
СУРДОПЕДАГОГІКА, ТИФЛОПЕДАГОГІКА ...

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УКРАЇНСЬКА ГЛУХА ДИТИНА В ЧУЮЧІЙ РОДИНІ

Стаття є коротким викладом дослідження про життя та проблеми чуючих батьків в Україні, які виховували нечуючих дітей від народження до вступу у перший клас спеціальної школи для глухих або слабочуючих.

Ключові слова: глухота, глухі діти, чуючі батьки, соціокультурний підхід, медико-патологічний підхід, білінгвізм, українська жестова мова.

Статья является коротким изложением результатов исследования, целью которого было изучить жизнь и проблемы слышащих родителей воспитывающих неслышащих детей от рождения до поступления в первый класс специальной школы для глухих или слабослышащих.

Ключевые слова: глухота, глухие дети, слышащие родители, социокультурный подход, медико-патологический подход, билингвизм, украинский жестовый язык.

Background

Families with Deaf Children and Education

By September 2007 there were 30,896 children of school age diagnosed with hearing loss in Ukraine. Following world demographic tendencies one can assume that in Ukraine most of those children were born into hearing families however there are neither statistics nor any other demographic information on families with children who are deaf or hard of hearing as well as no published research on the experiences and feelings of parents raising deaf or hard of hearing children, the way members of the family communicate, or the services/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, counseling and any other services for families are not in place. Even 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 [1; 3].

Historically the use of signed language in the educational system was prohibited because of a ban imposed after Joseph Stalin's [10] 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 basic signing. 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 language and to transmit some components of Deaf culture.

The Deaf in Ukraine

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 52,000 members varies from mild to profound.

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. Deaf teacher Levytskyj 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. [5, p. 51].

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. Pathological attitudes toward deafness still prevail among Ukrainian professionals.

Call for Change

Recently in Ukraine, many professionals involved in the education of the deaf have started reporting problems and failures in the field [1; 2; 6; 7; 8; 12, 14; 15]. Besides critiquing the existing system of kindergarten and school education the authors often point out the lack of research in this area [4; 10; 13].

If professionals are to respond to this call to provide effective supportive services and rebuild the existing system of the deaf education, they must collect empirical information and analyze the situation. 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.

Objectives of the study

This is first research study in Ukraine which explores the experiences and feelings of a large 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,
- (b) to reflect retrospectively on the feelings, behaviors and thoughts of parents,
- (c) to explore parental views on the issues of the mode of family communication and Ukrainian Sign Language.

This study provides insight to understandings in Ukraine of what it means to have a young child with a hearing loss.

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 raising 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?
 - How do parents describe the nature of their relationship with professionals?
 - What kind of services were recommended, available, accessible, and accepted by parents?
 - What are parental thoughts and feelings about raising a deaf child in Ukraine?

Method

This study was designed as a two-phase, sequential mixed methods study. 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 [8] 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.

Sample

All hearing 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

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 and NVIVO 7 was used to process the transcribed interviews text.

Most Important Findings

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

Same 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;
- 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 case with hard of hearing children suspicions 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;

- 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 the existing myths and prejudices in the 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 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?*

- 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 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;

- Parents expressed general dissatisfaction with their home communication due to poor knowledge of signs by parents 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).*

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

- 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 and function mostly in the hearing 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 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.

- 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.

- In most cases parents were talking about problems in building trust in the relationships with the medical doctors and surdologists.

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

- From the parental perspective, most medical doctors they applied to steered the family toward a particular choice (oral) which may not necessarily meet the developmental needs of the infant, toddler, or family. Many professionals recommended keeping their children out of the special kindergartens as long as possible.

- 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.*

- None of the participants 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.

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 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.

- Almost all participants reported a lack of choice of educational placements and support in developing an effective family communication system.

• 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.*

• 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 as well as low awareness in deafness issues in the hearing society.

Conclusions

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 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.

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This article presents a short report of the study on life and problems of Ukrainian hearing parents who have raised their deaf or hard of hearing children since birth till enrolling in grade 1 of a special school for children with hearing impairments.

Keywords: deafness, deaf children, hearing parents, sociocultural approach, medical-pathological approach, bilingual, Ukrainian Sign Language.

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