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# Empowering the deaf. Let the deaf be deaf

Irma M Munoz-Baell, M Teresa Ruiz

## Abstract

**Deafness is often regarded as just a one and only phenomenon. Accordingly, deaf people are pictured as a unified body of people who share a single problem. From a medical point of view, we find it usual to work with a classification of deafness in which pathologies attributable to an inner ear disorder are segregated from pathologies attributable to an outer/middle ear disorder. Medical intervention is thus concerned more with the origin, degree, type of loss, onset, and structural pathology of deafness than with communicative disability and the implications there may be for the patient (mainly dependency, denial of abnormal hearing behaviour, low self esteem, rejection of the prosthetic help, and the breakdown of social relationships). In this paper, we argue that hearing loss is a very complex phenomenon, which has many and serious consequences for people and involves many factors and issues that should be carefully examined. The immediate consequence of deafness is a breakdown in communication whereby the communicative function needs to be either initiated or restored. In that sense, empowering strategies—aimed at promoting not only a more traditional psychological empowerment but also a community one—should primarily focus on the removal of communication barriers.**

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## Pathology/disability model versus sociocultural model of deafness

Over the past few years, two opposing perspectives of conceptualising deafness in contemporary society have been reported and discussed in scientific literature.<sup>1–5</sup> The first one defines deafness as a pathological condition, while the second one regards deafness as a cultural identifier. Consequently, both models have conditioned how recent research on deafness has been conducted,<sup>6</sup> and have strongly affected and determined the social view of deaf people and their education.

The pathology perspective focuses on the failure of the hearing mechanism. Deafness is defined as a medical condition that requires some kind of remediation, either through correction or compensation. This model finds that moderately and profoundly hearing impaired people can be analysed and grouped together for study.<sup>6</sup> Moreover, it emphasises the need to encourage speech and lip reading based on the assumption that competency in a spoken language is the only means for cognitive development in the child.<sup>5</sup> Its direct conse-

quence is, therefore, the rejection of the use of sign language in schools.

However, an ever increasing number of deaf people do not consider themselves to be handicapped or disabled<sup>7</sup> but claim to be seen and respected as a distinct cultural group with its own beliefs, needs, opinions, customs and language. Members of the deaf community define deafness as a cultural rather than an audiological term. The sociocultural model recognises significant sociolinguistic differences between people who label themselves deaf and people who label themselves hard of hearing, people who feel proud of their belonging to the deaf community and those who reject it, because in general they belong to separate cultural and linguistic realities. It is therefore reasoned that hearing impaired people need to be grouped separately for analysis.

As we have just put forward, both perspectives are contradictory because they uphold differing notions of deafness. When confronted, people who share one or the other standpoint usually end up in unsolvable conflicts, which are nothing but the result of differing expectations about each other's behaviour that necessarily clash. An example of this can be found at present in some schools for deaf children, in which deaf parents' advocacy of the use of sign language as part of the school curriculum in the education of their children comes into conflict with the hearing teachers anchorage in a still pretended importance of competency in a spoken language as the only legitimate way of educating deaf children.<sup>8, 9</sup>

## The hearing community versus the deaf community

### THE HEARING COMMUNITY

Historically, the dominant hearing culture has relegated deaf people to social categories such as "handicapped" and "outsider". The history of oppression and exclusion of the deaf community—although with important variations depending on the countries—and the ignorance and rejection of the natural and preferred means of communication of many of them is a well known and many times denounced phenomenon.

However, deaf people are disabled more by their transactions with the hearing world than by the pathology of their hearing impairment. Unfortunately, the social image of deafness is still marked nowadays in too many countries not only by a deeply rooted pathological stigma<sup>10, 11</sup> but also by negative stereotypes<sup>12</sup> and prejudiced attitudes<sup>13, 14</sup> toward the deaf that—attributable mainly to an extensive social lack of knowledge about communication mechanisms and how they work in conjunction

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with culture—have unfavourably influenced medical, legal, and educational policies for the deaf.

To a large extent, the world view of deafness has exerted an influence on so many issues of concern to deaf people that a review of the subject emerges as vital at this point.

#### THE DEAF COMMUNITY

Many are the implications of being deaf, however little is known about them. Congenital deafness has probably been the most and longest studied type of deafness because of the serious consequences early auditory deprivation has on the intellectual, behavioural, cognitive, psychological, and social development of the child. Within this group, a distinction must be made between (a) deaf children born to deaf parents, who acquire sign language as a first language, (b) deaf children born to hearing parents, who ignore the existence of or reject sign language,<sup>15</sup> and (c) deaf children of families in which another member is deaf.

The consequences of congenital deafness do not differ from those resulting from acquired deafness in those cases in which people are born with normal hearing and lose their hearing in early childhood, just before they come in contact with any spoken language. However, they do differ from the consequences resulting from acquired deafness when hearing loss occurs in late childhood. This is the reason we usually talk about preverbal (or prelinguistic) deafness to refer to the former and postverbal (or postlinguistic) deafness to refer to the latter.<sup>16 17</sup>

On the other hand, deafness acquired in adulthood creates problems that are different from those of people who are born deaf or lose their hearing in early or late childhood. Here again, though, we need to distinguish between occupational deafness and elderly deafness.

The hearing and the deaf communities share a linguistic challenge. Both encounter a communication barrier when having to deal with each other. The differences then lie in how this obstacle determines their lives and how they perceive of it.

For early onset deafness, prompt language deprivation has a direct effect on how the child acquires social knowledge, that is, if social knowledge is naturally tied to language and social meaning, how can a deaf child with no language construct his world? Low self esteem, childhood social isolation and parental stress<sup>18</sup> are some of the consequences of a communication disability in childhood. Deaf people tend to have little education, low status jobs and low incomes. Social rejection and alienation from the larger hearing community reinforce their view of themselves as a cultural and linguistic minority group.<sup>19</sup> Yet, the culturally deaf do not view themselves as handicapped or disabled but as members of the so called deaf community. Membership in the deaf community must be earned, and being deaf or having a certain degree of hearing loss is not the only criterion for potential inclusion. A common language, shared experiences, social participation and a sense of cultural identity are other recognised

criteria. What is more, belonging to the deaf community serves as “therapy” for deaf people<sup>20</sup> in many cases, and the importance of using methods of bilingual-bicultural education with deaf children rather than oralist methods is emphasised.<sup>21</sup>

Deafness acquired in adulthood is of a different nature. Communication breaks down when language has already been learned and is already in use. People grow reluctant to change or adapt their usual means of communication and find it extremely hard to adjust to the new situation. Changes after their hearing loss seem an insurmountable obstacle for them alone to cope with. Embarrassment, loss of confidence, anger and resentment are among the most common feelings they have to deal with everyday. Noisy groups and strangers are avoided and there is a growing preference to remain at home rather than to go out, which in many cases leads to inactivity, depression<sup>22</sup> and isolation. A persistent denial<sup>23</sup> of the new situation springs from a view of it as illegitimate, something to be ashamed of and hidden; hence, in great part, a dislike for or rejection of hearing aids. Deafness in the elderly can bring about additional difficulties, such as the inability to insert the earmould, to name just one,<sup>24</sup> as age related hearing loss means both an adaptation to the hearing loss and to old age.

Lastly, even though increasingly the number of persons with hearing loss in later life is much larger than that of those with hearing loss in earlier life, people in the second group tend to be better organised and active. The systematic use of a classification similar to the one just described would greatly contribute not only to obtaining exact figures on such a difference but also to conducting and evaluating any course of action.

#### Health promotion and deaf people

It is clear, then, how heterogeneous the deaf population is and how this fact has made it more difficult to establish a set of general measures to deal with the different issues facing this community.

It is also easy to see why there are so many associations and organisations nowadays (formed by prelinguistic deaf people, parents of deaf children, cochlear implanted people, postlinguistic deaf people, and interpreters, among others), not to mention the ferocious arguments and resulting confrontations and disagreements they are often drawn into.

To sum up, deafness implies diversity, and diversity in relation to hearing loss needs to be acknowledged, understood, and most importantly, respected.

It is paradoxical, if not highly reproachful, that there still exists nowadays an enormous gap in many countries between the legislation and their recommendations favouring equal opportunity for hearing impaired people on the one hand (The European Parliament Resolution on Sign Languages, 1988<sup>25</sup>; UNO Uniform Rules Resolution, 1993<sup>26</sup>; EU Committee Report, 1996,<sup>27</sup> just to mention a few), and the signs of incipient attention paid to deafness in many countries on the other.

European Union initiatives at both national and trans-national levels are making a significant contribution to the empowerment of deaf people. However, they also involve certain risks that need to be pointed out. Two of these projects shall be mentioned to illustrate such risks. In this respect, for instance, the European Social Fund HORIZON Chapter of the Employment Initiative should ensure that the distribution of projects to deaf organisations with different goals and levels of deaf awareness is carried out on an equal basis. In the same line, the EU Technology Initiative for Disabled and Elderly People should ensure that the devices being developed at present are disseminated to all countries and are affordably priced.

Knowing, understanding and taking into account the cultural, linguistic, sociological, psychological, educational and prosthetic aspects of hearing impairment is the first step in the delivery of quality health care for deaf people. Professionals who serve hearing impaired people need to be aware of what being deaf implies, and the obstacles they must overcome to be able to use their knowledge to counsel, advise, and advocate for the people they work for.<sup>7</sup> But also, deaf people need to be aware and well informed of what to expect and demand from the health care system. In this way they will be able to become sensible users of those services and make meaningful choices in relation to how they want to live their lives.

### Empowering the deaf

The concept of empowerment is extremely complex. Empowerment models are characterised by a bottom up strategy for change and a wide contextual framework.<sup>28</sup>

Empowerment primarily implies giving power and authority to a person. In that sense, it deals with a redistribution of resources and power, which brings up the question of whether an increase in empowerment for one group of people automatically means a decrease for others.

Within this framework, deaf people are regarded as being completely capable of self representation, decision making concerning their health and participating in health care work.

The notion of giving power to deaf people seems clear and easy to put into effect. However, the issue is not so simple and merits further analysis. Attempts made to increase the power of people have usually resulted in a highly objectionable situation of dominance/subordination; power is therefore seen as being in the hands of just a few people who wield it over other people. If applied to deafness, it leads to a painful hearing/deaf duality, which far from narrowing the gap between both situations, contributes to aggravating it. Strategies directed towards empowering deaf people should not result in reversing the above mentioned present situation.

Still, *power-over* is not the only option available. To give power can also be understood as *power-for*, which refers to power as a

#### KEY POINTS

- The medical point of view in the classification of deafness does not fit with the needs of health promotion strategies in so far as members of the deaf community define deafness as a cultural rather than audiological problem.
- Pathological stigma, negative stereotypes and prejudiced attitudes towards the deaf have unfavourably influenced medical, legal and educational policies. Deaf people are disabled more by their transactions with the hearing world than by the pathology of their hearing impairment.
- In dealing with this social issue, five strategies could be identified: improving legislation on communications barriers, providing the necessary information, improving patient's coping strategies, improving the health care setting and improving patient-physician communication.

synonym for capacitation—that is, the need to increase the decision making skills of people. It can also refer to *power-with*, which is concerned with the idea that people feel more powerful when they are organised and work towards the same goal. In that sense, *power-with* promotes the strengthening of organisations, social networks and alliances. Lastly, empowerment can also be seen as *power-inside*, which is based on increasing the self esteem, self acceptance and self respect of people.

*Power-for*, *power-with*, and *power-inside* bring about respect and acceptance of other people as equals and contribute to a notion of complementarity instead of one of duality and exclusion. Still, it should be borne in mind that actions aimed at empowering deaf people need both to take into account the risk of increasing conflicts instead of reducing them and to make sure deaf people are well aware of such risk.

These three dimensions of empowerment are not mutually exclusive. This is the reason why strategies, even though being directed towards fostering one of the three dimensions, should never be regarded as being restrictive, but rather as contributing to one same goal. Some of these strategies include the following:

#### ENHANCING LEGISLATION ON COMMUNICATION BARRIERS

Both to protect deaf people's rights and to take legal action when laws are infringed.<sup>29</sup>

- The present impetus given to the removal of architectural, urban and transport barriers should also include the removal of communication barriers in some EU countries, Spain in particular, as a distinct target and not as part of the other three goals.
- The high degree of non-compliance with laws governing the removal of barriers and equal of opportunity should be monitored and cut off.
- Legislation on the removal of barriers, too often incomplete, needs to be both implemented and regulated so that it can be put into effect shortly.

- Legislation that is being developed in many countries to be applicable only to certain regions within those countries should be broadened to become national in scope.
- Legislation should not only focus on transport, education and administration but also on health care. For instance, the recent regulation in some EU southern countries of the presence of interpreters or people trained in sign language in airports, bus and train stations should also extend to health care centres.
- Developing programmes that are responsive to families' needs as empowerment of the family has numerous benefits for the deaf child.<sup>30</sup>
- Developing programmes sensitive to the cultural and linguistic differences of the hearing impaired.<sup>31</sup>
- Starting rehabilitation programmes supportive of specific demands, problems and functional limitations of late deafened people.
- Helping deaf patients to face and examine their needs and develop strategies for coping with some of the consequences of being deaf: stress, loneliness or/and isolation.<sup>25</sup>

#### PROVIDING THE NECESSARY INFORMATION:

One of the obstacles numerous deaf people have to confront as part of their daily life is an overwhelming deprivation of their right of access to information. This is mainly because of the fact that many of them can neither follow the news on television nor, for instance, read a newspaper. As a consequence, many deaf people meet regularly in their local associations. Associations of deaf people become a way of seeking interaction with each other, accessing culture and exchanging information. In many EU countries, particularly in the southern ones, providing information on health issues is organised by the association and usually takes the form of short and infrequent speeches about AIDS, pregnancy, or any other related topic. It follows from this that:

- Associations, federations and organisations of deaf people should be contacted and profited as natural places for providing information to deaf people. Besides, agreements between health care providers and association presidents should be reached so that speeches on health issues no longer depend exclusively on an association's goodwill and initiative, but also cover a wide and varied range of themes, being given by professionals trained in dealing with deaf people. This could also lead to basic courses in sign language for professionals, which would result in a greater degree of trust and an improvement in doctor-patient communication.
- Television subtitling systems as well as news programmes should be created or improved (if they already exist), by making them the rule and not the exception, incorporating sign language to programmes for those whose preferred means of communication is sign language or whose reading comprehension is very poor, and most importantly showing them within hours deaf people can watch them.
- The interpreters' services should be made use of, their limitations known, how they work, and how to contact them.

#### IMPROVING PATIENTS' COPING STRATEGIES:

Impairment, disability and handicap are three aspects of the same reality. Yet, sometimes actions focusing on impairment and/or disability can result in turning it into a handicap when the goal pursued had been just the opposite. Strategies should therefore include the following:

#### IMPROVING THE HEALTH CARE SETTING:

The planning and design of an environment free from communication barriers should be one of the goals of any health care setting. This could be implemented by:

- Investing and equipping the setting with video-telephones, minicomps, faxes and the internet. This should always be accompanied by a previous consultation with organisations and representatives of deaf people.
- Installing emergency systems using visual/luminous means.
- Installing amplifying systems for hearing aid users.
- Presenting visually notices and important information on signs, panels or through the use of graphic symbols.<sup>32</sup>

#### IMPROVING PATIENT-PHYSICIAN

##### COMMUNICATION:

A recurrent topic in scientific papers over the past few years has been the growing concern for the doctor-deaf patient relationship.<sup>33-36</sup> The need for doctors to be aware of and understand the problems related to communication, low self concept and social functioning has been pointed out and emphasised to:<sup>37</sup>

- Deal with the initial crisis and resultant consequences for parents—parental denial of their infants' hearing loss,<sup>38</sup> guilt, grief, feelings of impotence, affection detachment, "doctor shopping"—when informing them of an irreversible hearing impairment in their child.
- Respond to parents looking for advice on the best education for their children at the point of entry into school.<sup>39</sup>
- Help deaf patients and their families overcome negative attitudes toward their hearing status.
- Contribute to the acceptance of prosthetic help by increasing the self perception and awareness of hearing impairment,<sup>40</sup> discussing the stigma related attitudes that prevent people from giving hearing aids a try, encouraging the use of hearing aids that are affordable and available to them, helping them select the most appropriate aid for their hearing loss and age.
- Reduce and dispel some of the serious misunderstandings physicians can provoke during a medical evaluation (underestimating their patients' intelligence, relying a hundred per cent on lip reading, giving oversimplified explanations)<sup>41</sup> because of ignorance

of the specific communication problems, needs and rights of their deaf patients (right to be assisted by an interpreter and to use sign language).

To sum up the matter, hearing loss is a social issue rather than just a pathology, hence the pressing need to remove the stigma of deafness as a pathology. Communication breaks down because language fails and language, as we all know, is the essential tool of human socialisation. Understanding the mechanisms that govern linguistic behaviour and production, how language and culture are part of the same reality, what deaf people's opinions, needs and knowledge are,<sup>42</sup> and what public attitudes, ideas, beliefs and assumptions toward deafness and hearing are, is the essential starting point for any action in health care. Medical professionals have the responsibility of reviewing and questioning the traditional medical model on deafness that emphasises pathology not only in their diagnosis and treatment of deaf patients but also in their definitions of deaf people's needs. Furthermore, because of its strong cultural bearing, medical research on deafness should no longer disregard research findings on non-medical areas when planning their research agenda and study designs.

Conflicts of interest: none.

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