

Urszula Bartnikowska Ph.D.,

Marta Wójcik Ph.D.

University of Warmia and Mazury in Olsztyn,

The Internet as a Source of Support for Families Raising Hard of Hearing Children

When a child with a hearing loss is born the situation of the family is difficult. Real troubles come along with the birth of a child in the family or when the diagnosis of the hearing loss is made. The fact of pronouncing the hearing defect has usually a negative and stressful influence on the whole family. The moment of finding out about the hearing defect or the time just after that is accompanied by harrowing emotional experiences. According to A. Löwe (1999), the first stage which parents go through is “mourning” for “losing” a fully able descendant. At this phase, parents are not able to look realistically at the events because of shock – the most natural defence mechanism. The next stage is denying the diagnosis which has been made. Parents undermine the accuracy of doctor’s statement. What comes next is a tendency to be angry at oneself, a spouse, doctors, God...An element which is typical of this stage is making attempts to find someone to blame for a child’s hearing loss. The way to accept disability is long. The first symptom of gaining to it is a passive acceptance of the actual state. The full acceptance usually comes later. Then, parents try to gain information about hearing loss and its consequences and what is more they start to take care of fulfilling child’s needs.

The significance of providing meticulous care and overwhelming support for parents from the very beginning is unquestionable. Meanwhile, as B. Odzimek’s research reveal (2000) 80% of parents do not even obtain information about place in which they could ask for specialist help.

These problems exist even later, in the families with older children (sometimes even in teenagers or grown – ups’ families) – that is a long time after the diagnosis. And a long time in which child’s disability remains in parents’ perception. A lot of parents, too many of them suffer from effects of severe trauma, they do not cope with a problem of being a mother (father) of a deaf child. They lack knowledge, understanding and acceptance of child’s disability. The major driving force in action taken by them is not accepting the disability, but rather overcoming it, actually – enduring (J. Kosmalowa 2000). That is why there is a great need for supporting parents at every stage of their hard of hearing children’s development.

According to Schafer (cited in: Z. Jaworowska-Obłój, B. Skuza, 1986) there are various kinds of support, they are as follows: emotional (it consists in obtaining communiqués which confirm an affiliation to specific group; this kind of support is also a confirmation of emotional relationships with other people), non – cash (including: loans, gifts and favours) as well as information (it is accomplished by giving helpful advice, which is essential for a specific person to solve his problems). S. Kawula (1996) names one more kind of support which is an evaluative one. Its major role is sending communiqués such as: you are significant and important to us.

Usually the support for hearing impaired children’s parents is given by people who work in specialist institutions, schools, centers, Polish Association of the Deaf or various charitable organizations which act in the aid of the deaf, governmental institutions and local authorities. The support may be also expected from the closest and distant family, friends, neighbours, people with similar problems, self – help groups, religious organizations etc. The offer, as can be seen, is rich, however parents do not always know where to ask for help and where to go with their problems.

Nowadays the Internet – the global system of connections among computers comes to people’s aid (Giddens, 2005). This tool has revolutionized the possibilities of gaining information, establishing contacts with other people without moving and bearing the costs. Do the hearing impaired children’s parents find here only the information support? Is it possible to get other kind of support by using the Internet?

To find this out we have written down entries like: “hearing impaired people” and “the deaf” in the Internet browser and we have gone through several websites. From all links which were found we have chosen ones which were devoted to or created by the deaf, with the thought of them and their needs. On these websites deaf children’s parents can mainly obtain the **information support**.

The most direct form of information support which has been found by us is the one on the website of the Institute of Physiology and Pathology of Hearing where during the week (from Monday to Friday) various specialists give on – line advice for an hour a day. The counsel concern: sudden deterioration in hearing; aural

interferences; rehabilitation of children with a hearing loss; delayed speech development; preparations for child's audiology examinations; giving a small child a hearing aid; disorders in speech fluency; unbiased examinations concerning parameters of stimulation with using the Cochlear implant; audiological care of children with cleft palate; problems connected with rehabilitation of children with hearing defects and/or delayed speech development; occupational diseases of vocal organ; Cochlear implant in small children – the assessment of advantages of early implantation; chronic inflammatory condition in children; throat conditions and laryngitis; the child with hearing loss – the assessment of intellectual development.

Via this website parents have the possibility to make an appointment with specialist from the Institute. There is also information about call centre which is free of charge.

On the www.głusi.pl website parents can find information concerning medical issues, interpretation of audiometric test results and other hearing tests, or information about Cochlear implants.

On many websites one can find links to various associations, foundations and other institutions which support people with a hearing defect.

For many parents the issue of communication with their child is a problem. They try to find information about this matter as they know they lack abilities in this field and in consequence they experience many difficulties within this issue. On various websites they can find information about different ways of communication – sign language, Cued speech as well as about courses and trainings in this matter. Sometimes parents can even find some short movies which present signs in sign language. A lot of information concerning these issues are put on websites of individual schools for deaf and hard of hearing children. What is more via these website parents have the possibility to get to know specific school, its offer, teaching staff and activities.

The extremely important matter for parents is their children's education. On www.głusi.pl and www.onsi.pl websites parents can find addresses of centres and schools for children with a hearing loss (both Polish and foreign ones). Information about centres for hearing impaired children can be also found on the www.surdo.pl website. Thanks to these websites parents have the possibility to get to know the educational offer and functioning of individual institution before making decision about sending their child to a specific type of school: Primary, Junior High or Secondary.

However, the education of the chronically hard of hearing children does not end on the level of educational centres. That is why there are websites which inform parents about possibilities of continuing education at universities as well as about programme called Student – which is directed toward disabled students. Information about deaf children's chance to study at the university is important not only to chronically hard of hearing teenagers' parents. It also gives small children's parents hope that their child can lead normal life in spite of body damage.

The next phase in one's life is work. That is why parents ponder over their children's future life including finding a good place to work and fulfilling themselves in it. And again the Internet is in handy for searching information concerning these issues. The www.onsi.pl and www.deaf.pl websites give information about deaf people's employment, sheltered workshops and others.

In the Web parents can also seek legal advice, information about new laws, changes in the existing ones, concessions for child with hearing loss and his family, the government's policy with regard to the deaf and to disabled people in general.

The www.orator.wroclaw.pl website shows how deaf children's parents' associations function. This website is a good example of mutual interactions between parents who act in the aid of their deaf/hearing impaired children. It shows what they can accomplish and how they can help their children and themselves.

As you can see the information support which exists in the Internet is wide. However, not every website is up to date and contain recent news.

Is it possible to find an **emotional support** in the Internet? To be precise, it is. Particularly thanks to the fact that on various websites one can find profiles of hearing impaired people, their achievements and further dreams. What is more, information about painting exhibitions, conferences, anniversaries and beauty contests are also available in the Internet. There is also information about the way deaf people unite with each other via the communication tools to help one another and solve problems together. Reading such information may give parents hope that their child is going to achieve a lot in his life, despite his disability; that he can lead a normal life, be beautiful, win contests, competitions and realize his dreams.

The next way in which parents can obtain emotional support is sharing their quandaries and problems with other parents or with the deaf themselves on the Internet forums.

We have found an interesting offer on the www.slabsloszacy.pl website where one can get on –line psychological advice.

For many parents religious life is a vital matter. On the www.onsi.pl website this important sphere of life is introduced. There are reports and reportages from retreats, pilgrimages, meetings as well as addresses of places (parishes) where Masses for hearing impaired people (with the usage of sign language) are celebrated.

The emotional support is the most important in the first stage after the baby has been diagnosed with a hearing defect. This is the time when parents go through a lot of negative emotional states. In such moments they can take, as we have already mentioned, psychological advice which is available in the Internet. They have also the opportunity to establish contacts with people who have similar problems and experiences and they obtain support from them as they are able to understand their problems. This kind of support is possible because there are discussion forums attached to many websites. However, establishing contacts via the Internet cannot replace the personal meeting with another person, and because of that the emotional support via the Web cannot be the only one which the person who needs help get.

The **non-cash support** is the most difficult to find on the websites. To certain extent information about PEFRON aid programmes, allowances, benefits, concessions, equipment – hearing aids and advice could be categorised as this kind of support. However, this is only information about possibilities of getting non-cash support and not getting it.

The last kind of support we have been looking at on the websites devoted to the deaf is an evaluative support (you are important to us). It seems to us that the fact that these kind of websites exist and parents can find there a lot of needful information is a indication that this kind of support exists. Moreover, the evaluative support is mainly given to parents by other parents. They exchange their experiences and support each other in discussions on the Internet forums.

Summing up, it is worth noticing that the structure of websites created for the deaf does not differ from the websites created by people with normal hearing – they contain current information, reportages, chats, cultural, movie, theatre information as well as their accessibility for hearing impaired people and others elements

of popular websites. Such situations may be a proof for hard of hearing children parents' that people with a hearing loss are really normal human beings, and they do not differ from the rest of the society.

The Internet changes the character of one's everyday life – it blurs the line between global and local dimension of reality, it opens new channels of communication and interactions. It enables to do a lot various operations via the Internet links (Giddens, 2005). This transformation may be positive if parents (families) of people with hearing defects are not surrounded by people who grapple with similar problems. At that time the blur between the local and global issues is to their benefit. However, one should remember that contact via the Internet is only a substitute for a personal contact, which occasionally may replace the real contact with people. The support which hearing impaired children's parents get is only partial and not always sufficient.

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