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# *Yerker Andersson: Views of the Disability Community*

# Views of the Disability Community

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In his article "The ICIDH and the Need for its Revision," David Pfeiffer concludes that the ICIDH and the ICIDH-2 "are dangerous and must be dealt with by the community of people with disabilities." (1998:520). In reply to this warning, T. Bedirhan st n et al. assert that "persons with disabilities and their international and local organisations have been actively in" (1998:829) the preparation of ICIDH-2. An examination of Pfeiffer's bibliography and citations, however, suggests that he has relied mostly on the views of disability scholars. These views are not necessarily similar to those shared by the disability community because like other communities, the number of scholars in any community of people with disabilities always is small. Elsewhere I have argued that researchers and scholars cannot function as policy-makers in any legislative or administrative procedure. Ideally disability scholars would have shared their criticisms with appropriate organizations of people with disabilities who could then publicize their views. Referring to the assertion by T. Bedirhan st n et al., I can - as a former president of World Federation of the Deaf - verify that WHO has regularly consulted international disability organizations in the past. It does not necessarily imply that international organizations of people with disabilities and their national affiliates will be satisfied with the final version of ICIDH-2. If health professionals, government officials and lawmakers again fail to develop an understanding that health requires both a consideration of the views of different human groups and modifications in social, attitudinal and physical factors, rather than adopting a single view, the organizations will likely demand that the ICIDH-2 be revamped in the near future.

In their above-mentioned reply, T. Bedirhan st n et al. have acknowledged that it is a mistake to treat "all aspects of disablement phenomena" as a purely medical problem. But the countries around the world have for a long time been expected and still are expected to accept the permanent limitations, shortcomings, or incapabilities of individuals as parts of human life or health, not as diseases or pathological conditions. If their limitations, shortcomings or incapabilities are bothering, deteroriating, or causing pain, they may then be labelled as diseases or pathological conditions. T. Bedirhan st n et al. state that "the vast proportion of persons with a disability around the world have chronic disease conditions that require and often do not receive adequate medical [and rehabilitative] treatments" (1998:829), a fact that the disability community cannot deny. However, we must keep in mind that medical and rehabilitative treatments also include modifications in environmental factors such as the societal understanding of sensory, physical

and mental capabilities; architectural and transportation designs; the accessibility of mass media and others. In short, health is a measure of the personal and social factors affecting health. Health is a variable, from non-working to working depending on the degree of interplay among the facilitating factors - both medical and non-medical which ICIDH-@ has already acknowledged. In most countries perfection or normalcy still is used as an indicator of health and the importance of support groups and environmental factors has not been recognized for health. An increasing number of publications has recently proposed normalcy as an example of social hegemony or human oppression.

As the emergence of ICIDH-2 is a relatively new international event, it may be too early to discuss its importance for the community of people with disabilities. Based on discussions with both international disability leaders and individuals with disabilities at international meetings and articles on different perspectives on disabilities in periodicals and research findings, I will, however, describe a few possible implications of the new measure of disability.

After having participated in several of the monthly meetings of DISTAB (Disability Tabulations), I have gotten the impression that the measurment of disability, as designed by DISTAB, is promising because it may yield much more data than in the past. Only the numbers of persons with categorized sensory, physical and mental incapabilities have been reported in the past measures. The new analysis of daily activities such as hearing, seeing, walking and the use of hearing aids, sign language interpreting services, braille services, wheelchairs, etc. will for the first time provide information about the degree of participation in society by people with both disabilities and no reportable disabilities. For example, the unavailability of hearing aids and interpreting or captioning services in a given country would reduce the involvement of deaf and hard of hearing individuals in daily activities. The number of wheelchairs could be used as an indicator of potential participation by people with mobility impairments. Participation and isolation have repeatedly been noted as important health improvement factors in sociology and psychology. This new approach will certainly require a high level of teamwork among not only health professionals but also the governments, parliaments, architects, designers, and disability advocates. It is consistent with the Prefinal Draft of ICIDH-2's shift from "a 'consequence of disease' classification" to a 'components of health' classification."

The old ICIDH has made some profound influence on the health terminologies in many countries. For example, the belittling term "invalidos" has been replaced by "discapacidos" in most Spanish-speaking countries. However, the old term "handicap" still is preferred to "disability" in other countries probably because the former is easier to use than the latter in their native languages. Both deaf and hard of hearing persons and their

organizations have rejected "hearing impairment" while those having a visual impairment have divided themselves into two categories: the blind and the visually impaired. "Mental impairment" has been replaced with several new terms, i.e. "cognitive disability." The World Federation of the Deaf and many of its national affiliates now prefer that deaf people be recognized as "a linguistic minority" instead of as "a disability group." These changes are not preventable and cannot be arrested. Classifications, typologies, categorizations or new terms often are necessary in research but any attempt to create new categories or to re-label the existing categories of the activities and functioning on the new measure will likely lead to either acceptance or rejection. For these reasons, the involvement of both disability scholars and organizations of people with disabilities will certainly reduce the number of potential or existing biases in discussions on the construction of measures.

The new word "activities" might be untranslatable in some countries, hence causing difficulties in measurability. Fortunately, the members of DISTAB and other research teams have been developing and comparing the new measures of disability in different languages which would certainly lead to a clearer concept of "activities." Inasmuch as I know, the concept of "activities" has not appeared yet in laws granting equality or banning discrimination in many countries. Here I must add that a group of government delegates, set up by the Organization of American States, spent about 3/4 of their entire meeting time on the attempt to find a better definition of "disability" in their review of a proposed policy forbidding discrimination on the ground of disability and, for this reason, were unable to reach a consensus at the end of their two-day meeting! The Americans with Disabilities Act bases its definition of disability in terms of access to architectural, mass transit and communication facilities, rather than physical, sensory and mental incapabilities. Accordingly, the definition of disability only in terms of body functions and structure will never be satisfactory in the future. All human beings have at least one limitation on their mental, sensory, or physical capabilities which may be more or less tolerable depending on societal or cultural demands. Their limitations can either emerge or disappear as disabilities whenever societal or technological changes occur. For example, a former teacher of mine would have been considered as an individual with disability in our computer age as he had some difficulties in dialing phone calls and, therefore, would not be able to acquire typing or computer skills, now required in several professional occupations. Obesity is another good example as it is appreciated in some countries and not tolerable in others.

In conclusion, ICIDH-2 in general is a great improvement of ICIDH but cannot be expected to be a perfect classification of health or disability. It will have to be constantly revised whenever the societal or cultural value of health or the tolerability of human shortcomings changes. For example,

individuals with a cochlear implant still consider themselves as deaf persons rather than hearing ones not only because the quality of their hearing cannot be comparable to that of unassisted hearing but also because sign language has for a long time existed as a part of their daily life. Organizations of the deaf in several countries have already announced that individuals with a cochlear implant would still be eligible for full membership. On the other hand, those having received a laser treatment for their eyes apparently believe that they no longer are visually impaired. Variations exist not only in disabilities but also within each disability. In its measure of disability, ICIDH-2 has now included activities, environmental factors, and participation, in addition to body functioning and structure and personal factors and now requires a multi-disciplinary approach to disability studies. This expansion will certainly make information about people with disabilities and no reportable disabilities more reliable and more useful for government officials, health professionals, lawmakers, and industrialists. In turn, it will enable disability organizations to prepare more realistic position papers. As long as WHO tries to measure the daily activities and sensory, physical and mental capabilities of human beings, both with disabilities and with no reportable disabilities, and the environmental factors affecting their health, ICIDH-2 will likely remain as a valuable reference. In other words, the measurment of disability must be designed so that its findings can satisfy the needs of different human groups, not only the disability community. As I have mentioned above, this conclusion is based on my understanding of the views expressed by disability leaders and individuals with disabilities and publications on disability issues, including those published by disability organizations.