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Ukrainian Hearing Parents and their Deaf Children

by

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Abstract

This study, which utilized a mixed methods approach, is the first research study in Ukraine which explored the experiences of parents raising deaf or hard of hearing children. The outcome of the study includes a documented analysis and synthesis of the perceptions held by Ukrainian-hearing parents raising young deaf or hard of hearing children regarding the emotional and communicational impact of the diagnosis on their family functioning, their perceptions of existing services and/or programs, and their perceptions of the relationships with professionals.

Three hundred and twenty-five families whose young children were enrolled in grade 0/1 in 48 residential schools for children with hearing loss across the country were sampled in a survey of the study and 17 families from among this number volunteered for follow-up interviews. The emotional impact of the diagnosis on the parents and other family members as well as such factors as communication mode, availability and accessibility of professional services, access to information on deafness, and educational choices were explored along with demographic and other characteristics. Parental thoughts and views in this study were consistent with international perspectives of parents that are documented in the literature: the need for informational support, guidelines and communication options for families were seen to be key factors. The responses of the participants of this study confirmed that greater access to educational options, support for overcoming stress and improving emotional well-being, as well as support for families in establishing healthy family interactions and empowering parents were among their most important requirements.

Additionally, the findings of this study, stress the importance of focusing on family resources and family appraisal as key factors in the hearing family adaptation process to having children who are deaf or hard of hearing.

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Chapter 1. Introduction

Statement of the Problem

Deaf Children, Parents, and Deaf Education

Five out of every 1,000 infants born yearly worldwide are born with significant hearing loss (>40 dB HL) (Olusanya, 2005). For several decades researchers have repeatedly found that ninety percent of deaf and hard of hearing children were born into hearing families (Andrews, Leigh, & Weiner, 2004; Calderon & Greenberg, 1993; Koester & Meadow-Orlans, 1999; Moores, 2001a; Scheetz, 2001). A study by Mitchell and Karchmer (2004) challenges this figure and reports that the US Annual Survey findings indicate that even less than five percent of deaf and hard of hearing students receiving special education are known to have at least one deaf parent. This is much less than the presumed ten percent reported in the many studies mentioned previously.

The birth of any child impacts the family. However, when a child is diagnosed with a hearing loss, the effects are likely to be greater, more challenging and more demanding on the family (Kampfe, 1989; Luterman & Ross, 1991; Meadow-Orlans, 1990a; Olusanya, Luxon, & Wirtz, 2004; Scheetz, 2004; Marschark, 2007). Deafness affects all of family life by creating challenges in communication which in turn test the creation of appropriate family functioning and parental management of children (Drobot, 2006; Lampropopolou & Konstantareas, 1998; Luterman, Kurtzer-White, & Seewald, 1999; Marschark, 1997, 2000, 2007; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Moores, 2001; Mertens, Sass-Lehrer, & Scott-Olson, 2000; Scheetz, 2001; Zborovska, 2006; Zhuk, 2006). Regardless of family structure, ethnic background, socioeconomic status, or medical condition all children have a need to feel that they are a part of the family unit. It is critical that this belonging is communicated to the child through a language that can be comprehended. "Communication is at the heart of everything human beings do because it defines and gives meaning to our emotions, beliefs, hopes, creativity, and life experiences (CADHHETF, 1999, p.1). According to Rodda & Groove (1987) "knowledge is transmitted, and the beginnings of socialization take place through language. When there is a barrier in accessing language and communication, the family itself is blocked and weakened" (p.315). Therefore, communication has become one of the main concerns, along with the availability and access to social support, for families creating a healthy home environment for children who are deaf or hard of hearing (Kulbida, 2005; Lederberg & Golbach, 2002; Luterman et al., 1999; Mapp and Hudson,

1997, Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Young, 1999; Zborovska, 2006).

The effective development, understanding, and expression of language are fundamental to educational experience and its acquisition is crucial for deaf and hard of hearing children (Ogden & Lipsett, 1982; Scheetz, 2004). Hearing loss creates a difference in the way in which individuals communicate and acquire information, but is not in itself disabling, provided that there is a full access to language (Bodner-Jonson & Sass-Lehrer, 2003). Because of their unique communication needs, deaf children are distinct from other children with disabilities or special needs. Children with learning or developmental problems can share the spoken language and can communicate with the world around them. However, because deafness can interfere with the acquisition of the spoken language of the community, children who are deaf and hard of hearing may find it difficult or even impossible to converse with other hearing family members and the parental challenge is to establish effective communication in their homes and to ensure that their children receive the necessary support from professionals and schools (CADHHETF, 1999; Meadow-Orlans, et al., 2003; Sheetz, 2004; Zhuk, 2006; Yoshinaga-Itano, & Mah-Rya, 1998). A fundamental consideration in the educational world is that deaf and hard of hearing children may not share an accessible language with their parents or family members and this distinguishes deaf and hard of hearing children from other children with special needs (CADHHETF, 1999; Lane, 1984; Yarmachenko, 1975).

Records of the first attempts to teach deaf individuals go back to ancient times (Densham, 1995; Yarmachenko, 1975), as does the debate between the oralists and the manualists regarding the method that should be used to educate deaf children. According to Abbe de L'Eppe, a founder of the French manual approach in the education of the deaf, in order to teach deaf individuals it is necessary to use the "same language, which is used by them and which is based on gestures, signs and pantomime" (Yarmachenko, 1975, p. 56). Historically, followers of this approach, called manualism, were strictly opposed by the German oralist school which recognized only the practice of teaching deaf persons to communicate by means of spoken language (Densham, 1995; Yarmachenko, 1975). The controversy of which approach is more effective for the education of deaf people has been at the center of the methodological wars that have plagued the field of deaf education for the past 200 years. To start, teaching in deaf schools used mostly sign. While early efforts led by the Abbe de L'Eppe in France in 1755 focused primarily on using the language which was understandable by the deaf, a resolution passed at the

Congress for the Amelioration of the Conditions of Deaf Mutes in Milan in 1880 marked the beginning of an era of oralism presented by the German *oralist* school, lasting three quarters of a century, during which “speech was the only accepted method of instruction for deaf children and the use of sign in the education of deaf children was taboo and strictly enforced in almost all European schools for the deaf” (Winzer, 1993, p. 197). Describing the development of education for the deaf LaSasso & Lollis (2003) stated that “historically, large-scale shifts in language and communication policies and educational practices with deaf children have occurred, in large part, because of dissatisfaction with low reading achievement scores of deaf students” (p.79).

Most studies exploring the academic performance and achievements of children with hearing loss report a two or three year performance delay beginning in the elementary grades (Bess, Dodd-Murphy & Parker, 1998; Ross, Brackett, & Maxon, 1991; Yoshinaga-Itano & Downey, 1996). Bess et al. (1998) in their study of 1218 children with mild hearing loss found that the academic performance of children with a hearing loss was poorer than their hearing classmates. Besides these reported delays measured by standardized academic achievement tests, the researchers found that the children in the studies tended to be one or two years older than their classmates, a fact that may well have psycho-social implications (Bess, 1986; Mauk & Mauk, 1998).

Inspired by the ideas of Stokoe (1960, 1965) on the nature and role of the American Sign Language and by Johnson, Liddell and Erting (1989) calling for radical changes in existing educational policy education of the deaf or hard of hearing children has been undergoing a significant paradigmatic shift over the last 50 years. It has been a shift away from a monolingual (speech only) approach, toward an approach recognizing that children's signed language must be respected and supported in order for them to acquire a second language – the language of the surrounding majority hearing community with more confidence (Johnson et al., 1989). Proponents of a bilingual approach to educating deaf and hard of hearing students argue that it lays the foundation for achieving greater educational outcomes than that which has been found in the research on educational achievements levels where the monolingual approach alone is used.

However, for parents of deaf or hard of hearing children, professional controversies regarding intervention techniques and communication options offer little comfort but rather continue to add an element of parental stress that may be unique to this group of special education consumers (Lederberg & Golbach, 2002; Meadow-Orlans, 1990; Schlesinger and Meadow, 1972). Despite the implementation of various

educational approaches at increasingly younger ages, children with hearing loss, as a group, are at significant risk for relatively poor academic performance, dropping out of school, and delayed development of language and critical thinking skills (Braden, 1994; Geers & Moog, 1989; Radutzky, 1993; McCagg, 1993). This suggests that factors other than the schooling of deaf or hard of hearing children are worthy of research.

Focus on Ukraine

The total number of children in Ukraine who are deaf and hard of hearing was difficult to verify as there was only one official source of information provided by the Ministry of Education and Science of Ukraine. By September 2005 of 8,907,492 children of school age in Ukraine, 28,907 were officially identified as deaf and hard of hearing children (Hrytsenok, Obukhivska, Panok, Ternichenko, Tkachuk, & Tsushko, 2005). Additionally, by September 2006 another 487 children were diagnosed as deaf and 1502 as hard of hearing bringing the total number of children with hearing loss to 30, 896 (S. Kulbida, personal communication, November 26, 2006). However, accurate statistics on children's hearing loss in Ukraine were not available at the time of this writing. It is suspected that due to problems with early identification and diagnosis of deafness in both the methodology and equipment used, hearing status of many more children has been overlooked, especially in rural areas (Baikina & Cret, 2005; Borshchevska, 2005; Fedoruk, 2001, 2003; Kryklyva, 2003; Zhuk, 2006; Savchenko, 2001).

There were 73.7 million children under the age of 18 in the United States (ChildsTrends Data Bank, n.d.) in 2006 and Marschark (2007) suggested there could be more than "100,000 children in the United States with some degree of hearing loss" (p. 29), which constitutes 0.14% of the total child population. The proportion of deaf and hard of hearing children in Ukraine is 0.33%, almost 2.5 times higher than in the US. This interesting fact has not yet attracted the attention of researchers.

Although Ukrainian legislation provides for a quota of working places for disabled persons it is common that deaf people, a disability group recognized by the Ministry of Health Care of Ukraine, (n.d.) cannot get well-paying competitive jobs due to their low level of education and poor vocational training (Bohachyk, 2003; Komendant, 2003; Yezhova, 2007). Deaf and hard of hearing graduates of secondary schools in Ukraine, in general, have low literacy (Chepchyna, 2001; Lulko, 2001; Parkhomenko, 2001; Piatnychuk, 2006; Shvets', 2001; Yezhova, 2007) and low self-esteem (Shvets', 2001; Malynovych, 2006).

In 1975 Yarmachenko stated that early identification and treatment of children, as well as support to parents, needed urgent attention from the government and identified it as the most important task for the future because without it “children come to school pedagogically neglected” (p.407). His statement is as applicable to the situation in Ukraine today as it was about 35 years ago. It appears that Ukraine is experiencing difficulties similar to those in the West in the education of young deaf and hard of hearing children such as poor academic achievement and social adjustment. It is suggested that this is attributable mostly to the lack of timely identification of hearing loss, the paucity of early intervention services and programs, as well as the prevailing oralist approach in current preschool programs (Parkhomenko, 2001; Zasenکو, 2001; Lulko, 2001). Additionally, educational opportunities for pre-school children with hearing loss are limited due to the absence of counseling and support services for parents, the shortage of educational materials/resources and negative attitudes toward Ukrainian Sign Language. All of that has characterized Ukrainian deaf education for decades.

It has also been noted that, with rare exceptions, counseling families who have young deaf or hard of hearing children or preschoolers is not organized. Generally, neither schools, nor teachers hold training sessions with parents. Rather group meetings, often in the form of teachers’ monologues are the mode of communication with parents (Y. Kramar, personal communication, March 16, 2006). Public kindergartens for children with hearing loss accept children only at the age of three years and limit their work with families to parental debriefings on weekends if at all (Komarova & Pursglove, 2004). The Surdological Centers of the Ministry of Health Care in large cities focus mostly on hearing tests, fitting of hearing aids, and providing speech lessons for selected children. A few commercial educational centers accept children with hearing loss at 3-4 years of age (Shepelenko, 2003; Leongard, 1991). There are no other organizations providing services such as psychological help or early intervention programs comparable to those services found in developed countries. As a result, parents do not have open and easy access to information that might help them deal with the challenges of raising a child with special needs at an early age (Adamiuk, 2007; Fomitcheva, 1997a) and to make effective educational choices for their child’s education (Zborovska, 2006, 2007; Zhuk, 2006). Hroza (2001), Zasenکو (2001), Khvorostova, (2005), and Zhuk (2006) called for the establishment of new medical and psychological services. Hroza (2001) identified the goals for these services:

A new psychological service will become an organizational factor and will stimulate the improvement of partnerships between families and educational institutions, between parents and children, between researchers and deaf adults. First of all, it should address those parents who might need help in crisis situations, as they experience problems with self-confidence or difficulties in their relationships with their deaf children, as well in situations related to the development of the child, or other such situations. We have to bring this issue to the government. (p. 221)

To date, there is not a single officially registered educational institution in Ukraine offering a program in family counseling in line with international practices (Hroza, 2006; Kisarchuk, 2003; Zhuk, 2006). As a result, when a child is diagnosed with deafness the parents are left to rely on medical doctors for information (Zasenko, 2001; Zborovska, 2006, 2007; Zhuk, 2006).

There is also a paucity of research in the area of educational psychology, in general, and in family functioning and parental involvement in educational processes in particular (Harniuk, 2005; Zasenko, 2001). This can in part be explained historically. In the Soviet Union, communist leaders saw the parental role and responsibility of raising children as secondary to the ideological effort targeted at children in the state school system (Grigorenko, 1998). In this political system there was, therefore, little motivation for researchers to explore the life and functioning of families with children with special needs. At the time of writing this thesis, no research of any kind exploring the life and functioning of families with deaf children could be found.

Statement of Purpose

Recently in Ukraine, many professionals involved in the education of the deaf and hard of hearing, and in deafness studies have started reporting problems and failures in the field (Adamiuk, 2007; Drobot, 2006; Fedoruk, 2001; Lukyanova, 2001; Malynovych, 2003; Parkhomenko, 2001; Synenko, 2003; Zborovska, 2006; Zhuk, 2006). Besides critiquing the existing system of kindergarten and school education the authors often point out the lack of research in the field (Harniuk, 2005; Savchenko, 2001; Zasenko, 2001). Calls for change in the educational options and provisions available to children who are deaf or hard of hearing have also increased in recent years (Drobot, 2006; Parkhomenko, 2001; Zborovska, 2006; Zhuk, 2006). Zasenko (2001), Deputy Director of the Institute of Special Pedagogy of the Academy of Pedagogical Sciences of Ukraine stated:

Families with deaf children need urgent help. Issues of raising young children with hearing loss and exploring the necessary conditions for their

successful development have not been researched satisfactorily and reported in the scientific literature in Ukraine. We have not succeeded in establishing effective intervention and preschool programs based on quality research. (p. 44)

If professionals are to respond to this call to provide effective supportive services and create an effective system for the education of the deaf, they must collect empirical information and analyze the situation. One step is to identify the salient characteristics of families and children; explore and describe family life, feelings, demands and hopes of hearing parents of deaf children, so that the services and educational choices will meet their unique needs (Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olson, 1997; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Steinberg, Bain, Li, Delgado & Ruperto, 2003).

Professionals are mostly involved in the lives of children for only brief moments compared to the time that children spend at home with their parents. Professionals' knowledge and understanding of the characteristics and preeminent role of parents and their respect of the position of parents in children's lives is critical to the development of effective professional intervention in these families.

The purpose of this descriptive study is to explore the experiences and feelings of a group of Ukrainian hearing parents raising children with hearing loss. This study has several objectives: (a) to document the characteristics of hearing parents and their young children with hearing loss enrolled in the early elementary grades in residential schools for children with hearing loss in Ukraine, (b) to reflect retrospectively on the feelings, behaviors and thoughts of Ukrainian hearing parents at the time of initial diagnosis and later in the process of raising their child who is deaf or hard of hearing, (c) to explore parental views on the issues of the mode of family communication and Ukrainian Sign Language. It was expected that parents would report their goals, hopes and expectations, their experiences with the health and special education systems and with the existing preschool programs, children's achievements, and challenges.

This study also serves the purpose of enhancing and furthering research in this field in general in Ukraine. In a society which inherited the model where an all-knowing party could set directions and manipulate research there is a need to reestablish research norms, show a model of research which has been tested in other countries and cannot be easily dismissed and to establish an evidence-based baseline for academic discourse about the education and other needs of deaf and hard of hearing children in Ukraine. In

order to provide for some comparison and international scholarly discourse the research questions were ones that had proven to be salient in Western societies.

Research Questions

The research questions have been adapted from various studies of the parental experience in raising a child with hearing loss. Questions were developed to meaningfully describe the parents and the children. Significant moments in their early experience such as the process around the diagnosis, questions of how to communicate with the child and the available support were to be documented by answers to appropriate questions. The concerns and needs from the perspective of the parent and family also needed appropriate questions.

With respect to the specific factors of parent's characteristics (*gender, education level, marital status, number of children, socio-economic status, communication ability*), child's characteristics (*age, level of hearing loss, age of identification of hearing loss, possible other special needs or disabilities*), communication issues (*parental communication ability, availability of parental training, access to the variety of information on deafness and options in deaf education*), available support (*support from relatives and community, professional help and early intervention*), several questions were investigated:

- What are the characteristics of hearing families with deaf or hard of hearing children in Ukraine?
- What factors are perceived as challenges by hearing parents raising deaf or hard of hearing children?
- How do parents describe the nature of child-family relationships, interaction and communication at home? Are parents satisfied with them?
- What is the parental knowledge and perception of Ukrainian Sign Language?
- How do parents describe the nature of their relationship with professionals at the time of early suspicion of hearing loss, before and after the diagnosis?
- What kind of services and/or intervention programs were recommended, available, accessible, and accepted by parents?
- What are parental thoughts and feelings about raising a deaf child in Ukraine?

This study was designed as a two-phase, sequential mixed methods study to first obtain survey data from a broad sample of parents with a follow up of interviews with a subset of families to probe or explore the survey results in more depth. In the first phase, which was a cross-sectional survey, quantitative and demographic data was collected

using a self-administered questionnaire based on the National Parent Project (NPP) questionnaire (Meadow-Orlans et al., 2003) which was revised and adapted to reflect specifics of Ukrainian context. In the second qualitative phase, interviews were utilized to explore the feelings experienced by parents at the time of diagnosis and when raising their child, as well as their views on the issues of early education programs, support services, family communication, and educational placement choices available to them. The interviews were used also to explore variables under investigation in greater detail and triangulate findings using quantitative and qualitative data. It was anticipated that by adapting a well-established questionnaire and providing an appropriately designed interview the participating parents would be able to directly focus their feelings towards parenting a deaf child and challenges related to raising a deaf child.

Significance of the Study

To date, no published research has been traced on a national level in Ukraine which explores demographic or other data that provides characteristics of families with deaf or hard of hearing children, or explores the difficulties that those families face, the way members of the family communicate, or the services/early intervention programs available. Although, there appears to be a growth in Ukrainian publications relating to deafness studies, not a single empirical research publication in the area of family functioning, which complies with international research standards, has been found. Therefore, there is a need for research and evidence-based insight into the experiences of hearing families with deaf or hard of hearing children to better understand family functioning and family needs, the feelings and attitudes of parents toward deafness and the processes available for family support. This study is the first research study conducted in Ukraine with such families. It provides a documented analysis and synthesis of the perceptions held by Ukrainian hearing and deaf parents who raise young deaf or hard of hearing children specific to the emotional and communicational impact of the diagnosis on their family functioning. This study also presents parental perceptions of existing services and/or programs (medical, educational, social) as well as of the relationships with professionals in different disciplines engaged in providing support to families with young children who have special needs. Increased understanding of parental experiences in raising a deaf child can help to provide a baseline for the discussion and development of guidelines for existing preschool programs, improving or creating new early intervention programs, and professional training programs.

The examination of background information including family, parental and

children's characteristics is extremely important in identifying factors of significance for future research into deafness in Ukraine. It is hoped that this study will encourage more empirical research publication in the area of deafness studies, which complies with internationally recognized research standards and that these studies will find their place in international scholarly discourse.

Definition of Terms

The Canadian Academy of Audiology (n.d.) describes hearing loss as a specific decibel loss across a continuum from minimal (15 dB for children and 25 dB for adults) to profound (90 dB or more). There are different classifications of hearing loss levels. Individuals with mild or moderate losses (26 dB – 70 dB) are identified as hard of hearing while those whose hearing is in the range from severe to profound decibel loss (71 and more) are identified as deaf.

In Ukraine according to Poleshchuk (2006) a similar classification presented in Table 1 is used.

Table 1

Classification of Hearing Loss in Ukraine

Range	Type	Label
26-40 dB	I group	Hard of Hearing
40-55 dB	II group	Hard of Hearing
55-70 dB	III group	Hard of Hearing
70-90 dB	IV group	Hard of Hearing
90 and up		Deaf

Mother- the biological mother, age 18 (majority age in Ukraine) and older and primary female caretaker for the child, who lives with the child.

Father- the biological father, age 18 or older and primary male caretaker for the child, who lives with the child.

Family - two or more people who regard themselves as a family and who perform some of the functions that families typically perform. These families may or may not be related by blood or marriage and may or may not usually live together (Turnbull & Turnbull, 2001, p.12).

Deaf or hard of hearing child (for this study) - a child of 7-9 years of age who is experiencing hearing loss of 26 dB and more and is enrolled in grade 0 or 1 of a special residential school for deaf or hard of hearing students in Ukraine (grade 0 refers to the old classification and is analogous grade 1).

In the Ukrainian context, besides the audiological aspect there is not any cultural or ideological difference in using terms deaf and hard of hearing but the term deaf is commonly used for both groups of individuals with hearing loss.

Audiological (medical) aspects of hearing loss. Within the traditional/disability framework in Ukraine children who are deaf or hard of hearing are viewed as having an audiological condition that is perceived as an illness or deficit in comparison to the standard of children with “normal” hearing” (Lane, 1993, 1996; Yarmachenko, 1975). Within this framework it is important to distinguish between different aspects which are important in the medical/audiological perspective: a) age of onset of hearing loss (Hull, 1997), (b) type of hearing loss (Hull, 1987; LaRue, 1978; Logan, 1988), (c) degree of hearing loss (Carney and Moeller, 1998). From an audiological perspective it is also important to distinguish between children who are congenitally deaf and those who become deaf later. Prelingual disorders are considered “to have a more deleterious effect on social, educational, and vocational aspects of the person’s life than if the hearing loss occurred after oral speech and language have developed (Hull, 1997, p. 21).

Cultural aspects of hearing loss. Within a cultural framework deaf or hard of hearing children may be viewed as being part of a distinct cultural group whose members share a common language (signed language) and Deaf culture (Carney & Moeller, 1998; Meadow, 1978; Meadow-Orlans, 1996; Padden & Humphries, 1988).

Deaf (uppercase) and deaf (lowercase). Throughout this document the convention of capitalizing Deaf to distinguish members of a cultural and linguistic group has been used. When the word “deaf” is used more broadly to denote the condition of hearing loss, it is lowercased. In this case is used to indicate a larger group of people who may or may not be members of the Deaf community, their language or culture not made explicit (for example, deaf students, deaf consumers of interpreting services) (Padden & Humphries, 2005).

Prelingually deaf - children who became deaf before acquiring language. There is no unanimously agreed definition related to the time range of the prelingually acquired hearing loss. Some have defined prelingually deaf people as those who have been deafened before twelve months of age a time preceding the acquisition of the first true word (e.g., Niocolsi, Harriman, & Kresheck, 2004). Others extend the time frame to the first 24 months of life (e.g., Katz, 1985; Laufer, Gabbay, Gold, & Katz, 1994).

Prelingual deafness, for the purposes of this study, means deafness in persons whose onset was before they learned the language of their environment, i.e., persons who

were either deaf at birth (congenital deafness) or who became deaf from disease or accident (adventitious deafness) prior to developing the basics of the grammar of the language of their environment (Malcolm, n.d.). Deaf children of deaf parents who use signed language may reach typical milestones in signed language similar to the spoken language use milestones reached by hearing children who have hearing parents.

Postlingually deaf - individuals who became deaf after acquiring spoken language.

“Sign language” and “signed language”. The phrase “signed language” rather than “sign language” is used throughout the text to distinguish between languages that are spoken and languages that are signed. When referring to a particular signed language the convention is to identify the language, such as American Sign Language (ASL) or Ukrainian Sign Language (USL) (Janzen, 2005). When quoting other sources, the phrases used by the original authors have not been modified.

Surdolog - an otolaryngologist (commonly used term for this specialty is ENT (ear, nose and throat doctor) who has additional training in Surdology and is certified to work with children and adults who have problems with hearing including prescribing and fitting hearing aids (Jobs-UA, n.d.).

Chapter II. Review of the Literature

Introduction: The Family Approach

“An understanding of what a family is and how families work is imperative for professionals who work with children and their families” (Bodner-Johnson, 2003, p.70).

Most people would not argue with the premise that the family is the primary and most powerful system to which a person ever belongs (Seligman & Darling, 1997). The importance of the family's influence in the lives and development of young children is widely recognized (Allen and Petr, 1996; Bodner-Johnson, 2003; Bruder, 2000; Calderon, Bargones, & Sidman, 1998; Turnbull & Turnbull, 2001). To understand this family influence you have to understand the world of every individual that this family consists of (Demydiuk, 2003). Each member of the family must be accepted and valued in a mutually nurturing family environment, including siblings, grandparents and other relatives living together. Each family unit relies on a shared communication system to convey values and beliefs to their offspring (Luterman, 1999; Meadow-Orlans, 1980). Furthermore, through daily interactions and common activities they model child-rearing practices that will be reflected in future generations.

Deaf and hard of hearing children add yet another dimension to the hearing family unit. Although these infants enter the world equipped with the same strengths and weaknesses as their hearing siblings, their inability to hear impacts the family communication system (Meadow-Orlans, 1980; Schlesinger & Meadow, 1972). When the diagnosis of hearing loss is confirmed and the needs of the deaf or hard of hearing child are identified the parents must cope with the emotional impact of hearing loss and devise techniques that will enhance communication (Feher-Prout, 2004; Marschark, 1997, 2001, 2004, 2007; Scheetz, 2001, 2004).

There are additional issues that may arise in the family with deaf or hard of hearing children. Parents may inadvertently focus their attention exclusively on this child while other “family members may feel their needs are being overlooked or that their concerns have become secondary to those of the deaf child” (Scheetz, 2001, p. 61). The extended family should not be overlooked as a potential source of much-needed support in dealing with challenges imposed by deafness (Hill, 1993; Koester, & Meadow-Orlans, 1990) as well as a potential source of secondary stressors that may be introduced into the home (Scheetz, 2001, 2004). That is, the family itself should be considered the primary group interfacing with both the deaf child and society, and therefore in need of resources,

counseling, and ongoing support as the child develops (Luterman & Ross, 1991; Marschark, 1990, 1997, 2007; Scheetz, 2004).

As was stated previously, there were 30,896 children diagnosed with hearing loss in Ukraine by September 2006. Following world demographic tendencies one can assume that in Ukraine most of those children are born into hearing families. Ukraine is still lacking effective early intervention programs and services for these parents and children (Hroza, 2001, 2003; Zasenka, 2001). To compound the problem of family-focused research in Ukraine there are neither statistics nor any other demographic information on families with children who are deaf or hard of hearing. As well, no Ukrainian published study could be found that reported on the experiences and feelings of parents raising deaf or hard of hearing children.

This chapter is organized into two sections. To provide a background of the state of research in Ukraine that is pertinent to this thesis the first section of this chapter provides a brief historical outlook of the Ukrainian way of dealing with deafness as a part of a disability category. This section introduces findings specific to the history of deafness and disabilities, official policies, attitudes to deafness in the general society, the ongoing contradiction between audiological versus cultural attitudes and its impact on parents and their children. The second section provides a review of North American and some European literature on factors related to the perceptions of families regarding child and family outcomes after the identification of deafness. This section covers an overview of some similarities families experience in their response to the identification of a hearing loss (i.e., parental reactions to deafness, communication difficulties, new challenges and competencies required) and to early intervention services (available help and support and family-professional relationships) as well as the family characteristics that are important to be explored and why.

Disabilities and Deafness in Ukraine: Attitudes and Perspectives

In order to set the context for a discussion of the present situation in Ukraine it is important to have a look at the issues of deafness and deaf education in the past. The documented history of the life of deaf people and deaf education in Ukraine is very long. A brief history of deaf people and deafness in Ukraine as well as a short description of prevailing approaches and attitudes to deafness and disabilities in general society aids in understanding the current situation and modern tendencies and provides contextual background for this study.

Concept of Disability in Ukraine

To a great extent attitudes towards deafness and deaf people in Ukraine have been influenced by (a) historical myths and beliefs about disabled people, (b) the ideology of deaf education in different historical periods, (c) the prevailing pathological approach to deafness in Ukraine in the 20th century, and (d) the isolation of Soviet Ukrainian humanities and social sciences including special education from international scholarship. This extreme isolation resulting from the Cold War after World War II impacted both research and practical work.

In the pagan past a belief in the demonic nature of diseases and pathologies in human beings was reflected in Ukrainian ceremonies, folklore, and apocryphal blessings (Drobot, 2001; Zahoruiko, 2001). This influenced the creation of the stereotype of a disabled person such as a cripple, blind or deaf person, as one who is also psychologically ill and mentally deficient. The following words referring to disabilities *kalika* (cripple), *chrometz* (lame person), *slipetz* (blind person), *nem* (deaf person) existed in the Ukrainian language up to the end of 18th century at which time word *invalid* (invalid) was borrowed from French (Ivanova, 2000; Yarmachenko, 1975). *Invalid* was first used to identify war veterans only and then was extended to mean a person with any physical or mental disability.

One of the reasons that *invalid* is still used in Ukraine in relation to persons with disabilities, special needs, or restricted mobility, lies in the problem of inadequate translation into Russian of the terminology used internationally and borrowed by Ukrainians from the Russian language dominant in the Soviet Union. In Ukraine, as in some other post-Soviet countries including Russia, the differentiation in terminology relating to disabilities and special needs is based on the ability to work or the severity of the illness or disability which reflects the following logic: disability (*leads to*) inability to work (*leads to*) social deficiency (Diachenko, 2003). In an educational or psychological context this approach assumes the absence of compensatory mechanisms of a person or his/her *pedagogical neglect* (this term *nepovnotsinnyi* is widely used in Ukrainian and Russian pedagogy and mostly in relation to children with learning disabilities and behavior problems).

Describing the scenario in Ukraine during Soviet times, Malofeev (1998) states that “for decades, the inherent problems faced by children with disabilities were recognized only by their families and those professionals charged with determining the

course of their lives” (p.181). Grigorenko (1998) confirms that this lack of disability awareness persists:

In the USSR, disability was considered unspeakable and invisible. Children were taught not to point to, stare at, or mention the impairments of the people they met (...). This attitude was pretty much inherited by the “new” post-perestroika Russia, and disability has not yet made its way into the public consciousness or the mass media. (p. 197)

Deafness in Ukraine: Past and Present

From ancient times. The first reference to deafness in Ukrainian history goes back to the 10th century. Historical chronicles describe attempts of monasteries to take care of and teach deaf people, record the negative attitude to deafness and the beliefs that deaf children were considered God’s punishment of the family (Yarmachenko, 1975). Therefore, parents were ashamed of their deaf children and did not consider ways to educate them. These attitudes existed for centuries.

At the beginning of 19th century societal attitudes to deafness started changing slowly and the first schools for the deaf appeared in Russia and in Ukraine. Those schools adopted the oral approach in teaching deaf students which was dominant in Europe at that time. At the beginning of the 20th century only a small number of deaf children in Russia and Ukraine could be enrolled in the educational system (Zahoruiko, 2001; Boichuk, 2001) due to a paucity of newly emerging residential schools for the deaf, the high cost of tuition fees, and the lack of information in the society about those schools. According to Yarmachenko (1975), parents of deaf students did not care much about literacy and were mostly interested in some vocational training for their children.

Ukraine: Soviet period (1917-1990). After establishing new schools for the deaf and incorporating them into the general education system, some educators questioned whether the existing oralist ideology was successful enough (Yarmachenko, 1975; Zaitseva, 1999). Vygotsky (1983) was one of the first writers to consider signed language to be a very specific linguistic system and he believed that signed language was a genuine language with a full wealth of functional meaning. Although his progressive idea of bilingualism was supported later in Western countries, Russia and Ukraine remained strongly oralist (Burch, 2000, Yarmachenko, 1975) and any new approach to the education of the deaf, which encouraged the use of signed language was banned (Zaitseva, 1999). The passage of time, including the post-war years and Gorbachov’s

perestroika era (1985-1990) did not bring major changes to the deaf education system (Burch, 2000).

Deaf education in independent Ukraine (since 1991). Cret (2000) and Malynovych (2003) noted that the number of children with hearing loss in Ukraine had a tendency to grow, however, any explanation of the reasons for this is missing from the literature. In 1952 there were 6,231 deaf students in 50 residential schools (Moskalenko, 2001). Themerykin (2003) stated that the number of children who had been diagnosed with a significant hearing loss by 2003, exceeded 10, 000 and he also suspected many more children in rural areas had not been counted. The majority of identified deaf and hard-of-hearing children (7,700) of school age were enrolled in 58 special schools (Bondar, 2004) which are traditionally divided into schools for the deaf (32) and schools for hard-of-hearing children (26). In Ukraine there are separate schools for deaf and hard of hearing children, however they all are referred to as “schools for children with hearing loss” or “schools for children with hearing impairment” (Yakymenko, 2001). The curriculum of those schools is almost identical. Eight hundred preschoolers were enrolled in 33 state kindergartens (Yakymenko, 2001).

As described earlier, deafness has been considered a pathological condition. Deaf people were considered mentally and educationally deficient (Yarmachenko, 1975). According to the medical/audiological perspective, the main goal, generally speaking, is to have children to approximate “normal” hearing. This is in line with the dominant approach in Ukraine where deafness is considered a disability (Ministry of Health Care Ukraine, n.d.). “Improving hearing” as well as the “development of speech” are considered the major goals in the education of deaf and hard of hearing children in Ukraine (Fomitcheva, 1997; 1997a).

Although the educational approach is oral and speech development is the main goal (Fomitcheva, 1997; 1997a), the majority of deaf and hard of hearing children in residential schools or special classes integrated within the regular public school system use Ukrainian Sign Language (USL) among themselves outside classes, either openly or secretly depending on the attitude of the school administration or class supervisor (Adamiuk, 2007; Chepchyna, 2001; Drobot, 2001; Zaitseva, 2000; Zaitseva & Slezina, 1971;).

Historically the use of signed language in the educational system was strictly prohibited and information on the use of signed language was unavailable because of a ban imposed after Joseph Stalin’s (1950) publication in which he condemned signed

language as a surrogate but not a language. There was and continues to be absolutely no opportunity for parents to learn basic signing. Some researchers have noted that hearing parents of newly diagnosed children in Ukraine often invent their own home sign/gesture system in an attempt to establish communication at home:

When a deaf child lives with hearing parents he or she creates gestures and signs which help him or her to communicate. Parents are also take part in creating those signs. As the result of that a local system of gesture communication is formed which is used only in this family. (Zborovska, 2006, p. 20)

However, no published study exploring this phenomenon has been found.

In reference to modes of communication and signed language it is evident that many researchers and key players in deaf education do not recognise Ukrainian Sign Language as a real language. Rather, it is viewed as “an auxiliary means of reproduction of learning material and communication with peers” as noted the new *Project of Assessment Criteria of Academic Achievements of Students in Elementary Grades in Special Schools for the Deaf Children* (Kovaliova, 2007; Gorlachov, 2007). Due to a long oral tradition this view that signing should be avoided as much as possible in the educational system and is “not the main means of communication but only an auxiliary one” (Gorlachov, 2007, p. 152) is still strong. Gorlachov (2007) states that “deaf persons have to rise to the level of the abilities of hearing people; to the ability to communicate with words, hearing people should not have to learn the gestures of the deaf” (p.152). The author ignores the latest international research in the field on the nature of signed language. In support of his position he relies on references to Soviet publications dated 1963 and earlier. This state of understanding is exacerbated by the fact that Ukrainian Sign Language research been launched only recently and there is no common understanding that spoken Ukrainian and Ukrainian Sign Language are two different languages. Some researchers still write about the necessity to “combine both languages” and “to balance signing and speech appropriately in the educational process” (Litovchenko, 2007, p.87).

Although there is confusion and misunderstanding among a number of researchers who have just discovered Ukrainian Sign Language for themselves, recently many researchers have started actively promoting signing as a new phenomena to be included in schools to improve the educational process (Adamiuk, 2007; Borshchevska, 2007; Dmytrieva, 2007; Drobot, 2007; Kovaliova, 2007; Kulbida, 2004; Litovchenko,

2007). Several of these researchers are currently involved in the research of Ukrainian Sign Language launched in the partnership with the Western Canadian Centre of Studies in Deafness (WCCSD, n.d.) at the University of Alberta.

Generally speaking, Deaf culture as well as signed language is not transmitted to the deaf or hard of hearing children by hearing parents who usually have not had prior knowledge of deafness or signed language (Schick, 2003). In Ukrainian residential schools for children with hearing loss it is deaf children of deaf parents, deaf parents, as well as a few deaf teachers who are able to provide knowledge of a visual language and to transmit some components of Deaf culture. However, socio-cultural understanding of deafness as well as Deaf culture, Deaf history and Deaf community, have only recently started breaking ground in Ukraine, increasing the interest in the issues of signed language communication among teachers in the schools for the deaf and parents of deaf children (Adamiuk, 2001; Chepchyna, 2001; Drobot, 2001; Moskalenko, 2001).

Attitudes to deafness in general society. The hearing population's information on deafness and the life of deaf people in Ukraine is limited to episodic publications in the press or TV broadcasts in relation to some event where deaf people have been involved. Veselova (2001) who is herself hard of hearing stated that absence of deafness and Deaf Culture awareness generates negative attitudes of hearing people towards deaf people as "deafness is often equated to being mentally or physically retarded. Doctors by writing a diagnosis as "deaf and dumb" make it impossible to get a job due to the above existing attitude" (p.207).

There is a strong community of deaf and hard of hearing people in Ukraine and almost all adults with congenital hearing loss and the prelingually deafened are members of the Ukrainian Society of the Deaf which is a national organization. The range of hearing loss in members varies from mild to profound; however, the society uses only terms "deaf" and "nonhearing people" to characterize its 60,000 members (UTOG, n.d.).

Contrary to North American trends indicating that both the status of deaf people has improved (Meadow-Orlans, 2001; Marschark, 2007) and attitudes of deaf people regarding deaf children have changed too (Meadow-Orlans., Mertens, & Sass-Lehrer, 2003), the situation in Ukraine has not changed much and in some cases has deteriorated. Deaf teacher Levytskyj (2003) notes:

People with hearing loss in our society do not have equal opportunities and are restricted in various areas of everyday life: choice of profession, communication, access to recreation and leisure, defense of their rights, etc.

Impaired hearing critically affects the overall development of the personality; deaf people are practically isolated in the society. (p. 51)

Yezhova (2007) states that the situation of securing jobs for adults with hearing loss has worsened since the number of jobs proscribed to people with hearing loss was increased significantly in a recent update of a list from 1970. Yezhova condemned the government for having no reason for doing so:

The developers of this new list of restrictions stated that their recommendations were based on the “results and conclusions of well-known studies” but failed to name those studies. These people, as well as those representing medical research institutions and government agencies in social care failed to give scientifically based reasons for the new restrictions imposed on deaf and hard of hearing people in the process of obtaining jobs and vocational training. (p. 16)

Research on Families Raising Children with Special Needs

Information on children with disabilities and/or hearing loss was not easily accessible by the general public in the USSR and that situation continues today. There is a very limited statistical data in the area. For instance, CSU-SSSR (1979), the most reliable and popular official statistical data source, gives national statistical information covering the educational system (preschool and secondary education), children and youth medical health care, recreation, sport and hobby groups. However, not a single piece of information was reported on children with disabilities, residential schools for children with special needs and hearing loss, or families with exceptional children. The absence of statistical information still reflects official Soviet policy towards persons with special needs, which was to prepare them for work as much as possible and not attract the attention of the general society to them (Ivanova, 2000).

No articles reporting research on families with deaf young children (infants or toddlers) or preschoolers were found in the journals covering issues in special education and educational psychology *Defectologia* [Defectology] and *Voprosy Psikhologii* [Issues in Psychology]. The absence of publications supports the note of Petshak (1990) on the situation existing in the Soviet Union that “till now the problem of emotional relations in the families with deaf children has not been a subject for psychological research” (p.18).

Even though researchers have stated that there is a critical need for research and publications, since 1972 (Bardian, 1972; Nazarova, 1989; Fomitcheva, 1997a) and later (Shvets', 2001; Zhuk, 2006; Zborovska, 2006) not one article can be found in the periodicals related to childhood and families published independently by the Ministries of Education of Russia and Ukraine respectively *Semia i Shkola* [Family and School] and

Doshkil'ne Vykhovann'a [Preschooling]. Only a review of the literature (Solovjev et al., 1998) revealed that every year deaf and hard of hearing children of 3-4 years of age newly enrolled in the preschool programs had “learning difficulties: children had no interest in learning new things, meeting new people or dealing with a new environment. Nothing could spark their interest” (p. 408). However, the authors of the study did not go beyond that statement and did not explore the reasons of the situation described.

To a Ukrainian reader the lack of interest in family education and raising children would not seem strange because it is a common perception that it was mainly the school system that was recognized as being in charge of education and raising children since the Soviet Union was established (Yarmachenko, 1975). In major books on the psychology of the deaf and deaf education (Yarmachenko, 1975; Fomitcheva, 1997, 1997a; Solovjev et al., 1998; Nikitina, 1989; Bondar & Zasenka, 2005) there is scarcely a reference to parents or family functioning. Even though there are some recent publications on families they are not based on research and contain mostly a review of literature and the thinking of the author (Mitko, 2007; Malynovych, 2007).

Summary

This overview of historical approaches relating to the life of deaf and hard of hearing children and adults in Ukraine explains in part the pathological or deficit approach which prevails in the present day in health, social care and education as well as a low awareness of deafness issues in the hearing society. Even though there exists a well-established system of deaf education in Ukraine, many children leave school with an inadequate level of skills required for successful integration into the hearing society or for pursuing the opportunity for quality post-secondary and vocational education.

The Communist Party of the Soviet Union dictated priorities, strategies and perspectives for the life of the society. Deafness was on the list of medical disabilities or pathologies, which in general were considered a negative phenomenon in the society with attitudes that followed that premise. Even statistical data on people with disabilities and special needs and special education were protected from public access. As a result of this official policy to minimize the information on disabilities and special needs in the society, many potential issues for research stopped attracting the attention of researchers because they got unclaimed, lost their research value, and later vanished from the focus of Soviet/Russian/Ukrainian educational and psychological researchers. Accordingly, in Ukraine there exists a serious gap in deafness studies research regarding issues of functioning in a family with a child who is deaf or hard of hearing.

Hearing Parents and Their Young Deaf or Hard of Hearing Children

This section contains a review of the literature related to the perceptions of hearing families regarding child and family outcomes after the identification of deafness in a child in their family. The literature reviewed is mainly English language literature, however, in some cases it is compared with the existing Ukrainian publications. Four aspects are discussed here: (a) the family-centered approach in research and important characteristics of families, (b) the impact of deafness on family life and parenting, (c) the effect of deafness on family communication, and (d) relationships between parents and the professionals providing services.

Family-Centered Research

Bronfenbrenner (1979) is credited with applying the term “family centered” to family research in the 1970s aimed at increasing the level of parent participation in early education. According to Bronfenbrenner, if you want to understand the way children develop it is necessary to investigate their behavior in their natural social context, while they are interacting with parents, familiar adults and other family members. Both the child and the context shape and accommodate each other as they interact. In this way, the more time the child is involved in such settings the more the settings impact the process of accommodation. In other words, a family systems perspective acknowledges the mutual impact of each member’s characteristics and highly values the importance of addressing issues related to family life. Henderson and Henderson (1991) stated:

Because the deaf child is a component of the family system, the deafness belongs not just to the child but to the entire family. Accepting this perspective makes it necessary for the family to seek ways to recognize itself so that all the components in the family system can participate, contribute, and draw on the family's resources equally. (p. 325)

Once a child is diagnosed as deaf, the family unit is no longer considered “hearing”; the parents may be hearing, the other members of the family (siblings, grandparents, other relatives living with the family) may be hearing, but the family unit becomes “hearing and deaf” or “deaf-hearing” and each individual creates meaning around the family experience (Henderson & Hendershott, 1991; Pollard & Rendon, 1999). Each member of the family must be accepted and valued in a mutually nurturing family environment, including the siblings.

Siblings’ relationships in the deaf-hearing families have been recognized in the literature (Cornett & Daisey, 2001; Dunn, 1995; Koester & Meadow-Orlans, 1990;

Luterman, 1987; Murphy, 1979) as very important. Luterman (1987), in discussing the issue of deaf and hearing sibling relationships, noted:

Siblings form the first social laboratory for the individuals' experiences with peer relationships. Within the siblings system, children learn how to resolve conflicts and support one another. The siblings system teaches them how to make friends and allies, how to save face while losing, and how to achieve recognition for their skills. In the siblings' world, children learn how to negotiate, co-operate and compete. . . . When children come in contact with the world outside the family, they take with them the knowledge they learned from their siblings to form their peer relationships. (p. 73)

Siblings can be older or younger to varying degrees, brothers or sisters, deaf or not deaf. They learn from each other and share resources in a variety of contexts. Hearing siblings are usually less reluctant than their hearing parents to use other communication modes besides speech such as signed, gestural or cued communication. Having established a reliable mode of communication with their deaf sibling hearing sibling very often serve as intermediaries between their deaf brother or sister and their parents and with people outside of the family as well (Marschark, 1997; Cornett & Daisey, 2001). However, the absence of a common language between siblings can lead to negative consequences as they may cut short or avoid more complex social interactions. "This reduced interaction will not only have a direct effect on social interaction, it will affect the learning of social skills and the ability to resolve conflicts" (Marschark, 1997, p. 175).

In general, siblings' interactions in deaf-hearing families, show very positive outcomes. However, Marschark (2007) described different situations when a lack of shared communication or misunderstandings between hearing and deaf or hard of hearing siblings might severely affect siblings' interactions and complicate family life. "Hearing siblings may be jealous of the increased attention that a deaf child receives from parents and upset at sometimes having to act like caregivers, explaining to people outside of the family that their brother or sister is deaf" (p. 215). They might feel that they have more household responsibilities than their deaf brothers or sisters. Such situations will often constitute another challenge for parents to handle. Luterman (1997) also suggested that a negative impact on siblings' relationships can occur when hearing siblings turn outside the family for relationships because they are unable to communicate with a deaf or hard of hearing sibling.

Besides siblings, some families might include grandparents and other members. North American research indicates that grandparents are an active and significant part of

the family; however, current grandparent roles have changed and are more affection oriented and entail much less responsibility. The most salient factor appeared to be the grandparents' role of helping out in times of trouble. With either explicit or implicit parental permission, grandparents are seen to be greatly helpful and powerful figures in the family adjustment process (Barranti, 1985; Dell & Appelbaum, 1977; Kennedy, 1992; Luterman & Ross, 1991; Mindel & Vernon, 1971; Nybo, Scherman, & Freeman, 1998; Vadasy 1987). Tinsley and Parke (1987) indicated that grandparents contribute to the development of their grandchildren in both direct and indirect ways. Directly, grandparents by participating in the process of raising a grandchild can enhance the grandchild's emotional and cognitive development and provide direct care services as well. Indirectly, grandparents can serve as social support agents for the parents. However, despite the significant role of grandparents, their reaction to the deafness diagnosis could have a negative impact on the rest of the family relationships system because they frequently have to deal with grief for their child (who is a parent for their deaf grandchild), as well as for their grandchild (Luterman & Ross, 1991; Scheetz, 2004). They feel unprepared to offer the kind of support often needed when a child has special needs and they usually lose hope for the extension of the family and a bright future for the child (Luterman and Ross, 1991; Vadasy, 1987).

Grandparents in Ukraine have an important role in raising their grandchildren. Contrary to the changes in the family role of grandparents in North America the role of grandparents in Ukraine still involves exercising power, authority, and responsibility. Many families include grandparents and even great grandparents because of the cultural tradition for several generations of one family to live together especially in rural areas.

Bodner-Johnson (2003), Calderon (1998), Henderson and Henderson (1991) and Jackson and Turnbull (2004) encouraged researchers to apply the family systems perspective to achieve a greater understanding of the impact of deafness on the parents and their young children. An understanding of the impact on family life, understanding feelings and thoughts of parents raising a deaf or hard of hearing child is critical to addressing all components of the family system in early intervention (i.e., family interaction, family resources, parenting, and support services for the child).

Identifying Important Characteristics of Hearing Families with Deaf or Hard of Hearing Children

The consistent theme of past research exploring family functioning and parental experiences of parenting deaf and hard of hearing children is the striking heterogeneity

among deaf and hard of hearing children and their hearing families (Calderon, Bargones, & Sidman, 1998; Easterbrooks, 2003; Holden-Pitt & Diaz, 1998; Hintermair, 2006).

Calderon et al. (1998) stated that “any attempt to create a “typical profile” of a child with hearing loss and his or her family is quickly defeated” (p. 354) and that is why child and family factors including demographic information as well as early intervention program factors are very important for understanding the children’s development and family functioning.

In North America one of the best sources of information on deaf and hard of hearing children is provided by the Gallaudet University's Research Institute (GRI) which has been collecting demographic, audiological, and other educationally relevant information on children who are deaf or hard of hearing since 1968 through its Annual Survey of Deaf and Hard-of-Hearing Children and Youth. This survey grew out of an expressed need for accurate and continuing demographic data on deaf and hard of hearing children in order to facilitate educational and communicational planning at the local, state, and national levels. These data provide valuable information on education and social program planning, legislation, and assessments that is useful well beyond the United States. It is shared internationally through numerous presentations, journal articles, and books (Holden-Pitt & Diaz, 1998).

Kluwin and Corbett (1998) explored families in which parents were highly supportive of their deaf or hard of hearing child but not actively involved with their child’s educational program. The main research question was about the importance of investigating the characteristics of parents/care providers and the possible correlation between those characteristics and parental involvement in the educational programs of their deaf or hard of hearing child. Answering this question the authors found strong relationships among age, education, physical resources, and parental involvement. These characteristics, parents/care providers are correlated with different forms of response to a child’s communication and education needs (Kluwin and Corbett, p. 425).

Pipp-Siegel et al. (2002) studied the stress experience in 184 mothers who had deaf or hard of hearing children. She identified factors which had to be taken into consideration when researching families with deaf and hard of hearing children and divided them into three broad categories: (a) demographic characteristics of the child (e.g., age, gender, presence of additional abilities), (b) factors related to the child’s hearing loss (e.g., degree of hearing loss, age of identification, language ability, mode of

communication used [oral only or sign]), and (c) characteristics and perceptions of the mother (e.g., maternal education, social support, daily “hassles”).

Scheetz (2004) pointed out that family structure, ethnic background, and socioeconomic status are all in place when infants enter the world. The environment, the unique characteristics of babies and interactions following this baby in the family represent variables that “give a broader perspective of the dynamics that occur when a deaf child is born into a hearing family” (p. 52). Cross-cultural studies also support the importance of ecological analysis in understanding deaf children’s functioning and social competence (Hintermair, 2006; Konstantares & Lampropoulou, 1995; Meadow & Dyssegard, 1983; Steinberg et al., 2003).

The literature identifies the following family characteristics of both children and parents as being especially relevant and important to the success of early intervention and family functioning: a child’s hearing level, age at identification, the presence of additional medical conditions, parental age, education, and hearing status, racial/ethnic membership, communication mode, family income, gap between age of suspicion and identification, and gap between age of identification of hearing loss and initiation of early intervention services (Kluwin & Corbett, 1998; Luckner & Velaski, 2004; Meadow-Orlans & Sass-Lehrer, 1995; Meadow-Orlans et al., 1997; Meadow-Orlans et al, 2003).

Professionals also face the challenge of the changing demographics of children in special education programs (Holden-Pitt & Diaz, 1998; Meadow-Orlans & Steinberg, 1993; Meadow-Orlans et al, 2003). During last decades one can witness the increasing change in the demographics of families with deaf and hard of hearing children. This change might become a new challenge for educators who must be prepared to serve children from families with more diverse profiles. In the last fifty years Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb (2000) have reported four major sociocultural changes influencing family life in the United States: (1) more mothers work outside of home; (2) more children live in single-parent families; (3) more fathers are involved in childrearing tasks; and (4) more homes where English is a second language. Deaf children clearly are influenced by these sociocultural changes, “but we know less about how these forces influence the participation of parents in the education of their deaf children” (Meadow-Orlans, 2001, p.141).

Although the above discussion refers to North America, several of these statements are true for Ukraine too: the number of single mothers in Ukraine has almost doubled since 1990 (from 11.2 percent to 21.45 percent) and the number of working

women has also increased, reaching almost 60 percent of the female population from 15 to 70 years of age (Statistics Ukraine, 2005). No information is available on the involvement of fathers in childrearing tasks.

Voices of parents to be heard. By the end of the 20th century there had been no effort made at the national level in the U.S. to explore the relationship of child and parental characteristics to early intervention services (Meadow-Orlans et al., 2003; Mertens, Sass-Lehrer, & Scott-Olson, 2000). The literature also revealed an absence of the voices of families in many studies investigating early intervention approaches and their influence on family life (Sass-Lehrer, Meadow-Orlans, & Mertens, 2000). To gain insight into the world where deaf and hard of hearing children grow, develop, and communicate the National Parent Project (NPP) was conducted in order to examine impact of deafness on the family and the complex relationships between the family and child characteristics and professionals and services. Another task was to review how individual differences among children with hearing loss and their families might influence services provided and how they help improve family functioning (Meadow-Orlans et al, 1997; Meadow-Orlans et al., 2003; Mertens, Sass-Lehrer, & Scott-Olson, 2000).

The NPP was conducted in three stages: (1) a national survey ($n=404$) of parents whose 6- and 7-year-old children were enrolled in educational programs for pupils with hearing loss, (2) telephone or TTY interviews with parents ($n=62$) randomly selected from survey respondents, and (3) face-to-face interviews ($n=17$). Meadow-Orlans et al. (2003) reported that the survey questionnaire for the NPP was designed with the assistance of the Gallaudet's Center for Assessment and Demographic Studies (CADS) staff. Drafts were revised after being reviewed by parents and professionals.

Data from the NPP survey suggest that certain characteristics of children (hearing level, age of diagnosis, additional conditions) and parents (hearing status, socioeconomic status, racial/linguistic status) which had been identified by the researchers of this study were correlated to parents' assessment of the impact of deafness on the family, their assessment of children's social behavior and language progress, their evaluation of the services and the support they received (Meadow-Orlans et al., 1997; Meadow-Orlans et al., 2003; Mertens et al., 2000; Schirmer, 2001). The results of the study provided empirical support for the theoretical supposition of the importance of family characteristics influencing parental feelings, experiences and attitudes while raising their child. In particular, the hearing status of the mother influenced the time of

the diagnosis: children with deaf mothers were diagnosed earlier. Parents of children with additional conditions reacted more negatively to the impact of the diagnosis, and received less support than parents whose children had no additional condition. A child's age at the time of diagnosis was a significant factor in the evaluation of services and family functioning: older ages of children at the time of diagnosis were associated with less positive evaluations. A mother's educational level and racial\ethnic group membership were related to language scores: children with more highly educated mothers scored higher than same-race peers whose mothers were less educated. However, neither educational nor minority group status was related to belated fitting of hearing aids, speech and auditory training.

In conclusion, families with children who are deaf or hard of hearing are heterogeneous and educators must focus on serving needs of these families across a broad spectrum of characteristics including race, ethnicity, socioeconomic status, and education, and should recognize the increasing diversity of children and parents in intervention programs (Meadow-Orlans, 2003).

Parental Reactions to the Diagnosis

Researchers and practitioners suggest that families who have a child with hearing loss experience many of the same successes and challenges as any other family. However, having a child with a hearing loss tends to change family dynamics and the home environment (Meadow-Orlans et al., 2003). The presence of a child with hearing loss puts significant pressure on the family with hearing parents and can potentially be a continuous source of stress (Calderon and Greenberg, 1999; Calderon & Greenberg, 1993; Feher-Prout 1996, Lederberg, 1993; Lederberg & Everhart, 1998; Lederberg & Golbach, 2002; Luterman, 1987, Luterman & Ross, 1991; Meadow-Orlans, Koester, & Spencer, 2004; Moses, 1985; Quittner, Glueckauf, & Jackson, 1990; Schlesinger, 1987).

According to Luckner & Velaski (2004) three specific issues are often highlighted: (a) hearing parents have a limited understanding of what it is like to have a hearing loss and may not be able to understand the child's speech, (b) during the critical years of language learning for the child, the parents of deaf or hard of hearing children are often challenged by emotional implications of the diagnosis and necessity of making decisions including communication choices, and (c) parents have to deal with a variety of professionals in different areas who may offer information or advice that sometimes may challenge the parents' authority or cause confusion.

Parents frequently experience a lag of approximately 6 months or more from the time they suspect a hearing loss to when the hearing loss is confirmed (Meadow-Orlans et al., 1997). According to Koester & Orlans (1990) professionals may unwittingly contribute to a delay in the diagnosis by convincing parents that they are simply overly anxious parents. They supported the note of Williams & Darbyshire (1982) who stated ten years earlier that the initial (negative) response of pediatricians might lead to unnecessary delays before referral for testing is made. Meadow-Orlans et al. (2000) maintain that this often still happens 10 years later.

On receiving the diagnosis of deafness, parents are faced with a child who will experience and respond to the world in a significantly different way. Society transmits pervasive messages about this difference. Historically, attitudes and ideologies have revolved around the belief that the family is normal and the deaf child is deviant (Henderson & Hendershott, 1991). Rodda & Grove (1987) stated that the “invisible” nature of deafness contributes to the ambiguity associated with the birth of a child who is deaf, because congenital hearing loss is often not detected at birth and parents continue to have expectations of a normal, healthy child well after the child’s birth. The diagnosis of a child’s hearing loss, then, can be a source of great shock and stress to many parents who did not suspect deafness or hearing loss. Therefore, the diagnosis of a child’s deafness or hearing loss might be associated with numerous, complex, variable and long lasting emotional reactions to the necessity of adjusting to new life circumstances, acquiring services, addressing financial concerns, making plans for life changes that may not have been previously considered, looking for new effective communication methods, being involved in educational decision making and increasing contact with professionals in a number of disciplines, purchasing and using technological supports, as well as the everyday experience of having a child who is “different” and cannot communicate in the usual manner (Calderon & Greenberg, 1999; Hintermair, 2004; Lederberg & Golbach, 2001; Meadow-Orlans, Spencer, & Koester, 2004; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Quittner, 1991; Quittner, Glueckauf, & Jackson, 1990; Spahn, Richter, Zschocke, Lohle, & Wirsching, 2001). Parental reactions to the diagnosis can be seen to parallel Kubler-Ross’ (1966) five stage model of grieving: (a) denial (shock and disbelief), (b) anger (toward God, relatives, self, and health care providers), (c) bargaining (trying to get more time, prolonging the inevitable loss), (d) depression, and (e) acceptance (adaptation to the loss and its consequences and adjustment) (Andrews et al., 2004; Frey, Greenberg, & Fewell, 1989; Hadadian & Rose, 1991; Kurtzer-White &

Luterman, 2003; Lane, Bell & Parson-Tylka, 2006; Luterman, 1987; Luterman & Ross, 1991; Marschark, 1997; Ross, 2001; Ryan 1992; Schirmer, 2001). These above-mentioned reactions were reported in a recent study which surveyed parents' reactions shortly after their newborns failed a hearing screening test (Yoshinaga-Itano and DeUzcategui, 2001). Parents in this study reported feelings of shock (forty two percent), anger (twenty two percent), confusion (forty two percent), fear (fifty two percent), sadness (sixteen percent), frustration (thirty one percent), depression (thirty seven percent), loneliness (sixteen percent), and blame (sixteen percent). "The work of grief is to face the reality of loss, to work through painful memories; experience the full range of emotions associated with loss, to cope with the situation and lifestyle changes resulting from loss, and adapt to the loss and reconfigure one's life" (Rich, 1999, p. J9).

Traditionally, mothers of deaf children were the focus of studies (Marschark, 1997) even though according to Meadow-Orlans et al. (2003) "both mothers and fathers recognized that their spouses' reactions might be different from their own" (p.148). Hearing mothers often assume more child care responsibilities than hearing fathers (Marschark, 1997; Meadow-Orlans & Sass-Lehrer, 1995). Fathers "are less likely than their wives to learn to sign and to attend parent meetings" (Meadow-Orlans et al., 2003, p. 147). Successful coping on the mother's part has a significant influence on the child's development. Hintermair (2006) noted that the more successful the mother is in acquiring helpful strategies for coping with her deaf child, the better the child develops emotional sensitivity, reading competence, and problem-solving behavior. Mothers' better coping skills have also a positive influence on children's behavior, increases cognitive flexibility, and improves their social competence

Pipp-Siegel et al. (2002) examined parental perceptions in 184 hearing mothers of young children who are deaf or hard of hearing. The researcher identified several aspects that might intensify the difficulties and stress of parents who raise children who are deaf or hard of hearing. Those aspects were classified as "demographic characteristics of the child, factors related to the child's hearing loss, and characteristics and perceptions of the mother" (p. 2). This study first identified possible correlations and relationships among the variables and then examined potential predictors of maternal stress. The researchers reported increased parental stress related to the hearing loss and its degree. Hearing loss also resulted in decreased language and speech ability of the children. Additional findings showed that "regular, high quality intervention may have reduced the potentially negative effects. Given appropriate early intervention services, mothers of

children with hearing loss do not exhibit more stress than would be expected from a group of mothers of hearing children” (Pipp-Siegel, 2002, p. 15). Also, contrary to past research which reported significant relationships between maternal stress and maternal education, with lower levels of maternal education related to increased stress (Deater-Deckard & Scarr, 1996; Singer, Song, Hill, & Jaffe, 1990) this study did not reveal a significant relationship between maternal stress and maternal education. This may, in part, be due to the early intervention services received by the families in this study.

According to Kampfe (1989), Mindel & Feldman (1987), Mindel and Vernon (1971), and Hintermair (2006) parental perceptions of their child’s hearing loss vary depending upon a variety of conditioning variables. Kampfe stated that “social status indicators such as parental age, gender and ethnic background might all have impact on the degree to which the event appears undesirable, disruptive, important, controllable or stressful” (p. 257). The education of parents and financial status might also influence (either increase or decrease) parental perceptions of the diagnosis and impact level of stress and grieving as well (Kampfe, 1989; Meadow-Orlans et al., 2003). Many studies have clearly demonstrated the effectiveness of “personal resources” such as personality and personal strengths, coping strategies and attitudes (Mindel & Vernon, 1971) as well as “social resources” (Hintermair, 2006) such as support from family, friends, other parents of children who are deaf or hard of hearing, society and service/education agencies (Calderon & Greenberg, 1993, 1997, 1999; Hintermair, 2000a, 2004; Konstantareas & Lampropoulou, 1995; Lederberg & Golbach, 2002; Luckner & Velaski, 2004; MacTurk, Meadow-Orlans, Koester, & Spencer, 1993; Meadow-Orlans, 1994; Meadow-Orlans & Steinberg, 1993; Meadow-Orlans et al., 2004; Morgan-Redshaw, Wilgosh, & Bibby, 1990; Pipp-Siegel et al., 2002; Quittner et al., 1990; Webster-Stratton, 1990).

Summarizing the body of literature on parental stress, parental resources, and socioemotional development of deaf and hard of hearing children Hintermair (2006) came to the conclusion that:

An overview of all the findings demonstrates that - primarily in early childhood and also later on - the parents’ stress experience and the resulting strategies for coping with a life situation changed by deafness represent decisive factors in the child’s development in various respects but especially for the child’s socioemotional development. (p. 498)

Grief is not something abnormal; rather, it is a normal and inevitable step in our journey through life (Rich, 1999), however, most previous research gave the majority of attention to the negative impact of hearing loss and pathology in the context of the child's deafness in a family. Hindley (1997) noted that "the most prevalent model used to explain parental response is that of crisis/adaptation in which positive confirmation of deafness is expected to create feelings of loss" (p. 114). Many authors consider hearing loss as well as any other disability of a child as an additional source of stress in the family (Calderon, Greenberg and Kusche, 1989; Feher-Prout, 2004; Kampfe, 1989; Kurtzer-White & Luterman, 2001; Luterman, 1979, 1987; Luterman & Ross, 1991; Mindel and Feldman, 1987; Mindel and Vernon, 1974; Mitchell, 1981; Moses, 1985).

However, recently some researchers who had traditionally focused on pathology and family dysfunctions, not satisfied with the kinds of change in families that was originally expected tried shifting the focus from the pathology to positive perspective in exploring family life (Beazley & Moore, 1995; Calderon & Greenberg, 1993; Dunst, 1985; Luckner & Velaski, 2004; Powell & Gallagher, 1993; Szarkowski, 2002; Turnbull & R. Turnbull, Young, 1999). Beazley and Moore (1995) demonstrated that so-called classic features of parental grief reactions are produced under the influence of professionals who adhere to a pathology perspective and assume deafness to be a tragedy, expecting parental reactions to be only negative and unchanging.

A considerable body of research has explored stress of parents who have children with different types of disabilities or medical conditions. Young (1999) examined whether hearing loss in itself may cause a greater parental stress than that reported for those parents. Young's conclusions in a qualitative study with 24 subjects conducted in England are very similar to those of Pipp-Siegel (2002). Besides acknowledging the vital importance of services and professional and social support to reduce stress, Young explored the concept of grief and adjustment in the light of the relatively new cultural-linguistic paradigm of deafness. The author argued that the existing concept used to understand grieving and adjustment was predicated upon a medical model of deafness. In contrast to the medical approach, the cultural-linguistic model views parents as engaged in a process of adjusting to a different version of "normal" rather than a damaged version of "normal" (p. 160). Young argued that "the characteristics of the deaf child *not being like us* are not something to be mourned, but to be accepted as a positive attribute" (p. 161). The author concluded that "the existence of

the cultural-linguistic model raises new adjustment issues for parents that hearing parents of deaf children have not had to encounter before” (p. 170).

Two studies conducted by Luckner and Velaski (2004) and Szarkowski (2002) can be considered unique. Contrary to existing research Luckner and Velaski concentrated on “healthy” hearing families with deaf children. They did not limit the definition of “healthy family” to a narrow medical definition, but focused on positive family identity, satisfying and fulfilling interactions, and successful functioning so that the needs of both the individual and the family were met. The authors accepted Luterman (1987, p. 8) definition of a “healthy” family which included the following five elements: (1) communication among all members was clear and direct, (2) roles and responsibilities were clearly delineated, (3) the family members accepted limits for the sake of conflict resolution, (4) intimacy was prevalent and was a function of frequent transactions between equally empowered individuals, and (5) there was a healthy balance between change and the maintenance of stability. Using this definition, Luckner and Velaski identified and interviewed 19 families of children who were deaf. The researchers looked for factors that contributed to family health as well as suggestions for other families with deaf or hard or hearing children. This study identified the most important features of a ‘healthy’ family: (a) all families learned new ways of interacting with their child and the majority of families chose to use some form of sign to communicate, (b) although support from extended family, professionals and friends were often mentioned as contributing to the health of the family the respondents reminded researchers that they were the experts on their family and their children and would like professionals to serve as information resources, (c) all families were very proactive after the diagnosis. The composite portrait of the family in this study which emerged was:

On learning that their child had a hearing loss, they gathered information about deafness, learned signed language soon after their child was identified, asked questions of professionals in educational and medical settings, met other families who had a deaf child, learned which educational programs fit their child’s needs best, were knowledgeable of parental rights and responsibilities as well as those of the child, and were willing to fight for what their child needed both educationally and medically. (Luckner & Velaski, 2004, p. 333)

Finally, the authors concluded that "regardless of gender, ethnicity, social class, or age, children and youth who feel cared for, accepted, and supported by their family are

reported to be healthier, happier, and more competent than their peers who do not feel this way" (p. 324).

Szarkowski (2002), following a new movement in the field of psychology called Positive Psychology (Seligman & Csikszentmihalyi, 2000), employed a positive stance in her study believing that parents of deaf children had unique positive experiences of raising a deaf child. She explored and highlighted hearing parents' experiences that would not have occurred if their child had not been deaf. Common themes which emerged among participants, fell into six *clusters of influence* on the parents. While some clusters represented situations that parents replied as being difficult aspects of raising a deaf child, other clusters highlighted the benefits of parenting a deaf child and the positive ways in which parents perceived their experiences with their deaf children. Parents appear to fall into one of three categories, Positive Parents, Struggling Parents, and Not So Positive Parents. These findings support the author's hypothesis that hearing parents of deaf children do have positive experiences in their parenting. The types of "positives" reported by parents were influenced in part by parental characteristics, as well as by the availability of exposure to the Deaf Community, and the quality of interventions provided to their child who was deaf. Szarkowski (2002) stated that even though families have different life circumstances the parental satisfaction with raising a deaf child depended on the parental ability to substantiate and appraise positive experiences in the process of parenting. The author's parenting model, in other words, considered negative aspects of the process of parenting a deaf child to be a part of the parental system. In this system "ups and down" of parental experiences were seen as normal and therefore created a balanced view of parenting deaf children in which both positive and negative experiences were acknowledged.

In summary, although the use of a stress and coping paradigm adopted from the field of psychology has increased our understanding of hearing family reactions to the diagnosis of deafness in a child, professionals in the field of deafness seem to be viewing the relationships between a family and a deaf child as much more complex than previously realized and the stress-pathology model has started losing its prominent position in the latest research.

Family Interactions: Language and Communication

Deaf or hard of hearing children of hearing parents typically are delayed in their exposure to language and therefore "communication is the central concern for families

with children who are deaf or hard of hearing” (Meadow-Orlans et al., 2003, p. 12). In a national survey report in the United States Meadow-Orlans et al. stated:

When national survey responses are compared on the nine items that measure family stress related to hearing loss, parents with deaf children and those with hard of hearing children have scores that are no different except for the three items specific to communication. On these items, parents with hard of hearing children have much more positive scores. (p. 46)

Communication is at the heart of lives of human beings. “Meaningful, elaborated, engaged, and smooth communication is critical for the transmission and education of socio-emotional competence” (Calderon & Greenberg, 2000, p. 171). However, deaf and many hard of hearing children’s access to and development of such a communication is often severely limited due to various reasons (Marschark, 1997).

The growth of personality depends on a language-rich environment, one with ongoing, and direct communication, and age-appropriate language opportunities. Contrary to hearing children for whom such an environment is naturally provided at home and in an educational setting, deaf and hard of hearing children have to have such an environment created by parents and professionals because it is a primary factor responsible for successful family functioning and superior educational achievement (Easterbrooks & Baker, 2002; Koester & Meadow-Orlans, 1990; Marschark, 1997, 2007; Scheetz, 2001).

The presence or absence of communication in early and later childhood has broad consequences for development. If they are to be prepared for academic challenges in the future, during preschool years, children with hearing loss must progress developmentally at the same rate and achieve linguistic, cognitive, social and emotional milestones along timelines typically achieved by hearing children (Erting, 2003). In terms of education and academic skills, deaf children often begin their formal schooling lacking the necessary language skills and general knowledge for normal language development among their age-peers, which further hampers their abilities to learn curriculum content in school (Johnson, Liddell, & Erting, 1989; Toth, 2002; Wilbur, 2000). Therefore, access to communication and language acquisition is vital. For deaf children with greater hearing loss, this most often might be signing communication which helps them to be better adjusted emotionally and to do better in school (Singleton, Supalla, Litchfield, & Schley, 1998; Wilbur, 2000). According to Mayer and Akamatsu (2003) “there should be no controversy over the fact that primary language instruction in a natural signed

language can confer cognitive and academic benefits and lead to primary language maintenance” (p.144). Deaf students of hearing parents when given the opportunity to master signed language before the age of six have systems of grammar similar to those of deaf students whose parents are also deaf. Research has shown that a strong first language base (e.g., in American Sign Language) will provide children with an easier transition to learning a second language (e.g. spoken language) (Mashie, 1995). Vaccari & Marschark (1997) stated that “deaf children who learn sign language as a first language generally have been shown to have better reading and writing skills than deaf children exposed only to spoken language (p. 796).

For children with mild to moderate hearing loss speech and spoken language which they can learn more easily, may become a communication vehicle. Deaf children with hearing parents may develop competencies in spoken language and/or ASL, depending on their skills in acquiring either language with exposure at home and at school (Andrews, Leigh, & Weiner, 2004; Preisler and Ahlstrom, 1997). At the same time it appears that the fact that a mother possesses good signing skills is more important than her hearing status (whether she is deaf or hard of hearing) or the precise age at which a child learns to sign (as long as it is early) (Akamatsu, Musselman, & Zweibel, 2000; Strong & Prinz, 1997).

During the last decade an interesting approach is on the rise in the United States and abroad in which families have been using both spoken language and signed language with deaf and hard of hearing children who are attending inclusive early childhood placements and those attending oral programs (Moeller, 1997; Preisler & Ahlstrom, 1997; Rushmer & Melum, 2002). For example, Preisler and Ahlstrom (1997) in their two-year longitudinal study in Sweden with 15 deaf and 12 hard of hearing children 2 and 7 years of age were looking for an answer to the question of whether signed language for hard of hearing children hinders or benefits their development. The study revealed that signed language seemed to have many positive effects on the language development of hard of hearing children. Their improved language skill had many other positive consequences for the children’s development, including the development of play, social development and also emotional development. The children in this study showed a good deal of flexibility in their use of the two languages. It was also stated that in the communication process there had been more communicative failures when the children or the child and the adult primarily relied on spoken language.

Rushmer and Melum (2002) described a similar situation which took place in the United States. In Oregon, the Columbia Regional Program for Deaf and Hard of Hearing (CRPDHH) incorporated family-centered practices into its services for parents who have deaf and hard of hearing infants and young children, respecting the central role of families in their child's learning and development. The program used two languages ASL and English. English was modeled through Sign Supported Speech and through spoken English alone. The children who were primarily visual language learners tended to acquire ASL and those children with good access to the auditory characteristics of spoken English learned ASL and spoken English. Of the 348 students, 39 children were birth to 5 years of age and the other 309 were 5 to 21 years of age. The providers of the program believed that children achieve the best results when their emerging signed language, speaking, and listening skills are reinforced in a context of acceptance and respect. It was observed in this program that the rate of language acquisition for hard of hearing children was earlier and more advanced than when learning speech alone. The addition of signs appears to facilitate understanding of and memory for new language. Rushmer (2003) stated:

The children will often sign a new word first until they gain confidence in their spoken utterance. They then tend to drop the sign. By the age of 5 years, many of these hard of hearing children score at age level or above on standardized language tests for hearing children. (p. 233)

There has long been a concern that the use of signed language with hard of hearing children would interfere with spoken language development. Yoshinaga-Itano (1998) in her study with 147 deaf and hard of hearing children between the ages of 14 and 60 months ($M = 33.6$ months; $SD = 13.7$ months) and who had normally hearing parents investigated the relationship of speech production and demographic and developmental factors on deaf or hard of hearing children in the United States. The mode of communication was determined by the use of signed language by the child and/or his or her parent(s) during a 25-minute videotaped parent-child interaction in the home. Oral communication only was used in thirty five percent of the dyads in the videotaped interaction; sixty five percent used some signed language. This study reported that “despite the increased likelihood of orally trained children developing better speech abilities, it is clear from this sample of children that the use of sign language does not necessarily preclude the development of good speech skills” (p. 199).

The results of Daniels (1993) study with 14 hearing children, who learned ASL, as preschoolers from their deaf parents, show that these bilingual youngsters achieved significantly higher than average scores on the Peabody Picture Vocabulary test. However, having identified the possibility for signed language to have a positive influence on hearing children's acquisition of English, the author left the issues of the interrelationships of both languages in the brain open. Petitto, Katerelos, Levy, Gauna, Tetreault, & Ferraro (2001) in a longitudinal study of two groups of hearing children (a) acquiring *Langues des Signes Quebécoise* and French, and (b) acquiring French and English examined the interrelationship between the two languages. They reported that "the signing speaking bilinguals did simultaneously mix their signs and speech, but in semantically principled and highly constrained ways" (p. 454). Petitto et al. (2001) concluded that "the capacity to differentiate between the two languages is well in place prior to first words" (p. 454). Marschark (2007) stated that there was no evidence to support the claim that signing interfered with learning to speak. Although it has been reported that ASL grammar sometimes intrudes into a young deaf child's speech, according to Krashen & Terrell (2000) and Baker (2001). That phenomenon is common among second language learners both children and adults. "Over time, deaf children will come to separate signed and spoken language just as children in Switzerland come to separate their use of German, Italian, and French" (Marschark, 2007, p. 122). However, Marschark (2007) also mentioned that the child who could not learn to speak was not being difficult or demonstrating lesser intelligence because "it has always been a minority of deaf children who acquire fluent spoken language. This is not an issue of debate, as the data is very clear" (p. 123).

One of the particularly important findings in the research literature is that the stress parents experience and the child's development are directly related to the child's communicative competence (Greenberg, Kusche', & Speltz, 1991; Hintermair, 2006; Knoors, Meuleman, & Klatter-Folmer, 2003; Mitchell & Quittner, 1996; Vostanis, Hayes, & Warren, 1997). One can witness less parenting and relationship stress in families with a communicatively competent child, with the child's development progressing better than in families without this prerequisite (Greenberg et al., 1991; Morgan-Redshaw et al., 1990; Pipp-Siegel et al., 2002; Vaccari & Marschark, 1997). According to Yoshinaga-Itano, Coulter, & Thomson (2000), young children who are deaf or hard of hearing and are enrolled early in an early intervention program are 2.6 times more likely to have language within the normal range in the first five years of life than a child who does not

have this advantage. After reviewing a number of studies, Vaccari and Marschark (1997) stated that “good early communication is an important ingredient for social-emotional development in deaf children” (p. 797) and “the most important thing is full access to some language and the earlier the better” (Marschark, 1990, p. 12).

According to Ollendick, & Schroeder (2003), “language is central to the lives of all individuals because it is the means for communicating with others and for thinking and learning” (p. 156). Tannen (2001) identified the role of communication in the life and functioning of families in the following way:

Communicating in a shared language with our parents and siblings is the primary means by which we become a part of our families and have our “voice” included in family decisions and events. In all families, communication is key to developing alignments or close relationships among family members. (p. 17)

The communication issue for deaf individuals has never been the degree of hearing loss but rather the ability of the deaf person to communicate in a language that others share (Schirmer, 2001). This statement is in line with the statement of Marschark (2007) that regardless of whether “their parents are deaf or hearing, deaf children who are better readers turn out to be the ones who had their hearing losses diagnosed earlier, had early access to fluent language (usually via sign language), and were exposed to English” (p. 170). All hearing family members must adapt their style of communication in order to accommodate the needs of the deaf or hard of hearing child. It is quite possible that this will entail learning a new language together (Koester & Meadow-Orlans, 1990; Marschark, 1990; 2007; Young, 1999).

If such an accommodation does not happen in the family and if there are no adult language models consistently available to deaf or hard of hearing children to develop conversational language most deaf children are at risk for delays in their language and overall development (Bess et al., 1998; Ross, Brackett, & Maxon, 1991; Marschark, 1997; Meadow, 1980; Moores, 2001; Yoshinaga-Itano & Downey, 1996). It is easier to learn language when the language is used consistently by adult family members and siblings in conversation with a deaf or hard of hearing child; it is more difficult to learn when the language is used inconsistently and conversation is infrequent (Schirmer, 2001). The most important issue facing parents in maintaining a family unit is that all family members have to be involved in the process of communication with the deaf child in the home (Adams, 1997; Adams & Rohring, 2004; Marschark, 1997) so that

the child can learn to distinguish between different individual peculiarities in communication. In that way adults mediate communication which allows babies access into the language system whereby they can express their needs and maintain emotional attachments (Scheetz, 2004). Later, as these exchanges between a child and adults become more advanced, the child learns how to model appropriate communication behaviors and responses (Scheetz, 2004; Marschark, 1997). Scheetz (2001) noted:

The family unit provides an avenue for children to express what they have done during the day and receive either praise or criticism for their actions. Through this exchange their insight into what they can accomplish is strengthened. If children are not included in the barrage of words and the exchange is blocked, their development will also be delayed. (p. 72)

In most cases deaf children who are not consistently exposed to communication through a spoken or signed language, or a spoken language supported with signs will develop home sign systems. These children without a language model cast their homemade gestures in some structured system (Goldin-Meadow, 2003, Goldin-Meadow & Mylander, 1993; Emmorey, 2002; Torigoe & Takei, 2002; Zborovska, 2006). Their communication and interactions with other family members will be limited and they may often remain confused and lonely in their “own little world”.

Luterman and Ross (1991) noted that “anyone who has written about well-functioning families (or dysfunctional ones for that matter) looks at the communication patterns of family members. Clear communication is by far the most important attribute of an optimally functioning family” (p. 55). As families recover from their initial feeling of shock and frustration upon the diagnosis, members are required to return to a “state of equilibrium” in which they can focus on their strengths, reconsider family priorities, and discover what works best for their child as well as their entire family (Bodner-Johnson & Sass-Lehrer, 1996).

Early Intervention Services and Parental-Professional Relationships

Many researchers have documented the positive effects of early intervention for the social and cognitive development of children born at risk for developmental delays (Carney & Moeller, 1998; Greenberg & Crnic, 1988; Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). During the last decades direct services have been put in place for families to support them to build competence and confidence that allow them to be actively involved in facilitating their children’s development. These services are believed to be more effective than child-

directed instruction which does not encourage involvement of families (Brown & Nott, 2006; Carney & Moeller, 1998; Kurtzer-White & Luterman, 2000; Sass-Lehrer, 2002; Sass-Lehrer & Bodner-Johnson, 2003; Yoshinaga-Itano, 2000). Family-centered service delivery was initially implemented by the health care profession in 1960s and proved its effectiveness in the treatment of children with special health care needs (Shelton, Jeppson, & Johnson, 1987). According to Sass-Lehrer & Bodner-Johnson (2003) this model adopted by early intervention providers from the health care profession “has become a foundational characteristic of the philosophy and practice of early intervention” (p. 66). The authors also noted that adopting the perspective that family and individual behavior should be understood within an ecological and family social system marked a paradigm shift in early childhood education in Western countries. According to Marschark (2007) “early intervention programs are often assumed to be for deaf children, but they are just as important to parents of young deaf children” (p. 21). That is why many of those programs are now referred to as parent-infant programs or family centered programs (Marschark, 2007; Sass-Lehrer & Bodner-Johnson, 2003). In addition, child-focused services remain an important component of early education for toddlers and preschoolers and provide support for learning and development in the child’s environment.

In the literature three broad categories have emerged to describe professional helping relationships with families (Dunst, Trivette, Boyd, & Brookfield, 1994). The "professional-as-expert" model presumes that parents/caregivers do not possess enough knowledge and skills and are supposed to rely on professionals for information and decisions. In the "direct guidance" model parents and caregivers are viewed as somewhat knowledgeable, however, the professionals are to determine what specific skills and services parents and caregivers are lacking and provide those services to the families. In the "partnership model," the professional and family members work in a team as equal partners. The “partnership model” assumes that families themselves are capable of solving their own problems. In the partnership with professionals families themselves will be able to acquire the information, resources, and determine the support they need to make important decisions and meet their family needs. Professionals consider the family-centered partnership model as the most useful when working with families with young children (Dunst et al., 1994). Collaborative and family centered early education utilizes family-professional partnerships (Sass-Lehrer & Bodner-Johnson, 2003). It is becoming evident that family-centered early intervention programs for young deaf children and

their families provide critical services that encourage positive developmental and educational outcomes (Marschark, 2001; Sass-Lehrer & Bodner-Johnson, 2003). For children with hearing loss who have been involved in family-centered early intervention programs, positive results of early intervention are reported in social and communicative competence. As well, support networks are related to positive mother-child interaction and better language development (Arehart, Yoshinaga-Itano, Thomson, Gabbard, & Stredler Brown, 1998; Brown & Nott, 2006; Calderon & Greenberg, 1997; Carney & Moeller, 1998; Meadow-Orlans & Steinberg, 1993; Yoshinaga-Itano, 2000). The linguistic deficit often noted in deaf children may be reduced or eliminated if they receive appropriate early language training and these children usually fare better in the social domain than do those without the benefit of such experience (Marschark, 1993; Moores, 2001a).

Family-centered intervention has been particularly important with regard to providing families with information and skills required to develop and support communication and language in deaf and hard of hearing children. Programs developing visual communication skills (Mohay, Milton, Hindmarsh, & Ganley, 1998), spoken language (Brown & Nott, 2006), or both, encourage communication between parents and their child in the context of every day life, fostering child learning and parent confidence. Sass-Lehrer & Bodner-Johnson (2003) noted that the early intervention program has to take into consideration that each family is different in its needs, priorities and methods of problem solving. Based on the uniqueness of each child and family the family-centered program has to “design services and curriculum that reflect developmental processes of learning within the context of the family and community” (p. 70). According to Moeller (2000) the primary result of family-centered intervention programs is greater parental involvement in their child’s activities which naturally leads to enhancing both early language development and later academic achievement.

Although professionals involved in intervention services may have different backgrounds such as teachers, early childhood specialists, audiologists, speech and language pathologists, social workers, or signed language specialists/interpreters, they all get to know the families and develop relationships that restore the families’ confidence and encourage and support them in the process of learning how to effectively communicate with their children and empower parents to become their child’s best advocate (Kurtzer-White & Luterman, 2001; Sass-Lehrer, 2002).

Key professional services include providing general information about deafness and its implications for the child and other family members and counseling and support in the process of coping and adjustment. The training component focuses on helping family members develop skills for effective communication and managing amplification and assistive technology devices. To be truly effective, early intervention needs to take place immediately following the identification of hearing loss and prior to age three to enhance the potential for language and psychological development (Andrews et al., 2004; Calderon, 1998; Calderon & Greenberg, 1997; Hintermair, 2000; Kurtzer-White & Luterman, 2001; Meadow-Orlans et al., 2003; Schirmer, 2001). Sass-Lehrer (2002) noted that:

Infants identified and enrolled in quality early intervention programs during their first year of life demonstrate language skills similar to their hearing peers by three to five years of age. When parents and children communicate effectively with each other from the very start of hearing loss identification, a foundation for language acquisition (both spoken and signed language) is established and language delays may be prevented or minimized. (p.10)

Although at present many effective programs exist, as yet, there is no validated ideal comprehensive curriculum for early intervention programs that will address all the needs of all deaf and hard of hearing children and their families (Andrews et al., 2004). Some of the reasons for that provided in the literature are paucity of sound methodological research on the effectiveness of early intervention programs, difficulties in matching all the linguistic, social, and academic needs of deaf children and their families due to the heterogeneous nature of such families, the high cost for programs that would incorporate a variety of competencies such as counseling, child development, linguistics, speech and hearing (Andrews et al., 2004; Calderon & Greenberg, 1997, Marschark, 1993, 1997; Moores, 2001a). Despite the variety of programs existing in the United States parents sometimes experience difficulty in acquiring quality services. For example, Steinberg et al. (2003) explored the impact of language, culture, minority status, and access to information and services on the decision-making process of Hispanic families with a deaf child. Hispanic parents reported that they often experienced complications due to language and cultural barriers and limited access to information, resources, and a full range of options.

Documentary evidence describes the dramatic changes in services, education and technology for deaf and hard of hearing children in the past 30 years in the United States (Meadow-Orlans et al., 2003; Sass-Lehrer, 2002; Sass-Lehrer & Bodner-Johnson,

2003). The fact that 70 percent of all newborns are being screened for hearing loss at birth was acknowledged as the “most important benefit for children with mild hearing loss who have often been overlooked in the past” (Meadow-Orlans et al., 2003, p. 178). Calderon (1998) enumerated the four most significant changes in early intervention services in North America that might also be true for most Western countries: (1) earlier identification of hearing loss leading to earlier commencement and, thus, longer duration of intervention services, (2) more direct parent involvement and support to and among parents, (3) increased prevalence of teaching the parent and child manual communication as a key method of communication, and (4) use of devices such as digital hearing aids and cochlear implants with increasingly younger children. Marschark (2007) stated that “although not everyone had access to family-centered programs yet, a family-oriented perspective helps to optimize opportunities and outcomes as new early intervention programs are established as the result of universal newborn screening” (p. 40).

Although the majority of programs provide opportunity for families to learn about the implications of hearing loss and other developmental issues, how to communicate with their deaf or hard of hearing babies and find social and emotional support, a persistent question for practitioners is how to best connect with families and eliminate difficulties for them in finding service providers (Arehart et al., 1998; Meadow-Orlans, 2000). Some families are frustrated by some professionals’ lack of knowledge about hearing loss, the difficulty in finding services that address their child’s specific developmental needs, or the difficulty in obtaining comprehensive and unbiased information (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Sass-Lehrer, 2003). One of the reasons might be that programs and services for infants and toddlers with hearing losses and their families are strained by the increase in the number of newborns identified with hearing loss (Sass-Lehrer, 2003). As a result, many children might be left behind lacking follow-up or experiencing limited access to quality early intervention (Culpepper, 2003).

Researchers exploring the effectiveness of services provided to families directly relate the successes in the creation and delivery of early intervention and primary educational services to the ongoing research on the ecology of the child and the child’s family (Meadow-Orlans et al, 1997, 2003). This finding is very relevant for Ukraine where at present the situation with early identification, early intervention, and preschool education is claimed to be unsatisfactory by many authors (Baikina & Cret, 2005;

Fedoruk, 2001; Hroza, 2001, 2006; Malynovych, 2003; Parkhomenko, 2001; Zhuk, 2006; Zasenko, 2001).

Family and professionals. From the moment of diagnosis parents are faced with a number of stresses and challenges such as coping with a perspective of “losing a perfect child”, frequent visits to speech therapists, choosing amplification and/or assistive listening devices, controversies about communication modes, and decisions about educational placements (Quittner, 1991; Lederberg & Golbach, 2004). Even parenting is no longer a private affair but is shared with many professionals, audiologists, psychologists, doctors, and teachers.

In the past, the relationship between parents and professionals in North America was typically characterized as paternalistic (Schirmer, 2001). During the last two decades the situation has changed: collaborative and family centered early education has amended the previous “professional-as-expert model” of professionals taking responsibility for the educational needs of the child and parents having only to follow the professional advice. At present early intervention professionals can significantly enhance the family ability to boost their child’s development by providing support through establishing effective relationships with families (Kelly & Barnard, 1999; Kurtzer-White & Luterman, 2001; Hintermair, 2006). With the help of professionals, families should understand the powerful influence they have over their child's development and be provided with support that enables them to direct their energy and resources toward participation in early intervention activities and the development of communication skills needed to foster effective communication in their families. However, while providing services and support and helping families in coping and in decision making, professionals still sometimes claim to know more than parents about their child; do not provide all the information about available choices and opportunities; and may usurp parental responsibility for decision making. The direct recommendations of a professional in some cases might become the most decisive factor for parents. Meadow-Orlans et al. (2003) reported that forty percent of parents in the NPP Project were not given a choice of early program for their child. The results of the Steinberg et al., (2003) study show that parents were often forced to follow the only option recommended by professionals when making a decision on the method of communication with their deaf and hard of hearing children which tended to be spoken English supported by signs. Alternative approaches such as bilingual/bicultural, which uses American Sign language (ASL) as the main form of communication; auditory/verbal, which emphasizes the optimization of residual hearing;

or cued speech, which claims to ease communication by visualizing phonemes, did not appear to be offered as options. However, it is not clear in the study whether the professionals guiding the parents presented only those options that were available in the geographical area or whether they simply lacked knowledge and information about alternative approaches. In addition the recommendations could have been ideologically biased as described by Meadow-Orlans & Sass-Lehrer (1995):

Those who work with children who are deaf and hard of hearing come from a field with long tradition of professional rather than parent-centered decision making. This tradition is reflected in parent meetings with topics selected by professionals who present information and provide limited opportunities for discussion or interaction. (p. 328)

This attitude may dramatically increase a sense of powerlessness in parents who might be experiencing grief after the diagnosis. Parents' inability to change their child's disability and the deaf child's lack of response to voice communication may undermine their normal parental power (Pollard and Rendon, 1999; Schlesinger, 1985). Providers of services have to trust parents' self-knowledge about the way they will be able to do the best parenting and language nurturing with their own child, provided that the parents are familiar with the options (Kurtzer-White & Luterman, 2001).

A growing challenge for specialized programs for deaf and hard of hearing infants is the need to continue to look at the development of the whole child because . . . (33). Some research has found that professionals in the area are unwilling to accept the possibility of additional disabilities being present in children who are deaf or hard of hearing. This often takes place due to "the historical resistance to a disabled identity. Professionals may fear the stigmatizing effects of assigning a child who is deaf or hard of hearing a disability label" (Jones & Jones, 2003, p.309). That is why families need accurate information and access to resources to support their ability to make informed decisions about important issues. As Luterman (1987) noted:

Many parents come through the experience of having a deaf child with a clearer sense of themselves than they had before their child was diagnosed as hearing impaired. Many parents find that their child's deafness gives their lives meaning and direction. Their joy stems from actively participating in their child's growth. They take nothing for granted. They can see what needs to be done and they can rejoice when a milestone is reached. They also know that they had a direct hand in reaching that milestone. (p. 116)

Summary

The intent of this literature review was to provide insight into the life, functioning and issues faced by hearing families with young deaf or hard of hearing children and into the issues and possible difficulties in the process of establishing relationships with professionals and accessing services and support. This literature was mostly based on North American and European experiences.

This review also included a discussion of some of the similarities that most families experienced in their response to the identification of a hearing loss such as, parental reactions to deafness, communication difficulties, new challenges and competencies required, parental relationships with professionals providing help and services. Special attention was paid in this review to a family-centered approach and to family characteristics important for establishing effective help and services for families. The most effective early intervention programs in North America and other developed countries embrace a family centered and developmental perspective and provide support to children and families through interdisciplinary and community-based collaboration, and endeavor to develop partnerships with parents, recognizing them as primary decision-makers. Besides the great advance in providing services and support some problems found in early intervention programs and in parents-professional relationships were also discussed briefly.

Because of a lack of similar literature in Ukraine another way was substituted in order to understand the Ukrainian context: deafness was analyzed as a part of the concept of disability predominant in special education in that country. This section reported findings specific to the history of deafness and disabilities, official policies, attitudes to deafness in the general society and available research in the field. Although, one can witness a growth in Ukrainian publications relating to deafness and education of the deaf recently, no empirical research studies in the area has been found as well as a very limited discourse on the theoretical framework and practices of parenting a deaf or hard of hearing child was found in the available publications.

Many Ukrainian discussions in deaf studies and the education of the deaf comment on the drawbacks of the special education system and support the need for change, especially referring to issues of language and communication. The discriminatory practice relating to the communication needs of people with hearing loss such as restrictions on the use of signed language emerged in Ukraine long ago and have remained present for decades. A call for change includes both (1) a review of the

dominant educational concept based on medical-audiological (i.e., “defectological”) perspective and a shift in perspective where the deaf or hard of hearing child is perceived as capable with special communication needs, and (2) the establishment of effective psychological services for parents and family-centered early intervention programs. A shift from the defectological approach could provide parents with a choice of communication mode to best fit their need. The introduction of a *family* voice may be of considerable benefit supporting a shift in a new perspective on hearing loss in Ukraine and organization of new family-focused services and intervention programs.

However, before these changes can happen, it is imperative to collect and analyze data on the characteristics of these families and develop insight into the circumstances of parenting deaf and hard of hearing children in the current society considering deafness as a disability. Presently, the “voice” of such families is completely absent in Ukrainian research. As a result, the intent of this study is to foster insight into the life, experiences, and functioning of hearing families and their young deaf or hard of hearing children. This insight should open the door to understandings in Ukraine of what it means to have a young child with a hearing loss. Such insight would be invaluable to all parents with deaf or hard of hearing children, special education systems (including kindergartens and preschool), and health care practitioners.

Chapter III. Methodology

Introduction

To address the questions of this study a mixed-methods design (Creswell, 2003, 2009; Gorard & Taylor, 2004) was used, combining both quantitative and qualitative methodologies. A mixed methods approach is one in which the researcher employs strategies of inquiry that involve collecting data either simultaneously or sequentially to better understand the research problems. The use of a combination of methods helps ensure credibility of the analysis and interpretation of the research (Babbie, 2002; Patton 2002; Creswell, 2003, 2009; Gorard & Taylor, 2004). Triangulating data sources was also seen as a means of seeking convergence of qualitative and quantitative methods (Gorard & Taylor, 2004; Babbie, 2002) in order to strengthen the reliability, validity, and trustworthiness of the study.

The first phase of the study consisted of a survey of parents of deaf and hard of hearing children involved in grade zero/one of special boarding schools for the deaf and hard of hearing children across Ukraine using a self-administered questionnaire. In the second phase the researcher followed up with interviews with families to obtain their “specific language and voices about the topic” (Creswell, 2003, p.22) using semi-structured interviews. A mixed methods design was used as combining both quantitative and qualitative data was seen as the best way to describe and understand some factors in the population that has never before been researched in Ukraine.

The Survey

Participants

All hearing families with deaf and hard of hearing children enrolled in grade 0/grade1 of special residential schools for the deaf and hard of hearing children across Ukraine (58 schools in total) were the target population for this research. The reasons for focusing this study on families with children in this age group were: (1) parents were close enough in time to the infant and preschool years to provide accurate retrospective reports and also sufficiently removed to gain some perspective on early experiences, and (2) a fairly narrow age span increased the homogeneity of parental expectations for developmental progress.

Parents were not differentiated due to the level of hearing loss of their children (deaf and hard of hearing) for the following reasons: (a) all hearing parents of children who are deaf or hard of hearing raise their children in a similar environment, (b) although children with different hearing loss (deaf and hard of hearing) were supposedly sent to

different schools this study has confirmed that the population in any particular school comprises both categories of children, (c) it was impossible to verify the hearing status of every child prior to the study, and (d) the difference between schools for the deaf and for the hard of hearing is minor and relates only to some curriculum differences.

Instrumentation

The questionnaire for this study was focused on the factors that might influence the level of parental stress; identifying the history of the hearing loss of the child; identifying communication modes in the families and the acquisition of language by young deaf children; picturing the relationships with professionals, and exploring deafness awareness of parents and their vision of the future development of their deaf or hard of hearing child.

The survey questionnaire was based on the National Parental Project Survey Questionnaire (Meadow-Orlans et al., 2003) which was specifically designed for families with deaf children and contained seven sections: (1) background information on hearing loss, age of identification, additional conditions, hearing aids, and cochlear implants, (2) services received and level of satisfaction with services: four items based on an instrument developed by Project Dakota (Cebe, 1996; Kovach & Jacks, 1989), (3) sources of help and degree of helpfulness: 14 items based on the Family Support Scale (Dunst, Jenkins, & Trivette, 1984), (4) child's behavioral characteristics: 10 items from the Meadow-Kendall Social Emotional Assessment Inventory for Deaf and Hard of Hearing Children, Preschool Form (Meadow-Orlans, 1983), (5) child's language/communication level: 14 items adapted from the SKI*HI Language Development Scale and from the MacArthur Communication Inventory (Fenson, Dale, Reznick, Bates, Thal, Hartung, & Reilly, 1999; Fenson et al., 1991), (6) parent's response to the identification of hearing loss, nine items from the Impact of Deafness Scale (Meadow-Orlans, 1990), and (7) family background characteristics.

There are several reasons for using the above-mentioned questionnaires for this study. One is that they allow for some comparison of the parental situation in Ukraine and in the West and, therefore, provide a basis for international academic discourse. A second reason is that established research instruments will be less easily dismissed as this pioneering research enters the scholarly discourse in Ukraine. The third reason is that it provides a model of international research standards in deaf studies for Ukraine.

For the purpose of this study this survey questionnaire was modified to fit the Ukrainian context (see Appendix B for the survey questionnaire). A few items which

were specific to the North American context were removed or changed and some questions were added to better capture Ukrainian reality (see Appendix B-1 for changes and modifications of the questionnaire). However, generally speaking, the questionnaire for this study preserved the same structure and the language, wording and terminology used in the original questionnaire as it did not require major transformations or adaptations.

The Interviews

The objective of the interview part of the study was to explore the feelings and perceptions of parents who are raising a young deaf or hard of hearing child in Ukraine and to understand more deeply the relationships between some variables that might arise from the analysis of the survey.

Participant Recruitment

A combination of purposeful homogeneous (surveys) and volunteer (interviews) sampling strategies was utilized in this study. Mertens (1998) while discussing Patton's (1990) definition of purposeful sampling provided as an example a sample of "parents of deaf children aged 6 through 7 who represent a group of parents who have had similar experiences with preschool services for deaf children" (p. 262). Kumar (2005) identified the primary consideration in a purposeful sampling as "the judgment of the researcher as to who can provide the best information to achieve the objectives of the study" (p. 179). Maximum variation purposeful sampling involves selecting cases that illustrate the range of variation in the phenomena to be studied (Patton 2002; Creswell, 2003). That is why there was made an attempt to include as many families as possible.

After preliminary analysis of the collected data from the survey all parents were divided into two major groups: (a) those that appeared to be satisfied with the relationships and communication they have achieved with their deaf child in their family, and (b) those who reported dissatisfaction with the relationships and communication. Up to 10 representatives were chosen from among each group of parents who expressed their willingness to participate in the follow-up interview. For the Ukrainian situation it was also very important to take into consideration the following: (a) presence of siblings and other family members besides a deaf or hard of hearing child and parents, (b) age of parents, (c) place of residence (urban/rural), and (d) the education level of the parents. Based on these criteria the sample of 20 was selected from the list of those parents who participated in the survey and agreed to take part in the follow-up interview. However,

due to the delay with responses to the survey and financial reasons only 17 families were interviewed.

Instrumentation

The use of a semi-structured open-ended interview was based on the interview protocol by Steinberg et al. (2003) who examined a sample of Hispanic families living in the United States and having a child with a hearing loss (both deaf and hard of hearing).

As Steinberg et al. (2003) stated the way the interview had been designed and conducted “provided for the collection of rich information that made analyzing the subjects’ experiences as well as their insights, cultural beliefs, and language possible” (Steinberg et al., p. 293). The authors stated that the interview had been developed in consultation with Meadow-Orlans who conducted the NPP Project Survey (Meadow-Orlans et al., 2003). The interview design allowed subjects to discuss issues of importance to them with guidance from the interviewer.

The original interview was restructured and adapted to fit the Ukrainian context. Several sections and questions which were irrelevant to this study or did not apply to the Ukrainian context were eliminated. On the other hand additional questions to gather information pertinent to the research questions of this study as well as specific items which reflected Ukrainian reality were added. The major modifications are described in the table in Appendix C-1.

The interview for this study consists of eleven sections, namely: (1) background information about the child, (2) prediagnosis (parental thoughts and feelings when they suspected problems with their child), (3) diagnosis (emotions and feelings of parents during the process of the diagnosis), (4) deafness awareness (the kind of information parents received at the diagnosis), (5) initial guidance at diagnosis (parental thoughts about advice they received at the diagnosis if any), (6) process after the diagnosis (parental thoughts on the things that were important in helping them to make decisions), (7) information on hearing aids, (8) postdiagnosis placements for the child (parental reflections on the educational and communication choices available to the family), (9) communication (parental attitudes to different communication modes and signed language and available choices), and (10) parental feelings (feelings and emotions experienced by parents from the period of suspicion of deafness to the time of the interview and highlighting major events and factors perceived as challenges while parenting a deaf or hard of hearing child), and (11) parental perspectives regarding the future in relation to communication and academic achievements. Appendix C contains the

interview questions. Some explanation of items that might not be readily known by all participants was provided. The reason for including questions concerning issues which might not be well known to Ukrainian parents such as cued speech, cochlear implants, auditory-verbal and auditory-oral was to identify potential gaps in the existing knowledge of parents and the services provided.

The interview allowed the researcher to elaborate on the information received in the first stage which was more focused on family characteristics and communication issues. The second phase of the study was focused more on parental reflections on their feelings and emotions since the time of diagnosis and how they considered their family communication.

Translation Procedures

Both the survey questionnaire and interview forms were adapted to the Ukrainian context and translated from English to Ukrainian. Professional translators, with formal university training in translation/interpretation, were employed. The accuracy and quality of the translation was then reviewed by two external specialists, fluent in English and Ukrainian, and familiar with research methodology.

Field Testing

Pilot investigations were conducted to ensure the clarity and relevance of the questionnaire items. A pilot version of the questionnaire and the interview was presented to a group of parents whose deaf or hard of hearing children were enrolled in the preschool program in L'viv and to several teachers who were teaching in elementary grades at Lviv Maria Pokrova School for Deaf Children. The participants in the field testing were asked to respond to an initial draft of the questionnaire. In addition, the initial draft was sent to two faculty members in the Department of Special Pedagogy in the Lviv Pedagogical College and to the one staff of Aurora Hearing Rehabilitation Centre. The participants were asked to provide feedback on the questionnaire. After feedback was received, some minor changes were made.

Data Collection Procedures

Survey

Survey packages were distributed to parents of the sample with the help of schools according to a jointly established procedure (see a detailed description in *Findings*). They were collected in three to four weeks depending on the timing of the next visit of the parents to the school. Those parents who lived in rural areas usually brought their young children to school on Monday and took them back home for the weekend.

However, some parents came only once every two weeks or even more infrequently. This resulted in a delay with the receiving the surveys back from the schools. The principals of the schools were asked to distribute the surveys and they agreed to send the packages back to the researcher after collecting them.

Interviews

Interviews were conducted with 16 hearing parents and one set of parents identifying themselves as a deaf family. All participants volunteered for the follow-up interview after participating in the survey. All interviews were conducted in a quiet room in the schools where the children of the participating families were enrolled. The interviews lasted no longer than 90 minutes. At the beginning of each session, a description of the study, its purpose, and its methodology was provided by the researcher, and parents were given an opportunity to ask questions. A professional Ukrainian Sign Language interpreter was helping the researcher during the interview with a deaf family. All participants signed a consent form. Other ethical considerations were dealt with as described in the ethical considerations section below.

The interviewer/researcher documented responses using audio recording. The digital recordings from the voice recorder were uploaded to the researcher's computer. These digital files were the basis for creating written transcripts of each session. The researcher created and saved the text document for each session using a recursive process of playing, pausing, transcribing, and rewinding the recordings to transcribe the discussions verbatim. The transcripts were sent to participants and they were asked to verify the accuracy of the text.

Data Analysis

Information gathered through the parent survey was analyzed for descriptive statistics to discover characteristics of the sample, the importance of which had been established in the literature review and research questions. In addition demographic information was analyzed to demonstrate the diversity of families participating in the study. The SPSS statistical package was utilized for this.

A methodology suggested by Auerbach (2003), Miles and Hagerman (1994), and Merriam (1998) was used to analyze the interviews. Using the NVIVO software a coding schema was created for the initial analysis of the interview data. A template analysis (Cassell & Symon, 2004), which involved inductive coding of the transcripts (both responses and comments) was used to establish categories and themes of potential influence on parental stress, communication, decision making and any other themes that

emerged from the data. The categories reflect the purpose of the research and the best effort of the researcher was made to ensure that they were exhaustive, mutually exclusive, sensitizing and conceptually congruent (Merriam, 1998). During this process, reflective journaling was used by the researcher to bracket personal assumptions and examine their influence on the categorization and interpretation of data.

Delimitations and Limitations of the Study

One of the delimitations that make this research distinct from other research in the area of parenting experiences of hearing parents and their deaf or hard of hearing young children is its narrow age range of children.

Another premise was that when considering the needs of young deaf children of deaf parents, their needs in the context of social and emotional, physical, cognitive and linguistic development are naturally met in the family where a hearing loss or deafness are not perceived as a disability. That is why this study was mostly focused on hearing parents of deaf and hard of hearing children; however, the participation of deaf families in the survey and one deaf family in the interview enriched the received knowledge significantly.

Two major problems that the interviewer faced in data collection constituted the main limitation for this study: (a) it was clear from the literature review that there had not been any evidence of research involving parents in the system of special education on the national level in Ukraine, and (b) in Ukraine there was no practice of collecting any survey information from the population by mail or in any other way, and in particular there had been no history of obtaining survey information from the school system either (O. Myakushko, personal communication, March 1, 2006). It was highly likely that the lack of experience in completing surveys might have made it difficult for parents to complete the survey questionnaires as designed by the researcher. It is also likely they were suspicious of this survey which they might have looked on as a private initiative that was not “sanctioned” by a higher authority. On the other hand, parents have had a traditional respect and trust in the school system and will participate in activities (i.e. research) if endorsed by the school principal. For this reason a letter of support from the Institute of Special Pedagogy, which has a national mandate for conducting research, was sent to each principal to acquire such endorsement.

In relation to the second problem, a major change of the data collection procedure was made by involving schools in the process of dissemination of the survey to parents and the collection of completed surveyed in sealed envelopes instead of direct

contact between the researcher and parents. All envelopes were mailed to the researcher by the principals of the schools.

Lastly, a potential for sampling bias may have occurred when recruiting participants for the interviews. Although all parents participated in the survey were invited to participate, it is possible that only the most motivated and willing parents chose to do so. The perspectives of these parents may not represent the perspectives, needs, and preferences of parents who chose not to participate. Those parents who did choose to participate, however, may offer the unique perspectives of an important group of stakeholders in the future reforming and reconstructing of the existing system of deaf education and services for both deaf and hard of hearing children and their families.

Ethical Considerations

Due to the involvement of human participants and the gathering of potentially sensitive information, this research study received a formal review by the Research Ethics Board, Faculty of Education. Furthermore, formal opportunities to review and address ethical considerations were incorporated into the research processes to ensure adequate time and resources were available to address all ethical concerns throughout the research study.

In addition to standard ethical requirements of the University of Alberta the permission for this study and a support letter were obtained from the Institute of Special Pedagogy of the Academy of Pedagogical Sciences of Ukraine which possesses legal responsibility for conducting research in the system of education in Ukraine.

Informed Consent

To help foster a trust relationship with the participants, a multistage approach to ensure ongoing commitment to informed consent was utilized. All potential participants from the sample were provided with an information sheet describing the research study along with a description of the participant's role, and a signature sheet for the consent form with explanations of his rights for anonymity and confidentiality, and right to withdraw at any stage of the study (see Appendixes D and E). The consent form also contained the invitation to participate in the follow-up interview. As stated earlier the exact procedure of collection of survey packages was established in an agreement with the Institute of Special Education and principals of the schools.

During the second phase of the study prior to participating in each interview, the issue of informed consent was reviewed and the participant was requested to verbally state his or her willingness to participate in the activity. Finally, at the end of

each session, participants were again given the opportunity to verbally commit to continuing their involvement in the research study. Furthermore, participants were again informed of their freedom to withdraw. Specifically, participation in this research study was completely voluntary and participants could refuse to participate at any time during the study. Participants were free to refuse to answer any question. It was also explained to the participants that if the individual might become visibly upset or indicate emotional vulnerability, a list of resources where they were able to seek support would be made available.

Privacy and Confidentiality

Necessary steps were taken to protect the privacy of the participants. This means that personal information that was collected for the research study was carefully kept confidential. As well, participants were informed in detail how personal information would be protected in the publication and presentation of the research findings (e.g., no use of identifying information). To protect the confidentiality of the participants, identifying information has been protected as fully as possible: while transcribing audio files participant names were recoded and transcripts contain only nicknames. Finally, no other persons, such as transcribers or any other assistants were used in the research process.

Data Storage

Data and material used for this study is stored in a locked room, in a locked cabinet, and will be kept for a minimum of 5 years and all files will be destroyed after that. All computer files will remain on one computer, with a back up file stored on the University of Alberta server.

Researcher in this Study

Traditionally, the researcher is considered to be the primary instrument for data collection and analysis in qualitative studies. “Data are mediated through this human instrument, the researcher, rather than through some inanimate inventory, questionnaire, or computer” (Merriam, 1998, p.7). However, since this human instrument has weaknesses and biases that might affect the study in many different ways, qualitative researchers must constantly acknowledge their preconceptions, beliefs, and possible prejudices, confront them and be able to hold them outside of the study. This process of staying neutral about a phenomenon under investigation is referred to as bracketing (Patton, 2002; Gall et al., 2003).

Through many years of my teaching experience in the school for the deaf in Ukraine and several years of studies at the University of Alberta, I have discovered that I have my own biases in the field, especially regarding parental reactions and deaf children. These biases are rooted in my view that signed language, deaf role models, deaf peers and contacts with deaf parents can be important aspects in the socio-economic adjustment of deaf children and their hearing parents. I also realized that my conceptions could differ from others and moreover, that my own understandings should not be used as a yardstick upon which other perceptions are based. My goal was not to judge others as right or wrong, or to find the voices of those who agree with me but rather to search and explore their varying perspectives.

Thus while conducting this research and analyzing data I worked hard through memoing (journaling) and bracketing to neutralize my own views. I tried my best to avoid or at least monitor any potentially confounding effects of my subjectivity such as mentioned above. Patton (2002) argued that subjectivity is inevitable, but the most important thing is “to be aware of how one’s perspective affects fieldwork, to carefully document all procedures so that others can overview the methods for bias, and to be open in describing the limitations of the perspective presented” (p.482). During the study I attempted to put my biases aside and to conduct interviews and review the data with neutral perspective. One of the steps to achieve that was made through reviewing the data and setting it aside for a period of time, in order to create some distance between myself and the transcripts, only to return again and reanalyze it. The following steps were also made to neutralize my biases:

- Prior to starting the research I spent some time in order to recognize and make a list of my own preconceptions and views (listed above) which could have confounded this research and later I always monitored and often recorded a changing awareness of my preconceptions as the research progressed;
- Before conducting the study I checked the questions of both the survey and the interviews to recognize and avoid biased questions which could influence respondent’s answer;
- While conducting the interviews I used journaling to fix parental reactions during the interviews and my own thoughts, ideas and observations. Later, comparing those field notes along with memos written while analyzing transcripts with the list of my preconceptions and biases helped me to keep

a 'neutral' status and to avoid my personal feelings and attitudes to influence the analysis and avoid using language of judgment;

- My constant consultations with the members of the committee have also helped to keep aside my own preconceptions and biases.

Chapter IV. Survey Findings

This chapter provides a complete report of the survey of the study regarding the inner life of families as well as families' relationships to support services and education providers. It also explores parental stress and deafness awareness of parents, as well as the resources and help available and/or accessible to families. This is done within the context of describing the sample and the characteristics of the respondents and their families as well as the characteristics of the child who was deaf or hard of hearing (age, level of hearing loss, age of identification of hearing loss, possible other special needs or disabilities).

The Sample

Schools

The target population for this research was all hearing families with deaf and hard of hearing children enrolled in grade 0/grade 1 in the special residential (boarding) schools in Ukraine for children who have hearing loss. According to Bondar and Zasenکو (2005), at the time of data collection there were 58 such schools. However, discussions with Dr. S. Kulbida, of the Institute of Special Pedagogy (ISP) of the Academy of Pedagogical Sciences of Ukraine, and Dr. O. Savchenko, of the Aurora Hearing Rehabilitation Centre, revealed that five of these schools were ineligible for this study: four schools had no students currently enrolled in 0/1 grades and one school hosted only orphans without official guardians. There was no information available on the number of children in grades 0/1 who studied in the residential schools and the only way to discover the number was to contact every school principal.

Participation was requested from 53 schools. The researcher contacted the principals of most schools (31) during two national conferences in Pidkamin (September, 2007) and Kamyanyets-Podilsky (October, 2007). Every principal at those meetings received an explanatory letter from the researcher, a letter of support signed by Dr. V. Bondar, Director of the ISP, and packages for the parents. The remainder of the letters and packages (22) were mailed by registered mail to those principals who had not been personally contacted by the researcher. Prior to mailing the survey forms the number of children in grades 0 or 1 was obtained through telephone conversations with the schools.

Subjects

School principals from the 53 schools reported that there were 419 students whose families were eligible for participation in this study. Four hundred and nineteen

packages were sent to the schools. Five schools were unwilling or unable to participate: 2 packages were reported by the principals as never arrived, 2 schools did not respond by the deadline, and one school refused to participate. Twenty-eight schools for deaf children and 20 schools for hard of hearing children participated in the survey; 195 (60%) surveys were returned from 28 schools for deaf children and 130 surveys (40%) were received from 20 schools for hard of hearing children. In total, forty-eight schools (91% of those contacted and eligible) with 388 eligible students distributed survey packages to parents and returned 325 of them. The response rate calculated for the participating 48 schools is 83.8%. The response rate for the entire sample initially proposed for the study was 77.8%.

Representation of Country Regions in the Survey

In Ukraine 24 oblasts (provinces), Crimea Republic, and Kyiv (capital of Ukraine) are distinguished as separate geographical and administrative areas having their own local administrations. On average there are two schools in every oblast, one each for deaf and hard of hearing children. There are more than two schools in the cities of Kyiv and Dnipropetrovs'k.

According to the State Statistics Committee of Ukraine (DerzhStat, no date), Ukraine still uses a geographical division of the country inherited from the Soviet Union. This division is based on potential for industrial development with the country arbitrarily divided into 5 geographic areas: West (7 oblasts), North (4 oblasts), East (3 oblasts), South (4 oblasts and Crimea), and Centre (6 oblasts). Every oblast in Ukraine is represented in this study and school representation varies from almost 6 returned surveys in the West (the lowest) to the highest 7.8 surveys in the East. In order to preserve anonymity and confidentiality no information will be directly affiliated with any school or oblast. Instead, references will be made to geographical areas.

Table 2 shows the number of returned surveys by geographical areas.

Table 2
Number of Returned Surveys by Geographical Areas

Area	Number of oblasts	Number of schools	Returned surveys	%
Center	6	13	90	27.7
West	7	14	83	25.5
North	4	7	44	13.5
East	3	6	47	14.5
South	4+Crimea	8	61	18.8
Total	25	48	325	100.0

Characteristics of Participating Families

Bailey (2002) stated that the adult age classifications most commonly reported in all types of research fit into 4 basic groups: young (18-39 years of age), middle-aged (40-59), older (60-74), old (75 and older). For Ukraine the upper age of the middle-aged group was reduced to 54 years (the age of retirement for women in Ukraine). Table 3 shows the age ranges of the respondents.

Table 3
Age of Respondents

Adult age classification	Number of respondents	Percent of respondents
Young - 18-39 years	265	81.5
Middle-aged - 40-54years	42	12.9
Older - 55-74years	14	4.3
Old -75- years	0	
Age not provided	4	1.2
Totals	325	99.9

The vast majority of respondents were young, with the youngest being 20. About 13% were middle aged, and 4.3% were older, with the oldest being 68 years of age. Four survey forms did not provide the respondent's age. The mean age of mothers was 31.2 years ($n=310$; $SD=5.6$). Mothers' ages fell into two age groups: 283 were young and 47 were middle-aged. Fathers also fell into two age groups: 216 were young and 47 were middle-aged. The mean of the fathers' age is 34.4 years ($SD=5.9$).

Of the 325 respondents who completed the surveys, 249 were mothers (76.6%) who also considered themselves to be the primary caregiver for the child. Thirty-three (10.2%) surveys were completed by fathers. Mothers and fathers together completed an

additional 17 forms (5.2%). Grandmothers completed 21 (6.5%) forms and 5 survey forms were completed by other relatives or guardians. Overall, 96% of family members who completed the survey indicated that they were the primary caregiver for the child who was deaf or hard of hearing. Of 248 respondents who indicated their marital status 183 (73.8%) were married. According to the survey 221 children (69%; $n=320$) live with both parents; 56 children (17.5%) live with mothers only and 7 (2.2%) with fathers only; 17 children (5.3%) live with mother and stepfather; 18 children (5.6%) live with grandmothers; and 1 child lives with father and stepmother. One hundred and sixteen children (35.7%; $n=325$) have only one sibling and 147 children (45.3%) have no siblings at all. Of 324 surveys, which indicated place of residence, 173 surveys (53.2%) came from families who live in rural areas and 151 (46.5%) surveys from parents who live in urban areas.

Hearing Status in the Family

Among mothers, 28 (8.9%; $n=316$) were deaf and 10 (3.2%) hard of hearing. Among fathers, 26 (8.7%; $n=300$) were deaf and 9 (3.0%) were hard of hearing. Respondents identified 26 families (8%) as a “deaf family” meaning that both parents are deaf. Eight children (2.5%) have both parents who are hard of hearing; 4 children (1.2%) have one deaf and one hard of hearing parent and 2 children (0.6%) have one deaf parent and one hearing one. Information on hearing status of grandmothers ($n=208$) revealed that 11 (5.2%) are deaf; 4 (1.9%) are hard of hearing. Among grandfathers ($n=169$), 5 (3%) are deaf and 3 (1.8%) hard of hearing.

Educational and Occupational Status of Parents

The level of the mothers’ education was reported in 314 surveys and 283 surveys provided fathers’ level of education. Parent’s educational levels were as following: some vocational training beyond secondary (high) school was reported by 57 (18.2%) mothers and 104 (36.7%) of fathers. Seventeen (5.4%) mothers and 11 (3.9%) fathers have 3 years of university or college which corresponds to the Ukrainian standard of “uncompleted higher education”. Additionally, 37 (11.8%) mothers have a university degree, as do 29 (10.2%) fathers. Only 11 (3.5%) of mothers and 12 (4.2%) of fathers reported their educational level as uncompleted secondary (high) school. One hundred and ninety-two mothers (61.1%) and 127 fathers (44.9%) reported having secondary education.

One hundred and fifty-seven mothers (52.5%; $n=299$) were reported as unemployed. Among working mothers 76 (25.4%) are employed at jobs which don’t

require high qualifications (e.g., cleaners); 18 (6.0%) work in health care; 17 (5.7%) work in clerical or sales; 10 (3.1%) are self-employed; 9 (3.0%) are teachers; 8 (2.6 %) in professional or managerial; 4 (1.3%) in blue collar jobs.

One hundred and twenty-four survey forms (38.2%) do not report the father's occupation. Available information shows that 28 (13.9%) of the fathers are unemployed. One hundred and nineteen fathers (59.2%) work as laborers. Twenty fathers (9.6%) are in professional or managerial jobs; 14 (7%) are self-employed; 16 (8%) work in clerical or sales jobs; 5 (2.4%) fathers are in military service.

Family Monthly Income

The Ukrainian living-wage minimum (LWM) was used as a reference to divide the participants into groups below the poverty line, low monthly household income, and middle monthly household income. LWM for 2007 was set by the Ukrainian government at 602 UAH (Hryvnia) for children of 6-18 years of age and 532 UAH for adults (Shid-Zakhid, 2008), while the poverty line in Ukraine at the time of data collection was set by the government at 506 UAH per person irrespective of age (Zakonodavstvo, n.d.). So, for this study family income was grouped into five categories: (1) 505 UAH and below, (2) 506-1012 UAH, (3) 1013-2024 UAH, (4) 2025-3036, and (5) (3037 and up). Categories 1 and 2 contain families living below the official poverty line. Category 3 represents the low household income group. Categories 4 and 5 represent middle household income groups.

In this study the majority of families reported (see Table 4) their monthly income as below the poverty line. About a third of the families fall within the low income group (1013 and 2024 UAH). Only 18 families (8.1%) earn between 2013 and 3036 UAH monthly and only one family earns more than 3037 UAH a month (.5%).

Table 4

Family Monthly Income

Income group	<i>N</i>	%
505 and less (below poverty line)	36	16.2
506-1012 (below poverty line)	92	41.4
1013-2024 (low income)	75	33.8
2025-3036 (middle household income)	18	8.1
3037 and up (high household income)	1	.5
Total	222	100.0
Missing	103	
Total	325	

Family's Primary Language

According to the Ukrainian Census 2001 (DerzhStat, n.d.) most of Ukraine is inhabited by Ukrainians and 77.8% of them speak Ukrainian. Russians constitute the next largest minority group at 17.3%. All other minority group nationalities in Ukraine, such as Belarusians, Moldovans, Crimean Tatars, Bulgarians, and others constitute 4.9% of the population. In this study the proportion of families speaking the Ukrainian language at home was less than reported in the Census: 185 families (58.2%; $n=318$). Russian is spoken in 88 families (27.7%); Ukrainian Sign Language is used as a primary language in 38 families (11.9%), and 7 families (2.2%) use another language at home.

Child Characteristics

Age of the Children and School Enrolment Delays

The child's average age was 91 months ($SD=11.9$). The youngest age was 60 months ($n=3$; 0.9%) and the oldest 124 months ($n=1$).

According to the Ukrainian Law on Preschool Education (2001) all preschool children are divided into several age categories. Children of 60-72 months of age belong to the elder age group of the preschool education. Children of 73-84 months of age are considered to be a transitional age group and can be enrolled either in the kindergarten or grade 0 in the elementary school. In this study grades 0 or 1 was combined. So, we can deduce that children 85-96 months of age would be enrolled in grade 1. For the purpose of this study grade 1 children, older than 97 months were deemed to be entering school late. To get a better picture of children's ages 6 age groups each representing a one year interval were used: Group 1 - 60-72 months, Group 2 - 73-84 months, Group 3 - 85-96 months, Group 4 - 97-108 months, Group 5 - 109-120 months, and Group 6 - 121-132 months. Age groups 1, 2, and 3 and enrolled in grades 0/1 show no delay in the child's enrolment in the school program while groups 4, 5, and 6 show 1, 2, and 3 years delay in being in grades 0/1 respectively.

Table 5 on the age distribution of children shows that the majority of children have no delays in school enrolment. Two hundred and thirty children fit into age groups 1, 2, and 3: 18 children (5.5%) in group 1; 79 (24.3%) in group 2; 133 (40.9%) in group 3). Ninety-five children are considered to be enrolled in school programs with the following delays: 72 in group 4 (22.2%) with 1 year; 22 in group 5 (6.8%) with 2 years; and 1 in group 6 with a 3 year delay.

Table 5
Delay in School Enrolment of All Children by Age Groups

#	Month Range	<i>n</i>	%	Delay in (years)
1	60-72	18	5.5	0
2	73-84	79	24.3	0
3	85-96	133	40.9	0
4	97-108	72	22.2	1
5	109-120	22	6.8	2
6	121-132	1	.3	3
	Total	325	100.0	

Hearing Status of the Children, Gender and Type of the School

One hundred and fifty-five (48.4%; $n=320$) children were reported as deaf; 110 children (34.4%) were reported as hard of hearing. Parents of the remaining 55 children (17.2%) stated that they didn't know which of these two categories applied to their child; 5 surveys returned this question unanswered. Thirty-five children with unidentified hearing status (58.3%; $n=60$) live in rural areas and the same number study in schools for deaf children. Only 90 respondents (28%) reported hearing loss of their children in decibels. Other respondents either did not provide this information or checked the "don't know" box.

Of 325 children, 175 were boys (53.8%) and 150 were girls (46.2%). Of the deaf children, 88 (56%) were boys and 67 (43%) were girls. One hundred and two (65.8%) deaf children were enrolled in schools for deaf children, and 53 children (34.2%) were enrolled in schools for hard of hearing children. Eighty-four deaf children live in rural areas and 71 children live in urban. Forty-eight deaf children were enrolled in school with delays of 1 to 3 years.

Of the hard of hearing children 55 were boys and 55 were girls. Half of these children live in urban areas. Fifty eight (52.7%) hard of hearing children were enrolled in schools for deaf children, and 52 (47%) children were enrolled in schools for hard of hearing children.

Identification of Hearing Loss

The average age when hearing loss was suspected was reported as close to 17 months. The average age when hearing loss was confirmed was reported as 24 months. (an elapsed time of 7 months between suspicion and confirmation). However, 77 parents (23.7%) reported no time gap between suspicion and confirmation; 16 (4.9%) reported

confirmation less than 1 month after the initial suspicion; 112 (34.5%) waited 6 months; 59 parents (18.2%) reported it took up to 12 months; 11 parents (3.4%) waited for confirmation up to 3 years; and for 5 parents (1.5%) it took between 37 and 48 months for their suspicions to be confirmed by a hearing test.

The degree of hearing loss seemed to influence the confirmation age. Children who were deaf were suspected to have hearing problems on average at age 15 months ($n=155$; $SD=11$) and had a confirmed identification on average at age 22 months. The elapsed time between suspicions and confirmations was 7 months. The first suspicion of a problem for those who were identified as hard of hearing appeared, on average, when they were almost 20 months ($n=110$; $SD=16$) of age and their hearing loss was confirmed at 27 months. Thus, children who are deaf received confirmation of hearing loss at a younger age than did hard of hearing children.

Hearing Aids

Two hundred and ninety-seven children (91.4%) were reported to have hearing aids. Twenty-eight children did not have hearing aids, 9 children who were hard of hearing (8.2%; $n=110$) and 19 deaf children (12.3%; $n=155$). On average children received hearing aids at 41 months ($SD=23.5$; $Mdn=38$).

The average time required for a child to receive a hearing aid was almost 17 months after their hearing loss was identified. Hard of hearing children received their hearing aids at 39 months ($Mdn=36$). Deaf children received hearing aids on average at 43 months ($Mdn=40.5$). The delay between identification and fitting hearing aids was 12 months for hard of hearing children and 21 months for children who were deaf.

Only 7 children in rural and 2 children in urban areas received hearing aids by 12 months of age. Seventeen children (5.3%) were fitted with hearing aids by 18 months. Another 43 children (13.2%) from 19 to 24 months (13.3% in rural and 13.2% in urban areas); 73 children (22.5%) from 25 to 36 months; 60 children (18.5%) from 37 to 48 months of age. There is no significant discrepancy between the numbers of children fitted with hearing aids between urban and rural settings.

Cochlear Implant Perspectives

Fifty five families (16.9%) reported considering cochlear implant surgery. From this group of families 15 children (4.6%) were examined for surgery, 2 children had already received their implants (.6%) at 42 and 60 months of age, and one family was awaiting surgery.

Additional Conditions

Twenty seven respondents (8.3%) did not report knowing whether their children had any additional medical conditions and 180 children (60.4%; $n=298$) were described without any additional medical conditions. Seventy one children (23.8%) had one condition, 22 children (7.4%) had two conditions, and 25 children (8.4%) had 3 or more conditions in addition to hearing loss. Visual impairment was mentioned most often (38 cases, 12.8%). Bad (poor) health was mentioned in 35 cases (11.7%). Twenty-four children (8.1%) were labeled with developmental delay; 19 children (6.4%) were reported to have behavior problems and 15 children (5%) were reported to be dealing with attention deficit disorder.

Relationships with Specialists and Educational Programs/Services Providers *Program Participation Prior to School*

Parents were asked to locate, describe, and evaluate programs in which their children participated prior to going to school. The survey asked about any program which involved an organized group with a formal curriculum in which their child was enrolled the longest. Of 313 reported cases, 124 children (39.6%) did not attend any organized program in special kindergartens for children who have hearing loss or any other preschool groups; 181 children (57.8%) were enrolled in one kindergarten program; 8 children (2.6%) were enrolled in 2 programs. Information on 12 children (3.7%; $n=325$) was missing. Table 6 presents enrolment of children in preschool programs.

Table 6
*Enrolment of All Students, Deaf Students, and Hard of Hearing Students in Organized
 Preschool Programs*

Number of preschool programs	All children		Deaf children		Hard of hearing children		Children with unknown hearing loss	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No program	124	39.6	62	41	39	37.5	23	39.7
1 prg.	181	57.8	86	57	62	59.6	33	56.9
2 prgs.	8	2.6	3	2	3	2.9	2	3.4
Total	313	100.0	151	100.0	104	100.0	58	100.0
Don't know	1				1			
Missing	11		4		5		2	
Total	12		4		6		2	
Total	325		155		110		60	

Of 151 deaf children reported in this item, 57% had been enrolled in one preschool program, 47% had been enrolled in no such program, and 3 children had been enrolled in two programs. Of 104 reported hard of hearing children, 59.6% were enrolled in one program; 37.5% had not been enrolled in any such program, and 3 children had been enrolled in two programs. Of the 60 children whose hearing status is unknown, 56.9% had been enrolled in one program; 39.7% had not been not enrolled in any such program, and 2 children had been enrolled in two programs.

Only 14.7% of respondents reported that they had a program choice for their child. Most of those families (58.7%) lived in urban areas. Respondents who lived in rural areas in the East reported no choices at all. Of those who had a choice, 23 selected the program because of the oral approach in the program, while 10 chose the program because of location. 13 gave no response to the question about preference.

Table 7 shows that on average children ($n=180$) entered a program at a mean age of 40.9 months ($Mdn=36$; $SD=13.7$) and finished at a mean age of 74.9 months ($Mdn=72$; $SD=12.4$). On average, mean lag time between all children who entered a program after their diagnosis was 17 months.

Table 7
Age of Children when the Program Started and Ended

	At what child's age program					
	started (All)	ended (All)	started (HH)	ended (HH)	started (Deaf)	ended (Deaf)
<i>N</i>	180	180	64	64	83	83
Mean	40.97	74.93	40.80	76.06	40.99	75.41
Median	36.00	72.00	36.00	72.00	36.00	72.00
Std. Deviation	13.692	12.396	12.723	11.922	13.904	12.496
Minimum	13	32	13	32	18	48
Maximum	13	113	60	113	60	84

Mode of Communication in the Pre-School Program

Of the 325 families 182 (56%) responded to the question about the communication mode used in the preschool programs (see Table 8). Seventeen percent of respondents reported that only speech was used in the pre-school programs attended by their deaf or hard of hearing children. Respondents reported 79.7% as having used speech and some signing, and only 3.3% of pre-schools were reported as having used signing alone. Ten respondents (3.1%; $n=325$) didn't know what communication mode was used in the program their child attended. Only 3.1% of respondents responded positively to the question of whether there was any deaf staff in the program.

Table 8
What Communication Mode was Used in the Programs

Program communication mode	<i>N</i>	%	Valid %	Deaf	Hard of hearing	Children with unknown hearing loss
Speech only	31	9.5	17	11	14	6
Speech+sign	145	44.6	79.7	70	50	23
Sign alone	6	1.9	3.3	3	2	1
Total	182	56.0	100.0	84	68	30
No program	124	38.2		62	39	23
No response	9	2.8		5	2	2
Don't know	10	3.1		4	1	5
Total	325	100.0		155	110	60

Evaluation of Pre-School Programs by Respondents

Parents were asked to evaluate the pre-school programs, the progress the child made in language and communication, their own participation in the programs, as well as their relationship with the staff. Four items regarding (1) how staff responded to family concerns, (2) if the help was based on the child's needs, (3) if parents have a feeling of having been a member of the program team, and (4) understanding by the staff of the families limits were assigned scores 4 'always', 3 'often', 2 'sometimes', and 1 'never'. The fifth item on overall evaluation of the child's success in the program was also assigned scores in range from 4 to 1.

Table 9 shows that in general, 31 surveys (16.8%; $n=184$) responded negatively to the first question, 35 (18.8%; $n=186$) to the second, 56 (29.7%; $n=185$) to the third, and 54 (29.5%; $n=183$) to the fourth. Over one half of the respondents were never or only sometimes involved actively in the program (56.2%).

Table 9
Evaluation of Preschool Programs by Parents

Evaluations of Early										
Services Received by										
Parents	<i>n</i>	Mean	Always		Often		Sometimes		Never	
			<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
The staff responded to family concerns	184	2.19	69	(37.5%)	42	(22.8%)	42	(22.8%)	31	(16.8%)
Help was based on my child's individual needs	186	2.06	82	(44.1%)	46	(24.7%)	23	(12.4%)	35	(18.8%)
I was an active member of the team	185	2.67	35	(18.9%)	46	(24.9%)	49	(26.5%)	56	(29.7%)
Staff accepted the limit our family put on time we could devote to the program	183	2.22	89	(48.6%)	19	(10.4%)	21	(11.5%)	54	(29.5%)

Of 186 respondents, 11 (5.9%) evaluated their child's language progress in the program as 'excellent', 64 respondents (34.4%) evaluated as 'good', and 70 respondents (37.7%) evaluated as 'satisfactory). Forty-one respondents (22%) revealed disappointment at the language progress of their child.

Table 10 presents the factors which may have influenced the parental evaluation of the program: average mother's education, character of child's hearing loss (deaf or hard of hearing), age of the child when hearing loss was diagnosed, place of living of the

family (rural or urban), and other disability conditions. No significant correlation was found between the character of the child's hearing loss; the age of the child at the time of diagnosis; the urban-rural factor, and the parental evaluation.

The situation with mother's education turned out to be more complicated (See Table 10). On average, mother's education (postsecondary vs. no postsecondary) did not affect evaluation scores. However, analysis of the mother's education in more depth revealed that mothers with full higher education ($n=24$; $M=12.13$; $SD=3.59$) reported higher scores and mothers with primary education ($n=5$; $M=13.20$; $SD=4.32$) reported the highest levels of satisfaction with programs. Unexpectedly, the lowest level of evaluation of the programs with a mean of 9.50 ($SD=3.63$) was reported by mothers with uncompleted higher education ($n=10$).

Table 10

Mean of Sum of Program Evaluation Scores by Mother's level of Education; Age of Identification, Level of Child's hearing loss, Place of Residence

Category	<i>n</i>	Mean of sum of scores	<i>SD</i>
1. Mother's level of education			
postsecondary	63	11.44	3.963
no-postsecondary	126	11.71	4.038
elementary	5	13.20	4.324
higher uncompleted	10	9.50	3.629
full higher	24	12.13	3.591
2. Child's level of hearing loss			
hard of hearing	69	11.59	4.558
deaf	85	11.05	3.767
3. Age of identification			
early diagnosis (under 24 months)	104	11.48	3.985
late diagnosis (24months & up)	82	11.74	4.091
4. Place of living			
urban	86	11.37	3.792
rural	102	11.87	4.183
5. Additional conditions			
no conditions	11.00	113	3.775
additional conditions	12.53	66	4.174

Services Available and Accessible to the Family

All respondents but one answered the questions regarding access to information on deafness, legal rights of children who have hearing loss, child behavior and existing options for school placement. Of 325 participants, 48.6% reported that they received sufficient information about deafness and hearing loss after the diagnosis, 51.1% about existing choices of school placement for their child; 65.2% responded negatively to the question regarding them having had information on legal rights of their children, and 72.3% of the respondents stated that they had not received information on behavior and developmental milestones of the children.

Table 11
Services Available/received by Parents

Who received	Signed language		Parental group meetings		Individual counseling	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
No services/ instruction	276	84.9	250	76.9	230	70.8
Mother	34	10.5	57	17.5	68	20.9
Father	2	.6	3	.9	5	1.5
Both parents	11	3.4	11	3.4	17	5.2
Other family member	1	.3	4	1.2	4 1 (guardian)	1.2 .3
Total	324	99.7				
Missing	1	.3				
Total	325	100.0	325	100.0	325	100.0

Answering questions as to whether any instruction in signed language had been provided to any family member, 84.9% responded in the negative. Some kind of signed language instruction was available only for 14.8% of respondents (See Table 11). One hundred and thirty-nine respondents who represent 155 families with children whom they identified as *deaf* indicated that no family members had ever received any instruction in signed language (see Table 12).

Table 11 also shows which other services were available to parents besides signed language training. Two hundred and fifty respondents (76.9%) reported that they had no option of accessing informal parental group meetings; individual counseling was available to 29.2% of families (including visits to doctors). Of this latter percentage that

accessed individual counseling 20.9% were mothers, 1.5% fathers, 1 guardian and 5.2% were both parents.

Eighty-seven respondents ($n=321$; 26.6%) indicated having some more services or consultations besides those mentioned above: 32 respondents (9.8%) got some extra services or instruction in the kindergarten based on their personal agreements with individual staff and 28 (8.6%) at preschool. Fourteen parents (4.3%) received some extra other services in the local surdological centres in the oblast children's hospital; 7 parents (2.2%) got medical services connected with the medical conditions of their children but also connected with the hearing loss; 4 parents received extra consultations (besides initial hearing test) at the Institute of Otolaryngology in Kyiv and 1 in Aurora Hearing Rehabilitation Centre (Kyiv). One respondent reported receiving extra service at home. Information on 4 surveys is missing.

Table 12
Received Signed Language Instruction by Parents by Level of Hearing Loss of the Child

Signed language instruction received by:	Level of hearing loss of a child		
	Deaf	Hard of hearing	Hearing loss unknown
No instruction	131	97	48
Mother	16	10	8
Father	1	1	0
Both parents	6	2	3
Other member	1	0	0
Missing inform.			1

Respondents' Evaluation of Available Sources of Help

Thirteen potential sources of help for families of deaf and hard of hearing children were listed in the survey. Participants were asked to circle the degree to which each source was helpful, since the identification of the child's hearing loss. To estimate helpfulness, five levels were listed with numerical values: 'not at all helpful' (score 0); 'sometimes helpful' (score 1); 'generally helpful' (score 2); 'very helpful' (score 3); and 'extremely helpful' (score 4). Parents could also indicate that a specific source was 'not available' to them. Table 13 gives a full picture of respondents' responses to all 14 sources of help and support resources listed.

Table 13
What Sources of Help for Parents were Available

Sources of Help	Not at all helpful		Sometimes helpful		Generally helpful		Very helpful		Extremely helpful		NA		Missing
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Spouse (or partner)	73	22.5%	31	9.5%	45	13.8%	34	10.5%	111	34.2%	27	8.3%	4
My parents	66	20.3%	35	10.8%	58	17.8%	2	12.9%	99	30.5%	23	7.1%	2
My spouse's parents	128	39.4%	43	13.2%	39	12.0%	38	11.7%	44	13.5%	30	9.2%	3
My relatives	126	38.8%	57	17.5%	46	14.2%	28	8.6%	37	11.4%	30	9.2%	1
My spouse's relatives	182	56.0%	51	15.7%	24	7.7%	16	4.9%	19	5.8%	30	9.2%	3
My friends/spouse's friends	143	44.0%	64	19.7%	44	13.5%	18	5.5%	28	8.6%	26	8.0%	2
Grandparents	114	35.1%	27	8.3%	42	12.9%	33	10.2%	87	26.8%	20	6.2%	2
Parents of deaf children	139	42.8%	48	14.8%	92	28.3%	8	2.5%	14	4.3%	22	6.8%	2
Church (pastor, rabbi)	267	82.2%	18	5.5%	1	0.3%	2	0.6%	9	2.8%	24	7.4%	4
Doctor/pediatrician	159	48.3%	62	19.1%	36	11.1%	19	5.8%	23	7.1%	22	6.8%	4
Specialist	110	33.8%	41	12.6%	55	16.9%	28	8.6%	58	17.8%	30	9.2%	3
Deaf adults	247	76.0%	18	5.5%	7	2.2%	5	1.5%	10	3.1%	35	10.8%	3
Help from teachers/tutors	92	28.3%	17	5.2%	44	13.5%	46	14.2%	100	30.8%	24	7.4%	2
Other sources	239	73.5%	13	4.0	4	1.2%	1	0.3%	6	1.8%	60	18.5%	2

Table 14 shows the list of help resources together with the mean score, median, SD, and the number of participants to whom each source of help was available. Nineteen respondents (5.9%; $n=325$) reported that they had not received any help at all. This table shows that spouses (partners) received the highest score of any support source; 111 respondents (34.2%) revealed that spouses provided help characterized as 'extremely helpful'; an additional 34 respondents (10.5%) presented it as 'very helpful', and 45 respondents (13.8%) as 'generally helpful'.

Table 14
Sources of Help for Parents, Their Degree of Helpfulness, Mean Ratings of Helpfulness (Scale 0-4).

Sources of help for parents	<i>M</i>	<i>Mdn</i>	<i>SD</i>	<i>n</i>
Spouse (or partner)	2.27	2.0	1.63	294
My parents	2.24	2.0	1.55	300
Help from teachers/tutors	2.15	2.0	1.66	303
Grandparents	1.84	2.0	1.68	303
Specialist	1.60	1.0	1.54	292
My spouse's parents	1.41	1.0	1.51	292
My relatives	1.30	1.0	1.42	294
Parents of deaf children	1.29	1.0	1.33	301
My friends/spouse's friends	1.07	1.0	1.31	297
Doctor/ pediatrician	.95	.0	1.27	299
My spouse's relatives	.76	.0	1.20	292
Deaf adults	.30	.00	.88	287
Church (pastor, rabbi)	.21	.0	.76	297
Other sources	.18	.00	.69	263

What Kind of School the Child Attends Now

The following choices were provided for the parents in the survey concerning questions about school placements: (a) residential school for deaf or hard of hearing children 5 days a week and being taken home by parents on weekends and vacations, (b) daytime placement in the same residential school with nights spent at home, and (c) children studying with hearing children in special classes within a residential school.

Of 323 children, 73.7% attended residential school staying 5 days and living in dorms with government-provided accommodation, meals, and textbooks; 25.4% of children attend the same residential schools but go home every evening and 3 children study with hearing children in a special class within a special school. Of the children attending 5 day residential schools, 35.5% come from urban areas and 64.4 % come from rural areas.

Method of Communication at School

Three hundred and twenty-four respondents answered the question about the communication mode at their child's school. Table 15 shows 84.6% of respondents reported that the schools used speech with some signing; 11.7% did not know how their child communicated at school; 3.1 % were enrolled in speech only, and 1 in sign only classes.

Table 15
Method of Communication at School

Communication		
mode	<i>n</i>	%
Speech alone	10	3.1
Speech+sign	275	84.6
Sign alone	1	.3
Don't know	38	11.7
No response	1	.3
Total	325	100.0

Family Life and Child-Family Relationships

Child's Behaviour and Communication

Parents were also asked to characterize their child's behavior and communication in their neighborhood and in school by reacting to 15 behavioral/communication descriptions. For example, "My child expresses concern or sympathy for others in pain or distress" or "My child has warm attachments as well as good communication with other family members" (See Appendix B Section 4). For these parental evaluations the scores were in the range from 1 to 4, with 1 indicating strong agreement and 4 strong disagreement. Several questions were formulated in a negative form in order to increase reliability of answers. Then, the answers were recoded. The results could range from 15 (all responses 'strongly agree') to 60 (all responses 'strongly disagree'). The mean of the sum of raw scores of parental evaluation of child's behavior and communication in 302 surveys was 24.25 ($Mdn=24.50$; $SD=5.314$). The mean of all scores was 1.62 which is in the range of parental positive responses between 1 and 2 which correspond to "strongly agree" and "agree".

Child's Language

Parents were asked to assess their child's language achievement (see Appendix B, Section 5 for the complete text) using a modified short-form version of the MacArthur Communicative Development Inventories (Fenson, Petnick, Renda, & Cox, 2000; Meadow-Orlans, Mertens, & Sass Lehrer, 2003). Parent-report measures required no child cooperation and evaluated children's skills in the home environment, based on multiple observations over an extended period of time. Accordingly, they potentially permit a more comprehensive and representative appraisal of children's language skills than is usually possible from brief samples obtained in the clinic or laboratory (Fenson, Petnick, Renda, & Cox, 2000). These measures also approximate the curricula

expectations for the deaf and hard of hearing children enrolled in special kindergartens or grades (Ministry of Education, 2005).

Table 16 shows these items in abbreviated form. Respondents answered questions by checking the child's usage as 'not yet' 'rarely' 'often' and 'always' for spoken/signed items (assigned points 1 to 4) , and 'yes' or 'no' for items referring to reading or writing (points 0 to 1). This procedure yielded a language score ranging from 7 to 34 points, with a mean of 17.87 ($n=295$; $SD=6.3$). Hard of hearing children ($n=96$) received significantly higher language scores ($M=19.26$; $SD=6.65$; $Mdn=17.0$) than children who were deaf ($M=16.89$; $SD=6.01$; $Mdn=16$).

Table 16
Children's Performance on Individual Language Items: All Children, Deaf Children, and Hard of hearing Children.

Language items	All children		Deaf children (n=155)		Hard of hearing children (n=110)	
	n	%	n	%	n	%
Child understands simple sentences (n=321)						
'often'	77	23.7	36			
'always'	72	22.2	24			
Total	149	45.9%	60	39%	65	59%
Child uses simple sentences n=320						
'often'	67	20.6	30			
'always'	23	7.1	6			
Total	90	27.7%	36	23%	39	35%
Child talks/signs about future events (n=322)						
'often'	88	27.1	38			
'always'	30	9.2	10			
Total	118	36.3%	48	30.9	48	43.6%
Child most often uses to express his/her thoughts (n=323)						
short phrases	86	26.5	37			
more complete sentences	26	8.0	11			
Total	112	34.5%	48	30.9	50	45.4%
Child asks "Why" and "How" questions (n=321)						
'often'	80	24.6	34			
'always'	32	9.8	13			
Total	112	34.5%	47	30.3	44	40%
Child uses sentences that express more than one idea (n=323)						
'often'	47	14.5	17			
'always'	11	3.4	6			
Total	58	17.9%	23	14.8%	24	21.8%
Child asks complex questions n=323						
'often'	32	9.8	14			
'always'	15	4.6	5			
Total	45	14.4%	19	12.2%	20	18.0%
Child can read						
single words n=323	297	91.4%	142	91.6%	100	90.9%
sentences n=321	214	65.8%	96	61.9%	79	71.8%
simple text n=321	154	47.4%	73	47.1%	56	50.9%
Child can write						
letters of the alphabet n=324	298	91.7%	142	91.6%	102	70.0%
his/her name n=323	256	78.8%	122	78.7%	86	78.2%
words n=318	212	65.2%	102	65.8%	74	67.1%
sentences n=305	92	28.3%	43	27.7%	36	32.7%

In order to have an unambiguous picture of how parents assess their children's performance two answers 'often' and 'always' were united in one category representing a positive statement about language competence. Parents reported that 45.5% of children understand simple sentences (like "We go to the store. We are late for the bus). Among

these children, 39% are deaf and 59% are hard of hearing. However, 27.7% children can use them 'often' or 'always' (23% deaf and 35% hard of hearing); 36.3% of children are able to talk about future events like "We will go to the park on Sunday. I will swing there"; 34.5% of children are able to use phrases and complete sentences to express their thoughts; 17.9% of children can use sentences that express more than one idea like "We will go to the park when dad comes home"; 14.4% of children are able to ask complex questions (like "What happened to that toy?"); 47.4% of children can read simple texts (deaf 47.1%, hard of hearing 50.9%). 65.2% of children can write words. 27.75% of deaf children and 32.7% hard of hearing children are among 28.3% of the children who are able to write sentences.

Controlling for two variables (additional medical conditions and age of the child when diagnosed with the hearing loss) had a considerable impact on language scores. Children characterized by the respondents as having no additional medical or educational conditions had a mean of 19.29 ($Mdn=19$; $SD=5.97$). At the same time children who have one or more conditions had lower scores: mean=15.53 ($Mdn=15.0$; ($SD=6.2$).

The age of diagnosis also had an influence on the language scores. Children with early identified hearing loss scored higher in language performance ($M=18.03$; $Mdn=17$; $SD=5.8$) than did children whose hearing loss was identified later ($M=17.3$; $Mdn=16$; $SD=6.8$).

Communication at Home

The way in which parents usually communicated with the child at home was also surveyed. Table 17 shows that the largest proportion of respondents (223; 70.2 %) reported using speech and some signing to communicate with the child. Sixty eight percent of deaf children and 67.3% of hard of hearing children are raised in those families who use speech and some signing. Speech alone was used with 17.2% children. Among those children 13.9% were deaf; 23.6%, hard of hearing and 13.8% with unidentified hearing loss level. Two respondents reported that they used another mode of communication without specifying it.

Table 17
Method of Communication Used at Home

Communication		
used at home	<i>n</i>	%
Speech alone	55	17.2
Speech+sign	224	70.2
Sign alone	38	11.9
Other	2	.6
Total	319	100.0
No response	6	
Total	325	

Use of signed language in the family. In 38 (11.9%) cases families reported using signing alone. Those families were raising 23 deaf children (15.2%); 10 hard of hearing children (9.1%), and 5 children (8.6%) with unknown hearing loss level. Two hundred and fifteen families (67.6%) reported inventing their own signs to communicate with their deaf or hard of hearing child. Of this number 119 families (37.4%) confirmed current usage of their invented signs at the time of the study and 78 families (24.5%) admitted using those signs occasionally.

Two hundred and fifty eight mothers (81.9%) and 168 fathers (56.8%) reported using signs with their children at home. Respondents ($n=313$) evaluated the mother's signing skills in the following way: 43 (13.7%) as excellent; 42 (13.4%) good; 172 (55.0%) poor; and 56 (17.9%) 'no skills at all'. Fathers' signing skills ($n=296$) are evaluated as excellent in 35 cases (11.8%); good in 18 (5.5%) cases; poor in 117 (36.0%) cases and as 'no skills' in 126 (38.8%) surveys (see Table 18).

Table 18
Parental Signing Skills

Level of skills	Mothers' skills		Fathers' skills	
	<i>n</i>	%	<i>n</i>	%
Excellent	43	13.7	35	11.8
Good	42	13.4	18	6.1
Poor	172	55	117	39.5
No skills	56	17.9	126	42.6
Total	313	100.0	296	100.0
Missing	12		29	
Total	325		325	

In 38.2% of families other family members also used signing with the child. Most often sisters ($n=41$; 33.6%) and grandmothers ($n=41$; 33.6%) were named. There were also 23 signing brothers (18.9%), 6 grandfathers (4.9%), and 5 other members of the family. In 6 surveys both grandparents were mentioned as signing. The signing skills of other members of the family were evaluated as excellent in 8.8% of surveys; good in 14.1% of surveys, and poor in 15.0% cases ($n=319$).

Parental Reflections on Raising a Deaf Child

The respondents were asked to respond to 9 statements designed to examine the impact of the child's hearing loss or deafness on them and their families. The respondents reported agreement or disagreement on a five-point scale. These statements are shown in the Table 19.

Table 19

Parental Answers on the Impact of Diagnosis and Parental Feelings about Deafness/Hearing Loss of their Child

Impact of Diagnosis on Parents and Families (Frequencies, Scale 0-4)	Frequency	Percent
1. We have more family discussions about our deaf child than about other things		
don't know /probably not	29	8.9
strongly agree	53	16.3
agree	152	46.8
disagree	74	22.8
strongly disagree	17	5.2
2. I feel proud of what we have done and are doing for our child		
don't know /probably not	32	9.8
strongly agree	77	23.7
agree	115	35.5
disagree	82	25.2
strongly disagree	19	5.8
3. Much stress in our family is related to child's hearing loss		
don't know /probably not	47	14.5
strongly agree	19	5.8
agree	113	34.8
disagree	111	34.2
strongly disagree	35	10.8

Table 19 (continued)

Impact of Diagnosis on Parents and Families (Frequencies, Scale 0-4)	Frequency	Percent
4. My skills of communication are adequate for my child's needs		
don't know /probably not	60	18.5
strongly agree	35	10.8
agree	47	14.5
disagree	137	42.2
strongly disagree	46	14.2
5. Because of hearing loss I had to forget many dreams and hopes for my child		
don't know /probably not	40	12.3
strongly agree	62	19.1
agree	142	43.7
disagree	75	23.1
strongly disagree	6	1.8
6. In spite of extra time devoted to my child I still find time for myself		
don't know /probably not	54	16.6
strongly agree	20	6.2
agree	149	45.8
disagree	91	28.0
strongly disagree	11	3.4
7. My child is regularly included in family conversations because we have an effective communication system		
don't know /probably not	52	16.0
strongly agree	18	5.5
agree	90	27.7
disagree	142	43.7
strongly disagree	23	7.1
8. My life is very difficult because my child requires so much time and additional efforts		
don't know /probably not	26	8.0
strongly agree	34	10.5
agree	159	48.9
disagree	87	26.8
strongly disagree	19	5.8
9. I feel that there are many things I cannot seem to communicate to my child		
don't know /probably not	14	4.3
strongly agree	126	38.8
agree	126	38.8
disagree	50	15.4
strongly disagree	9	2.8

Lack of communication with the child turned to be the most frustrating issue for 77.6% of respondents. Only 25.3% of the respondents considered their skills of communication as adequate for their child's need. As the result of poor communication at

home only 33.2% of children were regularly involved in family conversations (See Table 20).

Looking at the nine statements of impact it appears that they were confirmed by respondents answering ‘agree’ or ‘strongly agree’ in the following descending order of impact common to the respondents:

Table 20

Impact of Deafness on Parents and Families

9. I feel that there are many things I cannot seem to communicate to my child %	77.6
5. Because of hearing loss I had to forget many dreams and hopes for my child %	62.8
1. We have more family discussions about our deaf child than about other things %	63.1
8. My life is very difficult because my child requires so much time and additional efforts %	59.4
6. In spite of extra time devoted to my child I still find time for myself %	52
2. I feel proud of what we have done and are doing for our child %	59.2
3. Much stress in our family is related to child's hearing loss %	40.6
7. My child is regularly included in family conversations because we have an effective communication system	33.2
4. My skills of communication are adequate for my child's needs %	25.3

In order to compare hearing families with families with deaf and/or hard of hearing members means of scores were calculated. Positive responses received a score of ‘3’ (agree) or ‘4’ (strongly agree). Score ‘0’ stands for ‘don’t know/probably not’; ‘1’ stands for ‘strongly disagree’; 2 stands for ‘disagree’. Items 3, 5, 8, and 9 were recoded as they had been compiled in a reverse mode (negative). In this context the higher scores reflect a more positive response to the diagnosis of their child. Maximum score could have been 36. Mean of all rating scores for all parents is 18.49 ($n=325$; $Mdn=19.0$; $SD=5.84$). In order to get an overall picture of parental feelings towards raising a deaf or hard of hearing child and compare families a combined mean was computed for all nine items ($M=2.05$; $Mdn=2.11$; $SD=.65$) (see Table 21).

Table 21
Parent's Feelings on Deafness: Mean of Ratings; Combined Mean of Ratings

	All families (N=325)	Families with D/HH members (n=26)	Hearing families (n=299)
<i>Mean</i> of all ratings	18.49	20.88	18.28
<i>Mdn</i> of all ratings	19.00	23.50	18.00
<i>SD</i>	5.84	8.315	5.54
Combined <i>M</i> (Sum of scores:9)	2.05	2.32	2.03
Combined <i>Mdn</i>	2.11	2.61	2.0
<i>SD</i> (for combined mean)	.65	.92	.61

Families with deaf or hard of hearing members show more positive attitudes to deafness and reveal less stress: mean of rating scores is 20.88 ($n=26$) vs. 18.28 ($n=299$) in hearing families, and combined mean is 2.32 vs. 2.03 in hearing families (maximum possible is 4).

Summary

The data presented in this section details demographic and sociological characteristics of the participating families and their deaf or hard of hearing children as well as those characteristics which have been identified in the international research as very important when exploring family functioning and early intervention programs.

The most striking finding about family characteristics is that according to the data presented most families in this sample can be identified as those living in poverty according to Ukrainian standards. Another finding is that, on average, the proportion of children who have other medical conditions is higher than the data presented in the international research.

The survey data shows that late diagnosis and long lag time between the identification of hearing loss and fitting of hearing aids was common for participants in this study. Even though most parents positively evaluated preschools programs their children were involved in, only 40.3% of them were completely satisfied with the language progress of their children.

Findings also revealed a lack of resources and support for parents regarding communication (signed language), a lack of information on deafness and educational placements for their deaf or hard of hearing children as well as information on behavior and developmental milestones for the children who are deaf or hard of hearing.

Survey findings also revealed that families with deaf and hard of hearing members show more positive attitudes to deafness than families consisting of hearing members. Almost 60% of respondents reported being proud of what the families had done and were doing for their deaf or hard of hearing children.

Chapter V. Interviews Findings

The interview transcripts were analyzed using qualitative methods described by Miles and Huberman (1994) and utilizing a combination of template analysis (Cassell & Symon, 2004) and constant comparative analysis (Benton, 1991; Morgan, 1993). Codes were developed and applied to the transcripts using a computer program NVIVO 7 which allows for easy compilation of all segments coded with a particular theme.

The starting point for constructing the initial map of themes was the interview topic guide used by the interviewer (see Appendix C for a list of sections/questions). All transcripts and notes were coded using these 11 topic areas as categories. The coding process was further expanded by reading each of the transcripts and attributing a code to sentences, paragraphs or sections. Data analysis was inductive as the study sought to promote the understanding of individual perceptions.

The number of codes was also predetermined by the number of questions of the interview. Some of them were dichotomized (e.g., parental evaluation of the *specialists' attitude* positive vs. negative). Having coded the first transcript, each subsequent reading of this and other transcripts was carried out in the same manner. In addition to using this top-down approach, bottom-up approach was used as well whereby new codes, categories and themes were generated from a line-by-line review of the data. In the course of the process of coding, inadequacies in the initial map were revealed and some new codes were assigned, others deleted, or merged. After all the transcripts had been coded the map of themes was updated. The map was considered ready for further work after coding had been scrutinized twice and it is used as the framework for reporting interview findings.

A synthesis of the themes is provided as an overview and summary of the meaning of the experience of parenting a young child who is deaf or hard of hearing.

Figure 1

Map of Themes

Identifying the problem

- Recognizing there is a problem: Suspicions and hesitations
- Deciding to get outside professional advice
- Reaction to the diagnosis

The journey of getting help and support

- Seeking for right resources: Confused and exhausted
- Parental opinions of professional attitudes
- Looking back: What parents expected
- Access to support and resources: Face to face with the trouble

- Decision making.

Experience of parenting and accommodating

- Living with a child
 - Comparing own children with others
- Family communication preferences
 - Communication in the preschool: Signed language in the underground
 - Parents about their child in the preschool
 - Communication realities: Home
- Living with others

Personal reflections and transformations

- Coping: Ups and downs
- Changes in life and major events
- Additional challenges
 - Financial issues
 - Separation from the child
- Looking to the future

Identifying the Problem: Suspicions and Hesitations

The first challenge parents had to face was the fact of their children's hearing loss or deafness. The main aspects of this challenge included struggling with suspicions that something was wrong with their child, obtaining and understanding the diagnosis, interpreting what this fact means in terms of their family life, their personal life and life of their deaf or hard-of-hearing child.

When the first suspicions of hearing problems arose, most families, with the exception of one deaf family interviewed, knew almost nothing about deafness, had not met any deaf people and knew nothing about life of the deaf community. Only three participants reported that they had had some contacts with deaf people living in their vicinity. But they knew nothing about their lifestyle or their mode of communication. One of two participants who tried to get information about the issues of hearing loss and deafness prior to the hearing test reported that the information she received seemed mostly negative. She changed her attitude as she got closer to deafness issues (Myra). Several respondents revealed that before their child was diagnosed with deafness they had thought that people who were born deaf and used "signing and mimicry for communication were probably not normal mentally" (Yara, p. 1). Katia from a small village commented:

We had not met any people with hearing loss prior [to the hearing test]. To tell you the truth...I had always thought that deaf people whom I could watch sometimes in the big city might probably be mentally not fully normal. I

thought at that time, 'How could a person be normal if she or he cannot speak? They can only use their hands to talk ... communicate to other deaf people. How can they study? Who can teach them?' (p. 2)

(...) in my mind hearing loss or deafness was equal to mental retardation...because I did not know anything about deafness...How can you study if you cannot hear? (Ihor, p. 3)

Lack of information and existing myths and beliefs in the society may have had implications for seeking their child's diagnosis.

Recognizing there is a Problem

All participants were asked to speak about their experience in coming to recognize that their child had some problem. The first thing parents were asked during the interview was to describe the first time they suspected something was wrong with their child's hearing. Although there were some similarities in the experience, each family had its own unique story.

All parents except for the deaf family revealed that when their child was born they never considered the child's hearing. None of respondents reported any worries concerning hearing of their children during delivery or after birth (including deaf parents). Several mothers wondered why anybody should worry about hearing problems if the child was born healthy:

No, it looked like everything was fine with hearing after birth...to tell you the truth nobody, including me, thought that there could be any problems... most concerns were if the child is o.k. physically... I mean normal body shape, no physical deficiencies... no brain injury, no problems with skin, normal breathing ... (Katia, p. 1)

I thought that there probably were no problems with hearing at birth... Nobody checked the hearing and there were no suspicions... we were not in a risk group that should suspect any medical conditions. Actually it did not even come to mind at that time... (Lida, p. 1)

Of the 17 participants 14 suspected that something was wrong with their children long before they were identified with hearing loss. In two cases medical doctors were the first to discover symptoms of hearing loss and in one case it was a grandmother who insisted that there was a hearing problem. Seven participants noticed that their child did not react to sounds:

With the birth of our daughter our family life changed so much! We were so happy... both my husband and I tried to do our best to make our child happy too. We devoted ourselves to her and were planning to have more kids. But

once we noticed that something was not going right... we noticed ... or it just seemed to me that our daughter was not reacting to sounds. We tried different things but almost always would fail to attract her attention with sounds or music. We first suspected problems when our girl was almost 12 months old. (Ania, p. 1)

When our child was approximately one year old we noticed that his reaction to sounds was not consistent...sometimes it looked o.k....but in many cases it seemed to us that our son didn't respond adequately ... I mean he would not respond in the way normally hearing children of his age did. (Nusia, p. 1)

For some parents suspicions and worries were triggered by something specific:

I remember when we first found it. My older son got a new toy and started playing with it. It was very noisy but there was no reaction from my daughter. My husband said, 'It is strange... I cannot believe... she is not responding'. Both my husband and I got scared. We tried different things like clapping, shouting etc. Everything was in vain. She never flinched. (Katia, p. 1)

Seven parents started worrying because of their child's speech delay but could not imagine that hearing loss might have been the reason for the absence of babbling and imitation of sounds in their children. Lida expressed a common thought that it was "not the child's hearing but problems with babbling and speech sounds made us start worrying" (p. 1).

In three cases the presence of another medical condition or frequent ear infections masked the presence of, and thus lessened suspicions of, hearing loss. Vlada revealed the following:

My daughter was very sick when she was born. Right after the birth she got pneumonia. She received medical treatment with antibiotics injections. After recovering from pneumonia she was diagnosed with hydrocephalus. The doctors said that this disease was congenital and it was not alone but in conjunction with encephalomeningitis. So our daughter had two brain surgeries. It is called shunting... at the age of two and five months. Since she was born my daughter and I were continually in and out of the hospital. Back home for a day or two and then again in. At that time, I thought that she's not going to make it. She was always in the hospital and I was always crying... I didn't know anything about hearing at birth nor later because there were so many life threatening situations... Only in the hospital in Kyiv did the doctors decided to conduct a hearing test... just in case... they said because she was in the 'high risk' group. (p. 1)

Only a few parents took the option of seeing a doctor right away with their worries and suspicions that something was wrong. Most parents hoped that everything would improve and waited for some time before seeking professional help:

After several months of observing and suspecting something was wrong we turned to the pediatrician. I think that we made a mistake for waiting so long but we both hoped that everything would improve. But it did not... The doctor referred us to the ENT doctor who examined our son. He confirmed our suspicions. (Ihor, p. 2)

While admitting that a problem existed several parents spent time trying to find explanations or excuses that would help them deny or at least explain possible hearing loss as temporary and not permanent. Three families delayed their decision to seek professional help having similar hopes that some other medical condition (not severe as described above) might be a possible reason for the child not reacting to loud sounds at the moment. Dara's expectations were similar to Katia's in hoping "there was something wrong with the ears...maybe wax...or middle ear infection ... and decided to wait for a while before seeking medical help (p. 2).

After having discovered alarming symptoms parents tried to test hearing reactions on their own and were frustrated with the results like Katia (p. 1) who used "clapping, shouting etc. ... but everything was in vain. She never responded" or Ania and her husband who also "tried different things but almost always failed to attract her attention with sounds or loud music" (p. 2). Tania by using similar 'technology' to test hearing of her son was confused with the uncertain results of such 'testing':

I would try to check my son's hearing at home. I would bang pots and pans together, turn on loud music or the TV, watching for his reactions. Sometimes he would respond, and I would think, 'Oh, o.k., definitely he can hear'. Other times he would not respond. (p. 1)

In another situation such a 'testing' turned to be misleading and delayed parental request for a professional advice:

No noise ever woke him up. However his reaction to a loud noise such as dropped things like a sauce-pan or a toy when he was awake was normal. So we did not worry much. We thought he was very even-tempered. (Taras, p. 1)

Some parents admitted during the interview that even though they had been almost sure that there was something wrong with their child's reactions to sounds they

would just continue to wait for a while. Some mothers owned up to the desire to just ‘bury her head in the sand a bit’ (Svita, p. 2) or not wanting to ‘invent’ any troubles (Taras, p. 1):

You know, every parent wants to have a healthy and happy baby. Even though my suspicions were growing I did not want to trust my feelings. I just calmed myself down with the thought that my son’s time to speak had not yet come. But after several months I got really worried ... but still did not believe that there could be a very serious problem with hearing ... I just could not believe ... there was absolutely no reason for that. (Tania, p. 1)

It took a lot of courage to admit to oneself that there was something wrong with one’s child:

Both my husband and I were very surprised to think that there might be something wrong with our child’s hearing ... we did not believe it ... He was born very healthy and later had no problems except the ear infections. At first it was strange: three or four weeks before we had had an absolutely normal little boy, now we had same boy ... changing in front of us. We could not understand ... My husband and I were scared to death. (Olia, p. 1)

With the exception of a deaf mother who reported that she is “a second generation deaf family member, for whom having a deaf child was kind of expected and normal” (Olena & Petro, p.1) the reactions of hearing parents who suspected their child were having some hearing problems were similar: they were all deeply worried, scared, and frustrated. Many parents found themselves helpless because they could not rely either on their own experience nor the experience of their parents:

It seemed to me that there could be nothing worse. It was a tragedy. I would cry round the clock. I was overwhelmed with grief. I was very scared to even think that my child might be deaf. Everything was black and white for me. My older son was a normal boy and my daughter would be. I even don’t know how to describe what I was thinking at that time. (Katia, p. 2)

We were greatly worried and stressed. You know ... she is our only child ... no previous experience of parenting ... we thought that it will go away ... we had some doubts about our suspicions and ... strong hope that we were wrong ... It was a real tragedy for both of us. During my pregnancy I was very cautious and there was not any hereditary factor. We did not know what to do and how to find help in order to dispel our suspicions and worries. (Ania, p. 1)

Most participant mothers spoke about their spouses’ role in the process of recognizing the problem and their reactions to suspicions. In one case the mother stated

that her husband “packed his belongings and left us. He said that my child was completely my problem” (Zenia, p. 3) and in two more families tensions and even separations took place as well. In most cases, though, fathers’ reactions were similar to those of mothers even though they seemed to be stronger emotionally and tried to calm their spouses (Halia, p.2; Yulia, p. 3; Dara, p.2). However, one mother spoke about the difference between mothers’ and fathers’ reactions to a child’s disability and said that mothers usually carry a bigger load of suffering than fathers:

My husband was very upset and devastated too. But you know, it is the mother who usually spends most of her time with the child. I don’t work and my husband works in construction. So, most of the time he is not at home. He is also not at home on many weekends. (Myra, p. 2)

Deciding to Get Outside Professional Advice

Sooner or later all respondents came to accept the necessity of seeing a professional. However, parental expectations regarding visiting a doctor differed. Some parents hoped that the doctors would dispel their fears. They expected to be told that it was a false alarm. Other parents seemed more realistic and had fewer illusions concerning their child’s hearing. They expected to hear the doctor say that the hearing loss, if any, was minor. However, all parents were very despondent:

When my first suspicions arose ... at first I was in shock. Then I thought I probably made a mistake. And I thought somebody would confirm that my suspicions were wrong. (Zenia, p. 2)

When my son was 20 months old my mother told me that she thought my son’s speech was delayed. She said that she also suspected some hearing problems. At that time my mother stayed at home with my son while I spent most of my time at work. I did not agree with my mom because I didn’t see any problems but she insisted on a medical examination ... I agreed to visit a doctor. (Tania, p. 1)

Most parents named the local pediatrician as the first person they contacted to share their suspicions. In one case the parents visited a speech language pathologist for a consultation because their child did not show any indication of babbling and producing speech sounds in time. Six parents out of 16 were assured by the pediatricians that there was nothing wrong with their children. In some cases the doctors’ refusal to understand parental concerns caused a delay in obtaining a referral to an Ear, Nose and Throat doctor or an audiologist:

The pediatrician tried to assure us that there was no problem... At first we believed her ... because we wanted to believe that everything was o.k. ... Later the pediatrician referred us to an Ear, Nose and Throat Doctor ... It looked like this doctor [ENT] had never seen small kids that might have problems with hearing ... he almost did not say anything but referred us to the hospital. So for a couple of months we traveled from one doctor to another. (Ania, p. 2)

... Communication [with the pediatrician] continued for several months. It took me almost eighteen months to get a proper diagnosis. I would also like to point out that it was not the pediatrician who was concerned, it was always me. She always told me my child was just fine ... later she said she was so sorry ... I am pretty sure that if the doctors had listened to me it wouldn't have gotten to this point! (Myra, p. 2)

In four cases the parents reported misunderstandings they had with the ENT doctors. They revealed that not only did pediatricians misdiagnose but also ENT doctors sometimes could make a mistake:

The ENT doctor also did not identify any serious problems with hearing. Actually ... he said that there were no problems with the ears at the time of the examination ... He just said, 'Your son might have problems with hearing', period. And he said also, 'You have to have a hearing test'. He also said children were not his specialty. So he referred us to the clinic in Kyiv. There was a long waiting list and we finally managed to get an appointment for a hearing test when our son was almost two years old [first suspicions at 12 months of age]. (Nusia, p. 2)

When the ENT doctor admitted that there was a problem ... and suggested a small surgery but refused to refer my son to a big clinic I was shocked ... I felt so helpless. You cannot go to another doctor if the previous one you saw states that there is no serious condition that requires a referral to a hospital ... and during that first visit to the ENT doctor I was sure that there was a serious problem. I was trying to convince the doctor but he would not listen. (Tania, p. 2)

Another ENT doctor refused to talk to Olia about their son's hearing. He "himself did not make any diagnosis. He said that he was a specialist in medical problems and could not test a child's hearing" (p. 1). In another case a hearing test conducted in the local clinic when the child was 18 months of age did not confirm suspicions of hearing problems. Although after several years, at the age of 54 months, the girl was diagnosed with deafness in the Kyiv clinic (Zenia, p. 2).

Of the 17 children, only 3 had their hearing tested in local oblast (province) hospitals and, as was stated earlier, one failed to provide a proper diagnosis. The issues of 'a reliable clinic', 'reliable equipment' and even 'sufficiently qualified personnel to

conduct hearing tests with small children' were present in 14 interviews. Almost all the ENT doctors (and one pediatrician) recommended that parents go to the same 'reliable' clinic in Kyiv (Lida, Ania, Katia, and Svita). The arguments and motivation for making this recommendation were similar and differed only in their presentation: some said straightforwardly that the local children's hospital lacked either appropriate equipment and/or an audiologist with adequate qualifications to test hearing in small children. Others would just recommend going to Kyiv to the clinic which they described as "the best in the country" (Olia, p. 1). Katia and Lida made the following statements:

The pediatrician said that the best way to clear the things up and get the best service and appropriate advice was to go to Kyiv and look for a good clinic to do a hearing test. She also said that the equipment in our provincial clinic might not be sensitive enough for such a small baby. The pediatrician probably wanted to say that the doctors who were doing hearing tests on children were not qualified enough to test hearing in such young children. (Katia, p. 2)

The ENT doctor referred us to an audiologist. He recommended going to some good hospital as the local children's clinic was not likely to have either a competent and skilled child audiologist nor appropriate equipment for reliable testing of such young children. (Lida, p. 2)

Reaction to the Diagnosis

As stated earlier most parents got referrals for a hearing test in Kyiv. Other than being "curious if their child could hear anything" (Olena & Petro, p. 1), only deaf parents did not show any notable emotions before the hearing test. However, all hearing parents reported being very frustrated while travelling to the capital city in the overnight trains. Many of them reported that they could not sleep the night before the hearing test and felt similar to Tania:

I was so worried ... my body was shaking like in a fever ... a sharp pain in my heart didn't let me sleep on the night train. I was praying all night during the trip to Kyiv ... I was hoping that my son would be healthy like the other children in the neighborhood. (p. 2)

Some parents were hoping that the hearing test would refute the preliminary diagnosis. Even those parents who had accepted their child's hearing loss, which was obvious and confirmed by the local hospital, were hoping for a mild hearing loss confirmation. Some parents believed that the doctors in the famous clinic would be able to heal their child with surgery or medication. But reality crushed the hope of parents:

I expected some mild to moderate hearing loss. All of a sudden I realized that my child appeared to be disabled ... The diagnosis almost killed me. I did not understand. There was no one who was deaf in either my husband's side or my side of the family. It seemed like such a huge coincidence that somehow our genes came together and our daughter was deaf. (Katia, p. 3)

I was hoping that the doctors would be able to help with some medication or surgery ... at least they would try something ... and then at some moment they would say, 'Look, we were wrong ... his hearing isn't a hundred percent now but he's still going to be able to hear,' or 'there is something that we can just implant in his ear, don't worry, he's going to be fine'. (Lida, p. 2)

Besides the one set of deaf parents who "did not have any notable emotions because they had expected that their child might be same as them and were happy that their child was healthy and had no ear infections" (Olena and Petro, p. 3), all parents reported similar feelings of shock, frustration and grief. Besides the diagnosis itself some parents also named other reasons that caused their emotional reactions:

Besides the diagnosis which was a shock ... a disaster ... I realized that nobody was able to help ... there was no hope left ... for me and my daughter ... (Katia, p. 4)

That information made me very sad. I understood that my child had a very illusionary chance to start speaking, to become a normal child. I understood that there was no chance for my son to regain hearing ... (Olia, p. 3)

However, one participant admitted that "besides shock and devastation the identification of hearing loss alone was probably a relief" because he "was frightened by the thought that the hearing loss could develop into an intellectual deficiency" (Ihor, p. 2). Several parents (Yulia, Lida, Taras, and Svita) accepted the disability [of the child] as a punishment from God.

Deaf parents Olena and Petro had their own view and interpretation about why hearing parents were so devastated when their children were diagnosed with hearing loss:

If I were a hearing person and had a deaf child not ever having been in touch with any deaf people nor having learned signed language growing up, I would probably have been as shocked and devastated as all hearing mothers are. It is a common sight when we come to visit an ENT doctor or an Audiologist. There is usually a lot of tears, sadness and unhappiness around ... because hearing parents are so scared, they have no information on deafness ... have no clue what deaf people are, how they live, what their beliefs are ... Usually hearing parents cannot communicate freely with their young deaf children. So I often notice how surprised they are when they

watch me and my husband talking and playing with our son. I feel that in such moments there is a strong impetus for change in the attitudes and beliefs of those hearing mothers. (p. 2)

The Journey of Getting Help and Support

Searching for the Right Resources

Almost all parents admitted that they had experienced an acute lack of information on the issues of hearing loss, deafness, child behavior and hearing aids. Right after the deafness had been identified all of them had long discussions with doctors and other professionals involved in the process of testing their children. But only a few of them were able to comprehend the information presented by doctors due to their acute emotions of shock, pain and grief caused by the diagnosis. Some mothers were so frustrated that they almost lost consciousness:

And I did not ... I could not listen attentively at that moment [at and after the hearing test] because my mind exploded. (Zenia, p. 2)

I wanted to lie down and close my eyes ... I cannot remember anything they said after the word 'deaf ... deaf ... deaf'. (Katia, p. 3)

Some parents were disappointed with the information the doctors provided right after the child was diagnosed with hearing loss. Other parents revealed that the only thing they remembered from the hearing test besides the diagnosis was the discussion of hearing aids and their specifications to best meet their children's needs. Most parents did not understand much from that conversation:

I did not get any information besides the level of hearing loss in decibels which I don't understand to this day. (Katia, p. 3)

Parental opinion about the promotion or selling of hearing aids by the same staff conducting hearing tests in the clinic appears in 11 interviews. To most parents it seemed that one of the goals of the staff besides conducting hearing tests was to pressure them to buy hearing aids at the clinic right after the diagnosis. Svita and Ania thought that the staff was conducting its private business at the government clinic:

After my child was diagnosed the main focus of the conversation was on purchasing quality hearing aids. I did not understand what that meant at the time. I could not think about anything but my difficulty. (Svita, p. 3)

Parental Opinions of Professional Attitudes

In general, parental opinions of professionals' attitudes fell into several categories: (a) those who were completely unsatisfied with the doctors, (b) those who were unsatisfied or confused with some of the institutions they applied to, (c) those who expressed gratitude to the doctors and other professionals for their help and support during this difficult period of stress and grief, and (d) the unique reactions of deaf parents to the clinic visits and recommendations of hearing doctors

Several parents (Zenia, Katia, Ania, Svita, and Vlada) described the doctors' behaviours as being indifferent and uncaring. They characterized the doctors as persons doing their routine work and not paying attention to the emotional state of the parents. Parents not only described their own reflections but some shared their generalizations:

Often I would have the feeling that none of the people giving recommendations really cared about children and parents. Often in the waiting room or in the hallway in the hospitals or other institutions while waiting for our appointment I talked to other parents. Most of them complained that they did not feel any real desire on the part of doctors or other specialists to get really involved. Just formally doing their job ... just sitting their required amount of hours every day in a chair to get a paycheck. (Katia, p. 5)

The environment in the [name withdrawn] clinic was not good-many people arrived from different regions of the country. They sat everywhere. There were lines to every specialist that you have to visit. Nobody cared that we were visiting the clinic for the first time and were scared, worried, overwhelmed. Our child was so small. Nobody cared that we had travelled from a distant part of the country and had to travel back home by night train. We were so tired and exhausted even before the testing ... so, too, were other people. (Ania, p. 2)

Svita had a chance to compare three different institutions. While comparing the government clinic and the [name withdrawn] center she expressed her deep satisfaction with the center and was so angry about the clinic that she and her husband were ready to file a formal complaint to the Ministry. Unfortunately, the same family had another unpleasant experience with another institution belonging to yet another Ministry:

We also had an appointment with the Medical Psychological and Pedagogical Committee which is in charge of the medical, psychological, and educational assessment of children with disabilities. I don't like the people working there. They were so indifferent ... so high-minded ... they won't listen to you. I asked for an explanation of what was going to happen and the response of one specialist was, 'You will see'. They briefly examined

my son and talked among themselves. They did not explain anything in plain language. It was like, ‘We are professionals and we know what you have to do’. And the most strange about the situation was that their written conclusion about my child was like a final verdict with no right for parents to ask questions ... no place for any doubts about their decision, and no way to appeal. (Svita, p. 5)

Two mothers described their first experiences of contacting doctors and obtaining the diagnosis as unpleasant and thus they insisted on a second opinion. They were happy with the reception they received later (Zenia, Yara). However, a group of 6 parents expressed general satisfaction with the way they were dealt with by doctors and staff at the clinic conducting hearing tests. Yulia expressed her great appreciation to the doctors who did not talk down to her but explained things in terms she could understand. They also explained her son rights and suggested starting the paperwork to apply for the child’s pension. In contrast to her previous unpleasant experience with the doctors in a local clinic the doctors in the Kyiv clinic seemed to her very sympathetic and caring. Because this happened in the same clinic which was criticized by other parents the only explanation could be that Yulia was dealing with another medical team in this clinic.

Looking Back: What Parents Expected?

In completing this section of the interview about the emotionally hardest and toughest period of the diagnosis of the hearing loss, the participants were asked, in hindsight, considering their current knowledge and experience of raising their deaf or hard of hearing children, what kind of recommendations they thought would have been appropriate to receive at that time. Many parents demonstrated understanding of this issue and provided insight into this situation:

I think she ought to have said, ‘Well I think there is a problem with your son’s hearing but I cannot identify how great it is’ ... rather than increasing our fears and shock by keeping us in the zone of uncertainty for a couple of months until the next hearing test in Kyiv. (Svita, p. 2)

Doctors have to talk to them like ordinary people ... explain ... calm down ... try to empower somehow ... tell them about other successful children and their families. Just sit down face to face and explain in a way that they understand and acknowledge this challenge to an entire future life. Yes, getting to know suddenly that our child has become disabled was a challenge to the very existence of our family ... and we really failed to cope with this challenge. Our family just broke up. (Tania, p. 4)

Many parents while appreciating the help and support provided by professionals did not like the way they were treated by them and their manner of communicating. Of 17 participants, eight (Zenia, Katia, Olia, Lida, Ania, Ihor, Nusia, and Tania) described it as “strictly one way communication ... not even like communication but a kind of briefing or instructions” (Zenia, p. 4). Sometimes parents felt confused and discouraged after such briefing:

Nobody cared about our questions or doubts ... all specialists were in the position to talk, teach and instruct ... actually there was no teaching but it was like, ‘You have to do this and this’ (Katia, p. 4)

There was a very strange situation at the [name withdrawn] hospital...the Surdolog did not want to give any information ... did not even want to explain the diagnosis ... I asked questions ... I said, ‘Now what is decibel, what is this and what is that?’ but she was not very eager to talk to me ... she ignored my questions and my concerns. (Yulia, p. 3)

The above quote relates to the case when a mother was promised a 10 dB improvement of hearing if digital hearing aids were purchased.

Myra, Taras, and Svita reported mixed opinions towards their experiences and circumstances of dealing with professionals and receiving help. While describing moments they considered to be most typical they would also admit the existence of some other experiences:

Specialists differ. Some really wanted to help; they were kind and supportive; they would always first listen to you ... some were just disgusting ... like one meeting of the medical and ... a very complicated title of the committee we had to attend. That was the biggest farce I had ever seen ... It took us about three hours to get to the place ... After we waited for about an hour, and walked in ... and my son just went into the room, and wouldn’t say a word. And the specialist said, ‘How do you feel about your son? Are you satisfied with him?’ and I said, ‘Yes, he is a nice boy, thank you.’ And they said, ‘We have got a written characterization [a record of his achievements and behaviors] from his kindergarten teacher and she's satisfied with him. Come back and see us next year’. And that's all there was to it. There was also a doctor ... because of her wearing a white overall ... she looked in his ears. But you know, it lasted all of two minutes. They did not ask my son a single question. (Taras, p. 7)

Such attitudes of professionals made some parents think that they did not consider their deaf or hard of hearing children fully capable persons being able to grow up as ‘normal’ citizens:

I got a feeling that some specialists did not want us to develop high hopes for the future of our son. Sometimes those meetings or appointments were very encouraging but more often disappointing because we badly needed somebody whom we could trust. Some very knowledgeable people like doctors to support us, to talk with a positive perspective. But when you are constantly told, 'Remember, he is not a normal child like you thought ... your child is never going to talk ... never going to hear enough to hear you ... he will never do this and never will be able to do that' ... when we wanted to discuss and plan some events in the future. (Lida, p. 5)

Most parents would probably agree with the following statement of Ania who said that she "trusted those recommendations ... but ... hated the way they were made ... (p. 5). Deaf parents stated that they had been sometimes disappointed with the attitudes of professionals they visited because of the feeling that deaf people were not always treated as equals.

Access to Support and Resources: Face to Face with the Trouble

After some time had passed since the diagnosis when parents had been stricken by grief, they began to feel like themselves again. They discovered themselves quite confused with the information they managed to recall while in the Kyiv clinic for the hearing test. They felt that they had been left to face their problems with no direction as to who could provide help and or services in the place where they lived. Even more astonishing was that many of them did not know where to look for information regarding the most vital issues for them and their children. It took a lot of time, in some cases years, for some of them to get access to and actually obtain the information needed to seek help and support:

It took me almost 1 year to collect enough information, recommendations, talk to different people and understand what deafness was and its consequences for the child's development. (Yulia, p. 9)

Dara, Taras and Tania who live in small villages in different parts of the country had specific complaints about difficulties in accessing and locating required information and services and later accessing the required support services. Even to get an appointment with a doctor was a challenge! In such villages one is lucky if there is a doctor or a nurse at all:

We live in a small village more than 200 kilometers from the oblast city ... and there is no place at all to get any information. And you don't know where to get it. Later on [after the hearing test] I tried to collect all the possible information about deafness and deaf children ... but that was another challenge ... it looked like information on deafness and children who

are deaf was of no interest to society ... no information at all. A few brochures or books that I found in the library were difficult to understand because they were not written in plain and understandable language. When I asked the teachers in the local school [about possible educational placement] they were only able to say that we had to look for an *internat* (residential school) for the *deaf-and-mute* which was located somewhere far from our village. (Tania, p. 4)

Living in a village far from a big city makes it very difficult to visit a doctor. In the beginning it was a nightmare ... running from one doctor to another ... not knowing this big city well enough ... not knowing what exactly you were looking for. And always having to keep in mind not to miss the last bus to the regional town where you have to get yet another bus to your village. If you are late you have to walk to your village unless you are lucky and somebody gives you a ride. But nowadays traffic is very light at night. (Taras, p. 11)

Decision Making

After the hearing test deaf parents did not talk with the doctor about anything except the results of the testing. Olena and Petro said, 'At that moment we knew much better what we had to do ... actually nothing special. Just keep our child healthy and happy and teach him to talk ... I mean sign ... the way we were both raised' (p. 3).

It was hearing parents who were desolate and needed help and support. Even though almost half the respondents had complaints regarding professionals' attitudes and several of them revealed that they did not much trust professionals (Olia, Lida, Ania, Dara, and Myra) most of recommendations made by professionals were seriously considered by parents later when making necessary decisions concerning the next steps after the diagnosis. This delay in acknowledging at least some recommendations was explained by one mother in the following way:

The specialists in Kyiv were giving advice but neither I nor my husband was able to understand in full what they were talking about. When we returned home and visited our local clinic much became clearer for us. I am not blaming the specialist in Kyiv ... probably it was because some time had passed since the hearing test ... anyway they should show more understanding and involvement during and after the hearing test ... So the Surdolog in the local clinic recommended what we should do next and that was to purchase hearing aids as suggested earlier in Kyiv. (Nusia, p. 5)

Almost all parents mentioned that their first decision was about purchasing hearing aids. That recommendation was made where the hearing test of the child was conducted. Several parents were disappointed that even though there was a law providing free first hearing aids for children it was almost impossible to get them in time if at all

because of a long waiting list at the Kyiv clinic which was the only place distributing free aids. Some parents did not even know about the law.

Doctors and surdologs were the persons who most helped parents to make their decisions about the next steps following the diagnosis. Usually both doctors and surdologs recommended private lessons for speech development [oral approach]. Parents conveyed that their attitudes varied from “very skeptical regarding public preschool system for the children with the hearing loss” (Ania, p. 3) to sometimes aggressive statements:

Doctor said, ‘If you want your son to speak don’t let him go to the school for the deaf’. (Lida, p. 5)

Surdolog recommended, ‘If all you want is to lose your child in a few years then send him to the school for the deaf. He will never learn to speak and all his friends will be same as he is and he will marry a deaf girl in the future. That is why I would strongly recommend that you keep your child at home, start working on speech, and later send him to the school for hard of hearing children where at least some of them will use speech to communicate and not let him stay at school after classes’. (Nusia, p. 6)

Only once did a doctor demonstrated his tolerance for signing. Dara told that the doctor admitted that their deaf child would learn signing at school and encouraged her and her husband to start learning signs too even though they would like to use speech at home (p.3).

Almost all parents appreciated the help and support of surdologs except for the one who promised that if the parents purchased digital hearing aids [very expensive] they would improve their child’s hearing by 10 dB every year. In similar situations Nusia and Vlada expressed their confusion as they received differing recommendations from different professionals:

We also met other specialists. Some of them had conflicting recommendations as to what our next steps should be. I could not believe it. (Nusia, p. 6)

In all families except two where there were severe and even life threatening medical conditions the main concern for parents was how to communicate with the child. That issue was more urgent with older children. Even though the doctors and surdologs didn’t recommend a signing option many of them did recommend special kindergartens for children with hearing loss along with intensive speech therapy. Those parents who followed that recommendation considered it the right decision. Of 17 parents, 6 (3 in rural

and 3 in urban areas) enrolled their children in special kindergartens. Two families hired a speech language therapist for private speech and residual hearing development lessons and two proceeded with speech lessons on their own due to lack of finances. Two families (Nusia and Myra) ignored the recommendation and sent their children to regular preschool programs. Later they considered that decision a mistake as Myra stated:

Since our daughter was two years of age she was enrolled in the regular kindergarten. Later we moved her to a kindergarten for children with hearing loss. That was finally the right decision because the teacher in the regular kindergarten started to complain that our daughter's behavior was very often unsatisfactory and her speech was not developing. She did not know that our child was not able to hear the teacher and her peers well enough in all circumstances. (Myra, p. 5)

Many parents stated that there actually was no choice for their children except to attend special kindergartens or preschool programs in the schools for deaf or hard of hearing children. There was no way that a regular school system would accept a child with special educational needs or any disabilities. Svita stated that their request was rejected because they could not provide a special letter from the medical and pedagogical committee indicating that the level of hearing of their child was sufficient to be enrolled in the program for hearing children.

Despite their grief, struggles, frustrations, and disappointments the experience of getting help was, for several participants, very positive in strengthening their sense of self and setting clear goals:

Recommendations and conversations with professionals gave me the goal and helped me to start gaining control over my emotional condition and gave me a new hope. (Olia, p. 4)

I am very grateful to the doctor [Surdolog] to let us understand this [the potential of our deaf child]. I would say ... we got a moderately optimistic hope for the future of our son's hearing and his future. (Taras, p. 4)

Those recommendations helped us a lot because we did not have any information about deafness and hearing impairments earlier. We started thinking about our family goals and rethinking our priorities in the family life and planning. (Ihor, p. 5)

Experience of Parenting and Accommodating

Living with a Child

Comparing own children with others. Besides communication issues almost all parents named a number of challenges, some the same as those of parents raising hearing

children, and some specific to hearing loss and lack of communication and understanding. Several parents shared their thoughts about their children by comparing them to other children. One could witness two types of comparison: to hearing peers and to other deaf and hard of hearing children. Parental reflections on the differences they noticed between their own children and hearing children in the neighborhood go back to the time after the diagnosis. Parental stories related two contrasting experiences. Some parents wanted their child to be a part of the neighborhood cohort of children:

There never have been any problems with the children and their parents in the neighborhood. My daughter has always played out of doors and in homes of other children as equals. (Myra, p. 3)

Some parents (Ania, Taras, Nusia) reported that even though their children interacted with other hearing children where they lived at home, they “could not form close relationships and become friends because they spent 5 days a week far from home.”

Four participants had the opposite experience and reported on the early mistakes they made while trying to prevent their children interacting with others. Ihor stated that he “did not like him [son] to mix with other children” to avoid possible abuses. “It really annoyed us to think he [son] might start suffering because he was deaf” (p. 3). Svita (p. 8) admitted that attempts to keep the child away from other children might make both the child and the parents lonely. Similar thoughts are illustrated by Olia:

Now I understand our mistakes at the beginnings ... At first we were overprotective, watching him like a hawk, not allowing him to play outside with other hearing children in the neighborhood. (Olia, p. 8)

Later when their children were enrolled in kindergartens for children with hearing loss parents got a chance to observe deaf and hard of hearing children in the kindergartens and preschool programs and watch a different type of interactions between children and their parents. The respondents mentioned how surprised they were when they first discovered how fluently and smoothly deaf parents and deaf children communicated. They also revealed other observations:

Teachers often used to say that deaf and hard of hearing children who had deaf parents were much better developed. Deaf children of deaf parents usually are making better progress in acquisition of the curricula than their peers from hearing families. (Zenia, p. 7)

Several parents spoke about the other children in their family. Nusia was happy to describe how much time her younger hearing daughter spent with her older deaf brother becoming a kind of ‘communication facilitator’ at home. They both seemed happy and admired each other. In contrast another mother stated that her trying to give more support and parental love to the younger deaf daughter resulted in her older hearing son becoming unhappy:

I understood that both of my children needed equal love, support and help. I started to give both of them equal attention. I started even involving my son in taking care of his sister. (Katia, p. 9)

Family Communication Preferences

As participants described the positive and negative aspects everyday life communication emerged as the central concern of all families (except deaf parent families). It was the issue that challenged and impacted the family life style of all hearing participants the most.

The biggest problem is communication. You can deal with a child only if you can talk...I mean communicate in any acceptable way to a child. (Zenia, p. 7)

Communication issues are the biggest concerns for parents. All other things like family health, education and making plans for future build on communication. Communication has been a central issue in our life. (Ania, p. 10)

The primary factors that influenced the decisions of parents regarding the mode of communication were the parents’ personal beliefs and experiences, the information they had about communication options and the mode of communication parents chose for their children. One can witness that in Ukraine the attitude to signing as a mode of communication for deaf or hard of hearing children is still controversial. The term ‘signing’ [which corresponds to Signed Ukrainian] is in general use because Ukrainian Sign Language which is cultivated in the deaf community has only recently (2004) become a focus for researchers and was introduced in the schools for deaf and hard of hearing children as a separate subject in the curricula only in 2006. In this study only the respondents who were deaf parents were able to distinguish between Ukrainian Sign Language and Signed Ukrainian.

In deciding on options for communication, as was stated earlier, some parents reported that they received biased information like ‘don’t send your child to the school for the deaf’ because the child will not talk but only sign. Some parents received little

information or support and were on their own in making a decision. These parents reported on their struggle to establish effective communication in their families. The interview data shows that the parents' hearing status along with worrisome information received from the outside led to a misunderstanding of the nature of signed language and cultivated biases towards deaf people which greatly influenced their early decisions on communication. Most parents reported that they preferred their child to learn to speak, to stay oral, and function in the hearing society only.

Four positions of parents' views and preferences of the mode of communication and their attitudes to deaf people and the deaf community emerged from the reports. One was an aggressive oral position. The holders of this position rejected the use of signing in interactions with a child at home and did not show much tolerance of contacts between their children and deaf peers:

My attitude towards signing has not changed. I want my child to talk. No signing ... no deaf stuff at home ... (Lida, p. 7)

My views concerning the communication mode has not changed since the diagnosis. Our son can speak and we are working with the teachers to improve his skills. And he will live his adult life using preferably speech ... the thing is I don't want my son to mix with just deaf children. My aim is to get him to mix with more hearing children than deaf children. I want my son to stay oral and communicate mostly with hearing peers ... I would say all children except the profoundly deaf who use signing only. (Taras, p. 12)

Some parents held a softer position on signing preferring not to sign at home but permitting minimal signing in the case of misunderstandings. A group of parents (Ania, Yara, and Zenia), who showed some tolerance to signing while desiring their children to stay oral and avoid signing at least at home, said that they just wanted to give their children the same opportunity to succeed that children who are not deaf have. They believed that the more the children were able to fit into the hearing world the better were their chances of being successful. The fact that their child would speak was very important to them. They all feared that "more signing means less speaking" (Ania, p. 7). Even admitting the importance of signing for their children they wanted them to stay mostly oral:

At present time I still want my child to stay mostly in the hearing society. I am working hard to achieve this goal. Anyways, we just speak with each other. I try to avoid signing as much as possible ... I know that signing is more comfortable for her but I rarely use signs ... more just gestures but we

both like to speak. At school all children are signing so I want her to stay mostly oral at home. (Zenia, p. 8)

A third position could be described as parental views which evolved from a strong pro-oral position to understanding the need of the child to become bilingual and function in both hearing and deaf worlds. Several parents stated that they chose oral communication at home but later changed their mind for various reasons. Some parents commented that they changed their mind when they got a better understanding of the realities of their child's future and realized that they "would not be able to isolate her neither from other deaf children at that moment nor from deaf adults when she grows up" (Katia, p. 7). Yulia reflected how long and painful the process of accepting new realities was:

Of course, I was concerned and am now about how to communicate... That is why I did not learn signed language. I want my son to stay oral. He is hard of hearing. He is not deaf. I worried a lot that my son will stop using speech after he learns signing. But later I understood and that was a very painful process ... that he would have to fit into both worlds. We will not be able to prevent him from being a part of the deaf community after kindergarten and school for children with hearing loss. On the other hand our goal is to empower him with speech and language enough to be a part of a hearing world which is much-much bigger. (p. 7)

The fourth position reflected a positive attitude towards bilingualism. However, only one family made this very difficult, but right decision for them, to let the child become bilingual right after the diagnosis. They based their decision on the information they received from the doctor who realistically described communication options for their child and stated that they would not be able to prevent the boy from signing. He also advised the parents to start learning signs too if they wanted to successfully and effectively communicate at home. So, from the very beginning they "understood that there was no way that the child would talk clearly and distinctly enough to be fully understood by hearing people. Thanks to that doctor we made the right decision" (Dara, p. 6). Another two families (Halia and Myra) which accepted only the oral communication mode at the beginning, later made a radical change from a strong pro-oral approach to a bilingual approach realizing that "learning signs will make sense [for parents] too" (Myra, p. 7). The reasons for making that radical change are exemplified by Halia:

At first we wanted our child to be *only* oral. But the longer she studied in the kindergarten and the more we communicated with other parents of elder children from that kindergarten the sooner we understood that contrary to our expectations our child would communicate with signs too. So we did not mind to help our child to become bilingual. (Halia, p. 6)

The decision to accept signing as part of the home communication system did not make most parents happy and presented a dilemma for some of them reflecting their fears that “everyday use of signing will affect the ability to develop normal oral and written language”. (Myra, p. 7)

Interestingly, deaf parents Olena and Petro did not hold a very strong signing position. They indicated a high level of tolerance towards both communication modes acknowledging the right of children to learn speech as well as signing:

Every child has to have a right to choose the most appropriate method of communication. And a special school for deaf or hard of hearing children has to teach both languages to the children. They have to be able to use oral language when communicating to hearing people too. Because they will live in the society where the majority of population is hearing. (p. 5)

They also voiced a negative attitude to the idea of mainstreaming deaf children in regular schools for hearing children:

We know some deaf and hard of hearing adults who were raised by their parents in isolation from the deaf community. I mean they studied in the regular schools. They don't look very happy. They feel like social outcasts ... their adaptation to life in the hearing society was very painful and most of them failed to become full members of the [hearing] society. I use this word *adapt* because it is a deaf person who is supposed to adapt to the society but not the society that will make an effort to accept a deaf person. After school some of them tried to get in touch with deaf community. It was a painful process of changing ... some of them were successful ... some were not. (p. 7)

Almost all parents stated that the biggest impact of the child's hearing loss on the family was not the hearing loss itself which is an invisible disability but that natural vocal communication between parent and child was precluded. Looking for a way out several parents reported inventing their own means of nonverbal communication but that was only a temporary escape from a real solution to the problem. In order to establish satisfactory communication the parents, after a long time of searching and hesitating, had to look at the option of incorporating signing which became one of the most powerful

challenges for them besides the hearing loss itself. Learning new communication skills was reported as a great challenge by most parents.

Communication in the preschool: Signed language in the underground. As stated earlier all parents had to answer the quandary: to permit signing at home or to fight it. So many parents while answering questions concerning communication talked about their attitudes and experiences with signing. Several parents stated that it was not until their children entered a kindergarten or a preschool program that they were able to make a final decision about the mode of communication that might best fit the needs of their child. However, they were confused by the contradiction between official policies in the area of languages and communication and the reality they could observe. On one hand, the existing ban on signing by the Ministry of Education and Science of Ukraine in the system of the education of the deaf was in force and on the other hand one can see an amazingly wide and open circulation of signing in the kindergartens and schools of this system.

In only two educational placements as reported by Lida and Ania the official ‘communicational approach’ really implied speech and finger spelling only. In the rest of the kindergartens and preschool programs the situation corresponded to the following description:

I remember that when we first came to the kindergarten for children with hearing loss there was a kind of a list of communication rules on the wall and it was clearly indicated that ‘signing is a big obstacle for the development of a deaf child’. I was astonished as most children were signing around and teachers would not pay any attention to that. Later they [teachers at the kindergarten] explained, ‘You cannot prohibit or avoid signing. For some of them [deaf children of deaf parents] signed language is their only language from birth. If you are unable to prevent them from signing how you could prevent all other children [who have hearing parents] from learning it? However, officially we can use only finger spelling to support speech in case of difficulties’. (Myra, p. 8)

Many parents were surprised to discover that “deaf and hard of hearing children of deaf or hard of hearing parents were better developed and prepared for learning in the kindergarten. Deaf children of deaf parents were making better progress in acquiring the curricula than their peers from hearing families” (Zenia, p. 7). In addition, many parents were upset when comparing their communication with their children with that between deaf parents and their children:

Usually on Fridays all the parents would come to the kindergarten and take their children for the weekend. I would watch the children meeting their parents. There was a big difference between deaf and hearing parents. Conversations between deaf children and their deaf parents were always very animated and expressive as well as conversations between the children themselves. We were excited too to meet our daughter after a week's separation but our conversation looked very poor and consisted mostly of simple questions and answers. (Katia, p. 3)

I often watch deaf parents chatting between themselves. Their communication seems smooth, emotional, and very rich. (Nusia, p. 5)

In four cases participants pointed out that it was the teachers who inspired them to rethink their position and to change their mind about the prevailing opinion of signing (Zenia, Dara, Ihor, and Tania). The basic advice was to start learning signs from their children and other parents. All parents stated there were absolutely no resources and support to learn signing. Katia and Ihor wondered why signing was still not tolerated in the preschool programs when it was included in the curriculum in the schools for deaf and hard of hearing children as a separate subject.

Parents reflect on preschool training. Parental responses to the questions about communication were tightly connected with their reflections on the preschool programs their children were enrolled in. Five parents (Dara, Myra, Ihor, Nusia, and Tania) expressed satisfaction with the quality of education provided, the attitudes of people working with deaf children, and the progress of their children while in those programs as illustrated by Myra:

I am satisfied with the way things are going in the kindergarten. The teachers there taught my daughter to read, to write, to recite poems and create crafts. They even have had lessons in music and dancing. They [teachers and children] understand each other well. Isn't that amazing? That is why I now I worry about the future of my daughter much less than earlier. (Myra, p.10)

Parents who moved their child from a kindergarten for hearing children to a special kindergarten for children who are deaf or hard of hearing were happy to share their success story:

I feel that after we moved our son to a special kindergarten it was a relief for him. He became much more active and happy. He started learning signs and has never been out on the sidelines during class activities or play as often would happen when he was enrolled in a regular kindergarten. (Nusia, p. 8)

However, not all parents were happy with the preschool education of their children. Most concerns related to speech progress of their children. Ania and Vlada complained that teachers did not spend enough time when teaching sounds and speech according to the curricula. Another parent said that she considered five years spent in the preschool a complete waste. She said that the teachers had not taught her child anything:

The teachers were complaining that his behaviours were not suitable to study in the kindergarten. The teachers did not want to admit that probably it was not only the boy's fault but they would never discuss the situation with us but usually only complained. (Yara, p. 6)

Communication realities at home. All parents seemed to understand that the effectiveness of communication between parent and child would have a significant impact on the overall development of the child. Parents were asked to share how they feel about the effectiveness of their communication and relationship with their child in the family. Parental thoughts on their level of satisfaction fell into three groups 'mostly satisfied', 'not completely satisfied', and 'totally unsatisfied'. Two participants stated that they were totally unsatisfied with the communication with their children because they both didn't know signs. In one case parents and the child didn't understand one another and were unable to discuss "family issues or events at school" (Lida, p. 7). In the second case the girl did not speak nor did she understand anything said to her. She was able to understand basic things however the mother was not able to explain all the things she would have loved to. To get her daughter's attention she usually stamped on the floor and the daughter responded to the vibrations. The daughter had hearing aids which she was reluctant to wear because she said they hurt (Vlada). Neither family attempted to use any form of signing to improve communication.

Seven participants expressed disappointment in their attempts to establish reliable communication with their child (Halia, Zenia, Katia, Ania, Svita, Nusia, and Yara). They all admitted that there were many things they could not communicate to their deaf or hard of hearing children. One mother informed that her desire to communicate orally with her deaf daughter had failed but she still persisted in favouring the oral mode of communication:

I am absolutely not satisfied with the level of our communication. There is so much that I cannot communicate to her. I try to avoid signing as much as possible ... I rarely use signs. At school all the children are signing so I want her to stay mostly oral at home. (Zenia, p. 8)

All seven parents spoke about the children's poor Ukrainian vocabulary and their own poor sign vocabulary:

My son tries to talk to me too. I mean he always tries to imitate speech pretending he is talking. It sounds like babbling to me. At school he has already learnt several words and signs and is progressing. But in the kindergarten he has not learnt anything at all. I mean to talk. (Yara, p 7)

Our son does not understand speech well and hearing aids won't help. I think that if anybody convinced us learning signs when our child was just diagnosed with deafness ... our family communication would have been much better. But at that time everyone around us talked about speaking and listening. Now I think that was a mistake. (Svita, p. 7)

Four parents expressed that they were not completely satisfied and felt that there was a lot of room for improvement. One mother explained that she was not completely satisfied with the communication with her daughter when comparing the way deaf parents communicate with their deaf children and their abilities. She blamed herself for not "being persistent in finding ways to learn signed language" (Olia, p. 4).

Another mother (Nusia) described the mutual learning going on at home: their son was very good at teaching signs to the parents and other family members. Her younger hearing daughter learnt signs from her brother very quickly and very often helped the parents in communication, 'They play together most of time. They don't speak much, but they use both speech and signing. She always knows what her brother means. And such a situation also exists in some other hearing families with deaf children' (p. 9).

Four participants (Dara, Myra, Ihor, and Tania) reported that they were mostly satisfied with their family's system of communication; however there still were difficulties, as revealed by Myra and Dara:

We are satisfied with the level of communication at home and at school. We had to learn so much like signs and even Ukrainian [the school is Ukrainian in the Eastern part of the country where most population speak Russian]. You know, now I kind of blame my parents and myself for not learning proper Ukrainian earlier at school. (Myra, p. 7)

Our son at home knows and understands everything. We speak and sign with him on all topics. He often starts conversations, asks questions ... sometimes it is difficult to explain everything in full because we still have a limited number of signs and our son a limited vocabulary of words but we and the school are working hard on his active vocabulary. We would like to get training in signed language. (Dara, p. 7)

While reporting satisfaction with their home communication system, Tania confessed that it had always been a very hard process to catch up with her son's growing abilities in communication and fluency in signing:

I am constantly scared of failing to be able to understand him in the future as much as I understand him now... It was okay when he was a small boy but things changed when he went to school. I have a feeling of falling behind since he is progressing fast. And there is no place where I can learn signing except from my own son. (p. 9)

Surprisingly the deaf mother of a deaf boy stated that even though her boy was very fluent in Ukrainian Sign Language she insisted that he practice speech with her:

Really, he feels much more comfortable when signing. However, I try to talk to him very often and push him to reply orally too. I hope that the teachers at school will help him to improve his lip reading and acquisition of speech. (Olena & Petro, p. 6)

The most tolerant attitude regarding the place and role of signed language in the educational system was presented by Ihor who said:

Current educational practice with very young deaf children (in the kindergarten) discourages the use of any form of signing probably due to the ultimate aim which is to integrate children into normal [hearing] society, and to be able to communicate with hearing people. It is felt by many that this is best achieved by the intensive use of oral language. However, I think that children should be taught any possible means of communication to be able to make their choices when they grow up. Otherwise, later it might be too late. (p. 8)

Living with Others

Contrary to the experiences of several families (Ihor, Olia, and Svita) who admitted they had tried to limit the contact of their child with other children in the neighbourhood in order to avoid any abuse, another group of parents revealed their despondency due to the attitudes of neighbours and relatives. Zenia, Yulia, Lida, Taras, Vlada, and Yara recollected very sad experiences with their relatives as well as neighbours some of which stopped all contacts and did not allow their own children to play with their deaf or hard of hearing child. Vlada reported:

Relatives and neighbors did not allow their children to meet and play with our daughter. And when we walked down the street they would cross the street and walk on the other side in order not to say, 'Hello'. They think that

my daughter has a kind of infectious disease. You know, I don't blame them. (Vlada, p. 3)

However, in several other cases parents reported the development of increasingly more positive attitudes in their neighbours:

Now he plays with their hearing children and their parents don't mind. But earlier they probably did not accept him as a normal child. (Zenia, p. 5)

Almost all parents considered the lack of information about deafness and deaf people as a major reason for prejudice and bias in the society.

We, parents who have children who are deaf or hard of hearing don't think that there's any information about deaf children and deaf people available. We find deafness is a problem people don't attach very much importance to, probably because it's not a visual handicap. I don't think enough notice is taken of it. I don't think enough attention is given to the deaf at all; it is really a terrible disability. But there is so much misunderstanding in the community. (Svita, p. 3)

Going out with their child turned to be another challenge for some parents. Several parents related their experience of being out in public. They encountered people, looking askance at the child's hearing aid or quick to judge and openly show their surprise when they heard atypical speech sounds produced by children communicating with their parents. Rather than trying to understand they would sometimes ask questions like "I am sorry he is deaf but why doesn't he speak?" (Svita, p. 8).

Most parents related their negative experiences when going on weekly trips to the school or kindergarten, going to church on Sundays, taking a trip on the city bus, or going shopping.

You know regular public events like going to church every Sunday ... and my son asking questions very loudly ... he cannot manage his voice ... and his speech is very specific. So this hearing aid squealing and everybody goes 'whoosh' ... turns around and ask, 'What is that sound? Or, I see...that *abnormal* boy' ... And you just wanted to dissolve ... to disappear ... to meltdown. (Lida, p. 9)

Every Monday I have to bring my son to school and take him back home on Friday. It takes us up to two hours on the bus. Every time the people we are on the bus with are different. Everybody looks at him and I know what he is on about and they haven't got a clue, you know. I feel embarrassed and very often frustrated. And that's just about the worse bit I think because in a shop or any other place you can walk in and walk out but on a bus you're stuck.

And they all look at you for two hours and discuss you and whisper ... very often ask silly questions. I am so frustrated with those bus trips. (Nusia, p. 9)

Some parents reported that in order not to put themselves through a negative experience they would often stay at home or only go to certain places. But that brought a sense of loneliness and in time parents stopped avoiding going out because they came to understand that they could not hide for the rest of their life.

One mother expressed a pretty common view of parents towards signing in public places by stating that both she and her husband were afraid “of further shame for using signs in the street. People might think that deaf people are mentally retarded and I probably would think the same if not for my own child” (Halia, p. 6).

The majority of parents found that structured settings such as a special kindergarten or a special school were generally a positive experience for both them and the child. That was the place where all the children were the same and there were almost no obstacles to their communication and functioning.

Parents' Personal Reflections and Transformations

Parents in this study had certain common experiences: similar reactions to the identification of the hearing loss, similar difficulties while searching for the best services, attempts to explain their children's needs (as well as neglecting their own) in a society that did not tolerate difference, and living with the fear of isolation and loneliness as well as finding some relief when they enrolled their children in educational placements which met their specific educational and social needs.

Coping with Ups and Downs

For many parents in this study, the discovery that their child was deaf resulted in an abrupt change in their lives and in perceptions of themselves as parents. Participants were asked to talk about their feelings and emotions in retrospect from the time of the diagnosis until the time of the interview as well as to assess their levels of stress on a 10 point scale (see Table 22).

Table 22
Levels of Stress as Reported by Parents

Name of the parent	Levels of stress		
	At the moment of the diagnosis	One year later	At the moment of the interview
Halia	10	9	8
Zenia	10	10	5
Katia	10	9	5
Olia	10	9	8
Yulia	9	9	9
Lida	10	6	2
Ania	10	10	8
Dara	10	6	2
Myra	8	3	3
Taras	10	9	9
Ihor	8	3	1
Svita	10	10	10
Nusia	10	10	5
Tania	10	9	2
Olena & Petro	n/a	n/a	n/a
Vlada	10	10	8
Yara	10	10	8

In the years since the diagnosis they were asked to assign 10 points to the highest level of stress they experienced. In the retrospective view of 16 participants (excluding deaf parents who did not state any stress regarding the diagnosis) 13 assigned 10 points to the initial stress at the time of the diagnosis and another two evaluated their stress with 8 points. In retrospect 6 participants still rated their level of stress at 10 points in the year following the diagnosis; for 6 participants it dropped to level 9; two participants rated their stress at 6 points and another two at 3 points. At the time of the interview 4 participants rated their level of stress at 8 points; 3 participants at 5 points; 3 participants at 2 points. Svita and Taras still evaluated their levels of stress very high at 10 and 9 points respectively and Ihor reported a significant drop to 1 point from 8 points at the moment of the diagnosis. Of 16 participants 13 stated that the diagnosis was a huge shock which brought a feeling of pain and grief that “will never go away completely”:

As far as I know every person lives through this grief in one own way.... Emotions were eating my brains and burning my soul... Over the years I have been reconciled to the diagnosis and to my destiny... but the feeling of pain will never go. (Zenia, p. 8)

Several participants revealed that they were still in pain at the moment of the interview even though it has been several years since the identification of hearing loss. Thoughts of Taras, Svita, Vlada, and Yara were in line with those expressed by Halia:

I would say that the word stress is too weak to describe our feelings. I would call it grief. The period of grief and mourning has not finished. I don't think that it will ever stop or even reduce considerably. Every time when I look around and see lots of happy parents playing with their children I always ask myself, "Why me? Why my child? What did I do wrong?" (Halia, p. 7)

A few participants reported that they had managed to cope with the grief and mourning but still could not say that they were completely happy (Lida, Dara, Tania, And Ihor). It had taken years to adapt to the situation. Many parents spoke about how important it was to have somebody to rely on during their coping process who could really help with their own experience and practical advice. Several parents stated that other parents had helped them to rethink the situation positively. Ihor was one of them:

Surprisingly, the shock and devastation ... frustration have almost gone. Instead, fear for the future of my child appears to be the most powerful feeling besides grief. Actually this feeling of fear is ongoing. I think it is important to go through a grieving process and have support with that. It is very important to find somebody who has either been through it or understands what that is like and kind of gets you go through that. Meeting and talking to other parents in the kindergarten helped us a lot. (Ihor, p. 9)

Additional Challenges

The diagnosis also posed several additional major challenges. The most common were financial issues, attitudes to deafness and deaf children in the society, separation from the child while in a special kindergarten or a residential school (5 days a week), and a lack of help and support.

Financial burden. Financial issues were related to the purchase of hearing aids, expenses for additional services and transportation to the educational placements which in most cases were located far from home. Right after the diagnosis recommendations were made to all the families to purchase expensive imported digital hearing aids. Of 16 families (except deaf parents who ignored this recommendation) 13 stated that their financial situation would not permit them to purchase hearing aids right away. One family reported selling their car and another selling their cattle to raise money for this expense. Three families were not financially capable of buying hearing aids at all and received free cheaper models from the authorities with a wait of 18 months to 3 years. Besides describing the financial burden imposed by the need to purchase hearing aids and hire private teachers several parents also reported a constant lack of money for everyday needs and transportation expenses. One mother confessed, in tears, that she could afford

to take her child home from school only once a month due to high transportation costs (Lida).

Separation from the child. The greatest challenge right up to the time of the interview was the children's stay in an educational institution for 5 days a week. These separations as well as long trips twice a week to the school and back were reported as the most exhausting, painful, and expensive:

You stay at home 5 days without your child. Very often you hear about different bad events occurring ... diseases or even epidemics among children when regular educational institutions are closed ... those epidemics are not necessarily very dangerous like viral flu ... but usually all schools for normal children are closed for a week or so. And you cannot even phone to the kindergarten because you do not have a telephone at home. (Zenia, p. 10)

... our son has to be at school from Monday till Friday ... strangers are raising my child ... as soon as it is time for him to go back, I say, 'I'm not going to send him back.' I always say it, but I know I have to do it again and again. Yes, he has made a lot of progress, but he would probably have made the same progress at home. (Svita, p. 9)

Participants also claimed that the separation was destroying family relationships and bonding with the child as well as impacting the child emotionally:

If you live close to school you can take your child home everyday. Other children are allowed to come home every week, but we just cannot afford it. Usually I work late on Fridays. You know, it is so hard to get a good job now ... So my wife travels by two buses to get our child. And that takes almost all Friday afternoon and evening. But it seems hardly worth it. You only get one full day Saturday with your child. Then on Sunday you have got to go back again. When he first comes home, he is always kind of lost, he needs time to get to update what is going on and to where he is. He is overwhelmed and tired, and on the next day as he gets used to being at home, being his old self again he is to go back to school again. (Taras, p. 11)

Changes in Life and Major Events

The threads of the past intertwine through the themes, making connections with present. Recollections and experiences from past contexts such as hard times after the diagnosis, relationships with others, communication difficulties and schooling affected how participants interpreted and responded to changes in their day to day experiences. In describing their current life nine parents used the same expression 'we devoted our life to the child' though sometimes meaning something else by it said they sacrificed their career in order to spend more time at home teaching their child (Olia, Yulia, and Ania). Others said that they actually 'lost their private life' (Halia, Zenia, Olia, and Nusia) as

daily routines consumed their time especially exhausting trips to educational placements. In three cases mothers spoke about divorces or separations (Zenia, Lida, and Tania), and related their family breakdowns to the difficulties caused by the diagnosis:

My husband was very involved at the beginning but later he said that it was mostly my fault and did not care much. (Lida, p. 8)

My husband left us ... at first he started coming home late explaining that there was a lot of overtime work. But his attitude started to change too and his relatives stopped visiting us on holidays. That was strange because usually on holidays our house was overcrowded with guests. Later on we separated. (Tania, p. 10)

However, as Taras shows, some parents reported no significant changes in their life:

There were no big changes in our family life except that we had to devote all weekends to our son since he attends the residential school. I mean also Fridays and Mondays are spent with packing things, travelling ... and as you know ... our transportation system is far from satisfactory. This is really hard. (Taras, p. 9)

Almost all parents who reported life changes and those who did not, mentioned that they had to subordinate their family life cycle to the needs of their child. By saying that they meant trips to the kindergarten/school twice a week and having their child at home only on weekends during the school year. Most of them revealed that their “life is on wheels now”, Mondays and Fridays are spent travelling to school and back home” (Nusia, p.10) and that Fridays and Mondays are filled with packing things, travelling (Taras, p. 10). As a result of that some parents described their life as ‘very sad’ (Katia), ‘monotonous’ (Ania), and even “not a life ... but a kind of functioning” (Vlada, p. 8).

In answering questions about the most positive events in their family lives almost all parents remarked that the enrolment in either the special kindergarten or in a preschool program at the special school for deaf or hard of hearing children was the most positive. Several mothers provided details of their satisfaction with the positive impact the kindergarten or the school had already made on their children:

The most important event was enrolment in the preschool program. My son has learnt a lot to read, to write ... he has got many skills ... improved his behavior ... even at home on weekends he always makes his bed himself. (Tania, p. 7)

He has already been enrolled for one term and likes his school. It took him only one month to learn the alphabet both manual and Ukrainian and he can read words and sentences now. He also likes painting and doing different crafts. That is really a kind of a miracle we waited for so long. (Yara, p. 6)

Nine participants reported that hearing their children say their first understandable words was another major positive event in the family. Three other parents were happy to share their satisfaction with their children “developing as other normal children” [except hearing] (Halia, Taras, and Tania).

Looking to the Future

Thoughts and views of future were significantly linked to the present. Fears and dreams of what the future might hold played a part in how participants perceived the present.

Tears through fears. Fears both in the short term and the long term came to light in discussions of the future. A common thread running through these interviews is a concern for education and its possible outcomes for future adaptation to the hearing society. Besides concerns about communication issues and fears that their children might not get enough speech training, several parents also questioned the effectiveness of the vocational training in the schools. Thus, educational and social concerns were inextricably combined for many parents:

My major concern is whether the school education is good enough to impart the necessary knowledge and skills. Will it be enough for adaptation to the hearing society? (Halia, p. 9)

I don't think that my child will have an opportunity to get a good post school education that will allow her to get a good job. (Katia, p. 9)

I am pretty sure that even if my son successfully gets through high school and gets some vocational training at school ... it won't be enough to get a job good enough for a financially independent life. My main goal is to teach him to speak. Otherwise, he will have much fewer chances to accommodate to the hearing world ... to get job. (Yulia, p. 9)

Contrary to these previous opinions, another mother hoped that “school will be able to provide some good vocational training” (Lida, p. 10).

While talking about their vision of the child's future some parents provided good reasons for their fears and concerns about the post school life of their children pointing to the current situation of many deaf adults experiencing difficulties in finding good jobs. The parents stated that this unemployment may be due to a lack of

professional training or maybe because of restrictions arising from the individual's medical condition (deafness):

I know that many deaf adults are involved in illegal business like selling pornography, handling stolen goods ... They simply have no choice because they don't have good professional training ... many of them sell newspapers and magazines in the trains, buses and railway stations ... many of them cannot speak and don't understand speech. They are almost illiterate and lack vocational training even though most of them studied in special schools for the deaf. (Lida, p. 8)

I think that the list of jobs for the deaf is very short [due to medical restrictions] as all deaf people I know have no job now ... or maybe they officially don't work ... (Yulia, p. 9)

Some parents, in fact, had a limited vision of what they could hope for their child in the future, were unsure of the place their child might take in society, and expressed general pessimism:

I have no idea what kinds of jobs are available for deaf or hard of hearing people. I don't see any good perspective for him in his adult life ... you know, all the deaf parents of my son's peers in the kindergarten do not have a job. (Yulia, p. 9)

How will she survive? How long will I be able to support her? What will happen to her when ... when ... I die? My husband is very sick now, too. I think he got sick because he was so frustrated ... so worried about our daughter ... our daughter's health. (Vlada, p. 8)

A major concern for Halia as well for some others was whether or not her daughter would get married and live a 'normal' life:

And I want to have hearing grandchildren ... there is no way that my daughter would marry a deaf guy ... sorry ... maybe I will adapt and think that when she grows up she will have her own right to choose her friends. But not now. (p. 8)

Some parents did not look too far into the future. They had little experience of the deaf and worried mostly about current events occurring in the life of their child like adapting to the educational placement:

Now my child is in the transition from the kindergarten to the elementary school. Actually she has already been at school for two months. This frightens me a lot ... how she will find her way through this change of environment. On the other hand I am so happy now that my child completed the kindergarten program for hearing impaired children. My child looks so

much better in comparison with those children who have not had any preschool preparation and just have set foot in school. (Zenia, p. 9)

Another group of parents were more optimistic when talking about their concerns. Three hearing parents (Dara, Myra, and Tania) as well as deaf family (Olena and Petro) stated that they probably did not have any specific concerns at the moment besides those that all parents would have:

I think that I don't have any other specific concerns besides what all other parents have like I want to protect my son from alcohol and substance abuse, criminal involvements and other bad things when he grows up. (Dara, p. 9)

I am pretty sure that our daughter will have high academic achievements. She likes to study so much. We have our family plans for the future ... No too big concerns and worries now. Just expectations. (Myra, p. 10)

Dreams through tears. The hope and optimism expressed for the future was sometimes clouded by the fears and concerns that parents held for their children. Surprisingly, when asked about their vision of what might happen to their child in 10 years time most parents were less pessimistic. Often they presented "contemporary concerns" in more positive light. In fact, only one mother was completely pessimistic when asked about her vision of the future of her child:

I don't see any positive future for my child. I don't think that the government will take care of my child... no opportunity to get post school education that will allow her to get a good job. (Katia, p. 9)

The only dream and hope of the parents whose children had additional conditions was effective medical treatment. Myra and Vlada were not making any plans and just wanted their children be alive and start talking. Myra confided her secret hopes for a miracle to happen:

I still hope ... am waiting for a kind of a miracle ... waiting for the morning when I will get up and my child will be all right. Why not? Several doctors said, 'Let's cross our fingers and hope that after the next surgery things will go better'. But that never happened. But deep in my heart I still have this hope. (Myra, p. 8)

Despite these secret dreams and disappointments, several participants shared realistic hopes and dreams for their children even though they had revealed many concerns and doubts earlier. A few hearing parents and deaf parents as well expressed

general optimism and expectations based on their children's successes in the kindergarten or school but did not look too far in their dreams and expectations:

I believe in my child and her success very much. We are all working hard and we can see the results. (Halia, p. 9)

My child is wonderful. Despite her hearing loss she has no problems to start communicating with any person. All the people around us love her. This makes me believe that she will find her own way in this life. She will be fine. (Zenia, p. 6)

Three parents hoped that their children would get enough training to find jobs and "parents will do the rest" (Taras, p. 9) [meaning that parents will find jobs for their children] but revealed those thoughts without optimism:

When thinking about the future I don't feel too optimistic. I just hope that my son will do well ... just well enough to get some vocational training and get enough skills for an adult life. (Svita, p. 9)

He is smart enough to get some professional training in any area suitable for him. (Dara, p. 8)

Several parents described their children as having many good qualities such as being smart, determined, funny, able to draw very well, skilled in sports, good in math, and sensitive to the needs of others. Parents, whose children showed good success in education, provided a long term outlook while talking about their hopes and expectations and also spoke about plans for post school education of their children. Their hopes and expectations seemed to be well grounded and parents were ready to go the extra mile to realize their hopes.

I know that the future of my daughter is in my hands, and I hope that after kindergarten she is placed in the right hands, the right people that really are capable of giving her the knowledge and tools to succeed I hope for a bigger future for my daughter. I am thinking about college education. (Ania, p. 9)

I'm not terribly worried about the future. My son is very smart and has become a very independent child due to the kindergarten and I hope he will grow up to be a very independent person. We are not particularly bothered about academic achievements because he was among the best in the preschool group. I mean if he shows the inclination we will move heaven and earth to see that he gets to some postsecondary educational institution ... except for the fact that he is handicapped I feel I want to get him to the stage where he can stand on his own feet and live a normal happy useful life ... that's all I want ... we both want. (Ihor, p. 11)

How did mothers feel that having a deaf child might impact their dreams for their child's future? How did they understand the way to success in life for their children and how did they relate this issue to the attitudes toward deafness in the society? And how did mothers see the role of parents in the life of their deaf child when their child grows up? One answer may be found in the following parental comment:

You know ... once somebody said, 'Listen, hearing loss is just a special need ... your child is different' ... I don't think that is true. I don't think that is a good approach to such families as ours. Deafness is an illness which unfortunately cannot be cured. Do you think that parental feelings will change if you wrap up a disability of our child in a nice wording? [Accept that there is no big problem] My child's self-esteem and his future does not depend on nice wording. My child's self esteem and his future adult life depends mostly on how we parents will manage to provide a good education for him, a good vocational training, and good starting point for his adult life. (Taras, p. 9)

As mentioned earlier many parents at first spoke mostly pessimistically about their fears and concerns. However, in answering the next question switched to quite an optimistic mode sharing their dreams and thoughts for the future. Dara explained that amazing twist in emotions revealing what was inspiring and moving to the parents:

Every visit to a doctor or a specialist, every major event used to be a complex event. It would combine hope and fear, joy and disappointment ... I was always overwhelmed. Hope has always been the biggest feeling. Hope for some positive changes in my son's hearing ... hope for the progress in the development of speech ... hope for success in schooling ... hope for some good news for me and my son ... and a big hope for the future. However, while planning for tomorrow and dreaming for the future it is always important to keep in mind that we have to *live* today. That is why when we are sad we always keep joy in our heart and vice versa. (Dara, p. 8)

Summary

The data presented in this section details parental responses to questions which were intended to highlight and expand on data retrieved through the survey. It is organized through the Map of Themes which initially had been developed on the basis of the interview protocol before the analysis started. Thus basic categories were predetermined and corresponded to the section titles of the semi-structured interview. However, the Map was modified and expanded during the process of coding and analyzing as several additional factors surfaced alongside the research questions. New themes such as difficulties with arranging a reliable hearing test and obtaining the diagnosis, parental reactions to the diagnosis, strong prejudices and beliefs towards

deafness and deaf people as well as existing one-sided attitudes towards signing and signed language emerged from the study and gave insight into the experiences of the families.

After the identification of hearing loss in their children all parents were shocked and devastated. Participants described emotions similar to those experienced during the process of grieving. Most often they reported feeling helpless and not prepared to meet the challenges. Even though the outside professional view of the problem was expected to lower the stress of parents and provide clear guidance it often introduced additional stress and difficulties and parents attributed that to both lack of training and indifference of the staff and a lack of technical resources for reliable testing. Additionally, participants often felt they were abandoned to face their troubles alone and wasted much time in guessing and hesitating when an immediate reaction or decision was required.

Almost all participants reported lacking both choices in educational placements and support in developing an effective family communication system, as well as confusion and frustration in sorting out the official approach towards signing and the existing reality in the preschool programs.

In general, the data presented the following major issues and concerns of parents:

- A child's identified hearing loss is an unhappy reality for hearing parents which strongly impacts parents both emotionally and financially;
- After identification of their child's hearing loss parents confronted many challenges and decisions for which they were not only unprepared but did not even have any reliable information. They also were often confused and frustrated because of the existing myths and prejudices in the society along with the contradictory information received from different sources including professionals;
- Communication was identified as the most challenging and stressful factor which was also named as a lifetime concern by most participants;
- A low income reported by most families put those families in the poverty zone according to Ukrainian standards;
- Even though most parents reported lower levels of stress as compared with the period after the identification of hearing loss they did not demonstrate much confidence in the future of their children.

Additionally, the data emphasizes the importance placed on shared experiences among parents. Deaf parents, especially were named as one of the reliable and valuable

sources of information and support in the process of coping with the consequences of the child's hearing loss.

Chapter VI. Discussion

This chapter includes an interpretation of the data collected to address the research questions that guided the study. The interpretation parallels the list of research questions; except that, the discussion of communication and signed language is combined. The discussion includes the interpretation of the data taking into account the Western literature as well as the Ukrainian context .

What are the Characteristics of Hearing Families with Deaf or Hard of Hearing Child(ren) in Ukraine?

The survey findings regarding the demographic and sociological characteristics of the participating families and their deaf or hard of hearing children have been reported in chapter 5. This study revealed that Ukrainian families with deaf and hard of hearing children exhibited the heterogeneity found among deaf and hard of hearing children and their families reported in the international literature; however, in other respects the characteristics of these families differed from the data reported in international research. Differences also were discovered when this sample was compared to the general population of the country with respect to employment and family income. The differences that emerged are relevant to understanding deafness in the Ukrainian context and they are discussed separately for families and for children.

As was previously stated in chapter 2 Western literature identified the following family characteristics of both children and parents as being especially relevant and important to the success of early intervention and family functioning: a child's hearing level, age at identification, the presence of additional medical conditions, parental age, education, and hearing status, racial/ethnic membership, communication mode, family income, gap between age of suspicion and identification, and gap between age of identification and initiation of early intervention services (Kluwin & Corbett, 1998; Luckner & Velaski, 2004; Meadow-Orlans & Sass-Lehrer, 1995; Meadow-Orlans et al., 1997; Meadow-Orlans et al, 2003). The survey and interview data bare out the above statements on family and child characteristics to be important in the Ukrainian context too.

Families

The hearing status of the parents is a characteristic that has a bearing on the success of early intervention thus the proportion of hearing parents and parents who are themselves deaf or hard of hearing has been the focus of international research for a long time (Mitchell and Karchmer, 2004). Statistics on this proportion in Ukraine are not

available in the research literature since there has been no research conducted in this area. Based on the 325 respondents whose hearing status was reported in the survey, 12.1% of mothers and 11.7% of fathers are either deaf or hard of hearing. Altogether, the hearing status of 616 parents (316 mothers and 300 fathers) was reported in this study and 11.9% were deaf or hard of hearing. The proportion of deaf and hard of hearing parents in this sample is more than twice higher than that reported by Mitchell & Karchmer (2004) for the United States; however, it is close to that reported by many researchers in the past that indicate that ninety percent of deaf and hard of hearing children were born into hearing families (Andrews, Leigh, & Weiner, 2004; Calderon & Greenberg, 1993; Koester & Meadow-Orlans, 1999; Moores, 2001a; Scheetz, 2001).

Reporting ethnicity and cultural background of the participants which is common in research conducted in the West has not been the tradition in Ukraine. Instead, government and researchers report statistical data on nationality and spoken languages. According to the Ukrainian Census 2001 (DerzhStat, n.d.) most of Ukraine is inhabited by Ukrainians and 77.8% of them speak Ukrainian. Russians constitute the next largest minority group at 17.3%. All other minority group nationalities in Ukraine, such as Belarusians, Moldovans, Crimean Tatars, Bulgarians, and others constitute 4.9% of the population.

Of the 318 families in this study 27.7% named Russian as their primary language which is 10% higher than the national average reported in the Ukrainian Census 2001 (DerzhStat, n.d.). The number of families who spoke primarily Ukrainian was lower in this survey study than that reported in the Census data and comprised 58.2% of all participants. Additionally, 11.9% of families reported using Ukrainian Sign Language as their primary language; 2.2% families use another language at home which is half the number reported in the 2001 Census which stated all other minorities constituted less than 5% of the population of the country. The relevance of language identification for the success of intervention is yet to be established.

Family income can be expected to impact the effectiveness of intervention. The family income information collected in this study clearly indicates that more investigation on its impact is needed. Almost 58% of the survey respondents reported a monthly income officially below the poverty line and another 41.4% belonged to a low income group. Higher unemployment among participating families may be one of the reasons for the low family income. When comparing unemployment among the mothers who participated in this study with the national norm of 6.7%, as reported for adult females in

September 2007 (Derzhavna Sluzhba Zayniatosti, n.d.), the percentage reported in this study was much larger and reached as high as 52.5% . This situation may be explained partially by the fact that the respondents in this sample had young children in school or preschool and mothers may have chosen to stay at home, as was conveyed by several mothers participating in the interviews. However, the unemployment status among fathers comprised 13.9% and was almost twice the 7.0% national unemployment rate for adult males. This discrepancy between official unemployment levels and those revealed in this study is difficult to explain. No doubt being unemployed imposed additional pressure on the parents who raised financial issues frequently during the interviews and these issues likely have had an impact on family functioning.

Children

In the Western literature a number of characteristics of children were found to be salient to family functioning. They were: child's hearing level, age at identification, the presence of additional medical conditions, communication mode, gap between age of suspicion and identification, and gap between age of identification and initiation of early intervention services.

All children in this study were enrolled in special residential schools or preschool classes either for deaf or hard of hearing students. Information on the average age of the deaf and hard of hearing children when hearing loss was suspected (17 months) and identified (24months) as well as the time lag between these two dates (7 months) was close to the situation typical for the United States in the 1990s before newborn hearing screening (Marschark, 2007). However, in Ukraine, on average, children in this study received their first hearing aids at 41 months which constitutes a time lag of almost two years between the identification of hearing loss and the fitting with hearing aids. This delay in combination with the fact that 124 children in the study did not attend any preschool at all before attending a residential school is likely to have had a critical impact on the language development of these children and no doubt played a role in the low levels of parental satisfaction with communication and deserves further research.

In this study 39.6% of the children were reported as having one or more medical conditions. This number is 5 to 9 percent higher than that reported in the review of international literature (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Meadow-Orlans, Smith-Gray, & Dyssegard, 1995; Schein, 1996). However, according to V. Fedoruk (personal communication, March 12, 2009,), there might be more children who have hearing loss along with other medical problems and a diagnosis of more severe medical

problems could mask possible hearing loss. Fedoruk also expressed his opinion that it will take a long time for Ukraine to put in place an effective system of identification of possible hearing loss in such children.

Only two children were reported by the respondents of the survey to be fitted with the cochlear implants. This proportion for this age group is much below the average numbers published for Western countries. According to Sushko, Borysenko, & Srebniak (2007) this type of surgery is conducted only in the Institute of Otolaryngology and only 31 surgeries on cochlear implantation were conducted during 2004-2007. The surgery itself is free like other kinds of surgery in Ukraine but the parents are responsible for the purchase of the implant the price of which exceeds thirty thousands U.S. dollars. This price “looked unbelievable” to the participants of the interviews who were recommended to consider fitting their child with the cochlear implant. Taking into consideration family income of the participants discussed earlier in this chapter and the statement of Myra below one will understand the reasons why cochlear implants have not made their way in this sample:

I have heard about implants ... but you know ... there is no use to talk about such expensive things with such poor people ... we cannot even think about it. (Myra, p. 9)

What factors are perceived as challenges by hearing parents raising deaf or hard of hearing children?

The parental interviews include many long and short stories about the challenges and everyday hardships of their family life. These stories encompass life with a deaf or hard of hearing child from the very first suspicions of something amiss until the interview which took place right after the child had been enrolled in the residential school. The challenges that emerged as most prominent from the perceptions of the parents were: the shock of realizing one’s child has a disability; societal negative views of deafness; lack of information about deafness and family strategies for caring for a deaf and hard of hearing child; increased family stress; wearying transportation demands and separation from the child; and economic hardship.

Meeting with Deafness: Unknown and Shocking

This study shows that in Ukraine there is an almost unanimous understanding of deafness as a medical phenomenon. In order to understand what deafness means to the participants of this study it is important to consider what people actually know about

deafness and deaf children, how they perceive it and the way society views this phenomenon.

Scheetz (2004) noted that “volumes had been written about the grief hearing parents experience when they discover their child is deaf. Much of the grief is a result of the way society views deaf people” (p.53). Based on data reported in 1990 for the United States, Meadow-Orlans notes that “most parents of deaf children have never known a profoundly deaf individual (meaning born deaf and using signed language for communication)” (Meadow-Orlans, 1990, p.285). These findings of Western studies were confirmed by the respondents to this survey and set of interviews. At the time suspicions of hearing problems arose, most families participating in the interviews of this study, with the exception of one deaf family, knew almost nothing about deafness, had not met any deaf people and knew nothing about life in the deaf community. Answering the questions regarding available information on deafness, 51.4% of respondents reported that they did not have enough information even after their child had been identified with a hearing loss. Some of them spent years seeking and gaining important knowledge and information.

As a result of ignorance and a lack of information about deafness in contemporary Ukraine a widespread view about deafness, confirmed by study participants, equates it with mental retardation. This assumption is leading people to think that those who were born deaf and used “signing and mimicry for communication were probably not mentally normal” (Yara, p. 1). This myth likely contributed to and aggravated the feeling of shock and frustration in parents. They feared that mentally challenged people could not be effectively educated. Findings of the interviews indicate that in many cases, families clearly held the perception that people with disabilities were stigmatized by others in the community. Their perceptions of how and why this stigma existed did not vary greatly. Participants reported ‘strange’ looks from patrons in local grocery stores, in the church, or in the buses who would often think that “if it is a deaf child there is something wrong with him or his parents” (Ihor, p. 3). In several cases relatives or neighbors started ignoring the family with a deaf child. Some doctors and professionals were too critical and parents got a feeling that they intentionally were giving biased information to reduce expectations for the child. It seems that the lack of public awareness and prejudices against deaf people in Ukraine are more severe than in the West and may have caused greater stress for the parents of a deaf or hard of hearing child.

The situation on deafness awareness and availability of relevant information for parents in this study in 2000/01 (when most of their children were born) in Ukraine was very similar to that in the United States 10 years earlier in 1990 as reported by Meadow-Orlans (1990). In 1990 deafness and hearing loss were identified as a handicap according to the World Health Organization (1992). However, unlike the United States which according to Meadow-Orlans, Mertens, & Sass-Lehrer (2003) and Marschark (2007) has made good progress in developing awareness of the issues of children's disabilities and special needs in their society, the situation for deaf children and their parents in Ukraine seems to be changing very slowly.

Participants of both survey and interviews reported that there was no place where they could get balanced and reliable information they required as well as no specific support services were provided except hearing tests and purchase of hearing aids. The most vital information required by parents initially was "how my child would live with this loss" (Katia, p. 5). Parents badly needed specific information on how to raise their exceptional child because they had no experience from their parents or the raising of other children to draw upon.

Findings from this study supported other Ukrainian researchers who have stated that there is not a single officially registered educational institution in Ukraine that can offer a program in family counseling that would be in line with international practice (Hroza, 2006; Kisarchuk, 2003; Zasenکو, 2001; Zhuk, 2006).

Life changed after the diagnosis. The participants of the study confirmed that parents of children with disabilities face a long process of coping and adaptation. After noticing the first symptoms of something being 'wrong' with their child most parents reported feeling helpless, frustrated and fearful of starting to identify the possible problem. It took parents from months to years to realize that their child's behaviour varied from that which would be considered "normal".

Some parents tried to shield themselves by "simply trying to bury ... head in the sand a bit" (Svita, p. 1) or through denial. However, none of the participants claimed that they had actually denied the existence of the problem, rather, most of them hoped to find some natural explanation such as a possible effect of medications (Olia p. 1) or a temporary illness of the child (Katia and Dara). Others just decided to wait hoping that everything would be okay.

After the identification of deafness or hearing loss in their child all parents travelled a long road of coping and adaptation which was very similar to that described

by international research reports (Feher-Prout 1996, Calderon and Greenberg, 1999; Calderon & Greenberg, 1993; Lederberg, 1993; Lederberg & Everhart, 1998; Lederberg & Golbach, 2002; Luterman, 1987; Luterman & Ross, 1991; Meadow-Orlans, Koester, & Spencer, 2004; Moses, 1985; Quittner, Glueckauf, & Jackson, 1990; Schlesinger, 1987). The reactions of parents to the diagnosis and new life circumstances described in the above literature almost mirror feelings of most parents in this study who realized that “something had happened to the child and I did not have any idea what kind of trouble it was, nor the skill ... or even the knowledge of what to do to help her” (Ania, p. 2).

Many participants of both the survey and the interviews stated that the diagnosis of hearing loss resulted in an abrupt change in their lives. Some participants were more successful in gaining control over negative emotions while others were still in the process of coping and adapting. Both survey and interview findings in this area seemed to be in accordance. Three-thirds of all the interviewees stated that the diagnosis was a huge shock resulting in feelings of pain. They reported the highest level of stress on the provided scale. At the time of the interviews almost half of the participants stated that their stress was lower. The opinions split into two camps: twelve parents participating in the interviews expressed thoughts similar to Zenia who had “reconciled to the diagnosis and to ... destiny” (p. 8); while others stated that they had not yet adapted to new circumstances of their life and that “the feeling of pain and mourning is constant and something that started once and will not end. It will last forever” (Taras, p. 9).

According to the survey data the proportion of those respondents who stated that ‘stress in their family was related to child’s hearing loss’ (40.6%) was less than of those who did not agree with that statement (45%). Even though some of the participants stated that they had needed professional help and advice of a psychologist none of them even thought about seeing a professional since Ukrainian society connects such therapy with mental problems and the stigma would be unbearable. In Ukraine psychology has been a part of psychiatry for decades and has only recently become an independent discipline.

Life became more difficult. Almost 60% of survey respondents confessed that their life had become very difficult since their child had been diagnosed with special needs because their ‘child was consuming much’ time. At the same time 52% of them stated that they ‘could still find some time for themselves’. At first sight it seems that there is a contradiction between these two responses but the seeming discrepancy can be explained. ‘Having a difficult life’ is a much broader category than ‘still being able to find time for oneself’. Another more partial explanation of this contradiction might be

the fact that a number of families lived in the vicinity of schools and did not have to spend as much time as others on trips to schools twice a week.

Those weekly trips along with the five day stay of the child in the residential kindergartens and later in the residential schools were labeled as one of the biggest difficulties for the families. They disturbed parents emotionally and physically as participants reported trips from 50 to 200 kilometres. Several parents also reported that they could not afford to take their child home every weekend for financial reasons. Almost all parents who lived far from kindergarten or school locations mentioned that they had to subordinate their family life cycle to the schedule of those trips which made them “spend their life on wheels” (Nusia, p. 8) and weekends “were filled with packing and travelling” (Taras, p. 8).

Another finding was that parents from rural areas tended to evaluate the existing system more negatively than others. Families which lived in villages or far from big cities found themselves in the most disadvantaged situation. Their evaluations on a lack of adequate services were more negative than those reported by the participants from urban areas. Additionally their complaints centered on transportation problems when attempting to reach services in provincial centers or obtain referrals to the professionals.

The issue of ‘economic privation’ also proved to be critical in the context of this study. Many parents discussed the financial burden they suffered due to the huge expenses required to meet the added demands of an exceptional child. This common financial complaint heard in the interviews was supported by the data from the survey. Why were most of families in this study in the most financially disadvantaged group of the Ukrainian population? This issue might be a separate topic for further research.

Adjustment. Every individual family participating in this study has made its own unique adjustment to having a deaf child and each depended greatly on the extenuating circumstances and the context at the time the diagnosis first became known. Moores & Meadow-Orlans (1990) noted that “previous stability and communicative effectiveness within the family will be of critical importance on the positive side, as will resources of negative external pressure, such as economic privation” (p. 306). This statement was confirmed in this study too. Although one family reported divorce and another one separation, most families survived the hardest times of the diagnosis (frustrations and confusion and expressed circumspective optimism for the future). Both interview participants and survey respondents named their spouses as the main source of support.

Several parents “accepted the disability [of the child] as a punishment from God” which is similar to parental experiences in Latino cultures (Hernandez, 1999; Steinberg et al., 1997). For those families, faith and prayer were cited as main factors in accepting their child’s ‘disability’. These families perceived their religion and spirituality as a positive force in their lives.

Findings in this study also show that initial parental reactions to the diagnosis seemed to be grounded in prejudice and lack of information. Several parents stated that they probably would have not reacted so dramatically if they had known more about deafness and had known the information on deafness and deaf education they learned later.

How do Parents Describe the Nature of Child-Family Relationships, Interaction and Communication at Home? What are their Views and Attitudes towards Signed Language?

As was stated in chapter 2 one of the significant findings of Western research literature was that the child’s communicative competence has an effect on both the parental stress experience and the child’s development. One of the most salient findings of this study is that the greatest percentage of participants named communication as a challenge in the process of raising their child. The study also identified many factors that may contribute to this situation: from late diagnosis, poor support to parents in the child’s early years as well as promoted and discouraged communication styles.

According to the findings of this study, almost all hearing parents were more likely to choose oral communication and preferred their children to stay and function in the hearing society. They viewed deafness as a disability that needed to be fixed rather than a difference which might be celebrated as happens in many deaf families in Western countries (Marschark, 2007). This parental view of communication choice and deafness reflects attitudes which prevail in Ukrainian society.

Communication: Speech vs. Signing

Parents stated that communication issues introduced a great deal confusion into their families. Although a decision about the best mode of communication required time, parent-child relationships and language acquisition could not be put on hold. Lack of information and resources or biased, incomplete, and inaccurate information from professionals made their decisions on how to communicate with their child at home even more difficult. Stress and existing prejudices influenced parents who did not know the options, to fall back on the prevailing oral perspective of ‘child normality’. Almost all parents indicated that after the diagnosis they wanted their child to develop speech skills

and fit into the hearing world. They wanted their child to function “as normally as possible.” Only Dara’s family decided to incorporate signed language into their family communication system right after the diagnosis, not trusting a speech-only perspective. Later she and her family celebrated the consequences of that decision when she was able to compare her own daughter with other children enrolled in the first grade of the school:

Some of those children definitely have had much better developed speech due to private speech lessons and that might help them in communication with parents, however, they still look like strangers among other children who came from the special kindergarten or from deaf families. (Dara, p. 6)

Almost all families participating in this study preferred that their child stay oral but were trapped by the absence of help and support in establishing communication with their children. That is why hearing families looked for auxiliary means to satisfy basic communication needs and intuitively tried incorporating a kind of signing in their homes. Almost 67% of families reported inventing their own home signs. In the interviews parents explained that they had been forced by circumstances to invent their own home signs because before enrolling their child in the kindergarten for children with hearing loss there was absolutely no information, resources or access to signed language. It was much later that parents learned about Ukrainian Sign Language which was cultivated in the Ukrainian deaf community and Ukrainian Society of the Deaf. Several interview participants belonged to the 119 families who confirmed using home invented signs even after their children were enrolled in schools for children who are deaf or hard of hearing. The issue of home signs has been explored by many researchers at the international level. A situation similar to that of Ukraine was described by Emmorey (2002) who explored communication in Nicaraguan hearing families with deaf children. Being isolated from contact with deaf persons, these families developed their own home signs or an idiosyncratic gesture system. Later on, at school the children developed it into ‘pidgin’ and developed common rules of using it in that particular school. Luckily, many Ukrainian children in this study met other peers who were fluent signers. Interestingly, in those countries where national signed languages have been recognised linguistically long ago and knowledge and access to language resources are widespread the meaning of the term ‘home’ sign has changed. According to Marschark (2007) “*home signs* are signs used in much the same way as some special words and names are used in hearing families. Both are most common in homes with small children, often originating from

mispronunciations or mis-signs” (p. 76). If parents can easily get access to the existing signed language there is no need for them to invent their own signs.

Language confusion. Many parents were confused when kindergarten/school personnel advised them to learn signs but there was no support in place to do so. They were advised to learn signs from deaf parents and from their own children. As a result, the lack of communication skills made it almost impossible for parents to be actively involved in the educational process at the beginning of their child’s enrolment in the preschool program.

Additional confusion was experienced by parents when they explored kindergarten/preschool programs for their deaf and hard of hearing children. The confusion was caused by the contradiction between the officially adopted ‘communicative approach’ which was supposed to imply speech and finger spelling’ (Borshchevska, 2007) and the reality most parents discovered that all children were fluent in signing and most teachers and staff also used signing to support their speech. Actually, 84.6% of families reported in the survey that the schools used a combination of speech and some signing which might be characterized by professionals as Signed Ukrainian. Signed Russian was used in some schools located in Russian dominated communities (Kulbida, 2007).

When their children progressed from kindergarten to the school parents discovered another anomaly that signed language which was not officially allowed in kindergarten was taught in school as a separate subject. Every parent asked the same question, ‘Why does the same educational system have two opposite approaches to Ukrainian Sign Language?’

Parental thoughts about communication at home. Lack of balanced advice, absence of resources to learn signed language, an ideologically oriented educational system and negatively impacted family communication systems were reported in a vast majority of cases both in the survey and interview study. Parental general dissatisfaction with their home communication was described in greater detail as being due to poor knowledge of signs by parents and other family members and children’s delay in spoken language and poor vocabulary of spoken Ukrainian.

Although 276 survey participants (84%) reported that none of their family members had had any instruction in signing most families were using a combination of speech and signing at home. However, only 82 (25.3%) respondents considered their ‘communication skills as adequate for their child’s needs’. According to the survey only

149 children (45.5%; $n=321$) could understand simple sentences and only 90 children (27.7%; $n=320$) could use them 'often' or 'always'. Hard of hearing children received higher language scores than deaf children, however this issue requires further research because it is assumed that poor knowledge of signed language by parents did not allow them to properly evaluate their child's language when they communicated manually especially in the case of deaf children when speech was not involved.

There may be several explanations about why families could not communicate effectively with their deaf or hard of hearing child but one reason is common. Parents in this study were convinced that purchasing hearing aids had to be their priority and those hearing aids might improve the quality of communication (oral) considerably. As the participants of the study stated it took most of them a long time to get hearing aids. On average, children in the survey study were fitted with hearing aids only at 41 months. So, between the time of the identification of hearing loss (24/27 months) and getting fitted with the hearing aids (41 months) most of the children in this study could not have speech therapy because it would be useless without amplification. They also did not have access to signing because their parents at that time were afraid of special educational placements for deaf and hard of hearing children.

Most survey respondents did not report any specific problems in the child-family relationships and, in general, positively characterized their child's behaviour at home and in the neighbourhood at the time of the study. However, several parents in the interviews did report unprovoked 'bad' behaviours of their children or doing wrong things which had taken place earlier.

Besides speech delays there were some other problems like erratic behavior. He is our only child ... and we had no previous parenting experience. (Yulia, p. 5)

They had not realized that deaf children were often confused and upset about two communication factors: when they did not comprehend the orders or requests of the adults or misinterpreted them just because they did not hear; and when they could not effectively express themselves to others. Borshchevska (2000) explained that such situations often occurred in preschool placements where children with some unidentified hearing loss used to be enrolled and/or when parents either did not know about the hearing problems of their children or were hiding that fact. Orelove & Sobsey (1991) indicated that children with sensory impairments often use inappropriate behaviours to

serve pragmatic functions such as getting attention, obtaining a desired toy, or attempting to avoid an unpleasant situation.

The respondents' replies to the questions on communication reveal a widespread dissatisfaction which should give rise to concern. It is likely that the communication difficulties have increased family stress and impeded the academic progress of the children. There are several clear factors related to these communication problems. Although it was not the purpose of this study to establish causal relations, this cluster of factors certainly deserves immediate further applied research.

How do Parents Describe the Nature of their Relationship with Professionals at the time of Early Suspicion of Hearing Loss, before and After the Diagnosis?

Western research has identified the relationships with professionals as being critical to the deaf and hard of hearing family. They are critical because these relationships often give rise to early interventions and a growing body of research has documented the positive effects of early intervention for the social and cognitive development of children born at risk for developmental delays. Research findings (Brown & Nott, 2006; Carney & Moeller, 1998; Kurtzer-White & Luterman, 2001; Marschark, 2007; Sass-Lehrer, 2002; Sass-Lehrer & Bodner-Johnson, 2003; Yoshinaga-Itano, 2000) also suggest that interventions that support families and build competence and confidence are more effective than strictly child-directed instruction. What should this early intervention consist of? Research suggests that these are the most critical characteristics of interventions: providing families with the information and skills required to develop and support communication and language in deaf and hard of hearing children; providing general information about deafness and implications for the child and other family members; counseling and support in the process of coping and adjustment and training in managing assistive technology. To be truly effective, early intervention needs to take place immediately following the identification of hearing loss and prior to age 3 to enhance the potential for language and psychological development (Andrews et al., 2004; Calderon, 1998; Calderon & Greenberg, 1997; Hintermair, 2000; Kurtzer-White & Luterman, 2001; Meadow-Orlans et al., 2003; Sass-Lehrer, 2002; Schirmer, 2001).

Problems in Obtaining a Diagnosis

In the survey study hearing loss was first suspected by parents and other family members in most of the 325 reported cases. Responses to the interview question revealed that most parents contacted local pediatricians first, to share their suspicions. Survey data in this study revealed that 48.3%, of respondents evaluated input of pediatricians as 'not

helpful at all'. This finding is similar to that stated in the study of Meadow-Orlans, Mertens, & Sass-Lehrer (2003) which found that in National Survey of parents who were raising deaf or hard of hearing children in the US "many parents were critical of pediatricians who disregarded their concerns and did not quickly refer them to specialists for a hearing test. The most frequent piece of advice these parents gave was "listen to parents" (p.160). The explanation of such similar situations in both Ukraine and United States can be found in the work of Williams & Darbyshire (1982), who as far back as 1982 reported that pediatricians were not trained enough to identify symptoms of hearing loss in small children and suggested that doctors should be more aware of the possibility of hearing loss in their young patients, more willing to view the parents as 'experts' regarding their own child, and consequently more ready to make referrals. "Phrases such as 'It's just a stage' and, 'Wait and see' should be struck from the vocabulary of primary care physicians when there is even a remote possibility of a communication disorder" (p.29).

The average age when hearing loss was suspected for the children in the survey was close to 17 months and on average it was confirmed at age 24 months making the average time lag from suspicion to final diagnosis seven months which is longer than a lag of approximately 6 months confirmed by (Meadow-Orlans et al., 1997) who explored the situation in the United States in early 1990.

Parents participating in the interview started suspecting something was wrong with their child on average one month later than the whole cohort of the survey population and the time lag was two months longer on average than the rest of survey respondents. This time lag varied from 4 months (the shortest) up to more than 24 months in several cases when pediatricians and other professionals minimized parental concerns about their children's inability to hear. This prolonged the time the child did not receive appropriate language input and this kind of delay usually severely impacts the language development of the deaf and hard of hearing children. This particular finding is in line with the survey finding which shows that the age of diagnosis has also had an influence on the language evaluation scores reported by parents. Children with early identified hearing loss (prior to 24 months) scored higher points in language performance than those who were identified later. This is explained as follows: if there is unidentified and educationally untreated hearing loss in an infant, it "results in structural changes in the cortical auditory connections and is clinically evident as delayed speech and language development" (Kelkar, 2006).

The results of the study indicate that most families in this sample did not receive adequate and timely medical support in the health system of Ukraine in identifying hearing loss in the children. Of 17 families participating in the interviews 14 (82%) were referred to the Kyiv (capital of the country) Otolaryngology Clinic as local hospitals were not able to provide an accurate diagnosis because even if they had the required equipment they did not have the qualified staff. At the time that most of the children in this study were born (1998-2000) only two regions in Ukraine had equipment for testing the hearing of children whose age was less than 1 year (O.Savchenko, personal communication, September 28, 2008,). Often patients could be on the waiting list 3 months or longer causing additional stress for the parents. The clinic itself was described as being crowded with people who had come from all over the country waiting in lines.

Parents to professionals: Treat us equally. Parents who received a diagnosis of deafness in their child also noted the lack of informational support from professionals involved in their children's care. They often felt confused both by the way they were treated by professionals and by the information delivered to them right after the diagnosis. This study suggested that this is an area in which opinions are strong and there are relatively few people who are willing, knowledgeable, and able enough to provide all sides of the story and all available viewpoints in the field. Although international practice presents two views of deafness, a medical/audiological approach which perceives deafness as a disability rather than a cultural difference and an ecological model which views deafness as a difference to be accepted (Polat, 2003), Ukraine is more inclined to the disability view. Parents in their interviews stated that almost all medical doctors, except one, as well as many surdologists had repeatedly shown by the type of information they provided that their ideological perspective (speech only) was probably outdated and was not as helpful to families as might be. Because the medical field in Ukraine has historically supported oral communication, many parents were not presented with more than one option for the child. Parents expressed that they could have made more informed decisions had they been given more information about options other than choosing a speech only approach.

Several parents also reported that had they received adequate information they would not have placed their children in regular preschool programs for hearing children because they did not meet the communication and educational needs of children who are deaf or hard of hearing. This finding is supported by other research which indicates that parents want unbiased information from professionals (Christiansen & Leigh, 2002;

Mertens, Sass-Lehrer, and Scott-Olson, 2000; Meadow-Orlans, Mertens, & Scott-Olson, 2003).

Half of parents participating in the interviews pictured medical staff as indifferent and uncaring people doing their routine job, not paying attention to the emotions of parents. The lack of understanding and sympathy on the part of medical doctors and their tardiness aggravated the grief and increased the concerns and worries of parents. Besides diagnosis itself the biggest fear of parents was that their children would not be able to speak if they start learning signed language. This fear took place because neither doctors nor other professionals in Ukraine were aware of the fact that according to Marschark (1997, 2007) there had never been real evidence that learning to sign interferes with the children's ability to learn to speak. Furthermore, Western countries have developed new public awareness which along with newborn hearing screening have greatly decreased parental complaints about a lack of informational support as well as concerns that the information is too one-sided (Meadow-Orlans, Mertens, & Scott-Olson, 2003; Marschark, 2007).

Parents related their confusion caused by the initial information which increased their feeling of powerlessness. They were not able to comprehend the information due to the shock and frustration during the diagnostic process. These thoughts of parents align with the views which were disclosed by Luterman (1999) who pointed out that professionals should not give extensive information to parents [whose children were diagnosed with deafness or hearing loss] at the time of diagnosis and that parents needed time to process what often is devastating news. He also stated that more information can be absorbed during follow-up visits, though parents will experience grief reactions of varying intensity and varying duration.

While appreciating the help and support provided by professionals many parents did not like the way they were treated by them or their manner of communicating. Interactions were seen as positive when a doctor not only provided information and help but also was perceived by the parents as having a pleasant personality and demonstrating kindness, responsibility, openness and desire to help. However, such situations were rarely described by the participants. In most cases the appointment with the professionals was described as "a kind of briefing or instructions" (Zenia, p. 4). Katia expressed a very common view about specialists by characterizing them as people "who were in the position to talk, teach and instruct" (p. 4).

This study revealed from a parent perspective, that professionals who were involved in the process and identification and were supposed to ensure medical help and support failed to build relationships with families in a way that is psychologically comfortable for their patients. This particular finding is consistent with the findings of Early & Poertner (1993) who examined support in families of children with disabilities. They found that those families often appeared quite dependent on medical doctors and other professionals providing services and help; although they often expressed dissatisfaction with the relationships they had with those help providers. Specifically, doctors were reported as being not helpful in understanding the child's disability; its cause, diagnosis, and prognosis. They also failed to assist parents to cope emotionally with the perspective of 'losing a perfect child'.

Interview participants expressed their vision of the way their relationships with professionals should look. All professionals should consider working to build a trusting relationship with those that they care for. From the initial visit parents want to know that they are being heard; their questions concerning etiology, diagnosis, and prognosis are being addressed; and their doctor cares about their child and family. The last but not least is that communication is established in a way that parents trust the knowledge they are receiving concerning their child. Healthcare providers including doctors and surdologists are not only to listen to the parents questions but encourage parents to verbalize their feelings, fears, and worries throughout the testing and post diagnosis periods. Parents will trust the doctors and surdologists who exhibit a genuine interest and concern for their family and who take measures to help them feel valuable and accepted as was seen often in this study when meeting the teachers in the special educational placements. The use of positive reinforcement for concerns about appropriate care of the child (Yulia: doctors addressed parental concerns during a visit to the clinic in Kyiv) or for development of communication skills (Dara: a unique advice of the medical doctor to include signing in the family's agenda) might be a good strategy that a professional can use to establish trust. Unfortunately, parents in this study felt that most professionals they had contacted did not care about establishing trust and warm relations with them. But most importantly the relationships with professionals did not provide the needed services and the services that were provided were attached to serious time lags. The significance of this is that the children lost valuable time during which their communication and cognitive skills were not developing to the level that they could.

What Kind of Services and/or Intervention Programs were Recommended, Available, Accessible, and Accepted by Parents?

How and Where to Study

The preceding section and the Western literature outlines in some detail the services and intervention programs that can give deaf and hard of hearing children the developmental opportunities that can assure their cognitive development on par with hearing children. The information about signing, deafness, family functioning has already been noted.

Findings from this study revealed that there were only a few commercial hearing rehabilitation centres and surdological centres (affiliated with the hospitals) in the country which could provide sessions on speech development. Few participating families could afford them.

Parents talk about benefits of special educational placements. The survey study show that 189 (60.3%; $n=313$) children had been enrolled by their parents in organized preschool programs. In most cases these children were enrolled in special kindergartens or preschool programs in the special schools for deaf or hard of hearing children. However, some parents, hoped to protect their child from being involved in deaf education and the deaf world, and so enrolled their children in regular kindergartens for hearing children. Two families in the interview study acknowledged that this was a mistake as the setting was inappropriate for their children. They further shared their satisfaction when they corrected the mistake by moving their child to a special kindergarten for children with hearing loss. They witnessed amazing progress in the overall development of their children as compared to the preschool programs for hearing children. Nusia stated, with tears of joy in her eyes, that “after we moved our son to a special kindergarten it was like a relief for him. He became much more active and happier” (p. 8). After their children were enrolled in the special kindergartens or moved from the kindergartens for ‘normal’ children parents discovered those settings helped them to recognize, accept, and value their child’s positive qualities. A school setting in which children and parents encountered other children and parents who had already made successful adjustments to deafness provided needed solace to families. Furthermore, the modeling of fluent and ‘animated’ communication between deaf parents and their children encouraged parents in the study to learn signed language to communicate more effectively with their own children. Most parents participating in the survey expressed their general satisfaction about preschool programs and appreciated the progress in

language and communication their children had made at the time of the study as compared to the level of their children's communication skills and language prior to the program. Most importantly, they were grateful to have teachers and staff who were specially trained in educational methods designed to optimize educational opportunities for deaf children.

Parents also revealed that a lack of choice of educational programs left them conflicted between an academic program for their child and their own social needs. In short, they were afraid that if their child was enrolled in the specialized program for children with hearing loss they would lose hope for their child to speak and function in the hearing society. However, a deep immersion in the life and functioning of the preschool programs helped some parents to rethink their priorities and re-establish family goals concerning their deaf child making their vision of the future for them realistic including achievable goals.

Parents listed additional benefits of having their child enrolled in a special (residential) placement, namely having peers who signed and teachers who tolerated signing, having both individual and group speech sessions for children, child-focused programs, small groups during educational activities, caring staff. In fact, most parents characterized the special educational setting similarly to Marschark (2007) who wrote that special educational placements for the deaf "are the places where life-long friendships are formed, language and culture are learned, and where teaching occurs directly without the need of intermediaries such as interpreters" (p. 144). Interpreters have never been used in the educational placements for the children with hearing loss in Ukraine. Hearing parents in the study revealed that deaf children of deaf parents looked more prepared for education and credited that fact to the natural communication existing in the deaf families with deaf children.

Although some parents in this study at the time of the interview still insisted on their oral preferences for their child, all parents expressed how pleased they were that their child was able to openly communicate with their friends and teachers in their own language especially Svita, Ihor, and Olia who spoke about their intentions to overprotect their children in the past. It was only when their child was in the kindergarten that parents started realizing how the prior treatment of their children like small babies and attempts to protect from contacts with other children had reduced their child's potential autonomy and increased risk of loneliness for both the child and parents (Svita, p. 8).

Drawbacks of special educational placements. Parents expressed frustration with a lack of choice for educational placements for their children. State residential preschool programs (kindergartens) and special schools which are separate for deaf and for hard of hearing students remained the only option for this category of child. Mentioning this fact as one of the drawbacks of the whole system parents listed several concerns unique to the residential kindergartens or schools. The existing official ban on using signing to support speech was the most frequently reported concern. Several parents noted that according to the rules signing was officially considered a big obstacle for the development of a deaf child. However, teachers explained that the reason signed language prevailed in the communication process in the preschool programs was that “for children of deaf parents signed language is their only language from birth” (Myra, p. 8) and it was impossible to prevent them from signing and “to prevent all other children [with hearing parents] from learning it”. In order to successfully communicate with the children teachers were induced to learn signs from deaf parents and their children. Although the teachers understood the benefits of using signed language in the education of deaf and hard of hearing children the education system neither encouraged them to improve their signing skills nor provided them or parents with any help in learning signed language.

The thoughts of many parents expressed in the interviews reflect Y. Kramar’s (personal communication, March 16, 2006) view that, with rare exceptions, support for parents who have young deaf or hard of hearing children or preschoolers is poorly organized. Neither schools in general, nor teachers individually, have special sessions with parents. They only provide group meetings which cannot provide comprehensive guidance for parents (Y. Kramar, personal communication, March 16, 2006). Parents in this study felt that they were not encouraged to be actively involved in the preschool and school life or become a part of a decision-making team. Several parents expressed their disappointment, saying that there was no way for them to influence how the program runs and the way their children were being taught. This finding is in accordance with Malynovych (2007) who stated that the participation of parents in the educational process is weak and Hroza (2003) who found that there was no established systematic educators’ involvement in family counseling and support. Komarova and Pursglove (2004) also stated that special kindergartens for children with hearing loss limit their work with families to week-end homework if anything.

Finally, hearing parents who wanted their child to have more emphasis on speech development found no services to support them. They considered one of the biggest drawbacks of the education system was that every oblast had only one preschool program which often accommodated both deaf and hard of hearing students. This situation made many parents whose children had mild hearing loss feel uncomfortable with signing in the program but had no other choice except moving the child to a school in another oblast where signing was used less during classes. According to the survey data several parents enrolled their children in the schools situated in neighbouring oblasts which usually required extra paperwork and obtaining additional permissions.

What are Parental Thoughts and Feelings about Raising a Deaf Child?

Parents' Thoughts about Past and Future

One of the tenets of family-centered research of deaf and hard of hearing families was stated in chapter 2: an understanding of the impact on family life, understanding feelings and thoughts of parents raising a deaf or hard of hearing child is critical to addressing all components of the family system in early intervention. Mutua (2002) supports this tenet in the following statement: “research in the United States and elsewhere shows that parents’ ideas play a critical role in the outcomes those children achieve” (p. 189). This study is the first documentation of these parental feelings in research literature in deaf studies in Ukraine.

All the parents in this study when asked about their hopes, expectations, and hopes for the future expressed their desire for the successful accommodation of their child in hearing society. They defined the ‘future’ for their child as being able to ‘fit’ into adult life, which included acquiring enough communication and vocational skills and after the completion of education to get a good job that, would provide autonomy in their adult life.

These thoughts of parents are in line with Marschark (1997) who defined three factors which have central implications for deaf children’s competence in dealing with the world in their post-schooling life: early language experience, diversity of experience, and social interaction. Marschark (1997) also stated that “it is difficult to separate child-related from parents-related factors in deaf children’s successes and failures” (p. 237). This statement found its confirmation in this study too. Those parents who were more actively involved with their children and managed to develop more positive attitudes to their child’s hearing loss reported more positive evaluation of the current situation.

Even though they acknowledged the high level of unemployment among the deaf community members and that “the list of jobs for the deaf is very short [due to medical restrictions]” (Yulia, p. 9) they expressed their hope that academic achievement and vocational training at school and elsewhere would allow their child to build a successful life after schooling was completed. This study is in line with the reports of other researchers (Marschark, 2007; Moores & Meadow-Orlans, 1990; Mutua, 2002) that educational concerns and social concerns including careers and jobs after schooling were inextricably combined for many parents.

One finding of this study is that many parents credited the special kindergartens and special schools for giving them confidence that their children will have a successful life after the completion of school. These participants used their positive parenting experiences in the present to change and reconstruct their understandings of past experiences. They also expressed an appreciation of the results already achieved by their child by the time of the interview, which helped them to express more optimistic hopes for the future. Halia directly connected her family hopes with the already achieved success of the child; “I believe in my child and her success very much. We are all working hard and we can see the results” (p. 9).

Parents who expressed more positive attitudes often contrasted their past and present experiences. In their past parenting experiences going for a walk or going out in public became stressful and difficult. But with their latest experience of enrolling their child in the least restrictive educational environment and meeting other parents came an appreciation for the ordinary: a renewed sense of living more fully in the present and a renewed sense of hope and optimism for change:

I hope for a bigger future for my daughter. I am thinking about college education. (Ania, p. 7)

A few other parents in the sample expressed concern regarding the uncertainty of their child’s future. That is, they were not sure who will be helping them in taking care of their child after the completion of school because they were not ready to take the responsibility in full. These participants were more pessimistic concerning the future often referring to the fears and concerns associated with past sad experiences and even existing problems in the country, both political and financial. At the time of the interview they had not yet adjusted to their circumstances nor accepted the realities and unintentionally stigmatized their child by “waiting for the miracle” (Myra, p. 7; Vlada, p.

3) of their child starting to talk one day. They expressed a lack of confidence in themselves and their own abilities to manage the problem. At the time of the interview those parents considered their child as a disabled individual and they relied mostly on others (doctors or teachers) or the government to take care of their child in the future, by providing free vocational training or securing jobs. As a result they had a more limited vision for the future of their child and did not see “any positive future for the child” (Katia, p. 9). These responses were somewhat similar to responses in the survey where 62.8% ($n=325$) admitted that they ‘had to forget many dreams and hopes for my child because of hearing loss’. So, parental optimism about the future of their child was mostly based on the academic achievements of their child at the time of the study and their own confidence that they will be able to support their child after school completion.

Parents Advise Other Parents

The overall view held by parents in this study was that parents are to consider their children first, provide a normal childhood experience for them, and, most importantly, foster their child’s self-esteem as well as help them to develop good qualities such as being smart, determined, funny, and successful in learning. They suggested that the extent to which a child became really ‘different’ from other children depended on the parents’ approach to parenting and overall beliefs.

Parents stressed the need to get passed the stage of shock and grieving which emerged after the identification of a hearing loss because if the period of grieving, inactivity, and apathy of parents lasted too long, the child would suffer. Many parents emphasized the importance of meeting other parents who had similar experiences and seeking their knowledge and support. They revealed that meeting other parents, especially those who already passed the stage of grieving, helped them to pull themselves together and to start hoping for a better future for their child. This finding is in line with international research. Hintermair’s (2000) study in Germany revealed that parents who often met with other parents of deaf and hard of hearing children reported less isolation, stronger emotional bonds with their child, and greater acceptance of their own child. Calderon and Greenberg (1999) reported that American mothers adjusted more effectively to the hearing loss of their child due to the social support they received, including meeting with other parents and sharing their thoughts and experiences.

Special kindergartens or preschool programs were the only places where parents participating in this study had an opportunity to meet other parents who had deaf or hard of hearing children. There all contacts were informal as there were no organized support

groups. Parents mentioned that those meetings were very important to help them calm down as well as to learn about signing and signed language as an alternate communication option to the oral perspective. Several parents regretted that those meetings had not happened immediately after the diagnosis because sometimes it took them too long to muster up the courage to arrange a visit to a special kindergarten because they were afraid to enrol their child there. Parents also recommended that the kindergartens take advantage of meetings of hearing and deaf parents in order to formalize parental groups to discuss, modernize, and advance their curriculum and communication policies.

Parents also emphasized the importance of educating themselves and not completely relying on the professionals, as well as the need to thoroughly study the legal and educational rights and government provisions for their children and their families. Most of parents stressed the necessity to have another opinion from the medical field in order not to make the same mistakes as many of them had made when some of them had not insisted on getting a referral for a hearing test.

Even though the survey respondents named their spouses as the best source of help several mothers in the interviews expressed distress because of their spouses' low involvement in the raising of their deaf child. They recognized much help and support but many fathers were not involved actively in day to day parenting activities. Myra described that it was the mother who usually had to sacrifice her career and stay at home to raise a child according to the stereotype in the society: "It is the mother who usually spends most of her time with the child and is supposed to raise him or her" (p. 6). Participants strongly advised that both spouses equally participate in the education and interactions with the deaf child at home. And even though fathers were frequently not available to deliver their child to school and back many parents revealed that it was important that fathers be involved in those regularly scheduled family events too.

Deaf Family Talks about Raising a 'Healthy' Child

One deaf family that participated in the interviews reported many similarities with the situation of other deaf families described in the international research, namely, exploring life and functioning of deaf families with deaf children as well as family members' thoughts on deafness and other related issues (Andrews, Leigh, & Weiner, 2004; Lane, Hoffmeister, and Bahan, 1996; Leigh, 1987; Marschark, 1997; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Moores & Meadow-Orlans, 1990; Scheetz, 2004).

The Deaf parents in this study showed that they were very open to the possibility of having a deaf child, primarily because they called themselves “deaf in the second generation and having a deaf child was kind of expected” (Olena & Petro, p. 1). They described their reactions to the prescribed hearing test of their child as being “curious if their child could hear anything” and “not having any notable emotions because they had expected that their child might be the same as them and were happy that their child was healthy and had no ear infections” (p. 3). Contrary to hearing parents who were shocked and frustrated the deaf family showed confidence and stayed calm after the diagnosis.

Lane, Hoffmeister, and Bahan (2006) expressed an opinion that some culturally deaf parents could experience temporary disappointment if their child was also identified with hearing loss, considering that the child might face many extra challenges in life. However, the position relayed by the deaf parents in this study showed that although they admitted that it would be more beneficial for their son to have good hearing because it would ease his life, the fact he was diagnosed with hearing loss did not frustrate them. However, Olena did reveal that the biggest excitement would have been if “our son could hear and speak ... because it would be so nice to have somebody at home to talk to and have talk back to [her]” (p. 2) because she herself was hard of hearing and was teaching her son to talk.

The deaf family revealed that they had the same ‘normal’ concerns for their child as other families [with hearing children] and said that the most important thing was to have a healthy child.

In talking about their contacts with medical doctors and other professionals deaf parents were upset by the fact that sometimes they felt that they were not treated as equals by the people who did not know them. The deaf family wished that hearing doctors and other ‘professionals’ had some knowledge about the life and traditions of deaf people and the deaf community instead of operating with outdated myths and beliefs.

Surprisingly, the deaf mother of a deaf boy stated that even though her boy was very fluent in Ukrainian Sign Language she insisted that he practice speech with her. She explained that she wanted to improve his lip reading and acquisition of speech because as an adult he would have to spend a lot of time with hearing people in society which has not adapted to people who cannot hear. They did not express any offence and showed tolerance and deep understanding of the feelings and emotions of hearing parents whose children were deaf or hard of hearing. They said that they both were trying to help

hearing parents to learn signs and expressed disappointment in the fact that the government did not provide any support to hearing parents in learning signed language.

Deaf parents opted for the special school where they both had studied before. They described the school as a place that provided full communication accessibility and the best socialization opportunities with deaf peers and adults. They were very happy that signed language had been given its place in the school in 2006. Their only complaint was that they wanted some deaf or hard of hearing teachers to be hired and for the hearing teachers to make more of an effort to learn a real signed language.

“We Feel Proud of what We have done for Our Child”

The participants listed not only the many challenges both directly connected with the child’s hearing loss and those that usually accompany the life of any family they also highlighted bright moments in their life. Among other moments they mentioned the enrolment in either a special kindergarten or in a preschool program at the special school for deaf or hard of hearing children and the first understandable words spoken by their child. Some parents concluded that being a parent of a child with hearing loss is a hard and exhausting mission but no less rewarding for that. The diagnosis just changed their life; then the first words pronounced by their child inspired them and gave them new hope and new expectations. In spite of all difficulties, challenges and hardships more than half of the participants of the survey and interviews study felt proud of what they had done or were doing for their child.

Summary

This section summarizes significant findings referring to the research questions of this study.

1. What are the characteristics of hearing families with deaf or hard of hearing child(ren) in Ukraine?

As in international research the families of deaf and hard of hearing children are fairly heterogeneous; however, some major differences have been noted: the proportion of deaf children among the total number of the children of school age was 2.5 times higher than in the United States as well as the proportion of deaf and hard of hearing parents in this sample is more than twice higher that reported for the United States at present. It also turned out that unemployment among parents in this study exceeded two times the national rate of unemployment as of September 2007 and the monthly income of families was much below the national level too with 57.7% living below the official poverty line and another 41.4% families just above it.

As for the children the time lag between when a hearing loss was suspected and identified was close to the situation typical for the United States prior to the introduction of newborn hearing screening (Marschark, 2007). The average time lag of almost two years between the identification and fitting of hearing aids is much greater and should be of concern. Only two children from this study (0.6%) were fitted with cochlear implants. The proportion of children who have additional medical conditions was 5 to 9% higher than findings in other countries which usually report that one third of the total number of the children belong to this category. This also deserves further attention.

2. What factors are perceived as challenges by hearing parents raising deaf or hard of hearing children?

This study has identified and reviewed some of the challenges and stresses experienced by hearing parents following the diagnosis of hearing loss in their child. This study confirmed that for this sample of hearing parents it was common to go through stages of grief and coping traditionally described in international research. The data presented the following major issues and concerns of parents:

- A child's identified hearing loss impacted them both emotionally and financially and they did not have access and were concerned about the stigma attached to seeking personal counselling;
- After identification of their child's hearing loss parents did not have access to reliable information regarding how to best care for their child;
- Furthermore, because of the existing myths and prejudices in the society which they often shared until they experienced living with a deaf or hard of hearing child, they feared for their child and had to deal with family members, neighbors and strangers who exhibited these prejudices;
- Poor communication was identified as the most challenging and stressful factor which was shared and also named as a lifetime concern by most participants;
- Financial burdens were imposed on families by the necessity of purchasing expensive hearing aids, hiring private teachers for sessions of speech development as well as expensive weekly trips to the educational placements which were located far from the place of living;
- Separation from the child during the five-day stay at school was another stress factor for the participants of the study.

3. How do parents describe the nature of child-family relationships, interaction and communication at home? Are parents satisfied with them?

Participants identified communication as the most important issue in the process of decision making, and their biggest challenge and concern in the coming years. Decisions about how to communicate with their deaf or hard of hearing child at home imposed a lot of pressure due to a lack, biased, incomplete, and inaccurate information from professionals. Not having access to the Ukrainian Sign Language most families were compelled to invent their own home signs to make possible communication with their deaf child. It turned out that deaf children and their deaf parents were the only resource for learning Ukrainian Sign Language for deaf children whose parents were hearing, for their parents, and even for the teachers and staff working in those preschool programs. This resource, however, was not encountered by parents until their children were at least in preschool.

Parental thoughts both in the survey and in the interviews on the way they communicated with their children at home brought to light general dissatisfaction with their home communication due to poor knowledge of signs by parents and other family members and children's delay in spoken language and poor vocabulary of spoken Ukrainian: almost half children in the survey did not understand simple sentences and less than one third was able to use them (spoken Ukrainian). None of the interview participants knew anything about Cued Speech as another way of communication.

4. What is the parental knowledge and perception of the Ukrainian Sign Language?

Recent (2006) revival of the USL has caused confusion among Ukrainian academics and researchers and their unpreparedness to accept new realities. As the result of this confusion Ukrainian Sign Language has not yet been officially reintroduced in the special kindergartens for deaf and hard of hearing children.

Most of parents in this study considered signing and signed language as a necessity which will make the process of communication with their deaf child more comfortable. Also, they have understood that this is the best and natural way for communicating for their deaf children. The findings of this study revealed that vast majority of parents have no possibility to learn USL and most of them estimate their knowledge of 'signing' as unsatisfactory. However, many parents kept saying that they would prefer their child learn speech and function mostly in the hearing society.

Only deaf parents could explain the difference between Ukrainian Sign Language and Signed Ukrainian. All other participants were using terms ‘signs’, ‘signing, and ‘signed language’ interchangeably and did not know the difference between them. From the Deaf participants’ perspective, decades during which signed language had been excluded from the educational system and had been not a part of the research affected also attitudes towards deaf people as disabled persons and severely slowed down socio-cultural understanding of deafness in the society.

5. How do parents describe the nature of their relationship with professionals at the time of early suspicion of hearing loss, before and after the diagnosis?

Parents discovered their children’s hearing loss in different ways and all of them relied on the professionals who were treating their children to provide information and guidance about not only hearing loss but also available services, medical assistance, and families’ rights. However, many parents blamed pediatricians and in some cases other doctors in delaying the identification of their child’s hearing loss as well as the lack of informational support from professionals involved in their children’s care.

The findings show that the participants experienced additional stress due to the ineffective local medical services and were forced to seek a reliable testing and medical support in the medical clinic in the capital of the country. Most of parents participating in the interviews described that period as shocking and frustrating experience for both the diagnosis itself and attitudes of professionals which they characterized in most cases as not caring and indifferent. However, some parents described doctors as kind, responsible, open, and caring people showing their sincere willingness to help.

From the parents’ perspective many professionals including the interdisciplinary Medical, Psychological, and Educational Committees had little training with family-centered practices even though they had expertise in their disciplines. The two most common complaints of parents were the biased information that they received from the professionals recommending an oral approach and the way of communication and relationships with the professionals in which most of parents had got a feeling of being deprived their ‘voices’. As a result in most cases parents were talking about problems in building trust in the relationships with the medical doctors and surdologists.

Parents in this study welcomed the opportunity to provide advice to the professionals that serve families with children who were diagnosed deaf or hard of hearing. Their advice included listen to parents, do not patronize, provide information regarding a full range of choices and opportunities available and practically accessible,

involve parents in decision making process, and recognize that conflicts will arise in the parents' and professionals views. The most frequent advice was 'to listen to parents' which included not only to listen to parental worries and concerns but also to ask parents about the positives. Many parents noted that professionals were fixing what was wrong but did not try to build on the parental messages of positive experiences and that often aggravated stress and was decreasing parental expectations and hopes.

6. What kind of services and/or intervention programs were recommended, available, accessible, and accepted by parents?

Most of parents participating in this study reported that medical doctors were the first professionals they contacted. From the parental perspective, most doctors were pressed ideologically and by a lack of knowledge to steer the family toward a particular choice (like taking speech therapy lessons, purchase hearing aids and try to stay oral in communication with the child) which may not necessarily meet the developmental needs of the infant, toddler, or family. All parents were advised to purchase expensive digital hearing aids and start working on child's language development which would mean hiring services of professionals working in the Surdological Centers of the hospitals. Only a few parents were advised to consider the possibility of cochlear implementation due to the low financial status of other families participating in this study.

The study revealed that the only option for the families was to enroll their child in the special educational placement for children who are deaf or hard of hearing. However, many professionals recommended keeping their children out of the special kindergartens as long as possible or to enroll their children in several private commercial centers for deaf children.

Unfortunately, there was no system in place in which parents had a chance to become equal partners of the Medical, Psychological, and Educational Committees which were in charge of the educational placement of their child. Making a placement decision is a long process demanding frequent appointments with many professionals. Before considering placement of a child who is deaf or hard of hearing in an early childhood program (special kindergarten or a preschool program in the special school for the children with hearing loss), detailed information about the child had to be obtained and then discussed in details with parents during the meeting. Crucial for this process is input from the parents and their active participation in the meetings. However, in many cases the members of the Committee not only had not conducted a dialogue with parents, but

simply ignored them during the meetings and just issued ‘a verdict’ which the parents could not appeal.

Many parents spoke about their fears before enrolling the child in a special program but later almost all of them expressed their satisfaction. Those parents who managed to enroll their deaf and hard of hearing children in the regular kindergartens regretted such decisions and were happy that their children ‘revived’ when moved to a special kindergarten. Almost all parents expressed satisfaction about the quality of education and teachers’ attitudes in the special educational placements.

However, all parents spoke about confusion they experienced at the beginning because of contradictions of officially adopted ‘communicative approach’ which was supposed to imply speech and finger spelling but in fact all parents discovered that all children were practising signing and most teachers and staff would also use signing to support their speech.

Participants did not name any intervention program for the children besides special kindergartens, several commercial centers and Surdological centers in the hospitals which are mostly in charge of identification of hearing loss in young children, fitting hearing aids as well as providing private speech lessons to a limited number of young children. None of the participants of both the survey and the interviews reported receiving any psychological or any other specific help referring to the fact that the family had a child who was deaf or hard of hearing. Term ‘family-focused services’ was not present in the vocabulary of the participants of this study.

7. What are parental thoughts and feelings about raising a deaf child in Ukraine?

After the identification of hearing loss in their children all parents were shocked and devastated. Most often parents reported feeling helpless and not prepared to meet the challenges. The outside professional view of the problem often introduced additional stress and difficulties due to the attitudes of the staff characterized by the participants as low qualifications and indifference and a lack of technical resources for reliable testing as well. Additionally, often participants felt they were abandoned to face their troubles alone and wasted much time in guessing and hesitating when an immediate reaction or decision was required.

Almost all participants reported a lack of choice of educational placements and support in developing an effective family communication system, as well as confusion

and frustration in sorting out the official approach towards signing and the existing reality in the preschool programs.

Additionally, the data emphasizes the importance placed on shared experiences among parents. Especially, parents in the study named deaf parents as one of the reliable and valuable sources of information and support in the process of coping with the consequences of their child's hearing loss. Teachers of the kindergartens and preschool departments in residential schools were named as most valuable sources of help besides spouses.

The review of the literature showed some recent positive developments such as a change of attitudes towards Ukrainian Sign Language on the side of policy makers and researchers, recognition of the necessity of reforming an ineffective system of preschool education, and inclusion of signed language in the curricula of the schools for deaf and hard of hearing children. However, parents revealed that a deficit approach still prevails in health/social care and educational systems as well as low awareness in deafness issues in the hearing society. Even though there exists a well established system of deaf education in Ukraine, parents expressed their concerns and worries about the future of their children explaining that their fears had been caused by the fact that many deaf graduates could not find jobs due to their low literacy and low vocational skills.

It was interesting to note that notwithstanding the scale of negative views or a lack of public awareness on deafness that had a great influence on the parents in the study, at the time of the study the majority of the interview participants were open to adopting positive perspectives as they came to know deafness and the deaf community better. One can hypothesize that as these parents obtain more information and earlier support they will be in a better position to give their children the support they need earlier in their lives when it is critical.

Overall, the results of this study provide a profile of hearing parents' subjective experience of parenting a child who is deaf or hard of hearing in Ukraine at the beginning of the twenty first century and outlines the many concerns and issues of these parents. The need for informational support, guidelines and communication options for families were seen to be key issues both in the literature and in this study. The importance of increased access to educational options, support for overcoming stress and improving emotional well-being, as well as support for families in establishing healthy family interactions and empowering parents were also confirmed by the participants in this study. Additionally, the findings of this study indicate the lack of family resources which

are supposed to help in the adaptation process of the hearing family to the hearing loss of their child. Family communication emerged as the biggest concern of all hearing participants in this study.

It is hypothesized that if all these concerns and issues were targeted for implementing changes in practice of professionals the day-to-day life of families raising deaf and hard of hearing children would be improved, in turn increasing the chances for improvement in their children's opportunities achieving milestones in their overall development.

Implications for Practice

The analysis of the participants' interviews and survey data provides insight into the families' views of raising a deaf or hard of hearing child as well as their experiences with early education programs. Parental experience and thoughts provided a valuable basis for generating some considerations and propositions regarding early intervention following the identification of hearing loss. Many of the possible implications for practice are consistent with topics identified in the literature review. Many of the findings highlighted problems similar to those in other countries in the past as described in the literature. However, the successful measures and policies that have been implemented in other countries to improve problems in the past have to be researched in order to examine their applicability to the specific situation in the country of study, Ukraine. For example some societal structures and supports assumed in Western studies simply might not apply in Ukraine. However, overall, it is believed that there is merit in exploring such approaches to early intervention and parental supports.

Based on the reflections of parents, their thoughts and advice to other parents the following considerations regarding support and services for families, communication, and medical care deserve further study:

- What would be the optimum concept for delivery of family focused services most desired by parents in this study including psychological counseling?
- What would be an effective step to initiate establishing self-help groups involving hearing and deaf parents? What would be the criteria for assessing effectiveness of self-help groups involving hearing and deaf parents? Where is the optimum location of those groups? What should be the mandate of parental groups? (Regularly occurring parent workshops that emphasize general family communication practices that include having the child participate in language,

involving the whole family, assuring that children don't miss out on what is happening in their surroundings, and including children in all family activities?).

- What would be the optimum way of delivery of Ukrainian Sign Language courses for hearing parents and family members? Would it be courses involving volunteers as instructors or professionals? What are the qualities of effective instructors of Ukrainian Sign Language?
- Would it be beneficial besides introducing the instruction of Ukrainian Sign Language similar to the curriculum of the residential schools to officially allow Ukrainian Sign Language as another language of instruction (besides spoken Ukrainian)?
- Could parental concerns regarding the protracted identification of the symptoms of hearing loss in young children which resulted in diagnostic delays be related to the gaps in the education of pediatricians? If yes, how can those gaps be effectively filled?

The findings of this study were consistent with recent Ukrainian literature that urged the rethinking of existing approaches to providing support services for families whose children have disabilities or special needs. Participants' experiences and difficulties in finding knowledgeable professionals and community personnel suggest the need to consider the creation of a new type of service for Ukraine which would extend the current child-centered focus to incorporate a family-centered approach. These services would target not only the child but would serve to make a difference in the life of both the child and the family. The support should be tailored to be responsive to the various domains of the family life.

Suggestions for Future Research

The data of the study was solely based on surveys and face-to-face interviews. There are other possibilities and directions for future research which emerge from this study. First, the study demonstrates the usefulness of combining both quantitative and qualitative methods to provide a greater depth of understanding of the phenomenon of parenting young children who are deaf or hard of hearing. This combination of methods allows optimizing the understanding of family adaptation to the phenomenon of deafness that can be obtained through research.

A broader and richer picture of family life and family functioning could be developed by adding additional dimensions to the observation of family dynamics. Expansion of the study to other settings such as special kindergartens for children who

are deaf or hard of hearing and regular schools with self-contained classes for children with hearing loss would help to address the concern that the setting of this study, residential schools for the deaf, may have had an influence, which contributed directly to the findings.

Future studies could include the examination of differences in perceived impact and satisfaction with family life for families with multiple members who are deaf. Thus, the number of participants could be increased and involve more families with deaf and hard of hearing members as well as families with more than one deaf child. This study included a small number of families which called themselves ‘deaf’ in the survey and allowed for only few comparisons. Only one deaf family agreed to participate in the interviews. The inclusion of that one family highlighted some basic differences in thoughts and perceptions as compared with the hearing families. Therefore, another study could identify different perspectives of satisfaction and impact of deafness on family life, as well as perceptions of family-professional partnerships between hearing families and families with membership in the deaf community. To get an even broader perspective, families with children who were fitted with cochlear implants could be included in the new research.

Further research might explore the relevant factors affecting parental expectations and how these expectations influence their decisions regarding the education and socialization of their deaf and hard of hearing children as well as their hopes for future life of their children.

Personal Reflections

I first engaged with issues affecting deaf and hard of hearing people when I took a teaching position at the L'viv School for the Deaf (Ukraine) after graduating from the University of L'viv. At that time I did not expect my interest in deaf education to endure for my entire professional life. However, the longer I worked the more I liked my work at school. At the same time I felt a significant gap in my knowledge so I chose to complete another university degree in Surdopedagogy (Deaf Education) several years later.

In 2002 I enrolled in the Master's Program in Deafness Studies at the Department of Educational Psychology, University of Alberta. In my master's research I focused on the potential benefits that Ukrainian Sign Language (USL) which was precluded from the education of the deaf in Ukraine might give to Ukrainian deaf education.

After enrolling in doctoral studies I started thinking about a new priority for my research. By that time (2003) many professionals in Ukraine recognized the need for change in the system, however, they did not consider parental thoughts or perspectives. In other words, there still was no forum for parental voices. In fact, Ukrainian researchers did not suggest any change to the existing former soviet perspective which ignored the role of families in school life and the educational process.

For this research study, I cast myself in the role of a quantitative and qualitative researcher in the hopes of understanding the characteristics, experiences, feelings and desires of hearing parents who were raising deaf or hard of hearing children in Ukraine. I was interested in how they live, what they think and how they see their own future and the future of their children. My goal was not only to discover some truth that fits all parents across all situations, but also to understand how selected participants made sense of the experience of raising their children. By conducting this study in Ukraine with Ukrainian participants I also hoped to attract the attention of Ukrainian researchers in the field of special and secondary education and influence them to explore families' life and to discover and document parental voices that have been so much neglected.

After spending almost twenty years teaching deaf students I thought that I knew almost everything there was to know in the area of deaf education. However, after studying in a new paradigm, a Western paradigm, and having conducted this research I now understand that this vision was short-sighted and arose from living and working in a system which traditionally excluded parents and families from the focus of the research and schooling.

Spending almost two years studying the experiences of families with children who are deaf or hard of hearing brought me very close to the experience of parenting a young child who cannot hear. The extended and deeply personal interviews gave me a fuller appreciation for the challenges and joys of raising a child who is Deaf or hard of hearing. During the time that I was conducting these interviews I was heartened by the ability of the parents to find creative solutions and to create hope and meaning for themselves in the society which was not sufficiently ready to accept the difference of their child and which often seemed not very friendly to them or their child personally.

The necessity to remain neutral during the interviews was a great trial for me. During the interviews I had to remain impartial when parents often appealed to me to agree with their positions or views or would in return ask my opinions on certain matters pertaining to their children or to give them feedback. In such cases I had to remind them

of my role as a researcher and that I was unable to comment in the way I would if they were parents of children enrolled in my class. Even though I had to keep a neutral status as a researcher and monitor my own biases and beliefs, I also felt ethically unable to deny parental requests to share my knowledge and we usually continued our conversation after the interview had been completed and all formalities of the research protocol fulfilled. All parents expressed their gratitude for explicit answers to their questions.

All parents revealed being surprised by the way the study was conducted: they were free to talk, they were listened to, and nobody stopped them. Parents mentioned that this inclusive manner was a completely new way of being dealt with by professionals. Many of parents revealed that for the first time they felt that they were treated as equals and as experts.

I am enriched and empowered by the participants as this study left me with the reward of knowing how in small ways, I had touched the lives of parents and family members: their words of gratitude (written on the survey as well as spoken during the interviews) underlined that they felt heard. They acknowledged being validated for their knowledge and experience and appreciated my sincere interest in the world of their families.

As a result of this study I realized that my previous beliefs about the roles of families in the lives of children who are deaf or hard of hearing were not strong enough and that was probably because of professional prejudice that has existed in Ukraine against parents of children with disabilities and special needs. Realization of the roles of families, their challenges, needs, and requests as well as findings of the study forced me to reconsider many of the postulates of the existing system of the education of the deaf and hard of hearing children in Ukraine.

I have been profoundly influenced to advocate for the role of parents as key stakeholders in the planning and implementing of education for their deaf and hard of hearing children. This means that they must be included in research, policy development and feedback to decision making policies.

Besides urgent necessity for reforming the system of early intervention and preschool education I also realized that the system of training of new teachers and retraining of the current ones working with the students who are deaf or hard of hearing requires immediate modification in order to provide knowledge in family functioning, counseling, and providing help to families.

What I Learned as a Researcher

At the beginning of my program I experienced loneliness as I was struck by the realization that the research project and the goal of getting a Ph.D. appeared to be my responsibility alone even though at the back of my mind I understood that it was also my committee members' concern that I be successful. In any event, I knew that the outcome would impact me more than anyone else. I was faced with having to rely solely on myself to further develop the skills I'd already begun to acquire at the University of Alberta, in particular problem-solving, analytical and pro-active thinking. As a researcher I also had to learn time management and prioritization skills as I had no financial support in the final years of my program.

I learned to trust my research instincts. When it came time to decide my Ph.D. thesis topic, I was able to identify a topic on my own because of my previous research experience in the Master's Program. As mentioned in chapter 3 I chose this topic after having analyzed research priorities in the field of deaf education in Ukraine. Luckily I found a supportive advisor. With the help of my supervisors and other members of the committee I grew in confidence in my ability to not only pick good problems, but to pick a good direction to explore them.

I learned the importance of clearly defining the immediate and longitudinal tasks and goals and communicating them to the committee members. The open and friendly discussions regarding the progress of my work taught me that in cases of their misunderstanding of the situation in Ukraine to have confidence to provide evidence of my own knowledge while respecting the expertise of the committee members.

One very useful skill developed during my Ph.D. studies was the ability to work with people at all levels: academic institutions, school boards, school administrators, teachers, and parents- to achieve the research goals.

During the interview segment of the research I had to build rapport to get parents to open up to answer very sensitive questions. I had to present myself as a professional researcher, so that they'd trust me and have the confidence that the information they were providing would be treated responsibly and that their anonymity would be ensured. That was a difficult task in a country with a living memory of a totalitarian regime.

In terms of my future research this study confirmed for me the usefulness of mixed methods research with this population, however, on reflection I would buttress any future survey procedure with a method of distribution and collection of surveys by the

researcher rather than by anyone in any educational authority over the respondents' children. In terms of teaching and filling gaps in the existing research methods in Ukraine one of the important steps is establishing a series of ongoing seminars for graduate students on research methods.

I sought the Ph.D. because I wanted to move to a higher level of expertise. This might lead to a higher position at a university and influence the way that research and teaching is conducted in this area. Having learned different methods of research in the human and social sciences which are recognized internationally I can see a great need for this knowledge to be presented in Ukrainian research circles because this country is way behind Western countries. And I believe that I am able to bring gained "state of the art" knowledge to my country and not just bring yesterday's Ukrainian knowledge in this field one step closer to today but to help moving it forward to tomorrow.

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Appendix B: List of Survey Questions

Section I. Background Information

These questions should be answered by parents of the deaf or hard of hearing child.

Relationship of the respondent to child: ___Mother ___Father___Other _____

Age of the respondent: _____

1. Your child's date of birth:

___month ___ day ___ year

2. Gender:

___Girl __Boy

3. Who first suspected the hearing loss?

___ parent ___ other relative
 ___ medical doctor ___ other professional
 ___ other (who?) _____

3.1. How old -was your child then?

3.2 How old was your child when a specialist CONFIRMED the diagnosis?

4. What is the extent of your child's hearing loss?

___ Deaf: can't understand speech, even with a hearing aid _____dB?
 ___ Hard of hearing: can understand speech when in a quiet room, with a hearing aid
 _____dB?
 ___ Don't know

5. What kinds of instruction or therapy has your child received from a teacher or specialist?

Speech Language Therapy

This therapy is to prevent, identify, assess, and treat communication disorders which may be present in the areas of speech (production of speech sounds), language (vocabulary, grammar), voice (breath support, voice quality, nasality), fluency (stuttering), cognitive communication (communication after stroke or brain injury), and social use of language for different situations and people).

Auditory training

Auditory-Oral (or Aural/Oral)

This approach emphasizes the use of hearing aids, auditory trainers and/or cochlear implants to develop residual hearing that a child might have. *Speech reading* and talking are encouraged, while use of signed language is typically not allowed. Speech reading is lip-reading in combination with the reading of many other cues such as facial expressions, gestures, contextual clues and body language)

Auditory-Verbal

This approach is very similar to the Auditory-Oral approach with the exception that *speech reading is not supported* in order to facilitate optimal training of listening skills. Learning auditory skills on a one-on-one teaching basis is stressed. This approach is recommended for children with cochlear implants because a cochlear implant emphasizes the hearing abilities provided by the implant.

Ukrainian Sign Language

USL is recognized as a separate language distinct from Ukrainian. It is the signed language indigenous to the Deaf Community in Ukraine. It has been defined as a visual, gestural language where body and head posture, facial expression, lip movement and body language play a distinctive role in contributing to meaning. USL has its own grammatical structure and linguistic features.

Finger Spelling

This is the manual representation of the letters of the alphabet by 33 different hand positions. In Ukraine this is accomplished by means of a one-handed alphabet. Finger spelling is an integral part of signed language and sign supporting systems.

Cued Speech

This visual method is used as a supplement to speech reading and involves the use of hand shapes and hand positions near the mouth while speaking to represent different speech sounds. This helps with the identification of sounds that are not easily seen on the lips or sounds that appear identical when lip-reading. Although the hand shapes are manual, this method is an oral approach and is dependent upon speech reading spoken language. Cued speech may be used in addition to other communication approaches. As of October, 1993, Cued Speech had been adapted to 56 languages and major dialects including Russian.

What kinds of instruction or therapy has your child received from a teacher or specialist?

- ___ Speech therapy: age began: _____
- ___ Oral (auditory) training: age began: _____
- ___ Signed language: age began: _____
- ___ Cued speech: age began: _____
- ___ Other (1) _____
age began: _____
- ___ Other (2) _____

age began: _____

6. Does your child have any conditions other than deafness that might affect development or education?

- no, no other conditions
 yes (If yes, check all that apply):
 visual impairment cerebral palsy
 brain damage epilepsy
 health condition developmentally delayed
 behavior problem learning disability
 orthopedic condition attention deficit
 other: _____
 don't know

7. Does your child have a hearing aid?

no yes

7.1. If yes: age when first fitted with an aid:

years _____ months _____

7.2. How much does he/she wear the aid?

(a) at home?

always almost always sometimes almost never never

(b) at school?

always almost always sometimes almost never never

8. Has a cochlear implant been considered for your child?

What Is A Cochlear Implant?

A cochlear implant is an electronic device which is surgically implanted in the cochlea (inner ear) to perform the task of the damaged or absent nerve cell endings. It consists of two parts- the internal implant under the skin of the head and the external speech processor. The internal implant is surgically implanted under the skin and consists of a receiver/stimulator, antenna, magnet, internal electrode array and grounding lead. Currently there are two choices for the external speech processor, a body-worn device and an ear-level device which resembles a behind-the-ear style hearing aid. Additionally there are many accessories that enhance the ability to hear music, the television, on the telephone, in background noise, in theaters, in the car, at places of worship and at restaurants.

Has a cochlear implant been considered for your child?

yes no

If yes:

8.1. Has he/she been evaluated for an implant?

yes no

8.2. Was surgery performed?

yes no

If Yes: **8.2.1. When? (age):**

years____ months____

8.2.2. Are the results satisfactory?

excellent____ good____ satisfactory _____not
satisfactory_____

Section II. Special Services

1. How many different special education programs did your child attend before entering this school?

1.1. In what city (or county) was the program in which your child was enrolled the longest? _____

1.2. Child's age in that program: from____ to ____

1.3. What communication method was used with your child there?

speech alone speech + sign sign alone cued speech
 other

1.4. Did you have a program choice?

yes no

1.4.1. If yes: Why did you choose this program?

1.4.2. If no: What kind of program might you prefer?

1.5. Were any Deaf adults on the staff?

yes no

2. How do you evaluate that program?

2.1. The staff responded to family concerns, ideas, and questions:

always often sometimes rarely

2.2. The help my child received was based on his or her individual needs.

always often sometimes rarely

2.3. In my meetings with staff, I was an active member of a team, not just a listener.

always often sometimes rarely

2.4. Staff accepted the limit our family put on time we could devote to the program.

always often sometimes rarely

2.5. My child's language progress in that program was:

excellent good satisfactory disappointing

3. Please check all services available to your family since hearing loss was diagnosed:

3.1 ___ Information about (check all that apply):

- (a) ___ Deafness
- (b) ___ Legal rights of deaf children
- (c) ___ Child behavior and/or development
- (d) ___ Choices for future school placement

3.2 ___ Signed language instruction

Received by: ___ mother ___ father
 ___ others (who?) _____

3.3 ___ Parent group meetings

Attended by: ___ mother ___ father
 ___ others (who?) _____

3.4 ___ Individual counseling

(if yes) Where? _____
 Received by: ___ mother ___ father
 ___ others (who?) _____

3.5 ___ Other services or instruction

What? _____
 Received by: ___ mother ___ father
 ___ others (who?) _____

4. Please circle the letter of the one service listed in question № 3 that was MOST helpful to:

- mother a b c d
- father a b c d
- others a b c d

5. Which method of communication is used MOST with your child NOW?

5.1 At home:

___ speech alone ___ speech + sign ___ sign alone ___ cued speech ___
 other

5.2. At school

___ speech alone ___ speech + sign ___ sign alone ___ ___ cued speech
 ___ other

6. What kind of school program does your child attend now?

- ___ Residential (day student)
- ___ Residential (dorm: round the clock)
- ___ Partially mainstreamed (attending some classes with hearing peers)

Section III. Sources of Help

Listed below are sources that are sometimes helpful to families with a young child. Please circle the response that best describes how helpful each has been to you since the diagnosis of child's hearing loss.

- 0 = Not at all helpful
- 1 = Sometimes helpful
- 2 = Generally helpful
- 3 = Very helpful
- 4 = Extremely helpful
- NA = Not available

1	Spouse (or partner)	0	1	2	3	4	NA
2	My parents	0	1	2	3	4	NA
3	My spouse's parents	0	1	2	3	4	NA
4	My relatives	0	1	2	3	4	NA
5	My spouse's relatives	0	1	2	3	4	NA
6	My friends/spouse's friends	0	1	2	3	4	NA
7	Parents of deaf children	0	1	2	3	4	NA
8	Church (priest, rabbi)	0	1	2	3	4	NA
9	Doctor/ pediatrician	0	1	2	3	4	NA
10	Therapist	0	1	2	3	4	NA
11	Deaf adults	0	1	2	3	4	NA
12	Childcare giver	0	1	2	3	4	NA
13	Grand parents	0	1	2	3	4	NA
14	Other (who?)	0	1	2	3	4	XX

2. Do you work outside the home? __ yes __ no

2.1. Does your employer help you meet your child's needs?

0 1 3 4 5 NA

3. What is your (usual) occupation?

4. Spouse's (usual) occupation?

Section IV. Your Child's Behavior and communication

Circle the response that best describes your opinion of your child's behavior:

1 = Strongly Agree

2 = Agree

3 = Disagree

4 = Strongly Disagree

1. My child forms warm, close attachments to or friendships with peers at school

At school 1 2 3 4

In the neighborhood 1 2 3 4

2. My child is isolated, has no friends

1 2 3 4

3. My child communicates with children and/or adults by any means: gesture, sign, vocalization, pantomime, speech, and drawing

1 2 3 4

4. My child is happy, cheerful, and pleasant.

1 2 3 4

5. My child expresses concern or sympathy for others in pain or distress.

1 2 3 4

6. My child does not express a variety of emotions appropriately (anger, fear, joy, sadness).

1 2 3 4

7. My child has a good sense of humor and can appreciate funny situations or jokes.

1 2 3 4

8. My child is interested in communicating with others and tries to understand them.

1 2 3 4

9. My child forms warm, close attachments to teachers.

1 2 3 4

10. My child has warm and loving attachments as well as good communication with other family members.

Siblings 1 2 3 4

Grand parents 1 2 3 4

Other_____ 1 2 3 4

10. My child initiates communication.

With Peers 1 2 3 4

With Adults 1 2 3 4

At home 1 2 3 4

Section V Questions about My Child's Language

1. Does your child understand simple sentences (like "We will go to the store")?

not yet rarely sometimes often

1.1. *Does your child use simple sentences?*

not yet rarely sometimes often

2. Does your child talk/sign about future events, for example, referring to "bus/train" before you go on a trip or "swing" before you go to a park?

not yet rarely sometimes often

2.1. *Does he or she most often use:*

single words/signs: bus/train; swing OR

short phrases: bus/train to grandma's; swing in park OR

more complete sentences: We're going on the bus or train.

3. Does your child ask "HOW" or "WHY" questions?

not yet rarely sometimes often

3.1 *Does he or she generally use:*

single words: (How? Why?) OR

short phrases: (Why home?) OR

more complete questions: {Why are we going home?}

4. Does your child use sentences that express more than one idea? ("We will go for a walk when Daddy comes home")

not yet rarely sometimes often

5. Does your child ask serious questions, like "What does that mean?" or "What happened to that boy?"

not yet rarely sometimes often

6. Can your child read:

single words? yes no

sentences? yes no

story books? yes no

7. Can your child print/write:

letters of the alphabet?

yes no

his/her name?

yes no

words?

yes no

sentences?

yes no

Section VI. Questions about Your Own Feelings as a Parent (or Parent Substitute)

Please circle your response:

1 = Strongly Agree

2 = Agree

3 = Not Sure

4 = Disagree

5 = Strongly Disagree

1. We have more family arguments about our deaf (or hard of hearing) child than about other things

1 2 3 4 5

2. I feel proud of the way I have responded to the special needs of my child

1 2 3 4 5

3. Much stress in my family is related to my child's hearing loss

1 2 3 4 5

4. My communication skills are quite adequate for my child's needs

1 2 3 4 5

5. Because of hearing loss, I must forget many hopes and dreams for my child

1 2 3 4 5

6. In spite of extra time devoted to my child's needs, I still find time for myself

1 2 3 4 5

7. My child is regularly included in family conversations because we have an effective communication system

1 2 3 4 5

8. Parents of children with a hearing loss are expected to do too many things for them. This has been a burden for me

1 2 3 4 5

9. There are many things I can't seem to communicate to my child

1 2 3 4 5

Section VII. Background Questions: Family

1. Other children in family (living at home):

If none, write "none." _____

Boys: ages: ___/___/___/___/___/___

Girls: ages: ___/___/___/___/___/___

(circle the age of any child who has a hearing loss)

2. Hearing status of parents and family members:

Mother: hearing hard of hearing deaf

Father: hearing hard of hearing deaf

Other: hearing hard of hearing deaf

2.1. Marital status of respondents:

married divorced single

3. With whom does child live now?

mother only father only both parents

mother and stepfather father and stepmother

with grand parents

Any extended family members living together?

grand parents great grand parents

other: who? _____

4. Primary language used at home:

Ukrainian _____ Russian _____ Ukrainian Sign Language _____ Other: _____

4.1. Did you invent any home signs to improve communication with your child?

yes no

If yes: Are you still using those signs?

yes seldom no

6. Are signs or cued speech used with child by:

Mother:

no yes

If yes: signs cued speech

Skills are: excellent good fair poor

Father:

no yes

If yes: signs cued speech

Skills are: excellent good fair poor

Other: who? _____

no yes

If yes: signs cued speech

Skills are: excellent good fair poor

7. Highest school level completed by parents:

Mother:

Elementary

Secondary School

Vocational

Basic Higher education (3 years)

Higher education (full)

Other

Father:

Elementary

Secondary School

Vocational

Higher education (3 years)

Higher education (full)

Other

8. Age of parents

_____Mother

_____Father

9. **Where do you live?** (*city, suburb, small town, country, farm, other...*)

10. Do you work?

(*If yes*) Where? What is your family monthly income?

THANK YOU FOR YOUR HELP WITH THIS SURVEY.

WE WELCOME YOUR COMMENTS: PLEASE ENCLOSE ANOTHER SHEET OF PAPER.

A small sample of those responding to the questionnaire will be selected to participate in follow-up interviews in person. Are you willing to be contacted for an interview?

YES

NO

If you would consider participating, please complete the mailing label and enter your phone number.

Mailing label

Name _____

Street _____ Apt. _____

Town/Village & Oblast' _____ Postal Code _____

Phone: () _____ - _____

Appendix B-1: List of Changes Introduced into the Original Questionnaire of Meadow-Orlans, et al. (2003).

Section & item	Changes/modifications	Reason
SI. Background information		
4. Hearing loss level	<i>Don't know</i> option is added to the list of answers	Some parents/caregivers might not know the answer
5. What kind of instruction/therapy received	<i>No training/therapy</i> option is added	Many children enter schools with no preschool education
6. If a child has any other conditions	<i>Don't know</i> option is added to the list of answers	Overwhelmed parents might have overlooked some other medical or special needs condition especially in rural or mountain regions
S II. Special Services		
6. Educational options for the children)	To be removed from the list: (a) day school for hearing students, (b) classes with deaf students in day school for hearing students, and (c) fully mainstreamed.	All children in this study are enrolled in special residential schools (day or round the clock)
S III. Sources of Help		
List of people who might provide help	Grandparents are added to the list	Grandparents live together with the family very often
S IV. Your Child's Behavior		
1. Relationships with peers	Is complemented with two options (a) peers at school and (b) (hearing) peers in the neighborhood	It is assumed that peers at school are deaf or hard of hearing, and peers in the neighborhood are hearing
11. My child initiates communication	<i>With peers, with adults, at home-</i> are the options added to answer this question.	To address more precisely research questions
10. Added question	My child has warm and loving attachments as well as good communication with other family members. <i>With siblings; with grand parents; with others</i> are the options added to answer this question	To address more precisely research questions
S V. Questions about My Child's Language		

(2)	Word <i>airplane</i> changed for <i>bus/train</i>	Family trips by airplane and McDonald's are not typical for Ukraine
(4)	Word <i>McDonald's</i> changed for <i>walk</i>	
(7) list of what a child can print	Word <i>words</i> was added	

S VII. Background Questions

4. Primary language at home	Changed to <i>Ukrainian, Russian, Ukrainian Sign Language, other</i>	Adapted to Ukrainian context
4.1.	Added question on home sign system	Adapted to Ukrainian context
7. Parental Education	Changed according to Ukrainian classification	Adapted to Ukrainian context
8. Parental age	Added question on parental age	Important for comparison of attitudes and feelings
9. Place of living	Added question about geographical area of living	Important for comparing access to information and available services
10. Work and income	Question about work and monthly income	In Ukraine a monthly income is used vs. yearly

Appendix C: List of Interview Questions

Gender of the respondent (male/female)

I. Background Information

Which language is more comfortable for you to speak (Ukrainian/Russian)?

1. How old is your child?
2. What kind of hearing loss does _____ have (profound, severe, moderate, mild?)

II. Prediagnosis

3. When did you first sense that _____ might not hear well?
4. What made you think that? How did you feel?
What was reaction of your spouse?
5. Did you meet or know any deaf adults or deaf family before your child?

III. Diagnosis

6. How old was ____ (years & months) when a professional told you that _____ might have a hearing loss?
Who told you that? How was it said?
Do you remember the exact words they used to describe your child's hearing loss?
7. What did you feel at that moment?
8. What did you feel before the hearing test?
Where did you take the test? _____ (place)
9. What did the person conducting the hearing test say about your child during/after the test?
What did you *think and feel* when you first heard this news?
10. Who else was with you, or were you alone?
(*If not alone*) What was their reaction?
11. How do you feel now about your emotional state at that moment?
Having your present knowledge and experience do you think you would react differently now?
12. How did you family and friends react? (tried to give an advice, proposed financial or other help, mourned with you, were desperate, other...)

IV. Information on hearing loss

13. What information about hearing loss were you given at diagnosis/after the end of the hearing test? (*medical information, specifics of raising a deaf child, communicational choices, educational choices, other...*)
14. Who provided this information? (*ENT doctor, pediatrician, audiologist, speech therapist, hearing aid practitioner, educator, social service officer, other...*) _____
15. Were things explained clearly to you?
Do you think you were given enough, too little or too much information at that time?

V. Initial guidance at diagnosis

16. When you were first told of your child's deafness, did anyone advise you about what you should do next?

Who gave this advice? What did they advise you to do? (Step 1; step 2; step 3...)

17. What did you think of their advice? Did you trust them?

Why or why not? What do you think now?

18. Did that advice impact your emotional condition?

VI. Process (*immediately following diagnosis*)

19. What did you do next after the diagnosis?

Get a second opinion?

(If yes) Whom did you call?

Did you get any support?

20. Did you identify for yourself the most important issue to deal with immediately?

(If yes) What was that and why? Do you think now that that was a right choice?

21. Who or what was most helpful to you in making these choices (decisions) for your child?

22. What kind of help did you receive from your friends, relatives, neighbors, and other people?

VII. Hearing Aids

23. Were hearing aids recommended for _____? How soon after his/her diagnosis?

(If yes) Did you hope that hearing aids would "cure" your child or will at least improve his/her hearing significantly?

24. Has your hope to "fix" the hearing become true?

(If not) What did you feel when you realized that hearing aids had failed to improve hearing of your child to the expected level? Was it another factor of stress?

25. Did anyone ever talk with you about cochlear implants?

VIII. Postdiagnosis/Educational Placements/ Help from friends and other people

26. How did you find out which programs were available in Ukraine and what options were offered by your oblast' (province)?

Did you explore different educational setting and possibility of placing your child there?
(*public kindergarten, private center in a big city, preschool program of special residential school for deaf or hard of hearing children, mainstreaming or self-contained classroom in preschool program of public regular school*)

27. What made you choose the first special program or school attended?

28. Did the school/program advise you about how you should communicate with _____?

Did they suggest starting learning signing? (*If yes*) Did the necessity of new communication skills impose additional stress on you

IX. Communication

29. Was it more important for you that your child was able to speak orally with hearing people or with those who use signed language?

How do you think now?

30. Do you feel satisfied with your ability to communicate with your child?

(If yes) Do you think that an effective communication helped you to adapt to the child's hearing loss?

(If not) Do you think that if you had gained proper skills in signing after the diagnosis your family life might be different? What is your attitude to Ukrainian Sign Language?

X. Parental feelings (from the time of diagnosis until time of the interview)

31. What kinds of feelings did you experience when you learnt about the diagnosis?

(Shock/stress, despair, lost hope, challenge, hope, other...)

What positive feelings are associated with the process of accommodation to the hearing loss?

32. Can you describe your feelings from the time of the diagnosis (when probably your communication with the child was limited) in the timeline until present (year 1-year 2-year...)?
33. How much time passed since the time of the diagnosis until you understood that there was no any medical cure for the hearing loss? Who helped you to understand this? What did you feel when you understood this?
34. What major events in your family life in relation to raising your deaf child would you identify as the most important? (year 1, year2, year ...) As the most positive? As the most destructive?
35. If you measure the level of your stress caused by the hearing loss of your child using the scale from 0 to 10 it would be:
At the moment of the diagnosis _____
One year after _____
At present _____
36. How has your daily life changed since you found out about your child's hearing loss?

XI. Future

37. Imagine your child 10 years from now. How do you hope he/she will be communicating? How do you hope will be doing academically?
38. What are your major concerns for now?

I think we have covered all the topics we planned for today. Have you anything else you can add?

Thank you for your time and cooperation.

Appendix C-1. Modification of the Interview by Steinberg et al.(2003).

Section	Changes/modifications	Reason
I. Background information	Added question about a preferred language for the interview All questions except #1 and #2 are to be removed	Data known from the survey or does not relate to Ukrainian context
II. Prediagnosis	Number of questions reduced from 5 to 3	To answer research questions of the study
III. Diagnosis	Some more questions added about time of hearing test and after.	The whole section restructured to answer research questions in order to explore in deep feeling of parents during and after the diagnosis
IV. Information on hearing loss	Title changed from <i>Deafness</i> to <i>Hearing loss</i>	Parents avoid term <i>deaf</i> and <i>deafness</i> in the initial stages of the diagnosis
	Number of questions reduced from 5 to 3.	Questions were restructured to reflect Ukrainian context
V. Initial guidance at diagnosis	Number of questions reduced from 5 to 3	Questions were restructured in order to highlight parental emotions and feelings and fit into Ukrainian realities
VI. Process	Number and content of questions changed A new question about help from relatives, friends and other people included	Changed to fit Ukrainian context
VII. Hearing aids	Number of questions reduced from 6 to 2.	Changed to fit Ukrainian context
	One question about cochlear implants included	Cochlear implants is a very rare issue in Ukraine
VIII. Posdiagnosis	Number of questions reduced from 19 to 3.	Questions are compiled to reflect Ukrainian realities and seek answers to the research questions.
IX Communication	Two questions were included	Questions in the original

	about satisfaction of parents in their mode of communication at home	questionnaire either not fit into the Ukrainian context or reflect issues already existing in the survey
X. Parental feelings	5 new questions included in this section	To explore feelings and thoughts of parents according to research questions
XI. Future	Two question included about parental perspectives on their child and current concerns	

Appendix D: Project Letter to Participants

University of Alberta
Project Description Document

Dear _____

You are invited to participate in a research study entitled

Ukrainian Hearing Parents and their Deaf or Hard of Hearing Children.

Please read this form carefully, and feel free to ask any questions you might have.

Researchers

Ihor Kobel*	PhD, Provisional Candidate	University of Alberta	403 342 3325
David Mappin	PhD, Associate Professor	University of Alberta	780 492 5211

*This research study will partially fulfill Ihor Kobel's research requirements for his PhD in the Special Education Program in the Department of Educational Psychology at the University of Alberta.

Purpose and Procedures

This research initiative works to describe the circumstances in which hearing parents raise their deaf or hard of hearing children. Specifically, the purpose is to identify the characteristics of hearing families with young deaf or hard of hearing children and explore the feelings of hearing parents who rear deaf or hard of hearing children and their thoughts on the services. Also views, thoughts, and ideas of parents regarding the kinds of services received by parents and children and how parents view their child's social development and language skills will be analyzed.

You are invited to take part in the study which will consist of two phases.

Phase I.

Every hearing parent whose child is deaf or hard of hearing and is involved in the grade 0\1 in a special school for deaf or hard of hearing has been asked to participate in the first part of this study by completing the survey questionnaire. If you complete the survey form, I can assume that you have chosen to do so and that I have told you that you will not be placed at risk. All information is confidential. You may reply anonymously OR you may give us personal information in order to receive a copy of our report or to volunteer for a follow-up interview

Phase II.

A sample group (n = 20) chosen from the list of parents who volunteered to participate in a follow-up interview will be invited to participate in the 90-minute in-depth interviews. A semi-structured interview plan will be followed. The interviews will be tape recorded and then transcribed. Transcripts will be provided to the participants for review and validation. Individuals will only have access to their individual input. Aggregate results

of the study will be given to individual participants.

The research will be conducted at school premises. You will need to come to the school one time during the study. The visit will take about 90 minutes.

Conversations will be audiotaped and subsequently transcribed. You will have the opportunity to review your transcripts and make corrections prior to the next scheduled conversation.

The total amount of time you will be asked to volunteer for this study is 120 minutes.

Should a research assistant be used, their behavior will comply with the University of Alberta Standards for the Protection of Human Research Participants (<http://www.ualberta.ca/~unisechr/policy/sec66.html>). Furthermore, all other research and/or assisting personnel will sign confidentiality agreements.

Potential Risks & Benefits

There are no known risks associated with participation in this study. You will be fully informed as to the purpose of the study, and will be given an opportunity to ask any questions about the study or research process in general.

Your participation will help us understand how individuals consider their experiences parenting deaf and hard of hearing children and dealing with different professionals. Idealistically, this information could then be used to inform current practice and provide some valuable information for improving some services or establishing new ones.

Privacy and Confidentiality

Steps have been taken to protect your privacy. This means that only personal information that is pertinent to the research study will be solicited. The data collected in this study may be published or presented at a conference at a future date. To protect your confidentiality, identifying information will be protected as fully as possible. Your name will not be released to any source, and will not appear on any completed materials.

Storage of Data

Data and material used for this study will be stored for a minimum of 5 years by Ihor Kobel and David Mappin at the University of Alberta and/or at the Institute of Special Education (Ukraine). Furthermore, the data will be in a locked room, in a locked cabinet. All computer files will remain on one computer, with a back up file stored on the University of Alberta server. Furthermore, information will not be disseminated through electronic format outside the University of Alberta email system. At this point, it is not anticipated that external supports such as transcribers will be accessed to assist in the research process. Should research assistants and/or transcribers be hired, they will be required to sign confidentiality forms and be held to the same ethical standards explained in this document.

Freedom to Withdraw

Your participation in this study is completely voluntary and you may refuse to participate at any time during the study. You may also withdraw at any time without any penalty or

loss of benefits to which you would ordinarily be entitled (e.g., access to communication support services). If you withdraw, your data will be destroyed immediately following the session in which you participated. You are not required to answer every question: you may choose to not answer any question(s) of your choice. Should you appear to be experiencing discomfort during the study, the interview process will be discontinued.

Lastly, if any new information important to your decision to participate in this study becomes available, such information will be provided before you sign this form.

Questions

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension and Augustana Research Ethics Board (EEA REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EEA REB at (780) 492-3751.

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided above if you have questions at a later time.

*Appendix E: Project Consent Form***University of Alberta
Consent Form**

I am agreeing to participate in the research study entitled “**Hearing Families and their deaf or hard of hearing children**” I have read the study information form carefully and understand the information provided. I have also asked any questions that I might have regarding the research study and/or my involvement.

Rights

I understand that I have the right:

- To not participate
- To withdraw at any time without prejudice to pre-existing entitlements, and to continuing and meaningful opportunities for deciding whether or not to continue to participate
- To opt out without penalty
- To have any collected data withdrawn from the data base and not included in the study.
- To verify the transcripts from the interviews
- To privacy, anonymity and confidentiality
- To safeguards for security of data (data are to be kept for a minimum of 5 years following completion of research)
- To disclosure of the presence of any apparent or actual conflict of interest on the part of the researcher(s).

Consent to Participate

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described in the research study description document, understanding that I may withdraw this consent at any time. Copies of this consent form and a research study description document have been given to me for my records.

I understand that the plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension and Augustana Research Ethics Board (EEA REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, I can contact the Chair of the EEA REB at (780) 492-3751.

I can also contact either of the two individuals listed below if I have further questions or comments regarding the study.

Ihor Kobel	PhD Provisional Candidate	University of Alberta	403 342 3325
David Mappin	PhD, Associate Professor	University of Alberta	780 492 5211

Signature of Participant

Date

Signature of Researcher

Date