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). I returned last week from Croatia and the IFHOH Biennial General Meeting held last Sunday in Dubrovnik. This was my last meeting as president, a position I held for five years. Although I am relieved of presidential responsibilities, the incoming board has asked me to continue providing leadership for our involvement at the United Nations.

Let me tell you a little bit about IFHOH
IFHOH is a coalition of national associations of and for hard of hearing and late deafened people.
IFHOH was organized 1977, and currently has 49 general and associate members in 32 countries.

IFHOH came together for the purpose of providing a platform for cooperation and exchange of information...and to promote greater understanding among hard of hearing people worldwide. Now, nearly 30 years later--as an umbrella organization and through its individual organizations--IFHOH works worldwide for access for hard of hearing people.
The head office is located in Stockholm, Sweden.

IFHOH's involvement at the UN is with the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities
This is a mouthful and there's been a recommendation that it be renamed the "International Convention on the Rights of Persons with Disabilities." But for today's meeting I will call it the Ad Hoc Committee or AHC.

I have represented IFHOH at the last three meetings of the Ad Hoc Committee, which have been held at the United Nations in New York.

The AHC is a subsidiary body of the UN General Assembly and deals exclusively with the elaboration of the new convention on the rights of persons with disabilities. It was established in December 2001 by a General Assembly resolution...and its first session was held in August 2002.

Since then, there have been seven sessions of the Ad Hoc Committee and the eighth--and they hope the final session--will be this summer from August 14th to the 25th.

The mandate of the Program stems from the World Program of Action concerning Disabled Persons, which was adopted by the United Nations in 1982 and the Standard Rules on Equalization of Opportunities for Persons with Disabilities adopted in 1994.

The major objectives of the Program are the following:

1. to support the full and effective participation of persons with disabilities in social life and development
2. to advance the rights and protect the dignity of persons with disabilities
3. to promote equal access to employment, education, information, goods, and services.

The Ad Hoc Committee at its first session, decided to invite National Human Rights institutions to participate in its future sessions. Since then, the 59 Non-Governmental Organizations (NGOs) have played a vital role.

Dr. Donald McKay of New Zealand chairs the plenary sessions of the Ad Hoc Committee. At those sessions, representatives from countries worldwide react to input from the non-governmental organizations and debate their suggestions.

The topics discussed are in the form of Articles that range from Education (Article 24), Work and Employment (Article 27), Participation in Political and Public Life (Article 29), and articles on Children, the Status of Women to Health,whic is (Article 25), which I will address later in this presentation.

My main interest, however, and the interest of IFHOH is on Access (Article 9) and Access to Information (Article 21).

The Role of the IDA

IFHOH is one of eight NGOs that formed a strong coalition called the International Disability Alliance, the IDA. The other seven international organizations of and for people with disabilities are:

Disabled Peoples' International
Inclusion International
Rehabilitation International
World Blind Union

World Federation of the Deaf
World Federation of the DeafBlind
World Network of Users and Survivors of Psychiatry.

Together, IDA represents more than 600 million people with disabilities worldwide.

IDA was formed in 1999 with the purpose of being a spokesperson for the international disability movement in global policy matters and to facilitate co-operation and exchanges of information between the international disability organizations, primarily in relation to multilateral organizations. While all of IDA's member organizations have been actively involved in the development of the UN Convention on the Rights of Persons with Disabilities, IDA's focus is much broader than that.

IDA has the following goals:

1. To identify common positions on disability issues and to lobby UN agencies together on those to which there is agreement.
2. To encourage the membership of the international disability rights organizations to collaborate more actively at the international, regional, national and local levels.
3. To develop joint strategies and inclusive positions on cross-cutting issues that affect persons with disabilities.
4. To promote the involvement of people with disabilities in world politics on the world arena.
5. To strengthen existing networks within which the international disability rights organizations actively participate.

All IDA organizations have (or are about to have) consultative status with the Economic and Social Council of the UN (ECOSOC).

Until now, IDA has been fortunate to receive its funding from the Swedish International Development Agency (SIDA). That is because the former UN Special Rapporteur for disability was from Sweden and he was extremely supportive of IDA's involvement. In addition to covering complete expenses for two representatives from each organization, SIDA also has provided financial support to their assistants so that the reps could attend important UN events such as the meetings with the Ad Hoc Committee when negotiating the disability convention.

IDA has arranged special meetings with Sheika Hissa Al-Thani, the UN Special Rapporteur on Disability, José Antonio Ocampo, Under-Secretary-General of the Department of Economic and Social Affairs (DESA) and Jean-Pierre Gonnot, from UN DESA, Social Policy and Development Section. The meetings have proved to be 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 number of persons who have limited or no knowledge of English and the bureaucratic and massive UN documents are often perceived as too complicated.

It is heartwarming to see the cooperation among the member organizations and the large presence of members from developing nations.

International Disability Caucus (IDC)

In addition to the IDA, there is a larger group of 59 NGOs called the International Disability Caucus. This group meets early each morning during the sessions to review and evaluate the previous day's plenary session and to decide on an approach to take since not every organization is able to speak to the convention. The members of the caucus have their own priorities. Some are more concerned about education, and others about the rights of women, the rights of older persons, and about the ability to work, to name a few. The eight members of IDA are part of this caucus...and because we represent the largest group-- and we speak with one voice following consensus--IDA always is the first--and sometimes the only NGO--permitted to speak to the convention.

Access to the UN

While the UN has taken the step to develop a convention to protect the rights of people with disabilities and has worked to make them welcome in the process, at the same time, the UN has limited their participation because of access barriers. People with disabilities, while advocating for their rights during this convention process, have faced a number of logistical hardships from the UN Secretariat building itself. Starting with the first Ad Hoc meeting, people with disabilities have made their complaints known to the UN Department of Economic and Social Affairs, the bureau hosting the meeting. Complaints include: a lack of accessible non-gender bathrooms, too steep a grade into Conference Room 4 (where the meetings have been held) and heavy doors that make it 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 design, universal design, accessible design and inclusive design" are used throughout the articles and are often vague.

There are many references to sign language interpreters and Braille, but the needs of hard of hearing people were rarely spelled out.

That is why the proposal that interested me most was the one offered by the All Japan Association of Hard of Hearing People (ZENNANCHO), one of our IFHOH 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.

I also was pleased that the International Disability Caucus, in its draft of Article 21, recommended that State parties to this Convention take measures to "provide, maintain, and publicize the range of services and appropriate assistive technology used by and available to meet the access requirements of persons with disabilities--including sign language interpreters and speech-to-text interpreters, Braille and tactile signage, alternative augmentation communicative assistants, personal support services, live assistance, intermediaries, guides, readers, and effective methods of making oral communication available to people hard of hearing."

Even the IDA, whose member organizations are greatly concerned and knowledgeable about disabilities has much to learn about access. In addition to accommodating the variety of disabilities among the participants at a recent IDA meeting, language interpreters were also needed, but not present, to assist one man who spoke only French and another woman who spoke only Spanish.

In order for this meeting to be accessible to me, I used my FM receiver and transmitter. The transmitter was moved together with a system used by two other delegates who were both hard of hearing and blind by one of their aides. No one spoke unless they had both assistive devices in their hand.

A side event was planned by IFHOH and our Japanese organization at the last AHC where CART was demonstrated in English and Japanese in an effort to show the UN powers what true access for hard of hearing people is. They also realized that this would not only help us but it also would be extremely helpful for people for whom English is not a first language. As a result the United States and Canadian official delegates to the convention have begun working with IFHOH to provide CART at the general meeting of the convention.

Article 25-Health

And now to Article 25-Health

This is a very controversial issue. It was highlighted in the final statement by the Chair as on of the three key outstanding issues.

I have given you a copy of the article in the handouts. This article is still in the editing stages.

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 IDC is considering proposing a reference to "prohibiting any withholding of treatment based on disability."

In paragraph (b) the chairman's text still includes the reference to "prevent further disabilities," which is opposed by the IDC.

And paragraph (d) refers to "free and informed consent." The IDC is suggesting that this be a separate paragraph because of its importance.

Free and Informed Consent
During the last three months since the last AHC meeting in January, there has been much discussion via e-mail about the right to free and informed consent. At the January meeting, at least two countries opposed the concept (one by mistake, we hope) and one of the countries said that informed consent does not exist in the country. Despite countries (or perhaps the chair) opposing it, the committee on economic social and cultural rights has said that free and informed consent is part of the right to health.

The IDC recommends that no exceptions to free and informed consent by people with disabilities should be written into this Convention.

There also has been much discussion about who has the right to speak for people in a coma and how to word supported decision making in a coma or unconscious state.

Please note item 5 on the Informed Consent hand out...we are still working of this in the United States...when will it happen in developing countries?

Hearing Awareness and Information Program
Because today we are talking about global health, I want to tell you about IFHOH's program on hearing loss.

Together with the WHO, IFHOH has initiated a program for developing countries.

The IFHOH Hearing Awareness & Information Program for Developing Countries has two distinct parts: first, a pilot presentation that can be taken to developing countries to draw attention to the problems and needs of people experiencing hearing difficulties and to encourage the setting up of a national task force to develop new or improved hearing health care services in those countries.

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, therefore, the impetus to ask for personal help, let alone improvements in their country's hearing health care system.

The IFHOH Hearing Awareness & Information Program is intended to assist in dealing with this problem, which is also being tackled by the WHO through its World Wide Hearing project.

The mission of World Wide Hearing is to promote better hearing through the provision of hearing aids and training in developing countries and underserved communities.

The target audience for the pilot presentation are influential and suitable people with direct or indirect interest in hearing health care services--from government officials, social workers, medical and audiological professionals, manufacturers (commercial and not-for-profit), NGOs, to hard of hearing and late-deafened people themselves. In essence, the introductory presentation has the following detailed objectives:

(a) to stimulate hearing awareness in the developing country;

(b) to form the nucleus of a national self-help organization for hard of hearing and late-deafened people. This is so that hard of hearing and late-deafened people can come together to advocate for new and better services for people with their kind of hearing problems.

(c) to establish a recognized national co-coordinating body to implement and monitor any hearing awareness, training or other programs that may be arranged as a result of the pilot presentation. This body would include both professionals and consumers and it would liaise closely with IFHOH and other organizations supporting the national program;

(d) to recruit reliable people to train as 'trainers', thus encouraging the development of better local and outreach hearing health care services. This is an area, for 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.

Article 25
Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health services as provided other persons, [including sexual and reproductive health services] and population-based public health programmes;

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and the elderly;

(c) Provide these health services as close as possible to people's own communities, including in rural areas;

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and
raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.

1.The AdHoc Committee notes that the use of the phrase "sexual and reproductive health services" would not constitute recognition of any new international law obligations on human rights. The Ad Hoc committee understands draft paragraph (a) to be a non-discrimination provision that does not add to, or alter, the right to health as contained in Articvle 12 of the International Covenant on Economic, Social and Cultural Rights or Article 24 of the Convention on the Rights of the Child. Rather, the effect of paragraph (a) would be to require States Parties to ensure that where health services are provided, they are providfed 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.