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# Attitudes of Deaf and Hard of Hearing Persons towards Health Care System in Macedonia

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**Abstract**: If the deaf community in the world has reach the point of recognizing their need for health care and accessing the health care institution in a different way, then we can say that they have been accepted as a cultural and linguistic community. Even though there has been a growth in demand for improved service in health care system, respecting their individual lifestyle, very little has been done in that direction in Republic of North Macedonia. The different way of communication of deaf people and hard of hearing, in Republic of North Macedonia, disables them to get the appropriate health care services that they are entitled in equally as the general population. That is why we made a research with a purpose to recognize the initial problems that people with hearing impairments in Republic of North Macedonia face with when accessing the health institutions. In this research, conducted in two municipalities of Republic of Macedonia, Tetovo and Gostivar, participated overall 40 respondents, which provided us with their prospective of how they percept the health care system in this country. It was a qualitative type of research, were we used the technique of an interview, and all the answers of the respondents were recorded on a video camera, then analyzed with a technique called interim. The results of this research shows that, even though the deaf community in this state has the right of accessing the health care institutions with an interpreter, (secured by the law of sign language of Republic of North Macedonia), they do not enjoy those rights, they have been disadvantaged when trying to access the health care system. Our recommendation is to inform these people about their rights for using interpreter secured by the law of Sign Language, and then the state to respond to their needs by providing them not just an interpreter, but also facilitating materials and methods for information for every health care center.

**Key words***:* Deaf community, interpreter, Sign language, health care.

## Introduction

Access to health care without barriers is a clearly defined right of people with disabilities stated by the un Convention on the Rights of people with disabilities (Kuenburg, Fellinger, & Fellinger, 2016). Access is a broad topic, it involves access to communication, information, education and culture, as well as access to services, including to health services, which is why researches (Gulliford, et al., 2002) state access to health care is generally conducted with regard to sociodemographic factors, investigating the relationship between need, provision and utilization of health services. If language is a communication tool and a way of obtaining information, then hearing impaired persons, respectively total deaf person, are discriminated from the beginning, hence only a small percentage of the general population are familiar with their sign language. Thus, when seeking health care, the main obstacle faced by deaf people involve the professionals lack of knowledge of sign language, and the lack of interpreters in the units (Abreu, Freitas, & Rocha, 2014). In the literature for deafness, there are some distinction between "deaf" and "Deaf" (Kritzinger, 2011), the audiological condition that results in lacking hearing is commonly referred to as being deaf, whilst "Deaf" dentoted with capital letter refers specifically to a distinct cultural group which uses the local sign language in their daily lives and considers deafness as a problem located within society and not individual (Chon-Hee, Sadler, Fullerton, & Stohlmann, 2007; Jones, Renger, & Firestone, 2005). In this paper our main concern are Deaf individuals, that use sign language as dominant mode of communication, regardless whether they are deaf or hard of hearing, and their

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perspective towards access to information. The lack of informative and accessible systems for the Deaf increases their vulnerability to preventable disease as a results of lack of mechanisms that take into account the peculiarities of minatory groups when obtaining health information (Richardson, 2014). The information that patients receive support their relationship with medical doctors, and thus may reduce their feelings of isolation, as well as increasing their satisfaction and adherence to treatment because medical doctor have a duty to communicate health-related issues (diagnosis and therapy), thus patients have the right to receive such information (Chaveiro, Porto, & Barbosa, 2009).

So how a person with hearing impairments access information after all? In the contemporary life, we can access to certain information by using television or internet. The first presents audio-visual tool for passing new information and news, but the audio part hampers people with hearing impairment to get this kind of information, even though on the national television program of Macedonia it is provided translation in sign language by an interpreter, but only two TV casts with 15 min of translation during the main news. The latter provides more in-depth information for everything, however it is self-financed, he has to secure by itself the internet. So we can conclude from these last two paragraph, that the state hasn't done much to enable the deaf people and hard of hearing an equal access to information, and this is a very important issue that has impact in the quality of the services that they receive from public health care institutions, while for example in UK, a deaf person or hard of hearing is entitled to use several communication services that the Royal National Institute of Deaf provides, depending what their need is:

- A BSL/English interpreter, who interprets from one language to the other. In the UK, this will usually be British Sign Language (BSL) to spoken or written English, or spoken or written English to BSL.
- A lip-speaker, who repeats what a hearing person or speaker is saying without using their voice so that you can lip-read them.
- A speech-to-text reporter (also known as a palantypist or stenographer), who types every word that is spoken using a special keyboard. Everything that is said appears on a computer screen.
- An electronic note

  taker types a summary of what has been said. This appears on a computer screen for you to read.
- A notetaker, who is trained to take accurate and clear notes for deaf people. A notetaker does this in handwritten English or by typing the notes on a laptop computer.
- A communication support worker (CSW), who offers support to students in education in various ways such as taking notes, interpreting or clear communication. (2004)

In this paper we tried to give a brief analyze about the health care system in Republic of North Macedonia, its three main components of services that mostly impact the life and wellbeing of persons with hearing impairments, the legal rights that they enjoy and results of a research that we have conducted with persons with hearing impairments.

## What Includes Health Care Services in Republic of North Macedonia?

Health is defined as a state of complete physical, social and emotional well-being, and not merely the absence of disease or infirmity (WHO, 1946)**.** Hence, health care services include many aspects of health caregiving. For the interest of this paper, we summarized only three aspects that concern deaf persons in Republic of North Maxedonia. Early intervention as part of health care service refers to early detection of hearing loss, by using neonatal screening, then early rehabilitation and the use of hearing aids and cochlear implants. Early intervention as a strategy is differently regulated in different state, in North Macedonia, there is no such net of early intervention, there are several independent institutions that act independently as an early intervention, Neonatal screening represents measuring of otoacoustic emissions with a simple and relatively cheap device, first applied by David Camp. The complexity consists of organizing the team who will be responsible for the measuring process, as for the continuous counseling of the parents. It is used TEOAE method (Transient evoked otoacoustic emissions), which means that the device only inform us for existence of the hearing loss, but not for the level of the loss. (Богоеска, 1998). But not in every state, not even in Republic of Macedonia is imposed as a routine procedure, which is very important because , the newborn should be treated before the ending of basal maturity process of the auditory path. (Јачова, 2009).

As part of an early intervention are included hearing aids which can determined only with audiometry. Audiometry as an integral part of health care system, represents a test method for examining the degree of hearing loss, implemented by an experienced audiologist, who release sounds with a different frequency, so they can evaluate the degree of the hearing loss, is it a conductive hearing loss, or a perceptive, or combined. In Republic of North Macedonia there are several centers for audiometry where regularly are examined all persons with hearing loss, but unfortunately not everywhere the examination is implemented by an audiologist. In addition, cochlear implants are considered as part of early intervention, however the decision of whether to use an aid or to be subjected to a surgery is up to the parents after they are familiar with the pro and cons of each one. Most of the children with hearing loss have some residual remains, and the duty of multidisciplinary team is to use the remains of the hearing for choosing the most appropriate hearing aid, and only in case when there is no benefit from the aid, it is considered the possibility of cochlear implant. This famous operation has already turned on in routine operation with several benefits, but it costs very much. How does a cochlear implant function? The cochlear implant is a surgically implanted device that enables a development of a hearing sense to a person who has profound or severe hearing loss. (Јачова, 2009) The Republic of North Macedonia, the Ministry of health covers only several procedures, i.e. several children per year can be entitled to the operation where the state covers all the expenses necessary for the operation and postoperative period, and the procedure will take place in Macedonia. There are different opinions regarding the cochlear implant from deaf people, and precisely their attitude towards this procedure was one of our research question.

## Legal Rights of Person with Hearing Impairment in Terms of Health Services

The rights of persons with disabilities in terms of health care and health insurance are not particularly regulated in Republic of North Macedonia, but certain rights are provided in several laws and decrees, which implies an obligation to the state to create conditions where the right to health care will be practiced in an equal way. In the Constitutions of Republic of Macedonia, in article 39, it is regulated the right to health care, and the access to it for each one in equal conditions, but it is not highlighted especially for persons with disabilities. In the Law for Health Care in Republic of Macedonia are governed some rights, like reimbursement of travel and subsistence expenses and exemption from participation, (38/91, 46/93, 55/95, 17/97, 10/04, 84/05, 111/05, 65/06, 5/07, 77/08, 67/09, 88/10), respectively participating with personal means in the prices of health services and drug, except for treatment abroad. (19/2011, 91/2013) In the same law, article 9, line 3, a person is entitled to medical aids, where the state covers 80% of the costs. According to the National Convention on the Rights of Persons with Disabilities, respectively article 25 regulates the right to the highest attainable standard to health without any discrimination on grounds of disability. The state signatories are obliged to take all appropriate measures to ensure access to persons with disabilities to health services (Најческа, 2011). As we can see from the above text, the state has signed and adopted the necessary laws to enable an equal access to information and health care system, but how much of this is implemented on the field was a question that intrigued us to make this research.

Persons with hearing impairments in Republic of North Macedonia face difficulties when trying to access any information, however over time the state tried to reduce these difficulties, especially with the adoption of the Law for Sign Language in 2009 ,, which under Article 2, when sign language is recognized as a completely natural way of communication equivalent to oral communication, while in Section 4 a deaf person or hard of hearing has the right to use sign language as a party or as participants in proceedings before state bodies, health care services, local government bodies, judicial authorities, public enterprises, institutions, agencies, funds and other organizations. (2009/105).

According to the law, deaf and hard of hearing persons have the right to use an interpreter of sign language for different basic needs depending to their choice, in cases where hearing loss is an obstacle to his needs, but no more than 30 hours per year. One can legitimize this right after handing over the necessary proof about his hearing loss at the center for social affairs. (2009/105). In North Macedonia, the National Association of Deaf and Hard of Hearing counts 31 licensed interpreters for the entire state (2020), where the number of population is approximately 2 million. In 2014, the National Association of Deaf and Hard of Hearing in Macedonia, in collaboration with the Ministry of Social welfare, started with trainings for new interpreters which are now licensed, also they have started trainings for pharmacepht workers for the basic level, just to facilitate the communication with people with hearing impairments. The Association itself tries to improve the quality of life of every person with hearing impairment, but it is hard for them to realize everything without financial support.

The research entitled "The experiences of people with hearing disabilities in access to health services" conducted by Laura Ringham, in the UK, gives a clear picture of the accessibility of the health institutions in the same state. The final results were presented in 2012 in the Panel for Research of hearing impairment. The study involved 607 participants with varying degrees of hearing impairment, all 900 participants were invited to participate. From them 69% were users of hearing devices, 4% were users of British sign language, and 64% were of working age. The subject of research was to detect the difficulties faced by people with hearing disabilities in access to health centers, which were divided into three areas: experience in contacting and visiting the family doctor, adaptations in the family doctors center and counseling from the health personnel, and access to pharmaceuticals stores. According to the results in the first area are described which methods are used for contact by the deaf respondents and which one they would prefer to use for health center contact.

- 72% reported that through telephone they contact with their health center, but only 44% of them prefer this method of contact.
- 46% confirmed that they personally go to health center to schedule the examination, but only 10% prefer this way of scheduling.
- 9% contact the health center via email to schedule a review, but 31% would like to use this method of contact.

As for the second field, the results were divided into two areas: supply of health center with a visual screen in the waiting room and communication with the health staff. In the first concept the participants responded:

- 44% confirmed that their doctors' offices have visual information display in the waiting room.
- 14% said that at least once they missed the order for the review because their doctors' offices had no visual information display. The second concept included the following responses:
- To 28% the diagnosis given had not been clear;
- To 26% for the particular diagnosis given, the medical advices were not clear enough
- To 19% the prescript medication were not clear
- 59% think that the nurse is not always addressed face to face; (Ringham, 2012)

Krityinger (2011) has divided in two group the most frequent ways of, where in the absence of interpreter, providers very often turned to alternative inadequate form of communication with deaf persons, like speech reading (lip reading) as the most common alternative methods used, however it was inadequate in circumstances where face masks were used by health professionals, or hurried speech, not facing the patient while speaking, or having foreign accent, and written communication which also was inadequate because deaf personal lack vocabulary and t handwriting of health care professionals, which is why one proper way to overcome this kind of barriers is the use of interpreter. Interpretation is defined as a process of receiving a massage in one language and sending it in a different language, making sure that the exact message is conveyed (Pillay, 1999).

## Research Methodology

The **subject** of our research was to analyze the attitudes of people with hearing impairments in the municipalities of Tetovo and Gostivar, in relation to the health aspect, respectively access to health institutions. The objectuce was to determine the status of people with hearing impaired in terms of the function of health facilities and their access to the same institutions. Based on this objective we proposed several research question that then directed us to use appropriate technique, like interview. The research questions were as follows:

1. What kind of barriers do they encounter when they try to obtain information?
2. What kind of barriers do they encounter when they access health care institution?
3. What kind of facilitation do they use that is secured by the state to obtain information??

### Research Methods and Techniques

As a research technique it was used interview, i.e. as an instrument we used protocol of semi-structured interview, conducted with the help of pre-prepared questions of topics relevant to the survey, which provided direction for the development of the conversation, thus giving space for the full expression the participant. We used a convenience sample, snowball sample, which means that we chose subjects that were available, for which we had previous information from the Association of Deaf in Tetovo. Exactly 40 respondents participated, with varying degrees of hearing impairment, 20 of Gostivar, 20 of Tetovo, aged 18-65, all in good mental condition and were able to participate in research. We elected this two cities, because very little surveys have been conducted there, and the population is more than 50 % consisted from Albanians, that consist approximately 25 % of entire populations in Macedonia. The survey was conducted in the municipalities of Tetovo and Gostivar, at the Association for the Deaf and Hard of Hearing in the same city, and every interview was documented on video.

## Data Processing and Results

The data obtained from this qualitative research were analyzed by a type of analysis known as interim or interim analysis, where we grouped the most frequent and similar answers of the respondents, which were duvededi into topics. Regarding the first question of the survey, three topics prevailed, one regarding the language as a barrier, second the use of interpreter, and the satisfaction from the use of interpreter. For the first topic, 34 respondents declared that linguistic barrier is the biggest factor when accessing information and for that reason they ask for more translation/interpreters, while 6 respondents believe that they can be informed by other means such computer, newspapers etc.

> I think we need at least written translation on flat screen in the waiting halls, as in court, in the municipality, in health care offices, even though a translation with an interpreter would be better because there are people that don't know even how to read.
>
> No I have no problem when accessing information because thank God I can read, use the Internet, open various web pages, read newspapers, only if the TV show something more specific that is life streaming, otherwise every information you can find online.

The second topic resulted to interesting information, i.e. none of the respondents had ever used a translator/interpreter entitled by the Law of the use of sign language, because most of them, 33, weren't even aware for the existence of this law, while 7 respondents knew about the Law, but never utilized this right.

> No, I did not know, I am hearing from you for the first time, till now the Secretary of the Association accompanied us wherever we needed, but it is much better if this is true.
>
> I know, but I think they do not come to our cities because the state do not pay them, and I think that we should have interpreters in our town, there is no need t come from Skopje (capital city of Macedonia).

The third topic resulted in two concepts, 36 respondents believe that 30 hours of free translation per year are enough because until then they had not used even an hour, while four respondents thought that that number is very small**.**

> I think that 30 hours are enough, before we did not have even an hour, not 30, if we use 2,5 h per month, I think it will be enough for a start."
>
> I think it is very little, imagine if you are in a court trial and the trial lasts several hours, that means that you have wasted all the rights for other translations?.

Regarding to the second research question, three topics prevailed. The first one referred to communication with medical staff, i.e. 22 respondents have great difficulty in communicating in obtaining health services in primary health care (22), 18 participants consider that the primary health care institutions do not face any communication barriers, while all respondents unanimously said that there are communication barriers in tertiary and secondary health care facilities:

> I have difficulties when it comes to understand the doctor, I have learned Macedonian in Bitola, and the doctor thinks that because I'm Albanian I will understand him better, but I don't really understand anything that he says, I cannot read his mouth when he talks in Albanian because I don't know Albanian language"
>
> No, I don't have any problem to understand my family doctor, I speak and read from his mouth because I already know him, and he understands me.
>
> In the hospital I have difficulties when it comes to understand the doctors, sometimes I even want to take my kids to help me, but I don't want them to worry about me.

The second topic referred to facilitation method of communication, and it was divided into two concepts, where all respondents unanimously stated negatively for any facilitation materials or method.:

> No, at my doctor there is no help given, at least there should be a tv and while we wait to write our names, when it's our turn, we would know
>
> No, there is absolutely nothing, we don't have a live interpreter, not to mention a screen, those kind of stuff only the west has.

The third topic refers to the coverage of health services by health insurance, which prevailed positive responses, i.e. 34 have health insurance, only 6 respondents did not have any health insurance.

> I work, that's why I have blue cards, I never pay the doctor, I think I'm exempt from paying.
>
> I'm retired, I pay a little amount of money when I go to the doctor 50, 60, 100 denar.
>
> My husband works in a sheltered workshop, but they do not pay his health insurance, on the other hand in the Labor they said that because my husband is an employee I'm not entitled to health insurance by the fund, so everything we pay is private

The third research question prevailed with two topics, the use of hearing aid, and how much the use of the device is covered by health insurance. The answers were surprisingly, only 4 respondents use a hearing aid, 36 did not use, and to all the device is provided by the health insurance.

> I wear the aid, I have taken it from the fund, but I pay 2000den private for repairing it.
>
> Before I wore the aid, but now I don't because it broke down, and I can't afford myself to buy it private.

The second topic was divided into two perspectives, and it prevailed negative attitudes regarding the cochlear implant, i.e. 37 of the respondents were against, while only 7 respondents have a positive attitude.

> There is no way, it's too bad, you could end up paralyzed, everyone thinks it's very good, it can be done only to adults, example to those who become deaf after the year of 30, to experiment with children it's not nice at all, I have contacts through FB with parents who have children with cochlear implant, and they find it very difficult.
>
> No, there is no way, it's better to communicate with signs than to do surgery, because we have our own language, and why be like the others, it is very dangerous.
>
> Yeah, why not, I know a kid in Gostivar they operated him, he is great, he listens, talks, why not, while they're still children they can do it.

## Conclusion and Discussions

Regarding the first question of the survey, all respondents agreed that in media should be more long interpretations in sign language than translations in written, and the interpret should use the sign language that is used by the majority of deaf people in North Macedonia. 85% of respondents agreed that language barrier represents a very important factor in accessing information as a result of their poor reading and writing skills, although they master sign language relatively well. From the second and third topic of the first research question, we can conclude that that none of the respondents used the right for free interpretation, 83% of respondents were not even familiar with this right. 90% of the participants said that 30 hours for free interpretation are enough for a start, because till then they haven't used it at all, and they would used it mostly in public institutions like medical health care. As a conclusion of the second research question we found that 55% of respondents have difficulty in communicating with access to primary health institutions (family doctor), and never go alone, always accompanied by another person, with better communication skills, usually a person who isn't deaf, which overlaps with the results of the several researches like of Laura Ringham, where 44% of patients were not able to understand good the medical staff, not to mention the prescribed recopies (Ringham, 2012; Santos & Portes, 2019). In terms of secondary and tertiary health institutions, all respondents are faced with difficulties in communication with the health personnel, which is the case in other researches as well (Reynolds, 2007; Farias & Cunha, 2017). Unlike the results of a survey of Laura Ringham, where 44% of respondents reported that their doctors' offices have at least one visual display of information for patients, our research shows that the family doctors' offices of our respondents, none of them has provided adaptation for the access of the necessary information, but they hope that one day it will provide the state.

Regarding to the third research question, we found that 85% of respondents have health Insurance, but none of them are familiar with the right OS exempt participation, meaning all users of health insurance co-pay. In the context of health aspect, we separated the views regarding the cochlear implant, 82% of respondents consider it a risky procedure, unnecessary, because they feel as a special linguistic minority, and there is absolutely not necessary to adapt to the hearing population.

## Recommendations

Based on the discussion over the results, we have spoted some recommendation for the relevant institution in order to improve access to health services, and thus to improve the health of persons with hearing impairments, respectively Deaf persons. Firstly, we suggest, a proper informing of deaf people and hard of hearing with the right to use the 30 hours' free translations, as well as increasing the number of hours, then we suggest training of medical staff, starting with the primary health services than continuing with secondary and clinical health care, at least for the use of basic signs in sign language. In addition, we suggest that every primary and clinic health service to provide at least one visual screen in the waiting room so persons with hearing impairment be informed at least for direction and basic information. Furthermore, there is a need of proper information persons with hearing impairment about health insurance and benefits of cochlear implants for their children if they are deaf as well. As can be seen, there are many steps that need to be undertaken in order to improve the health of persons with hearing impairments.

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