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June 2, 2004 – ADDENDUM

[The following interventions from the morning session were inadvertently omitted from the June 2 Daily Summary. This addendum should be inserted at the end of the discussion of Article 21. We apologize for any inconvenience.]

ARTICLE 21: RIGHT TO HEALTH AND REHABILITATION (Continued)

Lebanon supported amending the Article title to read "Right to health and medical and paramedical rehabilitation." In many countries, rehabilitation services such as speech therapy and functional therapy are not recognized as medical, and are therefore not part of national health systems. In the chapeau, after "access," should be inserted "affordability, adequacy and continuity when needed." Lebanon supported Yemen's proposed new Article 21(bis), but suggested changing the title to "Right to habilitation and rehabilitation." Lebanon endorsed the Rehabilitation International text proposal:

The Chair opened the floor for comments from NGOs.

Rehabilitation International, joined by **Disabled Peoples International**, **Landmine Survivors Network**, **European Disability Forum**, **Inclusion International**, **World Federation of the Deaf**, the **World Blind Union**, and the **World Union for Progressive Judaism** called for the separation of Article 21 into the right to health and the right to rehabilitation, as proposed by India and Israel. The UN Standard Rules on the Equalization of Opportunities for People with Disabilities (SR) defines rehabilitation as a "process aimed at enabling PWD to reach and maintain their optimal functions." An equivalent formulation should be used in this Convention. The term "rehabilitation" includes both "habilitation," which applies to those born with disabilities, and "rehabilitation" which applies to people with acquired disabilities. The obligation to ensure access to rehabilitation does not supersede the obligation to alter the environment. States should "redesign society to allow for integration of PWD, rather than to predicate their integration on their realignment with society."

Rehabilitation and health should be dealt with in separate articles for several reasons. Both rehabilitation and habilitation aim at a goal broader than health, which is the aim to function at the maximum extent of their own personal capacities. Depicting rehabilitation against the background of health only heightens the fear of PWD that those exercising authority over them will impose rehabilitation, and claim the imprimatur of international law. The right to health should be interpreted broadly, but it cannot adequately capture the full range of rehabilitation services required by PWD. Telescoping rehab into health could inhibit in future monitoring for effectiveness of rehabilitation services. The Article should build on existing international law, and should universalize the right to rehabilitation. The philosophy of rehabilitation contained in the SR flows from the fundamental value of personal autonomy. Additional authority comes from the European Social Charter, the Inter-American Convention on the Elimination of All Forms of Discrimination against PWD, and the Convention on the Rights of the Child (CRC). A comprehensive right to rehabilitation should be contained in one

article, rather than having its elements sprinkled throughout the Convention, in order to give the right to rehabilitation the prominence it deserves, and in order to achieve textual elegance and completeness. These NGOs also supported the prohibition against forced rehabilitation which was proposed by Israel. Separate and clear language for women and girls with disabilities should be included in the health Article. Subparagraph 21(j) should be amended by inserting "with respect to each service offered" after "informed consent." To prohibit rationing of health care services, a separate subparagraph should be added, reading, "Prohibit the discriminatory allocation of health care resources and treatment based on disability." This should be interpreted to prohibit discriminatory practices in the health insurance sector.

Disabled Peoples International (DPI) supported separating the two Articles, and noted that in the UN SR, health and rehabilitation are dealt with separately in 2 and 3. DPI recommended that 21(b), which addresses counseling and support, should be strengthened by adding "peer support," which is a fundamental disability concept. Subparagraph 21(m), involving involvement of PWD and their organizations in the formulation and implementation of legislation and policies, is related to UN SR 3(7) and 14(2).

World Network of Users and Survivors of Psychiatry (WNUSP) stressed the importance of the non-discrimination provisions for health care services, particularly for people living in institutions, who are often denied access to medical care for physical problems, and die as a result. WNUSP supported the general call for separation into health and rehabilitation, but noted that its constituents do not want psychosocial services to be defined purely from a medical perspective. More diverse options should be available, such as psychotherapy, as well as psychiatry. The suggestions by NZ and Rehabilitation International, requiring free and informed consent for each service offered, should be adopted. Informed consent should not be predicated on legal capacity in the traditional sense, but should include the concept of supported decisionmaking.

Society for the Protection of Unborn Children (SPUC) spoke on behalf of its affiliate, **No Less Human**, and the **Pro-Life and Pro-Family Coalition**. A new paragraph, 21(n), should be added to read as follows: "ensure (i) that a PWD shall be provided food and fluids, nutrition and hydration, including assisted food and fluids, nutrition and hydration, necessary to preserve or sustain that person's life. (ii) A PWD shall not be denied medical treatment necessary to preserve or sustain that person's life." They also support deletion of the 21(a) phrase "including sexual and reproductive health services," because PWD need the full range of health care, so one type should not be mentioned; and also because the phrase "reproductive health services" includes abortion, and the treaty will be legally binding on States Parties, they reject this phrasing.

National Right to Life (NRL) supported deletion of the words 21(a) "including sexual and reproductive health services" because PWD need a full range of health services, and there is no need to single out reproductive health. Doing so would promote the use of genetic testing to abort unborn babies with disabilities, and abortion for women with disabilities (WWD). NRL proposed alternative wording to 21(n) as follows: "We ensure that under no circumstances may a PWD be denied medical treatment, food or fluids necessary to sustain that person without clear and convincing evidence beyond a reasonable doubt that the PWD, while competent, rejected it on the basis of information sufficient to constitute informed consent."

Peoples with Disabilities Australia, on behalf of the **National Association of Community Legal Centres of Australia**, **Persons with Disabilities Australia, Inc.** and the **National Federation of Disability Organisations**, supported all interventions proposing separation into two Articles, strengthening of both, and references to community-based rehabilitation. It supported inclusion and elaboration of women's health issues, health care for children and indigenous people, and involvement of PWD in the design and provision, monitoring and review of these services. It proposed amendments incorporating explicit reference to dental health and mental health. The Article should specify that persons subject to compulsory mental health services should be treated in the health care system, not the criminal justice system, and that provision of such care should never be used as a punishment. In 21(j), there should be added a carefully-worded emergency exemption, to allow sharing of medical information in situations where information is vital to preserve life, or the absence of information will lead to additional harm.

Handicap International and **Save the Children** supported the proposals made by Namibia, Costa Rica and Chile to add specific references to community based rehabilitation which is a key condition to raise societal disability awareness.

International Convention Solidarity in Korea proposed that Article 21 should not be separated. Any new article should mention all types of rehabilitation, including social, vocational, educational, and medical rehabilitation. An article specifically addressing rehabilitation could overlap with the content of Articles 17 and 22, leaving no substantive content. The rights of PWD can be explained without using the word "rehabilitation," as rehab is related to all disability issues.

International Labour Organization (ILO) supported the proposal by RI and other delegates to separate the right to rehab from the right to health, but emphasized that rehabilitation is a means to the end of achieving equality and inclusion in accordance with individual choice, rather than an end in itself.

World Health Organization (WHO) focused on the risks of separating health and rehabilitation, as proposed by Israel and India. Disability requires a multilateral approach. The UN Millennium Development Goals establish health as a primary goal, and to separate health from rehabilitation could weaken the possibility of realizing its goals, especially for those living in poor countries. Medicine is distinct from health: Medicine relates to actions taken to remove threats to the well being of people, while health addresses social conditions and living standards. Poverty is the principle cause of diseases and disabilities, and disability generates more poverty for PWD and their families. Good health could help eliminate poverty among PWD. In the draft Convention, rehabilitation is clearly mentioned in the articles on work, education, health and definitions, and is based on a human rights framework. These articles provide guidelines to the UN and to Member States. Rehabilitation is not a requirement, and when it is provided, it is for a limited time. Some PWD have had negative experiences during the rehabilitation process, but this is the exception rather than the rule. Rehabilitation has contributed to participation and involvement by many PWD around the world. In many developing countries, rehabilitation services are provided by organizations, and this leads to some governments failing to comply with their commitment to provide such services. The Convention should reinforce relevant actions by all Member States.

National Human Rights Institutions supported splitting of Article 21 into separate Articles

focusing on health and rehabilitation, as explained by of Rehabilitation International, and support the tenor of the Israeli proposal in this context. The content of rehabilitation is not limited to health.

The Ad Hoc Committee Daily Summaries are published by the Landmine Survivors Network, a US based international organization with amputee support networks in 6 mine affected / developing countries. They cover the proceedings of the UN Ad Hoc Committee elaborating a Convention on the human rights of people with disabilities.

The Summaries are posted in MS Word on www.landminesurvivors.org/library_learn.php. They will be posted on line by 10 am the following day at www.worldenable.net, and <http://www.un.org/esa/socdev/enable/rights/ahc3summary.htm>. They are translated into Spanish (Disabled Peoples' International at <http://www.dpi.org/sp/resources/topics/convencion/boletines04.htm>), French (Handicap International- <http://www.handicap-international.org/esperanza/news/adhoc2004.asp>), and Japanese (DINF - webmaster@dinf.ne.jp).

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