

# **Children Identified Early with Mild Hearing Loss: Parents' Views and Experiences**

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## **Abstract**

This study is an exploration of parents' experiences after the identification of their child's mild or unilateral hearing loss. The study also aimed to investigate whether these families had access to the Early Intervention Programme of the School of the Deaf.

The research adopted a qualitative research approach and a semi structured interview was carried out in order to explore the impact of the diagnosis of mild or unilateral hearing loss on the broader family. Nine families of children with mild and unilateral hearing loss, six with mild hearing loss and three with unilateral hearing loss, were interviewed. The interviews were transcribed verbatim and translated into the English language. The data was grouped into five themes.

The findings of this study suggest that despite the fact that in Cyprus mild and unilateral hearing loss is identified early in life due to the implementation of the Screening Programme, families are not referred to the Early Intervention Programme of the School of the Deaf for support. However, parents feel that as the diagnostic process takes a long time and requires regular visits to the professionals, it is a very stressful period and further information and support is needed. The information is vital to enable them to understand the type of hearing loss, the consequences that it might have on their child's development as well as to provide them with guidelines on hearing aid fitting in order to enable them to help their child wear the hearing aids. It was revealed that parents felt retrospective guilt as they could not understand the benefits of hearing aids and therefore did not persuade their children to wear them consistently. Parents also made valuable suggestions for the establishment of a coordinated support service.

The current study adds extremely helpful information to the existing literature concerning the challenges families of children with mild or unilateral hearing loss are faced with. Furthermore, it provides unique insight into the needs of parents

and points towards approaches that would most effectively support them as they themselves identify them. This can be a valuable tool for professionals to improve and adapt procedures when faced with cases of mild or unilateral hearing loss.

# **1. Introduction**

## **1.1. Background**

Traditionally, mild and unilateral hearing loss was identified later on in the child's life as initially screening programmes could not assess and diagnose hearing loss of less than 40 db.

The definition of mild bilateral and unilateral hearing loss was adopted from the National Workshop on Mild and Unilateral Hearing Loss Research (Centers for Disease Control and Prevention, 2005). Mild hearing loss refers to a pure-tone average (PTA) from 20 to 40 dB hearing loss at two or more frequencies above 2000 Hz, and unilateral hearing loss refers to a PTA  $\geq$  20 dB or thresholds  $>$  25 dB at two or more frequencies above 2000 Hz.

Early eighties research of Bess (1985), Bess et al, (1986), Bess & Tharp (1984), Oyler et al, (1988) exploring the impact of mild or unilateral hearing loss on school-aged children has shown that children with mild hearing loss lag behind their hearing peers in academic achievement. Similarly, initial research on the topic documented that older children with minimal hearing loss were less successful in developing social emotional skills to cope with issues of stress management, social communication and self-esteem (Davis et al, 1986; Bess et al, 1998).

In recent years, researchers, considering the existing evidence of the impact of mild or unilateral hearing loss on the language development and academic achievement of school-aged children, have begun to wonder whether the significant improvement of screening programmes which allows for early identification of mild or unilateral hearing loss would positively contribute to language development before school age. This has led to the first research on language development regarding preschoolers. That research has shown that children who are identified early in life are successfully fitted with hearing aids earlier on and therefore their language development is comparable to their normal hearing peers. Wake et al, (2006) showed that children with mild hearing loss do

not face significantly more academic difficulties than their normal hearing peers with respect to their receptive and expressive language and reading skills.

Furthermore, professionals have begun to look for ways in which families with children with mild or unilateral hearing can be effectively supported. Fitzpatrick et al, (2015) and Holstrum et al, (2008) showed that parents of children with mild hearing loss feel vulnerable and need considerable support and information in these early stages.

Therefore, the current research seeks to evaluate the impact of mild or unilateral hearing loss on the child's family leading to identifying appropriate intervention strategies in order to fully support them.

## **1.2. Outline of chapters**

Chapter two will review the existing literature on academic achievement and social emotional development of school aged children with mild and unilateral hearing loss as well as will explore strategies suggested by professionals for supporting school age children at school. Special interest will be shown in research related to the difficulties that parents with newly identified children with mild or unilateral hearing loss experience during the auditory management of their child, as well as to speech and language development of pre-school aged children. This chapter will also review the existing research on the challenges that children with unilateral hearing loss face in secondary schools, in Cyprus. Chapter three will address the methodological approach followed by the current study and will also outline existing procedures for hearing loss identification and management in Cyprus. Chapter four explores the results which arise from the interview transcripts which were clustered into five themes: Impact on the family, referral to the Early Intervention Programme, professional's uncertainty about the management of the mild or unilateral hearing loss, child's development and parent's needs after identification. Chapter five critically analyses the findings and discusses them in relation to the existing literature on the topic at hand. Finally, chapter six draws conclusions and makes suggestions for the future.



## **2. Literature review**

### **2.1. Introduction**

The literature review contains four sections. The first section reviews the literature on academic achievement and social/ emotional development of school-aged children with mild bilateral or unilateral hearing loss. It also explores strategies that arise from the literature to support this population in the school environment. The second section examines the current literature on speech and language development of pre-school children with mild bilateral or unilateral hearing loss, and the third section covers the key literature on the challenges parents face during hearing aid fitting and subsequent usage. The fourth and fifth sections review, in depth, parent's experiences and needs following the identification of mild or unilateral hearing loss. Finally, in section six the background and motivation for the current qualitative research study are described.

### **2.2. Academic achievement and social emotional development of school aged children with mild and unilateral hearing loss**

#### **2.2.1 The impact of mild hearing loss on the child's academic achievement and social emotional development**

The first research related to consequences of mild hearing loss on a child's development was published by Bess (1985) and Bess et al, (1986) in the 1980's. Before Bess' work, professionals believed that minimal degrees of hearing loss had little impact on a child's development. However, these early studies demonstrated that children with minimal degrees of permanent hearing loss were, in fact, at considerable risk of developing academic and behavioural problems. Those studies showed that children with mild hearing loss faced challenges in academic achievement, as well as in their psycho-educational and psychosocial development. They are at a higher risk of educational, speech-language or social-emotional difficulties than their hearing peers (Bess & Tharpe, 1984, Oyler et al, 1988).

Bess et al, (1986) have shown that 35% of children with mild hearing loss repeated at least one grade in school, and 13% of cases required additional educational support. Also, teachers reported behavioural problems in 20% of children with unilateral hearing loss. Blair et al, (1985) found that third and fourth grade children with hearing loss scored poorer in academic achievement than their normal hearing peers. The findings of Blair et al, (1985) were later confirmed by a wider study by Bess et al, (1998) who evaluated the hearing status and academic achievement of 1,228 schoolchildren in Grades three, six, and nine. Specifically, approximately 30% of the third-grade children with minimal hearing loss had repeated at least one grade, whereas nearly half (50%) of the ninth grade children with minimal hearing loss had repeated a grade. From the study findings it can be deduced that children from grades six and nine with minimal hearing loss exhibit greater dysfunction in the energy domain, as well as greater dysfunction in the domain of stress, social support and self-esteem in comparison to their normal hearing peers. Similarly, studies that evaluated the personality inventories of children with mild hearing loss found significantly higher tendencies toward aggressiveness compared to normal hearing children (Davis et al, 1986). These studies indicated that up to one-third of affected children failed at least one school grade (Lieu, 2004; Tharpe, 2008; Wake et al, 2004). This is supported by reports submitted by parents and teachers in the work of Lieu et al, (2012) which concluded that approximately 25% of children with mild hearing loss exhibit behavioural problems and have difficulties in learning.

Most (2004, 2006) examined the effects of the level of hearing loss on academic achievement in children attending regular schools. Defying researchers' expectations, children with a greater level of hearing loss had better results in the areas of: communication, participation, and total score of a screening instrument for targeting educational risks (SIFTER), than children with unilateral and mild bilateral hearing loss. The interpretation of these unexpected results, as pointed out by Kuppler et al, (2013), can be found in the fact that the children with greater

hearing loss had support in schools, used hearing aids, or were enrolled in programmes of early auditory rehabilitation.

Dokovic et al , (2014) conducted research with the purpose of establishing the influence of mild bilateral hearing loss on perceptual functions, verbal abilities, and nonverbal abilities of younger school-age children. Their findings showed statistically significant differences between participants with mild bilateral hearing loss and those with normal hearing in the majority of estimated developmental domains. However, those differences did not indicate any significant delay in development of assessed abilities, except in the domain of auditory discrimination and auditory memory.

There are a number of documented factors that affect the academic success and social emotional well being of school age children with mild hearing loss:

### **2.2.2 Classroom acoustics**

Investigations over the last 30 years have documented the detrimental effects of excessive noise levels on children's cognitive processing and academic performance. Despite the fact that in education systems little emphasis was put on the impact of poor classroom acoustics on children's learning, evidence highlighting its negative effect is increasing (Shield & Dockrell, 2008, Dockrell & Shield, 2006, Klatte et al 2010).

Children, regardless of hearing status, require more favourable acoustic environments than adults to achieve equivalent speech recognition scores. Crandell (1993), Ross & Giolas (1971), Boney & Bess(1984), Maxwell & Evans (2000) also provided evidence on the chronic effects of indoor noise on language acquisition and pre-reading skills in a preschool day- care centre where, due to poor interior acoustics, ambient noise levels averaged 76 dB(A). The authors concluded that chronic exposure to noise in early childhood affects the development of basic language functions

### **2.2.3 Phonological short-term memory**

Phonological short-term memory is highly sensitive to the negative effects of moderate intensity noise and is of major importance in the acquisition of oral and written language. Thus, researchers have come to the reasonable assumption that enduring exposure to poor acoustical conditions in childhood may affect the development of phonological working memory, which extends to both normally hearing children as well as children with hearing loss. Klatte et al, (2010) found significant effects of reverberation on speech perception and short-term memory of spoken items which demonstrate the importance of good acoustical conditions in classrooms. The performance of children from reverberating classrooms was lower in a phonological processing task, as they reported a higher burden of indoor noise in the classrooms than children from classrooms with good acoustics. The study also showed that children in classrooms with poor acoustic conditions found it more difficult to develop positive relationships with their teachers and peers.

According to Wake et al, (2006), children with slight/mild bilateral sensori-neural hearing loss developed poorer phonologic short-term memory and phonologic discrimination than their normal hearing peers although they do not face significantly more academic difficulties.

### **2.2.4 Ability to multitask in quiet and in noisy environments**

Data presented by McFadden & Pittman (2008) on the effect of minimal hearing loss on children's ability to multitask in quiet and in noisy environments suggests a lack of ability in all children, whether they have minimal hearing loss or not, to respond to a difficult listening task by drawing resources from other tasks to compensate. This does not apply to such an extent to adults who, when multitasking, have been shown to reduce their attention to a secondary task in order to accommodate the difficulty of a primary task.

### **2.2.5 Listening effort and fatigue in school-aged children**

Hicks' & Tharpe's (2002), research on listening effort and fatigue in school-age children with and without hearing loss found that children with even a relatively mild

degree of hearing loss may require more energy than their normal-hearing peers to listen in a classroom setting. No differences in measures of fatigue were found between the groups of normal-hearing children and children with hearing loss, whereas significant differences were observed on a dual-task paradigm designed to examine listening effort. Specifically, the children with hearing loss put more effort into listening to speech in quiet and in the presence of background noise than the children with normal hearing. This results in less energy or attention capacity left for the children to process what they hear, take notes, and undertake other activities required of school children.

### **2.3. *Strategies for supporting school age children***

Researchers suggested ways in which children with mild hearing loss could be proactively supported in order to achieve their full potential of academic ability.

More specifically Tharpe (2008) suggested that a child with mild hearing loss can, if necessary, be included in the individual special education and speech therapist treatment. Also, strategies comprising three levels of intervention were suggested: modifications of their environment (adaptation of classrooms to decrease background noise), technological modifications (implementation of audio technology such as personal frequency modulation systems and FM systems in free sound field), and educational modifications (instructions for teachers on how to interact with mild bilateral sensori-neural hearing loss children).

### **2.4. *Research on the development of pre-school children with mild hearing loss and unilateral hearing loss***

#### **2.4.1. *Speech and language development***

For pre-school children there is limited research on evaluating the effect of mild hearing loss on their speech and language development, or their communication skills. Furthermore, there is limited research exploring the parent's needs after their child's diagnosis with mild hearing loss. Population-based research by Fitzpatrick et al, (2010, 2014) has suggested that 40% to 50% of children identified with permanent hearing loss present with mild bilateral or unilateral hearing loss.

However, children with milder hearing loss were historically identified late and relatively little is known about the consequences of milder hearing loss when identified in early childhood. Research by Fitzpatrick et al, (2010, 2014), has also shown considerable uncertainty and variation in practice relative to management options including amplification and intervention for this population—an issue that has previously concerned investigators (Tharpe, 2008). The above research also showed that children with mild bilateral hearing loss achieved significantly lower results in the domain of morphology and syntax than their peers with normal hearing.

Moeller et al, (2007) in a longitudinal study of early word learning in hearing infants and infants with hearing loss, suggest that a delay in the phonetic and phonological development has an impact on the vocabulary of younger children with mild and moderate hearing loss. However, in contrast to the study by Moeller et al (2007), Dokovic et al, (2014), showed that children with mild bilateral hearing loss do not manifest more significant difficulties in the domain of vocabulary compared to their peers with normal hearing.

#### ***2.4.2. Speech and language development in early-identified children***

Fitzpatrick et al, (2015) examined the communication development in early-identified children with mild bilateral and unilateral hearing loss. The findings suggest that early-identified children with mild bilateral or unilateral hearing loss develop early communication skills comparable to those of their peers with normal hearing in the preschool years. These findings are consistent with the results of Vohr et al, (2008) who found that 12 early-identified children with mild bilateral or unilateral loss had better language scores at 12 to 16 months than 18 children with moderate to profound loss and that scores for the group with milder loss were similar to those for peers with normal hearing.

Fitzpatrick et al, (2015) were only able to find results on one auditory questionnaire (CHILD) at ages three and four years that showed lower scores for the children with mild bilateral hearing loss when compared to peers with normal hearing.

However, the current research did not examine the effects of various factors such as age at identification, age at hearing aid fitting, use of amplification. Despite the absence of a late-identified comparison group, it can be suggested, with caution, that early identification, amplification, and intervention are effective in reducing the gap in performance between children with hearing loss and their peers with normal hearing and that early identification is likely to have a positive effect on early auditory and communication outcomes. The results from this study represent an important first step in enhancing the knowledge base about the effects of mild bilateral or unilateral hearing loss on early communication development.

## **2.5. Challenges**

### **2.5.1. Hearing aid fitting**

A recent study by Tomblin et al, (2014) on the influence of hearing aids on the speech and language development shows that early provision of hearing aids to children with mild to severe hearing loss is likely to result in better speech and language development, particularly when the child receives good audibility from the hearing aids and has had a longer opportunity to wear them. Grimault et al, (1998) found a positive correlation between the length of time children are fitted with amplification and their performance on speech recognition testing.

### **2.5.2. Consistent use of hearing aids**

One of the most significant difficulties parents are faced with is the consistent use of hearing aids (Walker et al. 2015, Moeller et al. 2009). Parents of infants documented challenges to consistent hearing aid use more often than parents of preschool and school-age children. According to the parents, situations that presented challenges to consistent hearing aid use involved a child's state (e.g, mood, illness, fatigue, temperament), breaks in their routine (e.g, at home on weekends, after bath time), loud events (e.g, movie theatre, church), and equipment issues (e.g, feedback from hearing aid, discomfort from ear mould).

### **2.5.3. Emotional support and information**

Fitzpatrick et al, (2016) also conducted research to study the experiences of parents whose children had mild bilateral and unilateral hearing loss. The findings confirmed that parents, at early stages of the identification of their child's mild or unilateral hearing loss feel vulnerable and need considerable support and information about the meaning of hearing loss. These findings are in agreement with earlier studies (Holstrum et al, 2008, Fitzpatrick et al, 2008). The parents of children with mild hearing loss who were involved in the research were positive about screening and pleased to be aware early on of the presence of hearing loss in much the same way as parents of children with more severe losses (Fitzpatrick et al, 2007, Young & Tattersall, 2007). Professional communication and manner influenced the parent's perception of the early identification process. Some parents commented that technical expertise was of high quality but that emotional support was missing (Fitzpatrick et al, 2016). In some cases parents found professionals were not well informed on the consequences of mild hearing loss and, therefore, often interpreted the terms "mild" or "minimal" hearing loss to mean that the hearing loss is insignificant. Parents felt that their child was a lower priority because of the milder nature of the loss, especially when it was a unilateral hearing loss. The professionals' uncertainty about the auditory management, the different views about the potential benefits of hearing aids and the limited information about the risk of developmental delay lead professionals to a 'wait and see' approach and the belief that the family does not require early intervention (Fitzpatrick et al, 2016, Holstrum et al, 2008).

### **2.5.4. Technical information**

Parents with children with mild hearing loss presented a similar need to those with children with more severe hearing loss to acquire technical information as well as information on choices about hearing technology and intervention, (Fitzpatrick et al 2008). Especially in the early stages of identification, support and clear guidance were crucial to the parents so as to empower them on a practical level and make them accustomed to procedures such as fine-tuning Tomblin et al, (2014).



## **2.6. *The experiences of parents whose children have mild bilateral and unilateral hearing loss***

### **2.6.1. *Access to early intervention services***

According to the latest research results, (Fitzpatrick et al, 2016, Holstrum et al, 2008), families with children with unilateral hearing loss and mild hearing loss are in need to gain access to early intervention services. The provision of intervention services, however, is further complicated by a lack of understanding about the factors associated with both typical and atypical developmental outcomes for infants and children with unilateral and mild bilateral hearing loss. Monitoring through a developmental diagnostic process, should include diagnostic tests that are standardized for children without hearing loss, and are norm referenced. They should also measure skills in multiple developmental domains related to hearing, including speech, language, and functional listening skills at home, in school as well as in the clinical environment. This should include teaching skills that can help parents observe and assess their child's progress and can provide early intervention activities that facilitate development.

### **2.6.2. *Services evaluation***

In the work of Fitzpatrick et al (2008) all parents assessed the audiology and therapy services as vital components of the service delivery regardless of the severity of hearing loss. In particular they valued the emotional support and the specific coaching in language development provided through the continuous contact with therapists.

Parents also highlighted the need for a coordinated system to lead to a clear pathway from the diagnosis process to early intervention so that cases can be addressed immediately and parents are not left without support until they access the therapy service.

### **2.6.3. Parent support groups**

All families who were involved in the research valued parent support groups or access to parental input and suggested that parent support becomes an integral part of the health care system rather than it being the sole responsibility of a volunteer parents' group.

Parent support groups or access to parental input seemed to facilitate in the sharing of knowledge, practical information about hearing devices and community resources, prognostic information, and hope amongst parents; a fulfilment needed in the early stage of the management of their children's hearing loss. Moreover, for some parents, it also satisfied an emotional support need beyond that which could be offered by psychosocial providers in health care. A few parents commented that it supported healthy development of their child as children saw peers with the same type of communication disorder, (Fitzpatrick et al 2016, Holstrum et al, 2008).

### **2.7. Justification of the current study**

Participants of the National Workshop on Mild and Unilateral Hearing Loss (Centers for Disease Control and Prevention, 2005) which aimed to increase awareness of the significance of unilateral and mild bilateral hearing loss among professionals and families, developed suggestions for intervention and future research, about the potential effect of these losses and gave information on available hearing technologies.

Although not all infants with mild or unilateral hearing loss in Cyprus, will be identified when newborn, the number of infants being diagnosed with mild or unilateral hearing loss early in infancy is increasing due to the implementation of the newborn hearing screening programme. Research reviewing the experiences of children with mild bilateral or unilateral hearing loss in Cyprus is very limited.

A qualitative research, by Hadjidakou & Stavrou (2016), examined the challenges that children with unilateral hearing loss face at school age in secondary schools. In general, in this study, student responses showed that their academic and social

experiences were positive, and there were only limited academic, communicational, and social challenges. The participants in that study emphasised that they get enough support through one-to-one sessions which facilitate them to be prepared for lesson content that will come up, and to cope with their homework. The participants also stated that their teachers modify normal classroom delivery, use appropriate teaching methods, and apply preferential classroom placement for their students. The majority of the students stated that they developed friendships with their hearing peers. However, the participants stressed that within the classrooms (despite the fact they are acoustically treated), they face difficulties in listening when there is noise, when there is group discussion, when the teachers or children speak in a low voice, when they do not have eye contact with the teachers or classmates, when the speech is directed to the impaired side, or during the breaks. They also identified difficulties for listening situations outside school, such as shopping malls, parties, cinemas, playgrounds and generally in noisy environments.

According to the participants, their unilateral hearing loss causes them various feelings of discomfort, frustration, nervousness, embarrassment and anger, since they cannot listen in all circumstances, cannot detect the sound source, and they have to ask for repetitions or to withdraw because they cannot follow the discussion.

The findings of the above research (the only one carried out in Cyprus on older children with unilateral hearing loss) highlighted the need for a research aiming to examine whether families with children with mild hearing loss and unilateral hearing loss have access to an Early Intervention Programme, to establish the needs of the families after the identification as well as to seek positive strategies for support. Currently there is no research in the country on this topic at all.

### **3. Methodology**

#### **3.1. Introduction**

A qualitative research approach was applied to examine whether families with children with mild hearing loss have access to Early Support Services in Cyprus. The research also explores parent's experiences of the identification of hearing loss. Qualitative techniques were adopted to capture data that were meaningful to parents to express their feelings and needs at the very beginning of the diagnostic process. The qualitative approach identifies what is meaningful based on what emerges as meaningful from experience and not by what may be decided as meaningful by researchers when developing a closed set of quantitative questions (Silverman, 2005; Willig, 2001). The focus therefore in qualitative research is the "quality and texture" of experience and the meaning attributed to events by the research participants themselves and to describe and possibly explain events, but never to predict (Willig, 2001).

#### **3.2. Data collection**

A semi structured interview was set up with each family. One of the major advantages of the interview is its adaptability, where the interviewer can follow up ideas, probe responses and investigate motives and feelings which the questionnaire can never do. The way in which a response is made (the tone of voice, facial expression, hesitation, etc.) can provide information that a written response would not conceal (Bell, 2005). Furthermore, the benefits of using a semi structured interview are that it allows for the interviewer and the parents to develop "rapport" (Smith, 2003) during the interview process thus enabling parents to reflect on their experiences and share their personal needs after the identification of hearing loss.

Prior to the interview the parents were contacted by phone by the interviewer, an experienced teacher for the deaf, and were given information about the Early Intervention Programme, how it works in developed countries, its objectives, its distinction from the screening programme and the purpose of the intended

research. The majority of parents showed great interest in familiarising themselves with the programme and a willingness to participate in the research. There were, however, two mothers who decided not to participate and were negatively disposed to getting support from the programme, as they felt they didn't have that need.

One of the weaknesses that qualitative research suffers from is that the interview is a very artificial situation as it involves a researcher talking to someone who is a complete stranger (Rubin and Rubin, 2005). This unfamiliarity can prevent parents from expressing their true feelings, sharing their experiences and can generally interfere with their behaviours.

At the home visit, the interviewer allowed time to generally get to know the parents, provide them with written information, play with the child, familiarise herself with their home setup in order to allow rapport to be built prior to the interview. Developing rapport, which is a fundamental concept of semi structured interviewing (Willig, 2001), was perceived to occur smoothly and parents were felt to be at ease during interviews. In two cases where the diagnosis was very recent and the mothers were very stressed, the interviewer became aware of the need for further rapport development and so changed the plan by allowing time to answer their questions rather than proceeding with the interview. She also made arrangements for support by other professionals (psychologist and social worker), arranged another support visit a week later and, when she felt that conditions were mature enough, she then proceeded with an interview visit.

The intention was that during the interview the respondents would be free to talk about what is of significance to them. It is important to focus on their concerns, rather than those of the interviewer. However some loose structure to ensure inclusion of all topics of the study's interest was adopted, which helped to eliminate some of the problems of straight forward interviews. Thus, in-depth semi-structured interviews were used to gather data for this study (Drever 2003; Wengraf 2001). The guided interview structure adopted fulfils the study's requirements, where specific information is of great importance (see Appendix C). A framework is

established by selecting topics on which the interview is guided (Bell, 2005). The respondent is allowed a considerable degree of latitude within the framework. Certain questions are asked, but respondents are given freedom to talk about the topic and give their views in their own time.

### **3.3. Procedure**

A total of nine semi structured interviews were conducted with parents. The contact data of the families relevant to the investigation were supplied by the clinical audiologists of the “Centre for Preventive Paediatrics”. Information related to type of hearing loss, age at identification and hearing aid fitting details were also collected from the centre. Additional data related to parents education and child’s language development as well as other professionals’ involvement were obtained directly at the interviews. It was considered useful to select such data as other investigators pointed out parent’s education level and the family’s socioeconomic status as being contributing factors (Calderon 2000; Cole & Flexer 2011; Gilkerson & Richards 2009).

The meetings took place in the parent’s home, except for one, which took place at the school for the deaf in a quiet place, where nobody could interrupt during the interview. All the interviews took place in the presence of a psychologist according to the “Ethics” approved procedure (see Appendices A and B). The general issues to be investigated were formulated in the interview guide. The questions in the interview guide (which was developed by the author) were based on current literature on children with mild bilateral and unilateral hearing loss (e.g, Fitzpatrick, et al. 2008; Kuppler, et al, 2013; Tharpe, 2007) with the main aim of covering the important topics. The interview guide was formed prior to the visits to structure the conversation with parents. In order to make participants feel free and comfortable to share their experiences, the conversation started with open ended questions. Questions aimed at addressing issues such as:

- Emotional impact on the family
- Parents views on their children’s’ development

- Parents experience on hearing aid wear ability and fitting
- Concerns about children's further educational progress
- Family's needs during the first years

Questions were added in response to parent's comments to engage in a conversation with them. The interviews were audio recorded with participants consent and brief notes were written after the interviews to summarise the outcomes of the interviews.

### **3.4. Participants**

The sample frame for this inquiry was drawn from nine families who were recruited by the Paediatric Audiology Centre of the General Hospital. Three of the interviewed families were enrolled in the Early Intervention Programme during 2016.

Despite the fact that the early intervention programme supports families with children of ages from zero to three, the study included children beyond that age and up to six years, taking into account the fact that hearing loss is confirmed and hearing aid fitting for this group of children is taking place latter on in life, usually from 18 months to four years. Specifically, parents of children with the following characteristics were eligible to participate:

- (a) chronological age of the child with hearing loss less than six years at the beginning of the study
- (b) permanent mild bilateral or unilateral hearing loss
- (c) congenital or early onset hearing loss

Both parents, who could be hearing or deaf, were eligible to participate, whether they had Greek as their first language or not. The criteria had been developed by the researcher independently of the specific material analysed, and before its collection and analysis was defined for this study (Flick, 1998).

A mother with hearing loss participated in the study. She was using a cochlear implant and was communicating orally. No interpreter was used during the interviews. Children with hearing loss and additional complex disabilities were not included in the study. For the purposes of the interviews, the researcher contacted the families who had been indicated by the Paediatric Audiology Centre of the General Hospital and via the consent form ensured their willingness to participate in an interview. Attention was given to include parents of children with different hearing characteristics (e.g. mild bilateral, unilateral hearing loss), identified at different ages across the island to allow a diverse range of perspectives and experiences.

For a qualitative educational study, Smith, (2003), it was anticipated that nine participants would constitute a sufficient number to provide adequate data that conclusions could be drawn from. The qualitative research was generally flexible so as to have the possibility of inviting more parents as the study progressed. Ethical approval for the research was obtained from the University of Hertfordshire and written informed consent was obtained from the participants prior to the initiation of data collection.

Table 3.1: Description of children's age and type of loss.

<b>No</b>	<b>Participant</b>	<b>Age of child (years)</b>	<b>Type of loss</b>
1	Participant A	6 and 4	mild bilateral
2	Participant B	3.5	mild bilateral
3	Participant C	3	mild bilateral
4	Participant D	5.5	mild bilateral
5	Participant E	5.5	mild bilateral
6	Participant F	4.5	unilateral
7	Participant G	5	mild bilateral
8	Participant H	4	unilateral
9	Participant I	4.5	unilateral



### 3.4.1. Description of participants

Nine parents of ten children (seven mothers alone, two both parents together) participated in the interviews. All families had one child with hearing loss with the exception of one family who had two children with mild bilateral hearing loss. Child and family characteristics are shown in Table 3.1. Participants came from all over the island. Seven children had mild bilateral hearing loss and three unilateral hearing loss. Mild hearing loss refers to a pure-tone average (PTA) from 20 to 40 dB hearing loss at two or more frequencies above 2000 Hz, and unilateral refers to a PTA  $\geq$  20 dB or thresholds  $>$  25 dB at two or more frequencies above 2000 Hz.

All 10 children underwent the neonatal screening programme with the following results:

- a) Eight children fall in the early identified group having a mean age of confirmation of hearing loss before six months of age
- b) One child initially passed the screening and four years later returned to the audiologist for a retest due to parental concerns and the hearing loss confirmed.
- c) One child had the first audiological assessment at 18 months and was confirmed with hearing loss.

Table 3.2. Characteristics of children with mild bilateral and unilateral hearing loss

	Characteristics	N	%
Participants		10	
Sex	Male	4	40
	Female	6	60
Route to confirmation of hearing loss	Screened	9	90
	Not screened	1	10
Age of confirmation hearing loss	Before 6 months	8	80
	After 6 months	2	20
Type of hearing loss	Unilateral sensorineural	3	30
	Mild Bilateral sensorineural	7	70
Hearing aids	Fitted	8	80
	Non fitted	2	20
Age at Hearing aid fitting	3 months	1	10
	Around 6 months	3	30
	1.5-2 years	2	20
	3.5-4 years	2	20
Maternal education	Secondary education	3	33,33
	College/University	6	66,67

In the unilateral group, all three children had severe hearing loss in the ear with the hearing loss. One child, with atresia was fitted around three months of age; three children were fitted with hearing aids at around six months, two children were fitted around two years old and two children were fitted with hearing aids after the age of three. Two of the children are in the process of hearing aid fitting. One of the children had a family history of hearing loss; two were siblings with unknown aetiology. Parents of three children reported that their children were enrolled in the early intervention programme, the rest of the children were not.

The mean age of hearing aid fitting was 20 months (S.D. 11,85). This was a well-educated group of parents with six mothers having completed post-secondary studies and the rest of them completing secondary school.

### **3.5. Data analysis**

The nine interviews were recorded, transcribed and translated from Greek to English. Thematic content analysis was then executed. Themes were formulated by the author and then discussed by the psychologist and the supervisor until a recursive iterative process led to the final set of themes. At the end some themes were capturing the same overall idea and therefore clustered together. Participants were labelled with Latin letters from “A” to “I” and tabulated in table 3.1 with the respective age of child in years and type of loss for easy reference. Reference to participants refers to the child’s parents.

### **3.6. Reflexivity**

In order to acknowledge the researcher’s contribution to the research process, referred to in the literature as “reflexivity”, Willig, (2001), Nightingale & Cromby (1999), the following can be stated: The researcher, who is a teacher for the deaf with vast experience in preschool, primary and secondary education, has been actively involved with the Early Intervention Programme in recent years. Her main activities involve the support and guidance of families at the early stage of the identification of hearing loss. The practice followed was based on family needs formed over a long period of time. Advances in technology and audiology allow the screening and identification of mild and unilateral hearing loss at a very early stage. Therefore she has an interest in the fine tuning of early support, responding to family and children needs. In addition the researcher wishes to explore support strategies mentioned in the latest research in order to evaluate the extent to which such challenges exist in local communities.

### **3.7. Context**

Due to a lack of organised follow up services in Cyprus the so called “Centre for Preventive Paediatrics undertook a follow-up procedure in 2008, and has been completing the screening process with a diagnostic assessment of the referred infants. As a result, complete hearing status data only exists for infants screened after 2008. The age of diagnosis is under one month, whereas the age of verification and intervention is around 2-5 months.

For completeness, the current framework with respect to the early intervention services in the country is described briefly. An Early Intervention Programme is ran by the School for the Deaf with the aim of supporting families with children with hearing loss from 0-3 years old. The current legal framework related to mainstreaming education of deaf children does not include an Early Support programme for deaf children under the age of three. The School for the Deaf took the responsibility, back in 1990, to informally guide and support parents of children under the age of three with hearing loss. An experienced teacher of the Deaf was appointed and trained to deliver the Service. When the teacher is informed about new cases he/she immediately contacts the parents but the responsibility for taking action to receive services lies with the parents. Unfortunately this leads to a lot of cases being left behind and never getting the appropriate guidance until the child reaches three years of age and attends a public nursery. Due to lack of formal protocols regarding interdisciplinary work between health and educational agencies, the audiologist is relied upon to undertake the initiative of informing parents about the existence of the early support programme.

With respect to children with mild hearing loss and unilateral hearing loss who do not pass screening, they are referred for a diagnostic audiology assessment to the Centre for Preventive Paediatrics. Most of these children are diagnosed earlier than six months of age; however the hearing aid fitting is taking place at a much later stage. Because of the lack of supportive studies, determining which children are at risk of developing speech and language delays and later academic or social – emotional problems, as well as which are the best practices for early intervention support to families with children with mild hearing loss and unilateral hearing loss, the audiologists usually adopt a failure based approach. Families and children with mild hearing loss and with unilateral hearing loss are not given attention until significant delays are evident.

## 4. Results

Limited research has been carried out on parent's experiences following the identification of mild and unilateral hearing loss and very limited focus was placed on the impact on the broader family. This research thesis explores the complex emotional and varied experiences the parents encounter from the initial process of assessment of their child's hearing loss up to the identification and the final audiological management. Although the participants in this study constitute a small sample, the themes that have arisen might be used to understand the issues that a family with a child with mild hearing loss might experience. Interviews produced a narrative which enabled deeper understanding of parent's experiences. These parents were able to recall issues related to the identification and management of their child's hearing loss. Responses from the interviews were thematically analysed and five main themes were identified:

- Impact on the family
- Referral to the Early Intervention Programme
- Professional's uncertainty about the management of the mild hearing loss
- Child's development
- Parent's needs after identification

The first theme was of great importance to parents as they tended to describe many experiences relating to family impact including issues such as the advantages of early identification, the impact of early identification on the mother – child bonding, parents' feelings of helplessness and lack of support. Impact on the extended family and parents' feelings of disappointment and guilt were also mentioned. Time spent in the interviews for the various codes can be easily divided into two main parts, one being related to the different aspects of family impact and the other to the remaining themes. The researcher, having in mind the lack of literature related to the impact of mild and unilateral hearing loss on the family, purposely allowed the extended discussion of this theme.

### **4.1. *Impact on the family***

Recent studies have shown that parents of children with mild or unilateral hearing loss, at the initial stage of their child's hearing loss identification and monitoring, feel vulnerable and need considerable support and information. They are also positive about screening and early identification, regardless of whether the loss is mild or severe. (Fitzpatrick, 2005; Holstrum, 2008; Fitzpatrick, 2008).

#### **4.1.1. The advantages of early identification**

The majority of the participants expressed appreciation that their child's hearing loss was identified early. This however, does, not imply that it reduced the level of considerable stress they experienced during the screening process and until the final identification. Specifically, this had to do with their frequent visits to the audiologists, uncertainty about the auditory management of their child's mild hearing loss and therefore caused insecurity. Parents of children with more than three years experience, looking back, suggested that families should have been further supported and more properly guided at the initial stage of the diagnosis.

The statements from the parents illustrate this clearly:

*"Even though I was used to hearing loss, I was still upset... I am glad that we found out about her hearing loss early in life as I know the benefits of hearing aids and I want her to have every benefit to develop her language".* (Participant C).

*"Stress!!! A very stressful situation...But it is good that they offer it (screening) early because parents are aware that it may be a possibility and they are suspicious. If we weren't told, we would have not realised it on our own"* (Participant I).

*"Of course screening is positive, but it is hard! I was very shocked by the sight of the missing ear. I used to cry all day. I tried to find out why this had happened and I was sent for genetic testing. I needed support, but of course it is good to know early."* (Participant B)

*"Stress!!! A very stressful situation! We are worried about what is going to happen and what challenges she will have to face."* (Participant E)

*"It was a shock that she needed a hearing aid. The earth fell out from under us. We locked ourselves away as we could not accept this. All through the summer we went from doctor to doctor, hoping we would get a different picture. I spent hours searching on the internet and felt all I found was negative and depressing."* (Participant F).

#### **4.1.2. The impact of early identification on mother – child bonding**

Young & Tattersall (2007) showed that when parents demonstrated a positive view towards early screening this was based on the fact that they could promptly take any necessary actions, such as fitting hearing aids or obtaining a referral for a cochlear implant, without delay. This issue has also been identified in the current

study, looking at the views of parents with mild and unilateral hearing loss, with a mother stating that there is a significant difference depending on whether the child has mild or severe hearing loss, as with mild loss, the professionals do not suggest anything other than monitoring the child's hearing loss every month.

*"I realise that it is important to screen early but as there is no action that can be taken, a couple of weeks delay would not make any difference... As it was just a few days after the birth I was very vulnerable and felt desperate. Perhaps it would have been better not to undertake the screening so early on so that the mother has time to recover and enjoy her baby..."* (Participant A).

The background issues for this mother were numerous hospital visits and ongoing uncertainty about how, audilogically, to manage her daughter's hearing loss. Her daughter was finally fitted with hearing aids at 4.5 years

*"I used to cry all day. I tried to find out why this had happened and I was sent for genetic testing. I needed support!"* (Participant B).

#### **4.1.3 Parents' feeling of helplessness and lack of support**

Young & Tattersall (2007) also showed that for parents in their study, the essence of knowing early lay in not feeling helpless. They as parents could do something about it. Many talked in terms of preparation for the job ahead. A significant number of parents in our research, felt helpless and unsupported at the very beginning of their journey.

*"It was a difficult time for the family. We felt lost and unsupported. We did not know where to go to get help. We asked what we could do but the audiologist informed us that nothing could be done at that stage but that we should continue to monitor her hearing as hearing aids might be required in the future. When we returned home we realised we had many questions and wanted to investigate further. We did not know who to approach."* (Participant A).

*"My husband and I both needed psychological support but felt very alone."* (Participant D).

*"I would have preferred to have received more information and guidance from the beginning... I would have liked more guidance how to look after the hearing aids, or how to check whether they were working properly."* (Participant E).

*“We just want to know everything there is to know about this situation; how it might progress, what consequences there will be for her development, what I can do to help her. I need help with the hearing aid, and how to explain to her that she has to wear it!”* (Participant I).

*“My main complaint is that no one came to support us. I had to find information by myself on the internet...”* (Participant D).

#### **4.1.4 Shock for the extended family**

Within Cyprus, the extended family relationships are very strong. The majority of participants' encountered difficulties when trying to keep the family informed of what was happening with their child, when trying to explain why they needed to visit the audiologist so often, and explaining why they should proceed with hearing aid fitting. Particular comments were made regarding grandparents and coping with the grandparent's limited understanding of what was happening.

*“It was also a shock for the rest of the family, especially our parents, as we ourselves did not know and therefore we could not explain the implications or what was happening.”* (Participant A).

*“The first time my daughter's hearing aid was fitted was very traumatic for me. I was very upset. I found it difficult to cope with questions from the (extended) family as I did not know the answers.”* (Participant D).

*“My parents who are hearing were very sad. My father still finds it hard to accept and to convince himself that his granddaughter can hear well. He does not want me to proceed with hearing aids.”* (Participant C).

*“Guidance on how to explain to our child and her brother, that she needs the hearing aids. She still does not understand why she needs to wear them. We do not know how to explain it to her. It is also hard for us to explain to our son and our parents. We still have not told the (extended) family.”* (Participant F)

#### **4.1.5 Parents' feelings of disappointment and guilt**

In general parents experience disappointment and retrospective guilt from not understanding the consequences of hearing loss and not taking action to reinforce their child to accept the hearing aids. They insist that at this stage they should have had practical advice on how to assess their child's hearing and on how to make their child accept the hearing aids

*“... we did not know what we should be observing and just thought that keeping an eye meant going to regular appointments. My child started to speak early on and responded to our instructions. I have video where we ask her to point to the different parts of the body which she did correctly. We did not realise we should be observing specifics at home. It was only when I finally got practical advice from the Early Intervention Teacher for the Deaf that I was able to observe when my child could not hear properly” (Participant A).*

*“He is now three years old and I still cannot tell when he is wearing the hearing aid and when he is not. No one could help me understand what he could and could not hear.” (Participant B).*

*“When she was four years old we proceeded with the hearing aid fitting on her left ear, however, she has not accepted it yet. I need help with the hearing aid.” (Participant I).*

*“... This would have helped me to realise that my child should wear her hearing aids. Nobody stressed this to us. It was not made clear to me exactly what my child could and could not hear. If I was told that it was important to make her wear the hearing aid at that time, we would have made more of an effort.” (Participant E).*

*“Over the first few days I would have really needed support from a psychologist. I was ashamed of my child’s appearance and had difficulty explaining what had happened to anyone who came to visit. I should have had support at that time!” (Participant B).*

*“We have still not told the family. We have not told the nursery either as we do not want our child to be labelled. We must begin to accept the reality. Our friends get in touch but we avoid them as we do not want to tell them what is happening. In crowded or noisy situations we can see that our daughter cannot hear properly but my wife still resists giving her the hearing aid as she feels sorry for her.” (Participant F).*

#### **4.2. Referral to the Early Intervention Programme**

A ‘wait and see’ approach is still visible in Cyprus, for children with mild hearing loss, where, the professionals are undecided whether children should be referred to the Early Intervention Programme. In recent years, audiologists suggest that hearing aid fitting should take place early on, but they do not refer the families to the Early Intervention Programme. In the research for this thesis, three of the



families had entered the Early Intervention Programme one year before the interviews took place. The other six families were only informed that there was a Programme, when they were approached to take part in the research.

All these nine families unanimously stressed the positive value of Early Intervention.

*“I would have enjoyed the opportunity to visit someone who could provide me with further details. When the diagnosis was confirmed, we should have had access to information on the Early Intervention Programme offered by the School of the deaf so that we could have received greater support and advice. It was only when I finally got the advice from the early year’s teacher for the deaf that I was able to observe when my child could not hear properly.”* (Participant A).

*“I believe all families should be referred to the Early Intervention Programme. We need to know why our child needs a hearing aid. We need help with the baby until he uses the hearing aid. We need help on how to talk to him. Any written information would have been very helpful – especially if we were given of specialists’ contact numbers.”* (Participant B).

*“When my child was ten months old, a teacher for the deaf came to the house and gave me written guidelines and practical suggestions for activities that would help my child. This was very helpful. She also gave me attainment targets for different age ranges which helped me enormously.”*(Participant C).

*“At the hospital they gave me the telephone number of the early year’s teacher so I could contact her. She visited us at home and left us written information about the unilateral hearing loss. She was good and when she was here we managed to put the hearing aids on and the child liked her and cooperated. However, when I was alone I could not manage to persuade him to keep the hearing aid; he took it off... I needed help to put the hearing aids on. Even now he does not accept it at home but he does wear it at school.”* (Participant H).

*“Nobody told us that there was such a Programme, and I am really surprised... I am relieved to know that I will have somebody to support and to guide me for the next steps! I am really worried about what will happen when she starts at nursery. I have a lot of questions to ask and I believe that*

*since we will be in contact with her, we will have the opportunity to discuss about these issues further when the time comes.” (Participant I)*

### **4.3. Uncertainty about the management of the hearing loss**

Research, (Fitzpatrick et al, 2010, 2014), has also illustrated the considerable uncertainty and variation in practice relative to management options including amplification and intervention for this population — an issue that has previously concerned investigators (McKay et al, 2008).

#### **4.3.1 Uncertainty about the benefits of hearing aids**

Lack of clear and decisive guidance from the professionals led to parent uncertainty about the benefit of the hearing aids.

Some of the parents characterised the behaviour of some specialists as unprofessional as they left them to make the final decision about hearing aid fitting on their own. The fact that there was no consistency in the approach of different professionals, led the parents to experience confusion.

*“We asked what we could do but the audiologist informed us that nothing could be done at that stage, but we should continue to monitor her hearing as hearing aids might be required in the future. The results were given to us in a dry manner and we were just told to repeat the tests – no consideration for our feelings or explanations about the hearing loss were given and no explanation of what this would mean for our child’s development... Two months later, our paediatrician recommended an ENT specialist ...When we saw this specialist, he shouted loudly at the child. Both the child and I were startled and my child began to cry. From this he concluded that there was no hearing loss. We felt relieved at this, and did not pursue the matter further. But we now know that this delayed us as we did not take further action.” (Participant A).*

*“We were told that the decision regarding hearing aids was up to us. My husband insisted we wait as our son could hear without the aids. However, by the time he was three and a half it was clear that there was hearing loss in certain situations – when we were in a crowded room, or when he was far away from us. We then got the aids even though my husband is still unsure that they are necessary. The school, however, insists that they help.*

*I feel sorry for my husband who still cannot accept that our son needs a hearing aid. As we were told the hearing loss was borderline for hearing aids and the decision was up to us, it made it hard for my husband to*

*accept. If we had full information and guidance, it would enable us to understand and better accept the situation.” (Participant G).*

*“There is a need for clear and consistent diagnosis. Some doctors told us our daughter needed a hearing aid. Others disagreed.” (Participant F).*

#### **4.3.2 Need for support to understand the consequences of hearing loss**

The vast majority of the mothers stated that they did not understand the consequences of mild hearing loss, as nobody explained it to them in a simple manner that they could follow.

*“My daughter had her first hearing aids at the age of two. Up until then the hearing loss was mild and we were advised to ‘wait and see’. However, she did not actually wear them until she was four. We did not make her wear them as we saw that she was responding without them, and we were not really convinced that they helped. It was not made clear to me exactly what my child could and could not hear. I was informed about high and low frequencies but I did not know what that meant. It could have been explained in more layman terms.” (Participant E).*

*“I was just told he had mild hearing loss, and would benefit from a hearing aid. It was only the teacher of the deaf appointed at the Early Intervention Programme, who gave me specific examples of what to look for, and I started understanding, and telling the difference. Once when he was confusing two similar words ‘Valitsa’ (Bag) and ‘Balitsa’ (Ball) , I asked him to put on the hearing aid and also watch how I articulated the words. On doing this both he and I could see the difference with the hearing aid.” (Participant B).*

*“I needed someone to explain the audiogram to me. I needed to know how much she could hear. I wanted to know whether her hearing would deteriorate.” (Participant C).*

#### **4.3.3 Impact of Cyprus’ cultural issue of loud voice**

Within Cyprus, as in other Mediterranean cultures, people tend to speak loudly and to be very telling in their facial expressions. This behaviour usually tends to help people with a hearing loss understand speech better. However, in cases of mild or unilateral hearing loss this can create a misleading situation as due to the use of a loud voice by the people addressing them, children may not exhibit very prominent signs of a hearing loss. As a result, parents don’t realise that their children have a difficulty to hear.

*“We did keep a close eye on the child and it seemed she was reacting normally. However, we now realise that in our family culture we used to talk loudly. My mother who was a nursery teacher used to sing songs to her all the time and she used to copy the words and the actions. We did not realise this was because it was all done loudly and that we should have tested her in other situations such as speaking softly or in large groups.” (Participant A).*

*“We would have liked to have information to help me evaluate his progress and development. As he spoke early we did not think there was a problem. I do realise that we spoke louder than normal when we knew he had a problem.” (Participant G).*

*. “However, it was really difficult when the grandparents kept asking why their granddaughter had hearing aids when she could hear without them as they spoke to her loudly. I did not have answers for them and did not know how to explain everything to them “( Participant D).*

#### **4.4. Child’s development**

In contradiction to Moeller et al’s (2007) findings, Dokovic et al (2014) showed that children with mild hearing loss do not manifest more significant difficulties in the domain of vocabulary compared to their peers with normal hearing but they do however achieve significantly lower results in the domain of morphology and syntax than their peers with normal hearing younger school-age children.

The parents of younger children, up to three years old, felt that their children’s development was similar to that of hearing children. The majority of them believe that their children started vocalizing early, something that made it harder to believe that there was hearing loss. Parents of older children, from three to six years old, started noticing that their children began to have difficulties in syntax and articulation.

*“As this was my third child, I could tell that he was developing well. His speech was not clear but I thought that would improve as he grew. It was only when the Teacher for the Deaf explained to me that he possibly could not hear certain sounds that I became concerned about his speech.” (Participant B).*

*“I did not feel this need so much – mainly because I am a teacher and also because they were twins. I felt that their development was normal. She was always slightly behind her twin with regards development but not so far behind to be of concern. We could see that her speech was not very clear*

*and she had problems with word structure but we saw that her twin had the same issues so did not put it down to being a consequence of the hearing loss. As they grew, we saw that she lagged behind her twin in her speech development and expression.” (Participant E).*

*“We did not require this information because I felt she was developing typically at this stage.” (Participant F).*

Even though these parents did not see a difference in their child’s development in the early years, they did worry about their child’s future development and had many unanswered questions.

#### **4.5. Parent’s needs after identification**

In our case, parents who had three or more years experience with their child’s mild or unilateral hearing loss were very pleased that they could contribute with their suggestions for the establishment of a service for the families and they had interesting suggestions. Similar with Fitzpatrick’s et al, (2008) findings, parents stress the need for written information and guidelines. They also stressed the need for support from other professionals, such as a social worker or psychologist. As there were not concerned about the language development, it is not surprising that they did not emphasize the need for a speech therapist. Parents of older children, did visit a speech therapist for assessment

The actual suggestions from the parents:

##### *(i) Referral to the Early Intervention Program*

*“I would suggest that it is compulsory that audiologists are informed of the Early Intervention Programme so that they can pass on the information. I would also suggest that all paediatricians are aware of the Programme .” (Participant A).*

*“I believe all families should be referred to the Early Intervention Programme. We need to know why our child needs a hearing aid. We need help with the baby until he is used to the hearing aid. We need help on how to talk to him.” (Participant B).*

*“I find it of great benefit that someone comes to the house and can answer questions face to face”. (Participant H).*

(ii) *Written information*

*“... I would also propose that all paediatricians are aware of the Programme and have leaflets with written information to give pass on to any family in which they believe the child may have hearing loss.” (Participant A).*

*“If we could get a written leaflet with information and contact details at the time of diagnosis it would really help.” (Participant H).*

*“Any written information would have been very helpful – especially if it contained contact numbers for specialists we could contact.” (Participant I)*

(iii) *Multi Agency approach for support*

*“I found the multi-agency team to be really helpful and I believe it should be strengthened. It is difficult to get appointments as the School for The Deaf does not have psychologists and social workers who work for them full time.” (Participant A).*

*“An organized support system involving all specialists.” (Participant F).*

*“I suggest the School for The Deaf should have their own specialist psychologists and social workers to support the family from the onset and throughout the school career.” (Participant D).*

(iv) *Meetings with other parents*

*“Meeting with other parents and their children was invaluable. We would like more meetings like this to be arranged on a regular basis. We would also like to meet older children with mild hearing loss who can share their experiences with us. This was arranged once and it was of great interest.” (Participant A).*

*“I think it would be helpful to meet other families and other older children with hearing difficulties.” (Participant H).*

*“We would welcome opportunities to meet other families and other older children with hearing difficulties. “ (Participant F).*

(v) *Training for the parents*

*“It would be beneficial to have compulsory training for all parents to help us understand the need for and the workings of the hearing aids, with guidelines on how to help the child accept them. Parents need to have all the important information from the word go.” (Participant E).*

## 5. Discussion

The above study was carried out to qualitatively explore the experiences of families regarding early identification of mild and unilateral hearing loss. The interviews were recorded and the analysis of the quotes allowed for five themes to be detected enabling a deeper understanding of issues that a family with a new diagnosis of mild or unilateral hearing loss might face. The interview findings of the study will be discussed in the following sections. The first section will explore the impact of the diagnosis on the family. The second section will discuss the challenges that parents face during the audiological management of their child's hearing loss and the third section will address the parents' suggestions about their needs after the identification and positive actions that can be taken by the service providers in order to support the families.

### **5.1. *The impact of the diagnosis on the family***

Fitzpatrick et al, (2007) and Young & Tattersall (2007) found that all parents, irrespective of whether their child was diagnosed with mild or severe hearing loss were positive about screening and pleased to know about the presence of hearing loss early. However, all the mothers in our interviews stressed that it had been a stressful period and they needed support.

The fact that the professionals demonstrated varying and conflicting attitudes towards mild and unilateral hearing loss added to the stress for the parents. The professionals also neglected to provide further details which could have helped the families. The parents felt unsure on how to proceed. Mothers of older children demonstrated retrospective guilt about not persuading their child to wear the hearing aid. Professional communication and manner influenced the parents' perception of the early identification process. Similar to the findings from Fitzpatrick et al, (2016) in some cases parents found professionals seemed not to be well informed about the consequences of mild hearing loss and therefore often interpreted the terms "mild" or "minimal" hearing loss as insignificant.

Research by Gregory (1999, 2001) and Yoshinaga- Itano & de Uzategui (2001) has shown that identification might be too early for some parents, as it can have a negative effect on the normal process of bonding with their children

Almost all the mothers stressed the emotional support they needed after identification, with two mothers questioning whether the test should be done so early. These mothers' comments suggest that the relationship between a child and his/her mother may be negatively affected by her stress and preoccupation with

prolonged visits to doctors, audiologists and other professionals until the route to the child's audiological management is confirmed. According to the attachment theory developed by Bowlby, (1969, 1973, 1980), human infants need a consistent, warm, intimate, and continuous relationship with their mother to develop into healthy individuals. Parental unavailability due to the engagement with the child's hearing assessment or detachment due to the stress and shock brought about by the diagnosis may hinder the formation of such healthy relationships. It has been observed that children without such attachments are fearful and are less willing to seek out and learn from new experiences. Robertson & Bowlby (1952) also showed that short term separation from an attachment figure leads to distress.

### **5.2. *Parents challenges with the audiological management of their child's hearing loss and language development***

The mothers also noted that one of the most significant difficulties parents are faced with is the consistent use of hearing aids as similarly suggested by Walker et al, (2013). However, parents in our study admitted that they had not appreciated the benefits of the hearing aids as in the quiet environment of the home where their children seemed to respond adequately to speech, it was difficult for them and the extended family to be convinced there was a hearing loss. This is an area they now feel they needed more prominent support on and looking back, they feel guilty that they had not strongly encouraged and persuaded the children to wear the hearing aids consistently. Families of children with mild degrees of loss should be educated about recent studies pointing to the consequences of minimal hearing loss (Moeller, 2010). The mothers mentioned above felt that they had lost time, because they, as mothers, could not understand the need and the benefits of the hearing aids. Although professionals insisted on the hearing aid fitting, they did not manage to explain to them what their child could and could not hear. They stated that the announcement of the type and the degree of hearing loss did not mean anything to them until they found the Teacher for the Deaf, who explained it to them with real life examples of what their child could and could not hear.

The fact that parents felt helpless due to the lack of support is a wakeup call for professionals to appreciate that it is vital for the parents to receive clear and practical guidance so they can deal with the issues and procedures facing them. This needs to be provided early on to be of most benefit (Tomblin, et al, 2014).

Lederberg & Golbach (2002) suggest that the lack of high levels of parenting stress they found during preschool is a measure of the success of intensive early intervention. They further remark that these findings reinforce the importance of early identification and consequent enrolment in early intervention programmes.



The professionals' uncertainty about auditory management, the differing views about the potential benefits of hearing aids, and the limited information about the risk for developmental delay lead professionals to a 'wait and see approach', and the belief that the family does not require early intervention (Holstrum et al. 2008; Fitzpatrick et al, 2016). All parents stressed the positive value of early intervention and feel that they could have benefitted from it to an even greater extent had they been referred to it from the beginning.

### **5.2.1. Language development**

Fitzpatrick et al, (2015) examined the Communication Development in Early-Identified Children with Mild Bilateral and Unilateral Hearing Loss. The findings of that study suggest that early-identified children with mild bilateral or unilateral hearing loss develop early communication skills comparable to those of their peers with normal hearing in the preschool years.

Parents of older children over three years of age, however, started to identify some delays in language development, such as, using simple phrases to express themselves, morphological and syntactic abnormalities which they believed would improve in time and were not related to hearing loss. As the child could speak at a young age, the parents did not realise that the hearing loss may result in difficulties with their language development later on. However, these observations cannot be generalised as they merely arise from the parents' views and no professional assessment has taken place. Tarpe (2008) showed that pre- school children with mild and unilateral hearing loss achieved significantly lower results in the domain of morphology and syntax than their peers with normal hearing.

Prior to the current study, in Cyprus, cases of mild or unilateral hearing loss were not being referred to the early intervention programme of the School of the Deaf with the exception of three children. At that point in time the programme ran with fourteen families while during the study another eleven families with children with mild or unilateral hearing loss were admitted to the programme. The estimated percentage for children with mild and unilateral hearing loss, mentioned by professionals in secondary education is 40% of the whole population with hearing loss of that age. Thus, this is an indication that the current numbers in Cyprus, although not formally recorded through statistical research, are mostly in line with the findings of the population-based research by Fitzpatrick et al, (2010, 2014), which has suggested that 40% to 50% of children identified with permanent hearing loss present with mild bilateral or unilateral hearing loss. This is, therefore, a substantial percentage which creates the need for professionals to dedicatedly work with children with mild or unilateral hearing loss.

### **5.3. *Parent's suggestions about monitoring the needs of the families***

Parents were willing to take part in the study as they felt it was a forum for them to express the belief that all families whose children are diagnosed with hearing loss, irrespective from the type and the severity of hearing loss, should have access to the Early Intervention Programme. They believe that such a Programme should offer the family clear guidelines and practical support to enable them to understand and assess their child's hearing. As families value contact with other families with older children with hearing loss so that they can learn from their experiences, it was felt that the Early Intervention Programme should arrange this. They also suggested a coordinated system with a multi-agency approach for support would be invaluable.

## 6. Conclusions

The study has shown that mild or unilateral hearing losses have been of minimal interest for the professionals in this country but this is slowly changing. In recent years audiologists have been informed about the benefits of hearing aid fitting at an early age and they make recommendations for this to the family. However, the parents need greater support to go through the process and cope with the situation. It is highlighted that the parents of children with mild and unilateral hearing loss experience high levels of stress in the same way as parents of children with more severe hearing loss. The process of hearing assessment and audiological management can take longer, and require more frequent visits to the audiologist than for a child with severe loss, where it is more evident. Parents stated that during this period they felt vulnerable and unsupported.

It is important that audiologists are well informed so as to understand that hearing aid fitting on its own may not have the expected benefit, either because the parents do not understand the consequences of hearing loss on their child's development, or because the child is older and does not accept the hearing aids. In either case parents need support and therefore professionals need to work together with the teacher of the deaf of the early intervention program in order for the fitting to have the desired results and be successful.

The extended family is also affected and parents feel unable to explain and support siblings or grandparents. A referral to the Early Intervention Programme with a multi-agency approach of supporting the wider family would contribute to the earliest management of the child's hearing loss and the well-being of the family.

In conclusion the Early Intervention Programme has so far been of great benefit to many families of children with severe hearing loss, but there is a compelling need for it to include families of children with mild or unilateral hearing loss. The Programme therefore has room for improvement. In order to provide the best service and support for families of children with mild hearing loss it is essential that stakeholders proceed with informing health professionals and support workers of the existence and benefits of the Programme. It is also important to establish a Programme with multi-agency practitioners (e.g. speech therapists, psychologists, social workers, audiologists etc) as throughout the research parents seemed to place significant emphasis on the emotional and psychological impact the diagnosis has had on their families, which calls for a co-ordinated approach between professionals. The early years practitioners should assist in the establishment of regular meetings and discussion groups for parents to enable

them to share their experiences. Furthermore, the practitioners should work on the creation and update of written guidelines and information for parents. Additionally, it would be of great benefit to run a training course for the new families in order to provide the information and empower the parents to deal with the hearing aids and the management of their child's hearing loss.

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## APPENDIX A



### SOCIAL SCIENCES, ARTS AND HUMANITIES ECDA ETHICS APPROVAL NOTIFICATION

**TO:** Chryssanthie Demetriou Stavrou  
**CC:** Jane Peters  
**FROM** Ms Caroline Large, Social Sciences, Arts and Humanities ECDA Vice  
Chairman  
**DATE:** 05/12/16

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Protocol number: **EDU/PGT/CP/02760**

Title of study: Do families with children with mild hearing loss have access to the Early Intervention Program in Cyprus

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

**From:** 05/12/16  
**To:** 28/02/17

**Please note:**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

## **APPENDIX B**

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS  
(‘ETHICS COMMITTEE’)

### **FORM EC6: PARTICIPANT INFORMATION SHEET**

**Do families with children with mild hearing loss have access to the Early Intervention Program in Cyprus**

#### **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University’s regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

#### **What is the purpose of this study?**

Recent studies showed that there was no statistically significant difference in overall achievements (general score) on the Acadia test of developmental abilities between students with mild hearing loss and those with normal hearing. However, according to the age-norm deviation criterion in 1 and 2 SD, statistically significant difference was determined on the subtest that assesses auditory discrimination. Antia et al. (2009) found that although they may not be achieving their full potential, mainstreamed students with MMHL make adequate academic progress compared to typical hearing peers. Researchers suggest technological, environmental and educational modifications for school-aged children enabling them to reach their full potential. Only a few researches have addressed the issue of providing support for the families in the early stages of diagnosis of their children with mild hearing loss Fitzpatrick (2015) Holstrum et.al.(2008).

The current study will focus on addressing the needs of the family with a child with mild hearing loss right after diagnosis and identifying positive supportive practices, such as:

- parents’ need for written information on learning about and managing their child’s hearing loss
- support during the hearing aid fitting
- providing a monitoring and assessing protocol

- family group support

### **Do I have to take part?**

It is completely up to you whether or not you decide to take further part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

### **How long will my part in the study take?**

If you decide to take part in this study, there will be a 2 hours meeting for an interview which will be recorded.

### **What are the possible disadvantages, risks or side effects of taking part?**

No risks.

### **What are the possible benefits of taking part?**

I will share my findings with you and you will be able to make use of them when your child will go to nursery.

### **How will my taking part in this study be kept confidential?**

Data collected via recorded questionnaires will be anonymised before being used in the dissertation.

### **What will happen to the data collected within this study?**

Data will be anonymised and stored in accordance with the data protection procedures. All materials will be kept on a computer with security password or within a locked cupboard.

### **Will the data be required for use in further studies?**

No, the data will not be used in any further studies.

### **Who has reviewed this study?**

This study has been reviewed by:  
The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee  
with Delegated Authority

The UH protocol number is <EDU/PGT/CP/02760>

### **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

**Chryssanthie Stavrou**  
Specialist Teacher for the Deaf  
School for the Deaf in Cyprus  
a.stavrou@cytanet.com.cy  
TEL 99740349

## **APPENDIX C**

### **Parent interview guide**

#### **Purpose of the interview**

I am meeting with parents to better understand the impact of the early identification of milder forms of hearing loss through infant hearing screening on the family. I will be talking with several parents of young children with mild and unilateral hearing loss about their experiences with the identification of the hearing loss. I am also interested in your suggestions for improvement of our services.

#### **Procedure**

I will ask you questions to guide our conversation but feel free to talk about your experiences and to add any information you feel is important. Please don't hesitate to ask questions.

#### **Questions:**

1. Tell me how you found out about your child's hearing loss.
2. What impact do you think screening (or lack of it) had on you, your child and your family?
3. I am interested in understanding your needs when your child was first diagnosed and then later after the diagnosis?
4. What information or guidance did you need in the days/weeks/ months following the diagnosis (for example, after the confirmation / hearing aid fitting)?
5. Did you feel that you needed information regarding the cognitive, language, social and emotional development of your child?
6. At what stage were you informed of the Early Intervention Programme and who informed you?

7. Did you need support of other specialists such as social workers or psychologists?
8. If you could have input into the formation of the health support system what would you propose?
9. In conclusion, how are things now for you and your family?