

#### **Parental Insights: A survey of the challenges of raising young children with hearing loss in Ukraine**

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#### **Abstract**

This paper presents the results of the study on parents' subjective experience of parenting a child who is deaf or hard of hearing in Ukraine 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 there is a lack of family resources that are supposed to help in the adaptation process of the family to their child's hearing loss. Family communication emerged as the biggest concern of all hearing participants in this study.

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 and 17 families from among this number participated in follow-up interviews. The survey captured demographic data and then focused on items such as the emotional impact of the diagnosis on the parents and other family members, how to choose a communication mode suitable for their child, availability and accessibility of professional services, access to information on deafness, and educational choices. Parental insights and views in this study were consistent with international perspectives of parents that are documented in the literature: the need for informational support, guidelines for making informed choices about education, and communication options for families were seen to be key factors. The findings of this study confirmed that parents desire greater access to educational options, support for overcoming stress and improving emotional well-being, support for families in establishing healthy family interactions, and strategies for empowering parents as advocates, as their most important requirements.

#### **Introduction and Background to the Study**

##### *Families with Deaf Children and Education*

In September 2007 there were 30,896 children of school age diagnosed with hearing loss in Ukraine. However Ukraine does not capture any other statistics or any other demographic information on families with children who are deaf or hard of hearing. As well, there is no published research on the experiences of parents with deaf or hard of hearing children, or the manner in which members of the family communicate, or the services and/or early intervention programs available for them.

Ukraine has a well-established system of 58 residential schools and 35 kindergartens for children who are deaf and hard of hearing however the system is strongly child-centered, and with rare exceptions, there are no counseling and any other services in place for families. As well, schools do not hold training sessions with parents. 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).

Historically the use of a signed language in the educational system was prohibited 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 no opportunity for parents to learn sign language in order to communicate with their child. In Ukrainian residential schools for children with hearing loss it is deaf children of deaf parents, deaf parents, and a few deaf teachers who are able to provide knowledge of a visual signed language and to transmit some components of Deaf culture.

### *The Deaf Community in Ukraine*

Almost all adults with congenital hearing loss and those who lost their hearing at a very young age prior to learning to speak (pre-lingually deafened) are members of the Ukrainian Society of the Deaf, which is a national organization. The range of hearing loss in 52,000 members varies from mild to profound (UTOG, n.d.).

Even though Ukraine has a well-established system of deaf education, many children leave school with an inadequate level of skills required for successful integration into society or for pursuing the opportunity for quality post-secondary and vocational education. Deaf teacher Levytskyj (2003) noted:

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)

Throughout Ukraine there is a lack of awareness of the talents and abilities of Deaf citizens, and this lack of awareness generates negative attitudes towards deaf people. For example, in Ukraine, deafness is often equated to being mentally or physically retarded. Pathological attitudes toward deafness still prevail among Ukrainian professionals who work with deaf and hard of hearing children.

### *Call for Change*

Recently in Ukraine, many professionals involved in the education of the deaf 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). In addition to critiquing the existing system of kindergarten and school education, the authors also point to the lack of research in this area (Harniuk, 2005; Savchenko, 2001; Zasenka, 2001).

If professionals are to respond to this call to provide effective services and rebuild the existing system of the deaf education, they must collect empirical information and analyze the current context. The introduction of a family voice may be of considerable benefit supporting a shift in a new perspective on hearing loss in Ukraine and result in the creation of new family-focused services and intervention programs.

### **Objectives of the study**

This is the first research study to be conducted in Ukraine, which explored the experiences and feelings of a large group of Ukrainian hearing parents raising children with hearing loss. This study had several objectives:

- To document the characteristics of hearing parents and their young children with hearing loss,
- To reflect retrospectively on the feelings, behaviors and thoughts of parents,
- To explore parental views on the issues of family communication modes and Ukrainian Sign Language.

This study provides insight and a contextual frame to what it means to raise a young child with a hearing loss in Ukraine.

## 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:

- 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 with deaf or hard of hearing children?
- How do parents describe the nature of child-family relationships and communication at home?
- What is the parental knowledge and perception of Ukrainian Sign Language?
- What kind of specialized services are recommended, available, accessible, and accepted by parents?
- How do parents feel about raising a deaf child in Ukraine?

## Methodology

This study was designed as a two-phase, sequential mixed methods study. In the first phase, a cross-sectional survey was designed and implemented in order to collect quantitative and demographic data. A self-administered questionnaire was used, 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 while 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.

### *Sample*

All families (n=419) with deaf and hard of hearing children enrolled in grade 0/grade1 on September 1, 2007 in special residential schools for the deaf and hard of hearing children across Ukraine (53 eligible schools out of 58 schools in total) were the target population for this research. 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 for the entire sample initially proposed for the study was 77.8%. Seventeen families participated in the follow-up interviews.

### *Data Analysis*

Data gathered through the parent survey were analyzed for descriptive statistics to discover characteristics of the sample, which was important in address both a gap in the existing literature and to address the research objectives. In addition, demographic information was analyzed to demonstrate the diversity of families participating in the study. The SPSS statistical package was utilized for this and NVIVO 7 was used to process the transcribed interviews text.

## Major Findings

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

As demonstrated in other 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 the present time;
- 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. In families with hard of hearing children, parental suspicions about hearing loss appeared on average when the child was 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;

- Hard of hearing children received their hearing aids at 39 months (Mdn=36) and deaf children 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;
- The proportion of children who have additional medical conditions was 5 to 9% higher than findings in other countries.

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

The data presented the following major issues and concerns of parents:

- A child's identified hearing loss impacted parents emotionally. After identification of their child's hearing loss, parents did not have access to reliable information regarding how to best care for their child and coupled with the existing myths and prejudices in society, often increased their fears;
- Poor communication was identified as the most challenging and stressful factor which was 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 as well as expensive weekly trips to the educational placements which were located far from the families 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 and communication at home?*

The data presented the following major issues and concerns of parents:

- Participants identified communication as 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 great deal of pressure due to a lack of information or biased, incomplete, and inaccurate information from professionals;
- Most families were compelled to invent their own home signs as they did not have any access to learning Ukrainian Sign Language;
- Parents were unsatisfied with their home communication due to their poor knowledge of sign language, and the children's delay in spoken language and/or 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).

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

The data presented the following major issues and concerns of parents:

- Most of parents in this study considered signing and signed language as a necessity and they also understood that this is the best and natural way for communicating for their deaf children.
- Most of parents estimated their knowledge of 'signing' as unsatisfactory. However, many parents kept saying that they would prefer their child learn speech in order to function in mainstream society.

## *5. How do parents describe the nature of their relationship with professionals?*

- Parents relied on the professionals to provide information and guidance. However, many parents blamed pediatricians and other doctors for delaying the identification of their child's hearing loss, as well as for the lack of informational support provided from professionals involved in their children's care.
- Participants experienced additional stress due to the ineffective local medical services and were forced to seek reliable testing and medical support in the medical clinic in the capital of the country.
- In most cases, parents identified problems in building trusting relationships with the medical doctors and surdologists. (Note: Surdologists are medical doctors and language therapists working with deaf children in hearing centres in government-funded children's hospitals.)

*6. What kind of services were recommended, available, accessible, and accepted by parents?*

- From the parental perspective, most medical doctors steered the family toward a particular choice (oral language), which may not necessarily meet the developmental needs of the infant, toddler, or family. Many professionals recommended keeping their children out of the specialized kindergartens designed to teach deaf and hard of hearing children, for as long as possible.
- Many parents spoke about their fears before enrolling the child in a specialized 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 their decisions and were happy that their children were 'revived' when moved to a deaf and hard of hearing kindergarten. Almost all parents expressed satisfaction about the quality of education and teachers' attitudes in the special educational placements.
- None of the participants reported receiving any psychological or any other specific help, designed for families with a child who was deaf or hard of hearing.

*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, devastated, and helpless. The outside professional view of the problem often introduced additional stress and difficulties. When probed, families said the additional stress stemmed from the attitudes of the staff. Parents characterized the staff as having minimal or low qualifications to perform their work, and parents reported they were met with attitudes of indifference, as well as a lack of technical resources for reliable testing.
- Almost all participants reported a lack of choice of educational placements and support for developing an effective family communication system.
- Additionally, the data emphasizes the importance placed on shared experiences among parents. Specifically, parents in the study identified that deaf parents were seen as one of the most 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.
- 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.
- Parents also revealed that a deficit approach still prevails in health/social care and educational systems, meaning that the deaf and hard of hearing child is viewed as lacking, or less than. Finally, parents reported that they perceived there to be an overall low level of awareness about deafness issues throughout society.

## **Conclusion**

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 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 there is a lack of family resources that are supposed to help in the adaptation process of the family to their child's hearing loss. Family communication emerged as the biggest concern of all hearing participants in this study.

As Ukraine moves forward as a civil society, it will be important that these concerns and issues are targeted for implementing changes in practice of professionals. Changes are possible that can positively impact the day-to-day life experiences of families raising deaf and hard of hearing children, in turn increasing the chances for improving their children's opportunities for achieving milestones in their overall development. Future research could address the training needs of professionals serving deaf and hard of hearing children, as well as teacher practices to include educational via Ukrainian Sign Language.

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