Not an official UN document. For information purposes only.

UNITED NATIONS

PROGRAMME: No. 944 recorded 8 June 2004

GUESTS: Luis Gallegos

Chairman

Ad Hoc Committee on Convention on Disabled People

JOURNALISTS: Bill Reilly

United Press International/UPI

Michelle Makori

South African Broadcasting Corporation/SABC

MODERATOR: Tony Jenkins

"Towards a Convention on Disabilities"

The World Health Organisation (WHO) estimates that there are some 600 million people in the world - one in ten people, roughly - living with disabilities. Many of them are denied equal opportunities to access jobs, education and public services.

How can the UN help them fight discrimination? Will the rights and dignity of people with disabilities be better protected by an international convention? Can the rights of the disabled be protected in countries that are already having a tough time fighting poverty, conflict and disease?

In this edition of World Chronicle these questions are explored with the insight of Ambassador Luis Gallegos of Ecuador, the Chairman of the Ad Hoc Committee on Convention on Disabled People.

WORLD CHRONICLE is produced by the News &Media Division, Department of Public Information, United Nations, New York, NY 10017, U.S.A.

Duration: 28:00"

Executive Producer: Michele Zaccheo

Director: Tony Marshall

Production Assistant: Lebe Besa

ANNOUNCER: From the United Nations in New York, an unedited interview programme on global issues. This is **World Chronicle.** And here is the host of today's **World Chronicle**.

JENKINS: Hello, I'm Tony Jenkins and this is **World Chronicle**.

The World Health Organization estimates that there are some 600 million people in the world living with disabilities. That's roughly one in ten people. Many of them are denied equal opportunities to access jobs, education and public services.

Can the United Nations help them fight discrimination? Will the rights and dignity of people with disabilities be better protected by an international convention?

Those are some of the questions we have for today's guest, Ambassador Luis Gallegos of Ecuador, who is the Chairman of the Ad Hoc Committee dealing with the Convention on Persons with Disabilities.

Ambassador Gallegos, welcome to World Chronicle.

Let's jump right in. What is the purpose of an international convention on disability? Aren't these issues covered by existing human rights legislation? Or is this the United Nations expanding its reach, as some people say, becoming a vast bureaucracy?

GALLEGOS: Well, it's not really expanding bureaucracy because I don't have to deal with that. The issue is that we have 600 million people who are disabled – or more. This is an estimate of course, but the progression is the following: you either born with disability, you acquired it during your life, by sickness, by accident or by war, or by many...any other cause. But certainly, when you reach your older age you will be disabled in some way, so the progression is incremental more than a decreasing issue. Disability is something that is a complex issue to define, and obviously it's a complex issue to regulate a norm worldwide. You have to protect them, promote the people --persons with disabilities on the basis of saying, "What you can do to have enforceable rights worldwide in a universal norm in order to guarantee these rights to people." Each country may have its internal legislation, maybe its very adequate or maybe its very progressive, but the issue is that this has to take into consideration, not only the aspects of universality, but a real change in society and its mores to deal with disability.

JENKINS: Is that what you hope to achieve in practical terms? I mean, the reason I ask is because we already have international conventions against torture for example; we have conventions against child labor and we see how half of those are observed and practiced.

GALLEGOS: Well, I think that you have seven human rights treaty that are signed by a group of countries because the treaty is really signed and ratified by a group of countries; not all the countries in the United Nations have signed and ratified. But you have a monitoring

Page 3

group that keeps this up and monitors the complaints of governments about this. When you have a government that's willing to sign a convention of this type and be monitored, and this is fundamentally enforceability, you have a progression. And I do think it's also a guiding light to those that do not have their legislation up to par. The issue of human rights is something that we have to look to be enforceable in the sense of people really having the capability of going before a judge and saying, "These are my rights", wherever they are in the world and whatever the cost. And I think that's the merit of the legislation. Now if we get a number of countries, let's say – 150 or 160 or 170 of the 191 countries to sign this convention, we will be going in the right direction of norming the standards of human rights worldwide.

JENKINS: Joining us in the studio are Bill Reilly of United Press International/UPI and Michelle Makori of the South African Broadcasting Corporation/ SABC. Michelle?

MAKORI: Ambassador, approximately 80% of the world's disabled population lives in developing countries. Now given the numerous other challenges that these countries face such as extreme poverty, conflict and other diseases, what priority level is given to the issue of disability in these countries?

GALLEGOS: Well, according to the statistics I've read, 450 million people live in the under developed, or under privileged world.

JENKINS: 450 million of the...?

GALLEGOS: Of the 600 million. There is a limitation to everything and to take your question adequately, I would say that of course poverty is a violation of human rights, the basic violation of human rights. If you cannot survive, if you cannot feed your children, if you cannot educate them, you have one of the major issues there. But that is not to say that even in the poverty stricken country, you should not have a special care for vulnerable groups – I'm not talking about vulnerable groups both of gender, in women or in children, all in disabilities. There are certain norms and values that a society has to take care of independently of its situation. It's not only the resources that you require to leave poverty behind or develop, it's also the society's conduct and culture of changing the stigmatization you have for people with disabilities. It's being able to rationalize that people who are considered disabled today may not be considered disabled tomorrow. I'd like to tell you an anecdote about this because when I was elected to this charge, I got a group of experts together, the first quality experts in the world I would say, and I asked them, "What is a disability? Who is a person with disability?" And one of them told me, "You would be a person with disability because you use glasses. If you do not use glasses, you do not have perfect vision, and if you do not have a perfect vision 30 years ago, you would not have been able to fly a plane, you would not be in a military, or whatever". As the world has changed its perception of people with glasses, like myself, you

have left behind a stigmatization of somebody who in that nature would be disabled. In the poverty world of 3 billion people, you have people who cannot have glasses, so maybe that is the reparation that you should look for; but more than that it's the culture of integrating these people – not hiding them or not having treatment that is abnormal to any human being. I think that the major effort of this convention would be to have integrated and holistic societies.

REILLY: I was wondering how you could enforce rights from a convention? Where are we in getting this convention? How many more of these meetings will we have to have like we had just recently?

GALLEGOS: Well, I would have to say that I was ambassador of Ecuador in Geneva and that's where most of this treaty bodies meets. They meet and they analyze the country reports every two years on Children's Rights, on Women's Rights and whatever we have in this segment. And I have had the opportunity of giving an exercise of doctoral dissertation, which I would say was even worse, giving one of this monitoring issues because you sit down in front of the panel of 10 specialized experts, who are asking very pertinent questions of what the country is doing and how the government is doing this, and what society is in these countries are doing? So, the monitoring goes on in the issue of compliance of the country where the convention is assigned. So, I think it is enforceable to this point. Of course, it has to deal with internal legislation also. We have internal legislation, like in my country in Ecuador, where human rights treaties are incorporated immediately into their legislations, so a person gos before a judge and says, "The convention of disability gives me this right, and you have to be... and it's enforceable. Others will go through parliamentary ratifications and changes of internal law. How you can enforce it is also a societal issue because it's like looking at a...a society has to look at itself in the mirror and say, "Where are my weak points in relation to disability?" What are we doing on this as we are doing in other fields? It's not an ideal world. It's a very complicated world where human rights sometimes are put in danger because of a multitude of factors? But I would say that it is an effort in the right direction of a rules based society, a world rules based society, and I think the United Nations is the forum where these things should be discussed. Maybe it's the relevant issue of discussing this – the democratic and transparent way with civil society and governments.

REILLY: How much more discussions will it take though?

GALLEGOS: Well, we have programmed a meeting in the next few months and then we'll have some meetings next year. But it's progressing nicely because there are no substantive differences in a problem...in the convention. The problems I have now are fundamentally ones of procedure. This is an old system of traditions and negotiations between governments. Sometimes the integration of civil society and NGOs and the integration of

Page 5

private sectors, who have to deal with this issue, are sometimes complex in the milieu of the United Nations. I am very forcibly trying to get a convention, we have a draft convention already, we've covered most of it in this session, we'll cover in the next more...we will finish the first reading. My hopes ...and I am an optimist...that we have a major meeting in the United Nations in the millennium round revisions next...in the year 2005. If we can approximate the finalization of the negotiations toward that then I would be a very happy man, and so would be a lot of disabled in the communities.

JENKINS: You've talked about this from a values perspective. I'm wondering if you can apply some of the experience in dealing with some other issues? I'm thinking for example the rights of women, the rights of children where the UN has been able to go to countries and say, "These are a wasted resource. If you're putting children to work making rugs, you're wasting them. Send them to school and they can become information technology specialists and earn a lot more money for you— the same with women". Can the same argument be made with disabled people?

GALLEGOS: I think that you have to see that a person with a disability is not a person that you put in a corner. There are people with disabilities that are very...that are extraordinary individuals. Look, I am a diplomat and I've been a diplomat for over 37, years and I see people with disabilities coming into this forum and they can't see and they can't hear, and they have translators that go to their palms to transmit what the other is saying, and they can speak in public. Now, listen, they are a subject of admiration, not only by me but of other people because they have the force to go beyond their barriers and I think that's a lesson to all societies, all individuals in societies. I also think that there's a part where the scheme of gender and women discrimination is a reality; this is something that is happening and we have not gotten over it and we will not get over until societies are willing to do this. We've developed a positive segregation type of issue. So many women, quantitative; we've done this with children – said the children should not work at least should be educated. Children should not be combatants. I was just in the Democratic Republic of the Congo. You have 14, 17 years old carrying Kalishnikovs. This is not what you're looking for, you are trying to eliminate this. But as we compensate for this, trying to eliminate this type of a factor, try to get more women into positions of relevance in decision, the disability field is completely recountered – it's growing more than reducing. So, as the world ages we will have much more people with disability, whose rights have to be viewed by governments and by societies as defendable and as respected.

JENKINS: But I guess what I'm saying is, "Can these people become more economically productive? Is that an argument...? I mean, I have a brother-in-law who was

injured in a rugby accident many years ago and is paralyzed from the neck down. And for the first few years he just lay in bed, he wasn't feeling sorry for himself but he wasn't being productive. "I wonder", he said, "This can't go on any longer, I'm going back to college". And he studied and he became a lawyer and now he's teaching law. It's good to him because he feels that he's a useful member of society and he's also performing a useful function for society, and he's less dependent on society. Is that an argument that you're making to member governments?

GALLEGOS: Yes, and then there's not only the argument of integrating it -- selfdetermination, autonomy, lessons to institutionalization of people with disabilities. It's very easy to put a person in an institution and not recognize that he has evolved. Some of these disabilities are temporary. You have people that are a very important and valuable contribution today; especially with technology, you're talking about capabilities in computers and Internet. You don't need to move with an Internet based issue, you can work in many places. But these people are outstanding for that. Now when you limit a person's capability either by gender, by being a woman or by being a person with a disability, you limit the scope of the realization of this person as an individual or as a human being. You limit his capability of forming a family, of being self-sustained, of having children, of having political based rights. Can they be elected? Can they be candidates? And I think the value of this issue is that we have to change and revolutionize society. So this is the purpose of change, and I think the value of it is to put it in the front pages of society's discussion. These things have been relegated for too long a time; they have been viewed as a non-discussion item because, simply, they were not being looked at from a point of a societal issue but from a point of a health issue. These were people who are diseased and had medical care for them and this was how we were going to deal with this, while as a society issue many of these individuals will be integrated into a functional society; you cannot exclude them from an integrated society.

JENKINS: Let me cut you off there for a moment to say that this is **World Chronicle**. We're talking to Ambassador Luis Gallegos about what is being done at the United Nations to promote and protect the rights and dignity of the disabled. Let's take a look at this film clip from a documentary, called "Breaking Barriers", that shows some ways in which disabled people can be empowered.

We begin in California with Judy Hueman who was disabled by polio:

VIDEO ROLL-IN [TRT: 3'51"]
"BREAKING BARRIERS"

Page 7

HUEMAN: "...Can you get the pink socks? And we'll put them on...pull down the covers".

HUEMAN (VO): "Over the last 15 years I've really grown to recognize the importance of personal assistance in my life. People who can help me get up in the morning, get dressed, get out of bed, bathe, shop, toilet, drive my car. Basically it enabled me to be able to be like anybody else in the community. And not to have to ask people for assistance when I don't want to have to ask them to do me a favor."

"I pay for the service and it's valuable that I'm able to pay for it. But even in a case where someone is not able to pay for this assistance, the concept of being able to have someone work for me is what's very important here."

"The fact that I make the decisions about what time I'm going to get up in the morning, whether I'm going to eat breakfast, what I'm going to eat for breakfast, when I'm going to leave my house, where I'm going in the community. Those are the types of decisions that non-disabled people very much take for granted. And that if I'm going to be able to go about my life like anybody else, I have to be able to have control over those decisions. So for me, independent living is not at all doing everything by myself, but the important thing is my being able to give direction."

NARRATOR: For Judy, the priorities are that every person's life be valued, and that disabled people everywhere retain a sense of dignity. She feels it is critical to change attitudes of society and break down barriers of prejudice.

Disabled people throughout the world are often stigmatized for having a disability.

Hidden away in institutions or surviving on the streets, the disabled face similar prejudices. They may be the focus of taboos or superstition, sometimes the object of misdirected pity. In parts of Africa, for example, the children who cannot walk upright are sometimes called "serpent children". They are kept apart from others. They suffer psychologically as well as physically. They are more prone to diseases and infections, and their social development is stunted.

Simplice Armand Gotta was born in a village in Cote d'Ivoire 29 years ago. At age four he contracted polio, and was sent to live with his father who had remarried.

GOTTA: "When I arrived into the family I had a mother who helped me a lot, who made me understand that I wasn't a serpent child, that I was a child like all the others, and she helped me put myself on my feet. So that helped me to integrate into society"

"Starting from that moment I had the strength to fight like all the other non-disabled people and I went to school. They sent me to school so there was no difference between the other pupils and me."

"You are born with a disability, but you acquire a handicap. It is in the family where it begins, and it depends on the way the parents make the child see his own disability."

VIDEO OUT

JENKINS: That's horrible. When you think about the rights and the dignity of the disabled, as we saw in this film clip, how much of it is still, even in this day and age, about stigma rather than other issues of accessibility and what have you?

GALLEGOS: I think there's an enormous proportion of human conduct by stigma, by culture, by religion, by whatever cause you want. You have to look at this from an aggravated point of view; if you are disabled and you are a woman with disability; and besides you're maybe a black woman with disability or your race interest...you're three times segregated in relations. And if you are poor, its aggravated by that sense. So it's not only the social stigma, it's the reality of being able to compensate that and be able to enforcably get the community to accept you as a viable individual in their midst.

MAKORI: Well how can those stereotypes be tackled? Are their any educational initiatives that are planning to be launched - something that will address the issue at a grass roots level to change the stigma and the stereotype?

GALLEGOS: I think that every society has to look at itself and see how it does this because every society is particular in their context. It is a value issue: how you change the mores, how the political leadership, the private enterprise leadership, goes about this, and how the other groups, the religious leaders look at this as an objective or finality of a society. How we can become with less discrimination against ourselves as individuals – and as persons with values. I think that's the important question, which is being addressed here by this convention.

MAKORI: Well, another point coming off that, is highlighting the fact that people with disabilities can be self-sufficient given the right materials and the right tools and the right reinforcement. What has been their participation in the drafting of the convention? How much participation have you had from disabled people and their organizations?

GALLEGOS: I'm going to be a little crude in this because a...I'm a technician, I'm a diplomat, my function here is to try to put 191 parties together and have a convention. I have not seen a diplomat in the UN who is disabled. So, my understanding is that in order to have a convention, a viable, real convention – we have to address the needs of those people with disabilities, and these are people who we are asking to be integrated into the delegations that come for this negotiation. But the NGO and civil society participation is fundamental because we have to be explained, we have to be taught, we have to be sensitive to the issues that they can communicate to us and they can deal with. The NGO community has a slogan that says

"Nothing Without Us"; and I think that's a basis of it. Their civil society can move governments, can move parliaments, can move civil societies to rationalize that this is the moment we have in time to deal with discrimination on disability.

REILLY: I have a good friend who's paralyzed from the waist down, in the wheelchair, and is a television reporter here in New York. And I mentioned this convention to him and he was telling me that the state of the art for a wheelchair, the new wheelchairs now that balance and everything else, that can go upstairs and so forth is \$29,000; and how do you get that to the developing countries? And he also points out that these kids with Kalishnikovs you mentioned in the DRC are causing a lot more people to be disabled because of that. But, how can we get the castoffs say from the countries like the United States to the under developed countries?

GALLEGOS: Well, I have the fortune of being...my Ecuador has won the Franklin Delano Roosevelt prize for disability. And amongst one of the issues of the prize were a thousand wheelchairs that were donated by an NGO who does this. I don't think that anyone rationally can say that we need a transposition of funds to buy \$29,000 wheelchairs in this instance. I think they're adequate for some cases. In others really the issue is how to get these people into viable societies and families. I think the family plays an enormous role in the underdeveloped world. More than the...this is a chronicle of my beliefs also - more than in the developed world, because in the family, the structure of the family, the mother's role, the pregnant issue - of solidarity is there, even without resources. So, you have to look into how you solve these limitations, in many cases in the developed world is the access to elevators and lifts and electric stairs and access to buildings. In the developed world it's the availability of buildings, the availability of clinics.

JENKINS: Obviously, a lot of developed countries especially in the United States do very well on this issue. They have the resources. Can you point to any examples in the developing world where we see successful programmes?

GALLEGOS: Well, I think that there are a lot of successful programmes in the developing world, especially with those groups that have learned that you can integrate people with disability into the workplace, into their system of work, into their teaching systems; and that there are valuable contributions for an individual who looks at the person who wants to seek...

JENKINS: Can you give us an example?

GALLEGOS: Well educational systems in all of Latin America are not impeded of contracting people with...of hiring people with disabilities.

JENKINS: How about the work place?

GALLEGOS: The work place. If you have functionalities like you had before like people who received calls, the central reception of calls - can be very well done; the legislation in Ecuador demands that a certain percentage be contracted by this. But I was recently in China, and let me tell you that I was surprised by the evolvement of an issue in China, which is: people, who own enterprises in China, who are disabled - and that have disabled workers. I think that's an enormous contribution we're looking at. We're talking, in China, about a change in society from one system of economic and social systems to another - where you have this. I visited some of them. But I think that's a very good example of what we have to do. But more than examples of this, as in HIV as in other issues – we have to look at society's reaction to this. How we change society is the basic question that I think is on the level of platform here? What can we do to change the way we see people with disabilities, the way we appreciate them as members of society, what can we do to foster their integration into a holoistic society?

JENKINS: Ambassador Gallegos, that's all the time we have I'm afraid. Thanks very much for being with us on this edition of **World Chronicle**.

Our guest has been Luis Gallegos, the Chairman of the UN Committee that is working towards an international convention to protect the rights of disabled people. He was interviewed by Bill Reilly of UPI, and Michelle Makori of the SABC.

I'm Tony Jenkins. Thank you for joining us. We invite you to be with us for the next edition of **World Chronicle**.

ANNOUNCER: Electronic transcripts of this programme may be obtained free of charge by contacting World Chronicle at the address on your screen:

World Chronicle
United Nations, Room S-827
New York, N.Y., 10017.

Or by email at: besa@un.org

This programme is a Public Affairs Presentation from United Nations Television.

The views and opinions expressed on this programme are those of the participants, and do not necessarily reflect the official statements or views of the United Nations.