the knowledge of hearing screening is of great practical importance.

2. Method

2.1. Subjects

The interview studies were approved by the ethics committee for research at the University Hospital.

Sample 1: A total of 10 parents of 8 children were interviewed one to two years after confirmation. These children had been subject to hearing screening with traditional methods and, in the actual cases, the result was late detection of the hearing impairment. The children were between 2 years, and 5 years and 8 months of age when the impairment was confirmed (late confirmation). In all the children the hearing impairment was found to be bilateral and in need of habilitation, and in all the impairment was supposed to be congenital. The degree of hearing impairment ranged from mild to profound; one mild, five moderate, one severe, and one child had a profound hearing loss.

Sample 2: A total of 49 parents of 26 children who participated in OAE screening in the new-born period were interviewed. All parents were interviewed 8 to 12 months after the screening test. Three sub-groups were selected for the study and the persons were included with the explicit aim of describing different reactions. The first consisted of 11 mothers and 10 fathers whose children had passed the first test. The second sub-group comprised 11 mothers and 9 fathers whose children passed after re-testing. Additionally, in a third sub-group there were four couples whose children had a hearing impairment; two children had a unilateral, mild hearing impairment with no need for intervention, one had mild hearing impairment and was supplied with a hearing aid, and one had a profound hearing loss (early confirmation).

2.2. Data collection

The interviews were open-ended and lasted from 30 to 80 minutes and were characterized by dialogues with complementary questions when needed. All were tape recorded and then transcribed verbatim.

In cases of traditional screening (sample 1) the questions were aimed at exposing different experiences, feelings and opinions with regard to how and when the hearing impairment was suspected and confirmed, and the parents attitudes towards hearing screening of new-borns. Examples: How did you find out that your child has a hearing impairment? How did you feel when you were informed that the child had a hearing impairment? How did you react? Tell me about your communication with the child, and between other persons in the family and the child? What about your hopes and fears regarding your child´s future? Have you received any help and support? Tell me about what kind of help! Would you take part in a hearing test already at the maternity ward in case you will have a new baby?

In cases of universal neonatal OAE-screening (sample 2) the questions focused on the knowledge of OAE before the test was done, how the test situation was perceived, how the test report was experienced, the parents´ attitudes to the child, advantage and disadvantage of the hearing screening according to the parents´ own judgement. Examples: Describe your own attitude with regard to the test before it was done? Were you anxious for the test itself, or for the result? Describe how you experienced the test! Did the audiologist explain how it is done and what the result means? How did you feel when you were told that a second test was to be done! How did you feel when waiting for further testing? Do you feel that the hearing test caused you anxiety? Tell me your point of view! What advantage and disadvantage do you find with this test?

2.3 Analysis

The point of departure in the following analysis is that the parents had experienced very different situations, and the variation in experiences and opinions was the most interesting issue. To enable there to be a comparison between the parents´ reactions with regard to different hearing screening programs, and to find differences and similarities in the parents´ experiences and opinions, the interviews were carried out when about the same time period had elapsed after the hearing impairment was confirmed. The parents in sample 1 had experienced late detection of their child´s hearing impairment, but had no knowledge of OAE screening of new-borns. In contrast, in sample 2 the parents had experienced OAE screening enabling early detection.

The analytic procedure was carried out in two steps. The first step was taken separately for each of the two samples when different qualitatively delimited phenomena comprising concrete opinions and experiences, as expressed by the parents, were defined within descriptive categories. In a second step, the descriptive categories were used here as a starting point for comparison and further analysis. This process provided the possibility of finding similarities and differences in the two samples reflecting a general pattern, and providing a basis for defining core categories that apply to the whole material, see scheme in figure 1.

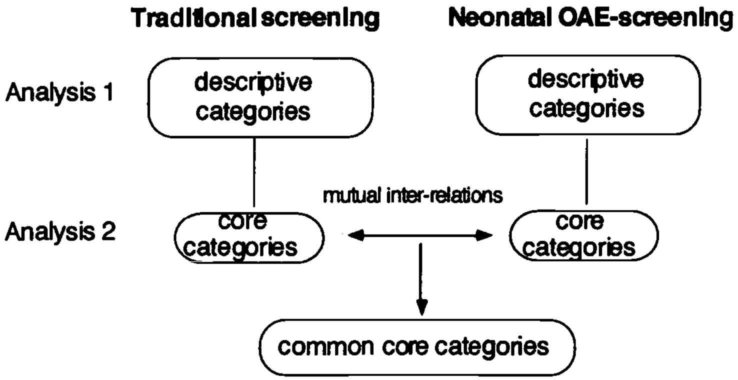

Figure 1. Scheme for the two step data analysis and the final core categories.

The current approach is descriptive by emphasizing meaning as the fundamental concern, using categories as the form of describing and generalizing meaning. It is comparative in emphasizing differences and similarities, and it is analytic in the sense that it differentiates and abstracts whole qualities. The result follows an analysis of the empirical material and emerges as a grounded theory. The theory becomes applicable by the fact that its core categories are based on the scrutiny of empirical data for generalized relationships between concepts and descriptive categories (Glaser & Strauss, 1967; Glaser, 1992; Strauss & Corbin, 1994). The validation procedure was performed throughout all the stages of the study and was thus built into the research process, involving continuous control with respect to the empirical material to make sense of the results (Kvale, 1996; Larsson, 1994).

3. Results

The quotes below are examples of statements made by the parents with regard to traditional screening and neonatal OAE-screening, respectively.

Traditional screening: "And we did not know what was the cause of it, if there was a brain damage, or whatever." ---"I think it came like a feeling of liberation, it was good to know what was the matter. At last we knew what it was all about. It was like, sort of – now, let us get started finally!" --- "I cannot even imagine going through all this one more time. I mean, had this been done already when Anna was born, then they had seen her hearing impairment in both ears right away. And in that case one could have started up much earlier. Now it took 4 1/2 years until the doctors even wanted to listen to what I was saying and we were allowed here. Just think of all those conflicts I had with Anna the first years! Had I known about her hearing impairment I could have worked with her very differently. Now when she has got hearing aids, she has become much more confident and is able to apprehend. No, I can certainly not see any disadvantage with early knowledge."

Neonatal OAE-screening: "We really appreciated being offered something like this since if my child would have a problem it would be good learning about it right from the beginning."--- "I found that the audiologist was very skilled when doing it. She informed us before starting the test and told us how she would do it, so I thought that she was very good. "--- "Yes, and the advantage is so obvious. I mean that Allan´s development will not be retarded, and even that we got the chance of participating (in the test). Had Allan been born in another town we would still be ignorant. While we hoped that that there was nothing to fear, we were anxious before we knew for sure – from the retest when they told us that the result could be due to vernix in Allan´s ears – until we were told that he had a hearing impairment. But I prefer that anxiety, compared to finding out about the impairment at three years of age."

The following four core categories, which were common for both groups, were discerned: Parents prefer early knowledge. Uncertainty creates anxiety. Information and individual counseling can reduce anxiety. Parents need a plan for the future.

3. 1. Parents prefer early knowledge

The study showed that all parents want early knowledge of whether the child has a hearing impairment or not in order to be able to help their child as early as possible if a hearing impairment is confirmed. Parents of children in whom the hearing impairment was confirmed late reported severe difficulties in the communication between parent and child that frequently lead to conflicts, and the delayed diagnosis was judged to have negative consequences for the child´s linguistic and social development. All would have wanted to participate in OAE-screening, had there been the possibility and, should they have another child, they would like to participate in OAE-screening. Parents whose children had been subjected to OAE-screening in the neonatal period judged the early knowledge of a hearing impairment to have a positive influence on the linguistic and social development, and all wanted to do the test in case they would have another child, except for some hesitation expressed by parents whose children had a mild unilateral impairment with no need for intervention.

3. 2. Uncertainty creates anxiety

The study showed that uncertainty is a primary cause of anxiety. When the two samples are compared the period of uncertainty and anxiety was considerably longer and more trying for parents in whose children the hearing impairment was confirmed late. Once the suspicion of a hearing impairment was raised, a period of anxiety and frustration followed, the length of which differed between families. The parent's suspicion of a hearing impairment was neglected in several cases. The anxiety lasted until the hearing impairment was confirmed, and in some cases the confirmation was delayed one or more years. In some cases the parents feared that some kind of brain damage was the reason for the child's different behavior. In these families the long time of frustration that was experienced before confirmation of the hearing impairment led to a feeling of distrust or even resentment toward the medical service provided by the home community. Parents whose children underwent OAE screening and where more than one re-test was needed also experienced anxiety. This anxiety, however, was present only during the limited period of time prior to the assessment being made, which provided the final answer. They were ignorant about the time needed for audiological assessment of the hearing impairment and explained how they watched the child closely to try to find out if it could hear or not. Although relatively shortlasting, this time of anxiety occurred during a sensitive period for the mother.

3. 3. Information and individual counseling can reduce anxiety

Parents of children whose hearing impairment was detected late were concerned by the fact that the child's development had been delayed and in great need of knowing the reason for the differing behavior of the child. They found that both professionals and friends wanted to comfort them when they expressed their fears over their child's late speech development. However, only objective, professional information about the kind and degree of the hearing impairment and its consequences could evidently reduce the parents' anxiety.

Regarding OAE-screening, the parents expressed a need for information about the test and how it is performed. The hearing tests *per se* caused very little anxiety, which was due in part to the fact that the parents could see how the test was performed, and in part to the audiologist's explanation of the procedure in a positive and informative manner. Much attention had been paid to informing the parents at the time of the test, and parents were generally interested in the test technique and trusted the audiologist. No anxiety was seemingly evoked in cases where a second test was necessary, because parents were reassured and informed about the reason. However, when the child had to undergo more than one re-test, there was an obvious need for individual, professional information, *regardless* of the final result. This also applied to cases where the child had a mild unilateral hearing impairment with no need for intervention. Individual counseling is the central issue but, since the parent's reaction is individual, it is not possible to know beforehand how much support and complementary information is needed. This depends on the sensitivity to stress and capacity to comprehend information.

3. 4. Parents need a plan for the future

When a hearing impairment was suspected, both in cases of late detection and after OAE testing of newborns, the parents were naturally apprehensive. However, in both cases the anxiety diminished when parents were told the final result, when a parent-doctor contact had been established, and a plan for action could be outlined.

The parents found security in the habilitation program. Once the hearing impairment was confirmed, and appropriate habilitation measures being taken, a dialogue grew between parents and audiological professionals. The parents gained understanding of the child´s difficulty as well as the possibilities that are offered to support the family and to improve the communication. In cases of late detection the parents soon experienced the benefit of the habilitation by the improved communication, and the fact that the child was happier and more joyful. In cases of early detection, the parents wanted information on all available resources, and were eager to start habilitation at once.

4. Discussion

4. 1. Early detection promotes interaction and understanding of the child´sneeds

The European Consensus Statement on Neonatal Hearing Screening (1998) states that implementation of neonatal hearing screening should not be delayed, since it will provide better possibilities and a higher quality of life in the new century for the new citizens. Davis et al.(1997) reviewed different methods and combinations of methods for detecting hearing impairment in infants and found that the use of universal neonatal screening was the most cost-effective. Experiences of OAE-screening in Linköping show that very few children needed audiological evaluation (Hergils, 2000). The parents´ perspective on cost effectiveness in the present study was to be able to understand and help their child at the earliest possible time. A congenital hearing impairment is found in only 1 or 2 per thousand newborn children. However, such an impairment can have serious lifelong consequences, unless detected early enough to enable habilitation during the crucial period for language development. The majority of children with a congenital hearing impairment have a mild to moderate impairment. With early fitting of hearing aids, these children can achieve a normal linguistic development.

Marcus & Vijayan & Bandi Rao & Vishton (1999) point out the importance of speaking to the infant since the new-born child is able to learn and understand the structure of the language. The study concerns hearing infants, but the same applies for deaf infants. The time course as well as the structure in manual and verbal language is similar, which implies that human language is founded on a common language ability (Petitto & Marentette, 1991). This early phase of the linguistic development, which is common for hearing and hearing impaired children, emphasizes the importance of early detection of a hearing impairment in infants to afford positive linguistic stimulation by the fitting of hearing aids and education in sign language.

The present study shows that parents want early knowledge of the child´s hearing impairment to be able to help and understand their child as early as possible. This is in agreement with findings of several other authors – an early

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intervention when a hearing impairment is confirmed is the best condition for the child's linguistic development (Apuzzo & Yoshinaga-Itano, 1995; Robinshaw, 1995). Magnuson (2000) studied the linguistic and social development for two boys who met at a specialized sign pre-school. Their preconditions were quite different because in one of them the hearing impairment was detected at the maternity ward, while the other was not detected until he was 2 years old. The results showed the importance of early sign language acquisition for infants with congenital deafness not only for the language, but also for the social development.

The lack of an early developed, effective and sophisticated language brings about negative consequences for all aspects of psychological development, and thus for the mental health of children (Hindley & Parkes, 1999). Identification of the hearing impairment at 6 months of age, followed by a suitable habilitation is the most effective strategy for obtaining a normal linguistic development in deaf and profoundly hearing impaired infants (Yoshinaga-Itano & Sedey & Coulter & Mehl, 1998). The deaf children who have participated actively in linguistic communication with their parents from an early age are most competent in their social, cognitive, and linguistic development By this interaction the child not only learns facts, but also gains successful behavioral and cognitive strategies, self-knowledge and knowledge of others, and a sense of being part of the society (Vaccari & Marschark, 1997). The attitude of the family with respect to hearing impairment, the acceptance of having a hearing impaired child, and the expectations of the family with regard to the child's social role in the family during upbringing and education are important factors (Luterman, 1999).

The child's hearing impairment tends to be neglected in too many cases (Robertson & Aldridge & Jarman & Saunders & Poulakis & Oberklaid, 1995). In our study regarding late detection, the parents explained that they had been in touch with the primary care repeatedly because they suspected a hearing impairment, which was not confirmed at this stage (Magnuson & Hergils, 2000). The parents reported conflicts with their children that could probably have been prevented, had the impairment been confirmed earlier, since the conflicts were related to misunderstandings caused by the deficient communication. Repeated misunderstandings lead to frustration and can have a negative influence on the child's development. In some cases the parents told that the hearing impaired child was understood better by a sibling than by the parents themselves. The relationship between siblings may not be without complications, but it is possible that they developed a joint way of communicating and understanding during the early fantasy play (Dunn, 1993).

4. 2. On uncertainty and anxiety

It is difficult for parents of children with a disability to make themselves a clear picture of the child's present and future development, since the normal developmental scheme is not valid. When the presence and severity of a possible functional impairment is uncertain, and in the absence of frame of reference, parents cannot envision the future. Stern (1995) describes this predicament by stating that a deficiency may arise concerning the ontogenesis of the parent´s representation of the child. This situation is valid also for parents whose child has a single impairment, such as a hearing impairment.

Citing an experience often stated by parents in the present study: "It is not so bad to know that the child has a hearing impairment, but to be told that there *might* be an impairment - that is the reason for anxiety". In parents who received a late diagnosis the time of anxiety was long-lasting; in some cases the period lasted one or more years. These parents worried over the child´s behavior and the poor speech development, and they were also misunderstood or neglected by the medical care officials. This prolonged uncertainty and anxiety led to frustration and anger. Both professionals and friends wanted to comfort them when they expressed their fears over their child's being late with speech development, but comfort is no good alternative in this situation. Rather, the rational move is to give early information on the signs that are typical for a child with a hearing impairment. When the parents find their suspicion to be well founded, referral to an audiological center for elucidating the suspicion is imperative. Early identification of hearing impairment is crucial to hearing impaired children reaching their potential language skill. There is a need to educate professionals as well as the general public about the importance of early identification. Continued education of general practitioners, nurses and pediatricians is necessary to ensure that the parents´ suspicion is taken seriously.

In neonatal hearing screening it is essential that any anxiety in the mother in this sensitive period after the birth be minimized by making the period of uncertainty regarding the child´s hearing as short as possible (Magnuson & Hergils, 1999). In a study of anxiety related to early hearing screening Watkin & Baldwin & Dixon & Beckman (1998) found that very few mothers felt anxiety, and that their uneasiness was slight and not caused by the test. Some emphasized that they were anxious when the child was taken from them to have the hearing test. In the Linköping screening program one or both parents are always present during the test.

4. 3. A plan of action prevents unnecessary anxiety

Parents are not prepared for the possibility that their child may have a hearing impairment, and most have poor knowledge of the function and importance of hearing. The general view on hearing impairment as a handicap has changed, however, and parents of today are well aware that habilitation is possible. Parents want to know as much as possible about the child´s hearing impairment and what kind of help that can be offered, now and in the future. Information should be given preferably to both parents, using an everyday casual language that parents can understand without difficulty – professionals often use a terminology that may be confusing, or even appears non-intelligible.

The interviews with parents of children in whom the hearing impairment was detected late revealed that they suffered much anxiety during the long time that elapsed from suspicion to confirmation. The strongly felt uncertainty with regard to the future development of the child means an explicit need for a plan of action. The parents needed information as to how the children would be enabled to catch up with the linguistic and social development that had been stalled for such a long time. Parents to children with early detection of the hearing impairment wanted information on all resources that were available, and wanted to start habilitation at once. Here the pedagogical and technical teams of the Dept. of Audiology can use their resources, giving information and starting up the habilitation process.

Only parents in whose children a mild unilateral hearing impairment with no need for intervention was detected with OAE screening continued to feel uncertain. It may be possible to improve the situation and make the screening program meaningful for this group also by giving individualized information, and by providing an ongoing parent-doctor contact with a follow up to see changes over time with regard to the child´s development of communication skills. This might lead to the establishment of a fruitful dialogue between parents and professionals, so the families do not feel neglected.

It is important to emphasize that parents themselves will play an important role in the child´s continued development; otherwise, a feeling of mistrust or intimidation may develop (Bergen, 1994). At the Dept. of Audiology, Linköping University all the different professionals work as a team, which seems to be a fruitful strategy both for the child and for the parents who participate in evaluating the child´s development. Providing good information and habilitation is founded on confidence between the child, the parents and the professionals, which was obvious in this study. The parents felt confident when the relationship with the professionals had been established and with the habilitation that was offered.

4.4. Early identification means new demands on habilitation

In order to meet the new demands subsequent to early identification of hearing impairment in infants with the aid of OAE screening it is necessary to reconsider the habilitation program with respect to the new conditions. Initially, the pedagogical and psychological support will be subtle and given on an individual basis. A keen attitude on the part of the audiological professionals to the needs of the family is central when infants and parents are enrolled in the habilitation procedure aimed to improve communication, e.g. by the use of hearing aids and/or sign language. The OAE screening program leads to many questions from the parents, who become more conscious about the importance of hearing, hearing impairment, and language. To be ready to answer questions raised by parents during this sensitive early period, the team must have a comprehensive strategy and a consensus, including questions regarding new treatment options, e.g. cochlear implantation. The education of professionals must thus be adapted to these new conditions derived from the early identification of hearing impaired infants.

5. Conclusion

The present study aimed to compare the parents´ experiences and opinions with regard to traditional hearing screening of infants and universal neonatal hearing screening. It has previously been feared that hearing screening of neonates might disturb the parent-child relationship. However, the present results show that anxiety was caused by the uncertainty of whether the child had a hearing impairment or not. From the parents´ perspective, OAE- screening provides the benefit of being able to help and understand the child at the earliest possible time should a hearing impairment be detected.

Both in late and early confirmation of a hearing impairment, the anxiety was relieved when a contact between the parents and professionals was established. A late detection of a child´s hearing impairment obviously lead to a much longer and more trying period characterized by uncertainty and anxiety and aggravated by recurrent conflicts between parents and child because of the disturbed communication. In cases of early detection, the anxiety experienced by the parents whose child had to undergo more than one retest with OAE was of relatively short duration and appeared while awaiting the final result of the audiological assessment. It is important to make this period of uncertainty as short as possible, since the anxiety faded when parents were told the final result of the audiological assessment.

An early detection constitutes a considerable advantage for the child who can be given appropriate habilitation and start developing language, enabling the child to take active part in the social life within the family environment as well as outside. The parents can start habilitation at an early stage together with their child, and the uncertainty will be of comparatively short duration. To optimize the potential benefit of OAE screening, the habilitation program should be adapted according to the new conditions that are present when hearing impaired infants are to be fitted with hearing aids and trained to communicate with sign language. Parents need a plan for the future; this applies also in cases where the child has a mild, unilateral hearing impairment. The program could be made meaningful for this group by establishing a parent-doctor contact and follow up. To establish a dialogue between parents and professionals, informing the parents of the degree of the hearing impairment and its consequences is a pedagogical responsibility.

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Study IV

INFANTS WITH CONGENITAL DEAFNESS:

ON THE IMPORTANCE OF EARLY SIGN LANGUAGE ACQUISITION

Two boys who both had a profound bilateral hearing impairment met at a specialized sign preschool. Their preconditions were quite different, since in one of them the hearing impairment was detected in the maternity ward with the aid of otoacoustic emissions, and habilitation had begun at age 4 months. The other boy's impairment was not detected until age 2 years; habilitation was thus much delayed. Data were collected on the two boys using interviews with parents and teachers, observation, and video recording in the children's own environment at home and in the specialized sign preschool. Characteristic differences between the boys are described regarding their social and linguistic development relating to the time of detection of the hearing impairment. This illustrates the importance of early detection and habilitation so as to avoid separation of individuals into different groups with differing social and academic prospects, depending on the lack of early linguistic stimulation and consequent poor language acquisition. Giving children the possibility of developing a language is the primary consideration.

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Linguistic proficiency is a central requirement for human life: spoken language for the hearing and sign language for the Deaf. Infants have a communicative competence that was previously unknown, and this competence is common to both hearing and deaf children (Jusczyk & Hohne, 1997; Trevarthen & Marwick, 1986). The newborn child is able to perceive verbal sound patterns, and language development begins in early infancy (Marcus, Vijayan, Bandi Rao, & Vishton, 1999). In deaf children, language development proceeds in a manner that is equivalent to that of the hearing, starting with manual babbling and evolving into linguistic expressions (Petitto & Marentette, 1991). It is well known that the sign language of the Deaf is an advanced language rich in shades of meaning (Sacks, 1989). However, more than 90% of parents of children with severe to profound hearing impairment have normal hearing, which makes communication between parents and child difficult. Since education in sign language can begin only when the hearing impairment is detected, deaf children with hearing parents thus start from a clearly disadvantageous position. During the very important early period of language development, these deaf children thus do not receive any natural language stimulation.

The conventional methods for hearing screening have not been sensitive enough, and a childhood hearing impairment often remains undetected until the child's different behavior and failing speech development make it evident. Apparently, when conventional methods are used, detection of severe to profound hearing impairments in children occurs belatedly in all communities (Bamford & Davis, 1998). The only way to enable early detection and an early start of habilitation is universal neonatal hearing screening, with the aid of auditory brain stem evoked responses (aABR) or otoacoustic emissions (OAE) (Davis, Bamford, Wilson, Ramkalawan, Forshaw, & Wright, 1997; Kemp & Ryan, 1993; Mason, Davis, Wood, & Farnsworth, 1998). In a National Institutes of Health consensus statement (1993), universal neonatal hearing screening was recommended. The European Consensus Programme (1998) recommends hearing screening of infants, and general perinatal screening is now practiced at several centers in the United States and Europe.

There is strong evidence that the benefits of early intervention made possible by neonatal hearing screening outweigh the anxiety caused by a false positive test result (Magnuson & Hergils, 1999; Watkin, Baldwin, Dixon, & Beckman, 1998). It is now recognized that early detection of hearing loss is essential if children are to have the chance to achieve their potential language skills. Of all the variables that were investigated in a thorough longitudinal study of children with profound hearing impairment (Levitt, McGarr, & Geffner, 1987), it was found that the age when intervention began exerted the largest influence on the development of language and communication skills. Robinshaw (1995) studied communicative and linguistic behavior in children with severe to profound hearing impairments who were supplied with hearing aids at the age of 3 to 6 months. The results showed that children with severe to profound hearing impairments who are identified and supplied with amplification by the age of 6 months develop linguistic skills comparable to those of hearing children. Yoshinaga-Itano, Sedey, Coulter, and Mehl (1998) found that identification of the hearing impairment at 6 months of age, followed by appropriate habilitation, is the most effective strategy for obtaining a normal linguistic development in deaf and profoundly hearing-impaired infants. This can be accomplished only by neonatal hearing screening.

The failure to develop an effective and sophisticated language at an early age has negative consequences for all aspects of psychological development, and thus for children's mental health (Hindley & Parkes, 1999). There is evidence that deaf children of deaf parents who use sign language in their communication have significantly better linguistic, social, and academic skills than their deaf peers with hearing parents. Deaf children of hearing parents who have contacts with deaf people and share the language seem to have a similar advantage. Thus, the deaf children who are the most competent in their social, cognitive, and linguistic development are those who have participated in active linguistic interaction with their parents from an early age. This applies both to deaf parents and to hearing parents who have learned sign language, which permits them to interact meaningfully with their children. The child not only learns facts through this interaction, but also gains behavioral and cognitive strategies, an understanding of self and others, and a feeling of being part of society.

Many hearing parents have little formal training in sign language and find the use of signs impractical for most everyday needs. They do not feel comfortable with sign language, especially in public, and tend to sign only when they communicate directly with the child (Vaccari & Marschark, 1997). This leaves the child ignorant of what is being said and constitutes an obstacle to the deaf child's learning of sign language. In analogy, vocal speech is primarily learned indirectly by listening to other people talking, from television and other sources, and less by direct teaching. Vaccari and Marschark state that despite their best intentions, parents who start learning sign language, and who sign with their children, tend not to continue developing their skills. In addition, the parents' communication is often limited to tangible things, a shortcoming that becomes even more pronounced when the child matures and needs explanations of more complex social and emotional subjects.

There is thus a consensus that early detection and an early start to habilitation yield better opportunities for the development of communication. The earlier the hearing impairment is identified, the better is the development of language skills. Results of previous studies (Magnuson & Hergils, 1999, in press) emphasize the importance of early detection, in terms of both linguistic and social development. Parents clearly express that they want early detection with the aid of neonatal hearing screening; they want early knowledge of whether their child has a hearing impairment in order to help establish good communication within the family (e.g., by hearing aid or sign language), and because of concern over the child's future development.

Aim of the Study

The aim of the present study was to illustrate early language development and the importance of early language acquisition by means of a comparative, in-depth study of two characteristic cases. A large amount of data was collected concerning two boys who both had a profound bilateral hearing impairment. When they met at a specialized sign preschool, their preconditions were quite different. In one of them, the hearing impairment had been detected in the maternity ward with the aid of OAE, and habilitation had begun at the age of 4 months. The hearing impairment of the other boy was not detected until he was 2 years old, and habilitation was thus delayed. Characteristic differences between early and late detection are described, based on interviews with the parents and teachers, and observations and video recording in the children's own environment, at home and in a specialized sign preschool. The issues focused upon in the present investigation were: What experiences, opinions, and judgments could be found regarding the two boys' communicative, linguistic, and social abilities? Of what importance was the sign preschool to these children?

The Specialized Sign Preschool

At the time of the present study, both boys were attending a specialized sign preschool, where children with impaired hearing were integrated with children who were not hearing impaired. The purpose was to give children with hearing impairments the opportunity to interact and play with hearing children. Experience showed, however, that the children with hearing impairments preferred to play within their own group.

Promoting communication between groups (using sign language or vocal speech, respectively), would require active guidance by the supervisors (Ellström, 1993). This was not practiced at the school; rather, the primary pedagogic aim was to enable the children with impaired hearing to achieve sign language competence and social fellowship within their own group. Thus, the child's individual needs regarding language development and social skills were the focus. At the time when the two boys attended the preschool, there were 10 children with different degrees of hearing impairment, and 8 hearing children. All personnel were fluent in sign language and one of them was deaf.

Method

Subjects

Both boys were the first child in their respective families, and both sets of parents were hearing. The family constellations were stable in both cases, and both boys later got a younger sibling who was hearing. The socioeconomic status of the two families was about the same. The families received education in sign language when the boys were 6 months, and 2-1/2 years old, respectively. The families attend periodic weekend courses where they meet deaf persons and others skilled in sign language.

"Rasmus" was 3 years 5 months old when the study was completed. His hearing impairment was detected with OAE in the maternity ward the day after birth. When he was 4 months old, a bilateral profound hearing impairment was confirmed with diagnostic ABR. When 6 months old, he was supplied with bilateral hearing aids, and he was admitted to a specialized sign preschool when he was 1-1/2 years old, after a 6-month schooling-in period.

"William" was 4-1/2 years old when the present study was completed. He also had a profound bilateral sensorineural hearing impairment, which was not confirmed until he was 2 years old. He was then fitted with bilateral hearing aids, and after 6 months of schooling-in he was admitted to the same sign preschool.

Measuring Instrument

The children were studied by means of interviews with the two parent couples, and the teachers at the sign preschool, of whom five were hearing and one deaf. In addition, two members of the pedagogic habilitation team from the Department of Audiology, University Hospital, who served as auxiliary teachers at the sign preschool, were interviewed. All interviews were done by the author using a tape recorder. The parents were interviewed on two different occasions; the first about 1 year after confirmation of the child's hearing impairment, and the second when the children were ages 3 years 5 months and 4 years 6 months, respectively. The first interview with the parents was semistructured (i.e., open-ended), and lasted 45 minutes. The second interview lasted 45 to 60 minutes and was carried out according to a scheme consisting of one structured part for background information, and one semistructured part to ascertain different aspects of communication in the home setting. The individual interviews with the sign preschool teachers and the auxiliary teachers from the Department of Audiology were semistructured and lasted 30 to 45 minutes for each of the teachers.

Examples of Questions

All questions were followed by supplementary queries. Some fundamental questions were used in all interviews, such as: What do you think it means for Rasmus/William to go to the sign preschool? In your opinion, what are the advantages/disadvantages of early or late detection of the hearing impairment?

Questions to parents focused primarily on the communication within the family: Tell me, what works well in communications with Rasmus/William, and what does not? Does Rasmus/William take the initiative to contact other kids and play with them, and how does he manage? How do you estimate the linguistic development of Rasmus/William? Give me your impressions of his difficulties and progress. What happens when Rasmus/William cannot make himself understood? How does he react? What is your opinion with regard to sign language? What are your plans and hopes for Rasmus/William?

Questions to the teachers at the sign preschool were meant to clarify linguistic and social development: Can Rasmus/William express himself so that you understand him? Tell me about his interaction when playing with his peers. How do you evaluate his linguistic development and his language skills today? How does he react when other kids do not understand him? What happens then? Do you see any difference between Rasmus and William concerning their development of language skills and behavior?

Observations and Videotaping

Observations were made and video recorded by the author and lasted about 1 hour in the boys' homes and 4 hours at the sign preschool, taking the "observer as participant" form, which enabled collection of as much information as possible with regard to interaction and communication. The observation exercise in the two homes was focused on interaction situations between the parents and the child. In the sign preschool, five different situations were observed: free play within the school, half- structured play, concept education with the whole group of 10 hearing-impaired children who attended the school, lunchtime, and free play in the schoolyard. Finally, a video recording was made covering 15 minutes in the home and 45 minutes in the sign preschool. The study was approved by the Ethics Committee for Research at the University Hospital.

Analysis

The precondition in the present study was that both boys had a profound bilateral sensorineural hearing impairment and that they attended the same specialized sign preschool, being supervised by the same teachers. From another viewpoint, their conditions were quite different, on the basis of the age at which each boy's hearing impairment was confirmed. The interviews were the main source of information for analysis, and complementary information was collected from observations and video recordings. The analysis followed a three-step procedure (see Figure 1).

Interviews

After the interviews were completed and the recorded material transcribed, different qualitatively delimited phenomena were defined, which consisted of opinions and experiences expressed by the parents and teachers, and descriptive categories were defined.

Observation

In the different situations both at home and at school, as accounted for above, it was possible to find characteristic similarities and differences with regard

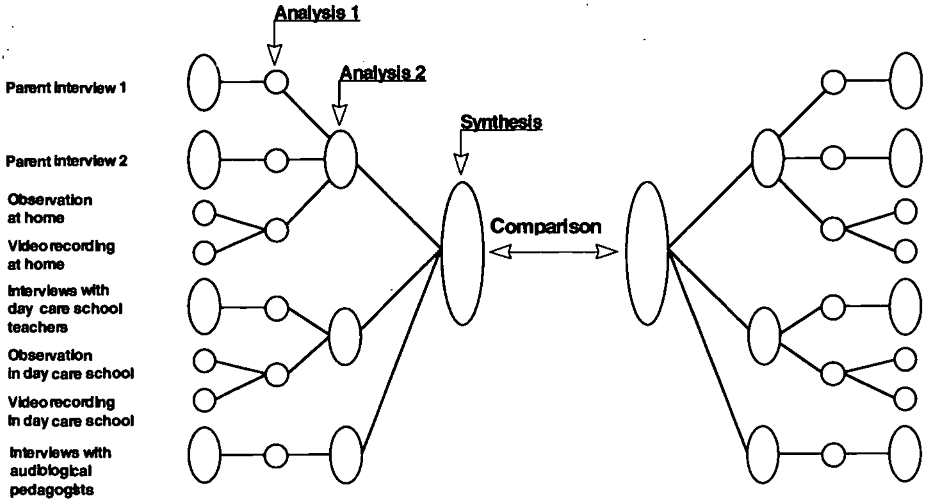

Figure 1
Scheme for data collection for each of the two children, the three-step procedure used in analysis, and the final comparison.

to the behavior of the boys, which served to complement the interviews.

Video Recordings

The video recordings contained samples from all the different situations described above; the differences and similarities were observed in the videos.

Synthesis

The three parts described above were used to find interesting aspects that characterized the communicative activities of the two boys (triangulation), which enabled a comparison between them. There is an unavoidable tension among the data obtained by means of these different modes of data collection, enabling a continuous reciprocal interaction among them that serves to deepen and extend understanding. The validation is a continuous process that is built into all stages of the study, one involving continuous control with regard to the empirical material, as the results are expressed and made comprehensible (Hammerslay & Atkinson, 1995; Kvale, 1996; Larsson, 1994; Merriam, 1998).

Results

Background Information

The second interview with the parents, when the children were ages 3 years 5 months, and 4 years 6 months, respectively, contained an introductory, structured part aimed at getting background information regarding linguistic stimulation of the child within the family, and the results showed a similar pattern for both families. About twice a week, the parents used to tell simple fairy tales to their children by signing, and they played games together sometimes. Playing music and singing with the children was unusual in both families, but the children watched television frequently. Both families used to borrow videotapes with signed fairy tales, and both children liked to watch them. The boys seemed interested in letters and numbers, and each was able to write his own name.

Synthesis

Different phases in the course of linguistic and social development of the children could be discerned in the analysis; these phases are used here to describe their progress. Both Rasmus and William are now doing well in a sign language environment, but there is still a large difference between them. Rasmus followed a development process similar to that of a hearing child with regard to his language and social skills. He was confident and soon gained a good command of and active use of sign language. William's linguistic and social development was slower. In the beginning, he had difficulty grasping and using sign language, and his social interplay with other children was primitive. As time passed, his language and social skills showed marked improvement, but, when the present study was terminated, he was still behind with respect to his age.

The Prelingual Phase in the Family Setting

Rasmus: When the hearing impairment was confirmed, when the boy was 4 months old, Rasmus's parents were eager to start up sign language at once, and education was supplied by the sign language teacher at the Department of Audiology. Rasmus's mother said she found sign to be "a different and interesting language. It is great fun to learn!" Rasmus was also fitted with bilateral hearing aids and was probably able to perceive low-frequency vibrations. Thus, his prelingual phase was very brief, not much longer than for hearing children. Rasmus is a placid child who learned linguistic and social rules early. At the first interview he was a little over 1 year old, and the communication by signing had already developed. The communication between Rasmus and his parents relied wholly on sign language. "Surely, we had no problem with communication; he never suffered from being deaf at all," his parents said.

In the parents' opinion, it was a great advantage that the hearing impairment was detected early so that they had the opportunity to learn sign language at an early stage and to be "in advance of the child regarding language, so one can understand each other; that is positive."

William: Before his hearing impairment was detected at age 2 years, William did not get any ordinary linguistic stimulation. Because of the lack of spoken or sign language, he developed a method of his own to make himself understood. He took the initiative by guiding his parents, by pointing, pushing them, and pulling their arms to make them understand what he wanted. William was a determined and ardent boy who made large gestures, repeating, and repeating once again when necessary, to make his parents understand: "He had his own language, very emphatic. If he was sitting on my shoulders and wanted to turn right, he just pulled my right ear. There was no question about it, it was just to follow his direction."

In the family setting, this special kind of communication worked reasonably well as long as the parents permitted William to be in control. Sometimes, however, the situation became chaotic when he did not understand what was going to happen, or when he could not himself have the initiative, or when he was not allowed to decide by pointing and pulling. When his parents did not understand him, they had to coax him. Outside the home, and when his family was with other people, the communication did not work at all, and the situation clearly could become difficult both for William and his parents.

Linguistic and Social Development in the Sign Preschool

Rasmus: When Rasmus started in the infant preschool at the age of 1-1/2 years, he had already reached linguistic maturity on a level comparable to that of a hearing child.. When he was 2-1/2 years old, he moved to a class for older children. At the time, he exercised active use of sign language and showed good understanding of concepts. He was fully aware of visual turn taking, and understood how to act during a conversation by watching the signing person. The teachers at the sign preschool and the parents took part in Rasmus's development with much interest, and, at the time of the second interview and observation when he was 3 years, 5 months old, he could pursue a fluent dialogue with them. His linguistic and social abilities in the interaction with playmates and teachers were judged as comparable to those of a hearing child of the same age by all the interviewed persons; some of them even considered him advanced for his age. The deaf sign language teacher judged his development to be equivalent to that of a deaf child with deaf parents, who gets sign language stimulation from the very beginning: "Yes, he was obviously ahead of his age, like a hearing boy then, only he used sign language."

Rasmus quickly grasped, ahead of the other children, the instructions given by the teachers—for example, when the group of children with hearing impairments were educated in the understanding of concepts. He was confident and helpful, and played calmly with other signing children. "That Rasmus was so calm was due to the fact that he got his language so early; he knew what was going to happen. He understood that people wanted to sign with him," a teacher said. At the preschool, Rasmus preferred to play with other children who signed, but he had no playmates at home. His parents found that playing with hearing children did not work well because of the language difference: "They simply do not understand each other. With deaf children there is no problem. They sign whatever they want to say, and then they play." Everyone who was interviewed agreed that the early detection of the hearing impairment was an advantage for Rasmus when he was acquiring linguistic and social competence, and were of the opinion that the sign preschool was very important for his positive development.

William started at the sign preschool at 2-1/2 years of age, after his hearing impairment had been confirmed. This certainly meant a large change for him. He now had to adapt to using hearing aids, and education in sign language was started for him as well as his parents. His social behavior was in accordance with his language development, and he did not know what to do outside his home environment. The special communication mode that he had developed within the family was impossible to use in the new environment, and the conventional sign language was totally unknown to him. He was at first insecure and sad since he did not understand his new playmates and teachers, and they did not understand him. "William, who did not get signs so early; he was very uneasy, making trouble, and seemed to avoid eye contact," a teacher said. Previously he had been used to taking initiatives, but now, when he could no longer take the lead and decide upon having a certain toy, for example, he would push his playmates. Sometimes he withdrew from the others, wanting to be left alone. He was unhappy and angry when he could not have his own way. "Then there was crying and despair unless he got what he wanted," was a comment made by the teachers.

When the sign language education had gone on for some time, William began to like learning signs. Little by little the communication improved, and it was easier to understand what he wanted and to explain things to him. "So much was missed the first 2 years, not getting to know things, what they are and what they mean–that must be very important," a teacher said. William's mood improved, and his family viewed the sign language as very positive. In the beginning, William's sign language skills developed slowly, but when he was between 4 and 4-1/2 years old, his linguistic development took a large step forward, and his social competence improved accordingly. "Yes, and then one must start to sign and suddenly understand how to use it. It must take some time, mustn't it? But now he seems to be getting along fine," one of the teachers remarked. William appeared happier and more secure and played in a more relaxed way with his mates. All interviewed persons found that the sign preschool was very important to William, not only for learning sign language but also for social development. He learned many concepts and was able to ask questions and give answers to questions, but he still had difficulty using the language actively and taking part in dialogues. He appeared to lack concentration, and the visual turn taking was an obvious difficulty–that is, making William focus on the signing person and keeping his attention as long as needed to convey the message. "The difficult thing is to gain his attention, to have visual contact long enough to think through the matter and convey the message," one of the teachers said. At the second interview (when William was 4-1/2 years old) his parents' opinion was that the communication worked much better since they could mostly understand what he wanted to say, as well as he them.

William showed himself to be social by making contact with other children and adults, although he was sad when he could not make himself understood sometimes; this improved as he learned more sign language. The companionship with hearing children was still poorly developed since the children did not understand each other, and he had no playmates at home. "He is quite a social boy who really wants to talk, but he does not know that the others do not understand him when he is signing," one of William's parents said. The parents sometimes found William's hearing impairment to be a handicap when they were outside the family environment, but never at home. The teachers at the sign preschool evaluated his linguistic and social development as being below average for his age: "His sign language was rather poor then, so it was difficult to communicate with him in any way. There has been a change, but there is still quite a good deal lacking."

The Future

Rasmus's parents viewed his linguistic and communicative ability as normal for his age and found it difficult to decide whether to let him have a cochlear implant. After careful consideration of possible advantages and risks, they ultimately opted for implantation. However, they are of the opinion that there are no activities for Rasmus in their home community and that he cannot get any playmates there. Since there is no school for the Deaf in their hometown, they plan to move to another town where such a school is located. The parents want him to go to a class for deaf children, using sign language. "Suppose he gets an implant so he can hear, he will still be in a group with deaf children, and, of course, what I want is that he will have his sign language," one of his parents said.

William's parents came early to the conviction that he should have a cochlear implant. They were also of the definite opinion that the best for him would be a class for children with hearing impairments. "It is really important that he meets other children with the same language," one of his parents said. Since there is no special school for children with hearing impairments in their home community, the family is prepared to move to another town where there is one. "He will go in a class for hearing impaired children; one cannot know if he will manage in an ordinary class," one of his parents said.

Discussion

The Role of the Parents

In the present study, Rasmus's and William's parents participated very actively in continuous sign language training. All four found the progress of their children to be very positive and were encouraged to continue learning and using sign language in interactions with their children. Parents must take responsibility early on for orchestrating an interaction based on waiting for the child's attention before starting to sign, and then maintaining visual attention long enough for the message to be given. As time passes, such attention switching becomes natural for both the parents and the child, and visual turn taking is developed, which promotes effective communication instead of directing it (Power, Wood, Wood, & MacDougall, 1990). Mothers with better social support are more positive in the interaction with their child. Receiving support as soon as possible after the diagnosis of the child's hearing impairment is particularly important. The parent then transfers the positive interaction behavior to the child, and children who have developed a good social and communicative ability within the family are better furnished to brave the step into the social world outside the family (Vaccari & Marschark, 1997).

In the present study, the parents were eager to learn sign language and used it consistently with their children. To learn more, they took part in weekend training programs with their children. As a result of the early detection, Rasmus's parents had a lead over their son with respect to sign language, which they regarded as very positive. The present study shows that it is important for hearing parents to start communicating early with their deaf child in sign language. The early start is crucial, even though hearing parents are naturally far from fluent in sign language at the time.

A simplified and partly nongrammatical sign language is used by deaf mothers in their communication with the child during the first 2 years. In order not to confuse the child, they tend to simply use hand signs with respect to *Wh-* questions, keeping a neutral face, while using facial expressions only when expressing affection. This permits the child to read only "one visual channel at a time." When the child reaches the age of 2 years, the mother, without being conscious of the change, shifts her strategy and starts using the adult language with "two simultaneously active visual channels," where the hand signs are complemented with grammatically correct facial expressions (Reilly & Bellugi, 1996).

For a deaf child with hearing parents, it is vital that parents start signing with their child to initiate communication, though the signing may first be simple and incomplete. This provides the opportunity for the child to start developing language. Thus, it is essential to communicate with the child by sign language, even though the parents may eventually opt for cochlear implantation.

The Importance of the Sign Preschool

One must pay attention to the fact that each child has a unique set of characteristics that will contribute to how development will proceed, and the child must be given individual support according to his or her own conditions. Thus, one important factor that will influence development is the flexibility of the habilitation, and a program adapted to continuous individual development can greatly reduce the risk of a social and linguistic handicap (Apuzzo & Yoshinaga-Itano, 1995).

The results of the present study were certainly influenced by the fact that the two boys and their parents were supervised by a habilitation team consisting entirely of professionals, who focused on their individual needs. The overall pedagogical framework was equal for both hearing-impaired and hearing children in the integrated sign preschool. However, in Sweden, sign language is regarded as the primary language for the Deaf, and this carried over into the pedagogical practice (Lgr 80, 1983). Since the teachers found it to be a necessary arrangement, the children with hearing impairments were often gathered together in a group of their own to practice sign language and understanding concepts. Even though the children were allowed to play freely with their mates, they were also trained through structured play, without knowing that the interaction was designed to develop the language. The teachers discussed and evaluated the needs of individual children with the auxiliary teachers, who were also working with hearing pedagogy at the Department of Audiology.

Sign Language and Spoken Language

Sign language holds a strong position in Sweden, where it is designated the first language of the Deaf. In 1981, sign language was declared the official language for the education of deaf children. This means that spoken and written Swedish is also seen as a second language for children with congenital hearing impairments who are candidates for cochlear implantation. Children with moderate to severe hearing impairments who are supplied with hearing aids are also given sign language training as a complement, with the aim of stimulating use of the language. To make speech easier to understand, signs are then used simultaneously with speech. Spoken and written Swedish is seen as the first language, and signs are used only to support speech.

Deciding which communication method the child will learn is a critical choice for the family and for the deaf child, and one that is influenced by a variety of factors (Reamy & Brackett, 1999). More than a simple choice of method is involved, since the method that is chosen is the decisive factor in how well the child will manage in the future, both inside and outside the family. The attitude of the family with respect to hearing impairment, the acceptance of having a child with hearing impairments, and the expectations of the family with regard to the child's social role in the family during upbringing and education are important factors (Luterman, 1999).

There is nothing to indicate that the combination of signs and speech mitigates the development of concepts. One study indicates that the child seems to be able to code-switch in relation to the actual context and his or her partner (Preisler & Ahlström, 1997). There are also no data to show that sign language as a first language will inhibit spoken language. Deaf children who learn sign language as a first language usually have better skills in reading and writing than deaf children who have only been exposed to spoken language (Marschark, 1993).

Several factors contribute to the choice of communication mode, such as the prevailing view toward sign language in the country concerned (i.e., the status of the language) and the access to specialized schools for the Deaf. Also, the time when the family starts habilitation does seem to contribute to a subtle difference of views.

In one of the families in the present study, the child's profound hearing impairment was detected early, and sign language introduced at age 6 months. The parents chose not to view Rasmus as disabled, since they accepted that he was deaf and used signs as a primary language. They were ready to move to another town where there was a school for deaf children. This view meant that the parents found it difficult to decide for or against cochlear implantation. However, they ultimately opted for the opportunity to do so.

In the other family, the hearing impairment was detected considerably later, and the sign language education did not start until William was 2-1/2 years old. The parents naturally chose sign language as a first language, but they were disposed to opt for a cochlear implant from the beginning. Therefore, they intend to let William join a hearing-impaired group. The family also intends to move to another town with a specialized school for children with hearing impairments, so William can get the best possible education together with his hearing-impaired peers.

Leaving their present homes and occupations to make a new start will certainly be a big change, but both families have considered the advantages and disadvantages thoroughly, focusing on what will be best for the child. A common factor that has prepared both families to move may be their conviction that a child is disabled only when not provided with optimal conditions for future development.

Conclusion

The examples of Rasmus and William demonstrate that a profound hearing impairment means a disadvantageous position for linguistic and social development, unless the impairment is detected early so that linguistic stimulation can be effected by the fitting of hearing aids, sign language education, or both. This early stimulation enables the child to gain confidence by knowing what is going on. The child learns where to look for visual cues, which makes communication meaningful and enables the child to feel that he or she is participating in a social relationship.

The early detection of Rasmus's hearing impairment meant that habilitation could start at the age of 4 months; he soon acquired sign language, which provided an effective means of two-way communication. Rasmus's parents and his supervisors at the sign preschool, including the auxiliary teachers from the audiological team, found his linguistic and social skills to be adequate and appropriate for his age.

In William's case, because of the late detection of the hearing impairment, a prelingual phase without words lasted more than 2 years. William's family started sign language education when he was 2-1/2 years old, and the start was not at all easy since the old "private code" that had been developed within the family was of no use in the new environment at the sign preschool. He had to learn new manners and an entirely new and unfamiliar language.

The specialized sign preschool, with teachers skilled in sign language and playmates who also used sign language in their interaction, was very important for both children in gaining social and linguistic skills. Obvious differences could be observed between the two boys regarding their social and linguistic development relating to the time of detection of the hearing impairment. This illustrates the importance of early detection and habilitation for the avoidance of an undesired separation of individuals into different groups with differing social and academic prospects depending on good or poor linguistic stimulation during infancy.

Universal neonatal hearing screening is the only means by which early detection and habilitation can be achieved. For a deaf child with hearing parents, it is a matter of vital importance to provide the opportunity for the child to start developing language by signing, even though the parents may eventually opt for cochlear implantation.

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