

**The United Nations Comprehensive and Integral International
Convention on the Protection and Promotion of the Rights and
Dignity of Persons with Disabilities.**

Marcia B. Dugan

I thank you for the opportunity to share some information today about two projects that I believe of interest to people concerned with global health.

I speak to you today as the immediate past president of the International Federation of Hard of Hearing People (IFHOH)

World Federation of the Deaf
World Federation of the DeafBlind

effective information sources and have provided an opportunity for IDA to obtain information as well as to voice the concerns and needs in relation to accessibility to the UN facilities, information, UN policies concerning the Special Rapporteur and procedures of the work of the convention on disability.

Panel of Experts (POE)

The IDA has also created a group from the South (Africa and South America) called Panel of Experts. This group is particularly important because it is in the South where most needs to be done. IDA's goal is to inform and involve those developing countries in the disability movement and encourage their participation in the development of the UN convention on disability and to provide for cooperation and exchange of information within IDA structures.

Interaction with the POE has created awareness that information needs to be greatly adapted for different groups because many do not have the experience or knowledge to assimilate information if documents are provided in original format. There are a

very difficult for wheelchair users to access the room, a lack of accessible desk spaces for wheelchair users, no CART services for severely hard of hearing people and a lack of seating acceptable for sign language interpreters.

Accessibility is a vital issue – how can people with disabilities discuss their rights if they cannot access the rooms?

The disability community was made aware of a UN access audit several months ago and informed the Department of Economic and Social Affairs (DESA) that they would like to be an active part of any access audit since our organizations are knowledgeable about such issues. DESA was agreeable. In addition, in meetings with Under-Secretary General Nitin Desai and his successor Jose Antonio Ocampo their expertise was offered and they were assured that they would be consulted in accordance with the motto “Nothing About Us Without Us.” There are qualified experts within the disability movement who can perform access audits.

Before an expensive reconstruction is undertaken, the disability community, asked to be allowed to be part of the access audit in a substantive way.

If we partner early in the process then we all can win. The UN will have an updated building that truly allows people with disabilities to participate in UN activities on an equal basis with other citizens.

ACCESS (Articles 9 and 21)

I have been particularly involved with the Articles related to access and was pleased to be present for the early discussions on Article 9--Accessibility.

The UN Standard Rules 1993 state: “In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of the States to take appropriate action to remove such obstacles.”

It is estimated that at least 70 member states do not have any access-related legislation and fewer than 10 of the 191 UN members have English as a first language.

Terms such as “design for all, barrier free de

organizations. It included the following requests in order to have a barrier-free enabling environment: Inclusion of text information and speech to text interpretation, inclusion of adequate hearing assistive devices such as induction loops and FM and infrared systems, and inclusion of lip-reading education.

By introducing these access needs of hard of hearing people, they created awareness, and they were the voice of IFHOH.

The bracketed information in paragraph (a) as you can imagine is controversial in Catholic Countries. The footnote is important because it reminds us that all health services are provided on an equal basis with others. Some states argue that there should be no reference to health services.

The second part is a follow-up national hearing awareness and training program in conjunction with the World Health Organization (WHO).

This Program is urgently needed. Most of the people living in developing countries --and, indeed, many people living in the developed world, too--do not have hearing aids and are therefore not able to communicate adequately with their families, friends, and others around them. In some countries they are outcasts. Furthermore, in the poorer countries there is too little knowledge of prevention and causes of hearing loss. Medical and audiological services may be non-existent or--at best--limited, and the equipment used is often outdated and inadequate. Professionals often have neither the motivation nor the means to improve their skills or the services they provide to consumers. Consumers themselves do not have the knowledge and,

example, in which hard of hearing and late-deafened people themselves can support those in rural and isolated communities who would otherwise not receive at all--or receive infrequently--practical hearing health care and support; and

(e) to provide the impetus for an epidemiological survey of hearing disorders.

The more data there is about the number of people in need of a hearing-aid or other types of hearing health care the easier it will be to persuade governments and other major funders that new or improved hearing health care services are urgently required for the people who need them most.

This exciting and important IFHOH project should make a great difference to the daily lives of people living in developing countries where there is currently little or no hearing health care service or support.

However, the success of this far-reaching IFHOH project is very dependent upon sufficient financial and other support being forthcoming from grant-giving bodies, corporate sponsors, donors and others interested in what IFHOH is trying to achieve. The future will see a period of intense work, including fundraising, in order to complete the first pilot presentation in India.

The WHO's project WWHearing currently is developing pilot projects in India and also in different countries namely China and possibly also in South Africa and Brazil.

In addition, the WHO has called on the private sector to provide affordable hearing aids in the developing world and emphasized that the price of hearing aids will remain prohibitive until all stakeholders work together to reduce costs.

The World Health Organization is working with member states toward reducing and eventually eliminating avoidable hearing loss and disability through appropriate preventive and rehabilitative measures.

Its strategic target is to eliminate 50% of the burden of avoidable hearing loss by the year 2010.

Four training manuals (basic level, intermediate level trainer's manual, intermediate level student's workbook, advanced level) have been prepared to equip primary level health workers and communities in developing countries with simple, effective methods to reduce the burden of ear and hearing disorders. Interactive training provides understanding of ear disease, and basic measures to prevent and manage common conditions and help people use hearing aids effectively.

Being involved with developing countries takes a huge amount of optimism and energy. It is my hope--and perhaps my dream--that because of what is happening at the United Nations, at the WHO, and through the human rights and disability organizations like IFHOH, that dream will become a reality.

provided, they are provided without discrimination on the basis of disability.

Free and Informed Consent

Free and informed consent is part of the right to health under the International Covenant on Economic, Social and Cultural Rights (ICESCR). People with disabilities must be guaranteed this right on an equal basis with others, as is now the case in article 25 of the draft Convention.

1. This means that we are entitled to exercise our legal capacity, with or without support, to accept or refuse medical treatment.
2. It means that we know what is best for us--families, doctors, judges cannot make a better decision than the person with the disability.
3. It means that there can be no laws or policies permitting forced medical interventions on people with disabilities--mental health laws would need to be repealed.
4. It means that people with disabilities have a right to know everything about the treatments that doctors want to perform on us--the positive and negative implications--so that we can decide whether the risks are worth the potential gains.
5. It means that all health information should be presented in accessible formats--including sign language, Braille, and plain text versions.
6. It means that doctors should be trained to consider the impact of treatments on a person's true well being, instead of a narrow focus on what medicine knows how to change.
7. It means that we should have access to peer support and to support networks of our own choosing, not only medical expertise.
8. No exceptions to free and informed consent by people with disabilities should be written into this Convention.