

WHAT DO DEAF PEOPLE EXPECT FROM SCIENTIFIC RESEARCH

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I am honoured to have been invited to this very important Conference to present the views of the Deaf Community. I apologize for not being able to present my speech in person. As Chair of the European Disability Forum (EDF) I am currently attending an Interim Board Meeting of the EDF in Dublin, Ireland to discuss and agree on the future work program of our newly formed independent EDF.

I am honoured that my friend Dr Olivier Perier is willing to read this speech to you. Mr Perier and me have been working together in the working group on cochlear implants initiated by the European Union of the Deaf on a request of the European Commission.

Through this working group we have tried to create a dialogue and mutual understanding between the medical world and the Deaf community. The existence of the working group has led to a constructive dialogue between these two groups of people-

The question to which I would like to give an answer today is : "What do Deaf people expect of scientific research ?" A very interesting question and I would like to share my point of view with you.

First of all, I would like to make a few comments on the definition of disabled people in general. Time and time again society has tried to define disabled people- With the International Classification of Impairments, Disabilities and Handicap (ICIDH) the World Health Federation tried to classify and define the different types of disability, in order to clarify the different types of disability for the medical world.

But more and more people doubt if one is able to give strict definitions of disability. In my opinion, strict definitions are not possible. The term disability has undergone an evolution in the past years, depending on the medical vision and social knowledge.

Disabled people themselves do not like the definition of disability based on the medical model.

Disabled people fear that this model is too much focussed on the rehabilitation of disabled people without taking enough into account the infrastructure of the working and living conditions of disabled people.

It would be a shame if some forms of rehabilitation would result in insufficient or no effects because the working and living conditions in society are inaccessible to disabled people.

The disability movement, including Deaf and hard of hearing people, wish a new concept: through the abolishment of material obstacles, disabled people need to get a chance to equal participation in society.

An example : through logopaedic training and hearing aids, one tries to create a more understandable speech of hard of hearing people. If the users of hearing aids cannot benefit from an audio-loop service or visual information in public buildings, theatres, cinema's, etc.. the results of the training will not be optimal due to these unsolved obstacles in society.

That is why, in my opinion, it is not useful to look for a new definition of disabled people at the moment. First, we ought to develop a vision of how, next to the medical possibilities, we should overcome and demolish the barriers created by society, to enable disabled people an equal participation in society. In this period, it is insufficient to opt for the medical approach of the rehabilitation and accommodation of disabled people. This old approach is now giving way to a much stronger emphasis on identifying and removing the various barriers to equal opportunities and full participation in all aspects of life of disabled people.

For example, 20 years ago. Sign Language for Deaf people was unacceptable by this medical approach as being unadapted to society because of its primitive nature. Today, according to linguistic researchers. Sign Language is a full and equal language, and highly valued by society when communicating with Deaf People.

The battle between oralism and manualism would not have been necessary, if these two had been placed in a broader perspective and if they had been seen and used as complementary. The same holds true for cochlear implants. Some otologists do not allow implanted children to use Sign Language, because this language would influence the language and speech development of the child in a negative way. I have to remark that there are no proofs of the negative development. But, I am concerned about the conflicts between the otologists and the Deaf community.

They both have a completely different vision towards cochlear implants and they do not even know the vision of the other ! Many otologists have never seen the living situation of Deaf people and Deaf adults do not know the medical perceptions of the doctors towards Deaf people. The mutual conflict is based on feelings of threatening of one another.

I am grateful towards the European Commission for having made financial sources available for the setting up of the working group on cochlear implants under the auspices of the European Union of the Deaf. Through this working group, representatives of the Deaf community and the medical world were brought together and so, a dialogue was established. This dialogue proved to be very useful and constructive. Even a member of the Deaf radical action group : "sourds en colere" participated in this working group. The dialogue contributed to a mutual understanding of the two opposed groups. Dr Perier was a member as well of this working group and has confirmed the functional value of this dialogue.

What I would like to make clear to you is that the medical approach cannot always result in sufficient outcome if the infrastructure of society remains inaccessible to disabled people. People with a cochlear implant still need visual information like subtitling on television. A cochlear implant does not make you a normally hearing person. And almost all commercial broadcasting companies refuse to subtitle because it would be too expensive...

There are many more cases demanding our full attention. Important questions in this framework are:

Following which vision do the medical experts wish to support the rehabilitation of Deaf and hard of hearing people to enable them to find their place in society ?

And what do Deaf people want ?

Too many conflicts between the Deaf community and the medical world are caused by not knowing and not understanding the "other world".

We are blaming and harming ourselves !

That is why I highly value the discussions between the medical world and the Deaf community to create mutual understanding. I am convinced that this discussion will lead to a surplus value for both groups.

The medical world must understand that Deaf people, despite the improved medical provisions, still do not have many perspectives towards equal participation in society in general and the labour market in particular.

Deaf people must know the medical and audiological possibilities to improve their quality of life.

It would be a shame if the medical world and the Deaf community would continue to live on their separate islands instead of opening the dialogue. The working group on cochlear implants has proved to be an excellent example of a constructive dialogue.

Finally, what do Deaf people expect of scientific research ?

Well, an open dialogue to enable Deaf people to understand the value of medical research and to enable the medical experts to understand the real position of the Deaf community. The dialogue can create new dynamics between the two groups. We should strive towards full participation of Deaf people in society, by using all complementary disciplines.

Dr. Perier knows me very well; I use all possibilities to enable myself to function in society. I use hearing aids. I am in favour of Sign Language. I use a Sign Language interpreter. I think reading is very important for Deaf people. I am extremely interested in the medical and audiological developments in the area of Deafness. Next to this, I monitor the technical developments taking place in society, like video telephony, internet, mobile phones for Deaf people, etc.

But, I am not willing to give up my Deaf identity for a so-called integration in society. Integration in society while keeping one's own identity, is only possible if Deaf people learn to organise themselves. Deaf people need to get self confidence to keep them going in society.

I sincerely hope that one day I will have the opportunity to exchange thoughts and ideas with you about the different positions of the Deaf community. I expect a lot from you researchers and I really would like to have been present at this symposium. I hope you have understood the intention of my speech namely the build up of a dialogue to reinforce the functional value of your work !

I wish you success in this Conference and I am looking forward to receiving the final report.