Washington Group Position Paper
Proposed Purpose of an Internationally Comparable General Disability Measure

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Preamble

Starting with the first meeting of the Washington Group (WG) in February of 2002, a core element of the discussions has been the importance of identifying the purposes of general disability measures, and the need to match purpose with measurement concept, i.e. the aspect of disability to be measured. In fact, a fundamental agreement of the WG was the need for a clear link between the purpose of measurement and the operationalization of the indicator. The WG also agreed that there is more than one possible purpose for which a general disability measure can be used and, therefore, it may be necessary to develop multiple general measures to suit specific purposes. We recognized that specific purposes of measurement address different conceptual elements of multi-dimensional disability models[a]. Therefore the disability measurement matrix was developed to delineate the association between measurement purposes, measurement concepts, and characteristics of questions used to reflect the concepts.

In order for the WG to move forward with our first objective[b], we need to focus our efforts on one or two principle purposes of measurement. It is imperative to recognize that the general disability measure developed to suit our proposed purpose will not necessarily satisfy other purposes and will not provide a comprehensive assessment of disability or identify the "true" disabled population, if in fact such a subpopulation exists. In addition, limitations of current data collection processes will affect our ability to capture some persons with characteristics of relevance. In other words, because of a variety of methodological issues, some persons with characteristics of interest for the purpose selected may not be identified by our measures.

As a result of discussions at the first WG meeting, it was agreed to use the International Classification of Functioning and Disability (ICF) model as a guide for our measurement development. In order to facilitate the discussion of this proposal, we felt that it was necessary to provide a glossary of (ICF)[c] terminology. In addition, we provide a methodological appendix in order to explain terms and ideas not delineated in the ICF. The glossary and the methodological appendix, located at the end of this paper, are not

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[a] The ICF includes multiple conceptual elements such as body structures, body functions, activities and participation, and environmental and personal factors. Other models, such as the IOM or Nagi model, include somewhat different conceptual elements such as health conditions (pathology), impairments, functional limitations, activity limitations, and the physical / psychosocial environment.

[b] "To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world."

[c] *International Classification of Functioning and Disability (ICF)*. World Health Organization, Geneva, 2001.

presented as stand-alone elements. They are intended to be tools to facilitate discussions of the proposed purpose. Standardized concepts and terminology are used, to the extent possible, to contribute to greater international comparability of measurement methods and outcomes.

Identification of purposes

The World Programme of Action concerning Disabled Persons (WPA)[d] provides a valuable guide for conceptualizing the uses of data on disability. The three major goals of the World Programme of Action are equalization of opportunities, rehabilitation and prevention. Based on discussions at the first meeting of the WG, a tentative outline of purposes and measurement concepts was developed. These elements were crafted into a draft of a disability measurement matrix presented at the second WG meeting. Elaboration of the matrix identified both individual and population or aggregate level purposes and matched them to general disability concepts. Due to our emphasis on census and survey methodologies, we have chosen to limit our selection of purposes to those at the population level. We concluded that general measures, necessary for large surveys, are not well suited to addressing purposes at the individual level, which require measures that capture detailed individual characteristics.

We believe that the purpose/s selected should meet two criteria:

1) Relevance: Is the purpose of relatively equal importance across countries with respect to policy (i.e. a central theme)?
2) Feasibility: Is it possible to collect the proposed information using a comparable general disability measure that includes a small set (1-4) of census-like questions?

Based on the matrix as presented at the second WG meeting, we selected three major classes of purposes for identifying persons with disabilities at the aggregate level: 1) to provide services, including the development of programs and polices for service provision and the evaluation of these programs and services, 2) to monitor the level of functioning[1] in the population, and 3) to assess equalization of opportunities. The provision of services at the population level includes, but is not limited to, addressing needs for housing, transportation, assistive technology, vocational or educational rehabilitation, and long-term care. Monitoring levels of functioning[1] includes estimating rates and analyzing trends. The level of functioning in the population is considered a primary health and social indicator, which characterizes the status of the population in a society. The assessment of equalization of opportunity involves monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programs designed to improve and equalize the participation of persons with impairments[3] in all aspects of life. The intent of these purposes for measurement is consistent with that of the World Programme of Action concerning Disabled Persons, which outlines major goals for policy formulation and program planning, internationally. The common goal is to promote the participation of persons with disabilities in all aspects of life by preventing the onset and consequences of impairments[3], promoting optimal levels of functioning[1], and equalizing opportunities for participation.[2]

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[d] *World Programme of Action concerning Disabled Persons*, United Nations, New York, 1983.

In this paper, each of the three major purposes for measurement at the population level is evaluated for international relevance and feasibility of implementation. The purpose we select should also be one that facilitates valid cross-national comparisons. Using measures that are minimally influenced by culture and context optimizes international comparisons by capturing a comparable population across countries.

Evaluation of purposes: relevance and feasibility

Provision of Services:

The need to identify the population of persons who may require specialized services or assistance is clearly important at the international level, as expressed in the WPA as well as at the first meeting of the WG. Rehabilitation, which is one of the three basic components of the WPA for example, addresses the need to provide persons with tools to change his or her life. Therefore identifying persons who require rehabilitation or other specialized services is an important element of data that should be collected. However, measures related to provision of services require detailed information about the person and may require detailed information about the environment[4], as in the case of addressing vocational rehabilitation needs. It is not always feasible to obtain the necessary level of detail to address the purpose of service provision with a small set of questions as required in a census format. Because of the greater need for detail, this purpose is better suited to a module or extended question set that can capture more extensive information on individual and environmental characteristics. Level of service provision and types of services provided are also highly variant across cultures making comparability difficult. While the purpose of service provision meets the criteria for relevance, it does not meet the criteria for feasibility of implementation using a small set of questions.

Monitoring the level of functioning in the population:

Maximizing the level of functioning in a population is an outcome of one goal of the WPA. Monitoring the level of functioning[1] in the population was acknowledged as an important purpose for disability measurement at the first WG meeting since it is used to track progress and evaluate interventions at the population or aggregate level. Some measure of functioning in the community is often used as a general indicator of health in the population. Since functioning[1] encompasses the conceptual domains of body functions[5] and structures[6] as well as activities[7] and participation[2], it can be represented by a variety of measures at any or all of these levels. However, most general indicators of population functioning target participation as a way to summarize the consequences of functioning in other domains. Participation requires the most complex measurement strategies as it involves at least three elements of measurement: *willful actions*[8], specific tasks[9] and organized activities[10], which are all influenced by the environmental context (see Measurement Appendix for an explanation of the concept to measurement transition). The most basic level of measurement of functioning is associated with willful or purposeful bodily or sensory actions such as walking, bending, reading, or speaking. A more complex level of functioning relates to performing *specific tasks*[9], such as dressing, shopping, and doing laundry. More commonly, the level of functioning in the population is targeted to the third most complex element, *organized activity*[10], including participation.[2] The level of participation in the community reflects the outcome of the combined effects of *willful actions*[8] and *specific tasks*[9] as they are combined to

accomplish an *organized activity*[11] within the environmental context and with the available accommodations. Persons with impairments who have adequate accommodations and favorable environments may have no participation limitations, similar to persons with minimal or no impairments. Therefore, it may also be useful to measure environments as mediators of impairment and actions, tasks, or activities. Monitoring functioning as it is presently defined by the ICF is a very complicated process involving components of measurement not yet fully developed.

An example of a contemporary measure currently used to monitor population functioning comes from the U.S. 2001 National Health Interview Survey. Information on participation is obtained from the following question: "*Are you limited in the kind or amount of work you can do because of a physical, mental, or emotional problem?*" An affirmative response to this question identifies persons with limitations in participation in the work role because of a health problem. Persons with impairments who have succeeded in adapting to their impairments may not experience work role participation limitations, and would not be identified as having a disability by this question. Therefore, they cannot be distinguished from other persons without impairments. Since the goal of monitoring functioning is to track the proportion of persons in the population who actually experience participation limitations, this approach is the most appropriate. If, however, we want to know about persons with impairments who successfully accommodate, this measure is inadequate.

Monitoring functioning presents a problem of response comparability. Since the standard against which persons rate their health, activity[7] and participation[2] in a community is culturally and environmentally determined, attaining comparability in responses presents a problem, particularly at the international level. Disability models (such as the ICF or IOM models) represent disability as a multi-dimensional phenomenon that occurs along a continuum. For dimensions such as body functions[5] and structures[6] as well as more basic activity which is represented by measures of willful actions[8], the standard against which respondents rate themselves is more explicit. For dimensions composed of more complicated activities, represented by measures such as performance of specific tasks[9] and organized activities,[10] also reflecting participation[2], the standard is less explicit and therefore leaves more room for respondent interpretation. Since respondents' subjective interpretations are, to some degree, socially determined, it is more difficult to achieve comparability between respondents in measures of complicated activity (such as organized activities or role participation[11]) than in measures of impairment, such as blindness, deafness or loss of limbs. This is particularly true at the international level where cultures, environments, and resources vary widely. Thus, the purpose of monitoring the level of functioning in the population meets the criteria for relevance, but does not meet the criteria for feasibility of implementation primarily due to the problem of international comparability.

<u>Assessing equalization of opportunity</u>:
Both the WG meetings and the WPA are consistent in their emphasis on the importance of assessing equalization of opportunities. While assessment of equalization of opportunities might seem to require measurement of activities and participation, such an

approach does not help to identify changes in the level of participation in the population in response to changes in opportunities. If we approach the assessment of equalization of opportunity without trying to tie impairment directly to participation, through the measurement of participation limitation, we reduce some of our methodological problems.

In the equalization of opportunity approach we are careful to measure the impairment separately from the organized activity, representing elements of participation. Disentangling the conceptual dimensions of impairment from participation provides the opportunity to determine the intervening mechanisms that facilitate or interfere with performance of tasks and organized activity. This separation differentiates approaches for the purpose of monitoring functioning in the population and for the purpose of assessing equalization of opportunity. When assessing opportunity equalization, *the connection between disability elements is made during analysis*, whereas for monitoring functioning *the connection is done during data collection*.

In order to address this purpose, we need to start by identifying persons who are at greater risk than the general population of experiencing restrictions in performing specific tasks or participating in role activities. This group would include persons with impairments who also experience limitations in activities and/or restrictions in participation whether or not they use assistive devices, have a supportive environment or have plentiful resources. It would also include persons with impairments who do not experience limitations in the specifically measured tasks or activities because the necessary accommodations or adaptations have been made at the person or environmental levels. The latter group would still be considered to be at greater risk for restrictions in activities and/or participation than the general population because of the presence of impairments and because the current level of accommodation might not always be available or might not continue to produce the same level of functioning.

Information about participation could be gleaned from other census or survey indicators, such as questions about employment, education, use of the transportation system, etc. For example, disability status, defined as the increased risk of experiencing restrictions in performing specific tasks or participating in role activities (the general measures being proposed), can be cross-classified with a measure of employment to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities. If policy interventions are initiated to enhance workplace accommodations, the effect on employment of persons with disability (i.e. equalization of opportunity) can be determined. In order to enhance the meaningfulness of the general disability measure that we are recommending, it will be important to collect data on a variety of forms of participation, such as education, employment, housing, transportation, social and health services, in addition to aspects of cultural and social life. From a theoretical perspective, if opportunities have been optimized then participation should be equivalent between persons with and without impairments and / or activity limitations, or trend analysis should show improvements

among those with impairments over a period of time[e]. Constraints in the number of participation questions or questions about accommodation in a census may limit the information on participation and restrict documentation of the types of adaptation or accommodation, but these are separate issues from the measurement of disability.

The purpose of assessing equalization of opportunities requires measurement of the presence of impairments and willful action limitations, measures with reasonable international comparability that are feasible to implement for the majority of the population via a small set of questions. Since one feature of this approach is identification of a large subpopulation, additional modules and extended survey sets could be used in conjunction with the general measure to further subdivide the population into groups of particular interest. Thus, the purpose of assessing equalization of opportunities meets the criteria for relevance and feasibility of implementation using a small set of questions that possess the most promise for internationally comparable results. As with the other purposes discussed above, there will be challenges in implementing this approach. What is missing from this approach is information about the possible mechanisms that facilitate or impede participation. Some elements of those mechanisms could be included in extended survey sets, such as use of assistive devices and access to personal assistance. Other mechanisms that are related to the physical and social environment are still in conceptualization stages and are not ready for use, although conceptual models such as the ICF indicate their appropriateness. Some mechanisms, such as programs that provide financial benefits, may be culturally specific but could be built in where appropriate.

Summary

We are proposing the assessment of equalization of opportunity as the purpose for the first general disability measure to be developed by the WG. This purpose meets the criteria of relevance and feasibility of implementation internationally. Benefits of choosing this purpose include identification of a broad subpopulation, which can be further described using detailed information obtained via extended survey sets. The extended survey sets can be administered as part of the same data collection activity or as part of a follow-up study where the questions used to identify the subpopulation are used as screeners. As stated earlier, it is imperative to recognize that the general disability measure developed to suit our proposed purpose may not suit other purposes. Nor will it provide a comprehensive assessment of disability or identify the "true" disabled population. Methodological challenges will affect our ability to capture all persons with characteristics of relevance (see Transition to Measurement Appendix for additional discussion of this topic). The WG must be aware of the limitations that accompany the proposed purpose and its operationalization in order for outcomes to be meaningful and comparable.

[e] Levels of functioning, as determined by questions such as that used in the NHIS, should also increase, but changes might be harder to demonstrate and measuring participation separately from impairment states has the potential of being more internationally comparable

Glossary of ICF definitions

[1] **Functioning -** In the ICF, functioning is an umbrella term encompassing all body functions and structures, activities and participation. The term demotes positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (ICF, p.3, 212).

[2] **Participation** – A person's involvement in a life situation. It represents the societal perspective of functioning (ICF, p.14).

[3] **Impairment** – Problem in body function or structure as a significant deviation or loss (ICF, p.12).

[4] **Environment -** The external or extrinsic world that forms the context of an individual's life. Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. These factors are external to the individual and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (ICF, p.16).

[5] **Body functions** – the physiological functions of body systems, including psychological functions. "Body" refers to the human organism as a whole, and this includes the brain. Hence, mental (or psychological) functions are subsumed under body functions. The standard for these functions is considered to be the statistical norm for humans. (ICF short version, p.190)

[6] **Body structures** – the structural or anatomical parts of the body such as organs, limbs and their components classified according to body systems. The standard for these structures is considered to be the statistical norm for humans. (ICF short version, p.190)

[7] **Activity** - the execution of a task or action by an individual. It represents the individual perspective of functioning. (ICF short version, p.190)

Transition to Measurement Appendix:
Conceptualization, Operationalization and Measurement

"The interrelated steps of conceptualization, operationalization and measurement allow researchers to turn a general idea for a research topic into useful and valid measurement in the real world. An essential part of this process involves transforming the relatively vague terms of ordinary language into precise objects of study with well-defined and measurable meaning (Babbie, 2001)."[f] This is the process we are developing as we move from the conceptualizations of the ICF model to the measurement of those concepts in a general way in a census or survey context. The ICF model has provided us with the conceptualizations of disability, body structure and function, activity and participation, and environment. The classification scheme itself has provided an abundance of categories representing empirical reality which can be considered a form of operationalization of the concepts. The piece that is missing is the measurement instrument, which will either utilize those categories directly or provide a link with other possible components that can be conceived to provide an empirical representation of the concept in question.

The following charts depicts the general model of transition from concept to observation, and the relationship of the ICF Model and classification scheme to that general model . Figure 1 shows the basic process of moving from a conception to a measure and finally a scale or index that represents the concept empirically.

General Transition from Conceptual Model to Empirical Measurement

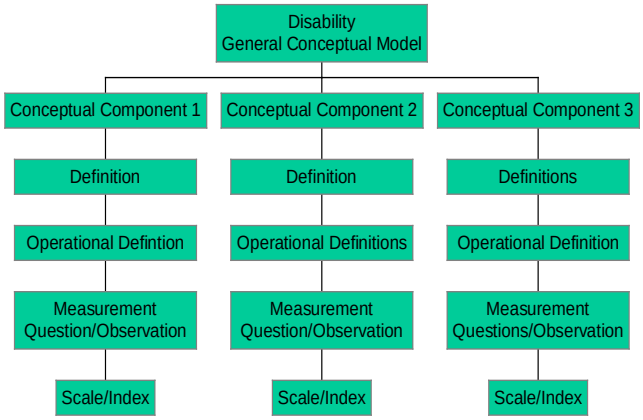

Figure 1

[f] Babbie E: *The Practice of Social Research*, 9th Edition, Wadsworth/Thomson Learning, Belmont, CA, 2001

Transition from Conceptual Level to
Observational Level Using the ICF

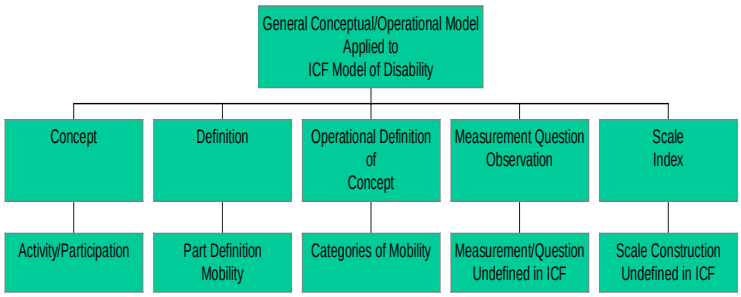

Figure 2

Figure 2 shows what components of the general model of translation from concept to empirical reality are captured by the ICF. The ICF model and classification scheme as it is currently constructed provides component concepts of the model, general definitions of those components as well the universe of domains that make up those components. It also provides operationalization categories or what can be interpreted as empirical representations associated with the domains for all the components of body function and structure, activity and participation and environmental factors. The ICF does not indicate the measurement questions or other possible methods of evaluation of the empirical representations, nor does it provide a way to combine the measures to create a scale or index that can be used in analysis as a representation of the combined empirical elements used to reflect the particular domain.

Measuring Impairment

In the ICF, impairment is identified as "problems in body structure or function as (sic) a significant deviation or loss." There are a total of 16 chapters or domains of body structure and function that have been identified, with each chapter or domain representing numerous functions or structures, for example Chapter 2 – Sensory function and pain – represents approximately 19 subheadings each of which is further subdivided. To represent the complete domain would require at a minimum a measure or question about each subheading. At this point there is no approximation of such a complete measurement of impairment as it is operationalized by the ICF. Even if there were, the restriction in the number of questions dictated by the census or survey format of data collection would preclude inclusion of all but a basic minimum.

Prior to the ICF model and classification scheme, impairment was most commonly represented in surveys in terms of sensory loss, loss of body parts, indicators of disease categories and symptoms (such as paralysis) or indication of "impairment" or "disability" without specific reference to the nature of the structural or functional loss. Even the complete WHODAS II, which was developed to implement the ICF, does not address the measurement of body structure and function any more completely than has been done previously before the development of the classification. The first gap in measurement needing attention, then, is related to body structure and function. What elements of body function and structure are most relevant to the relationship between the person and the environment that they would be considered impairments or to somehow contribute to the experience of disability? For measurement purposes are there a core group of body function or structure elements that need to be included in census or survey data collection. In this instance we have a very limited number of questions in general use that represent only a small portion of the body function and structure components of the model.

Transition from the Empirical Representation to the Measurement at the Observational Level

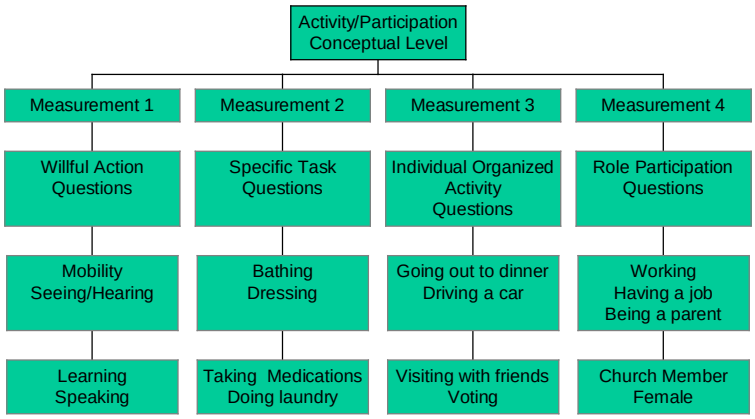

Figure 3

Figure 3 shows the variety of levels of measurement that are available to provide information about activities and participation. Unlike body structure and function categories which can be represented as present or not present and expanded by an indication of the level of severity when the problem is present, human activity is much more difficult to capture and exists at several levels of complexity. Some of the nature of that complexity is demonstrated in figure 3.

Measuring Activity and Participation

In contrast with the measurement of impairment, there are extensive sets of questions and a variety of approaches to questions that reflect the components of activity and participation. There are at least three levels of measurement when applied to the experience of the individual with an impairment or health problem that are elaborated in the ICF. At a very basic level, the ICF provides a detailed classification of activity at an action level, such as within the domain of mobility, where categories are defined on the basis of movements designed to change body position or location, such as bending, standing, sitting, etc. This domain also includes categories associated with carrying objects, using the hands for grasping, propelling the body on land or in the water. These activities can be conceptualized as measuring basic *willful actions*, or movement of bodily parts in a deliberate, intentional process to accomplish a physical objective, such as threading a needle. A more complicated level of measurement that goes beyond the coordination of bodily movement in a organized way is represented by the *specific task*, in which the individual is motivated to combine physical movement, intellectual activity, and use of assistive devices in an organized process in order to reach a recognized end. So for example, an individual would use what body functions and intellectual capacity necessary in order to dress themselves to go out.

At the most complicated level of mobility, the individual would be involved in an o*rganized activity* the most complicated level of measurement provided by the Activity domain of the ICF and would represent the ongoing willful action and specific task completion necessary to accomplish elements of an ongoing role. A particular quality of an organized activity is that it involves not just the person in question, but requires negotiating interaction with other people at some level or reflects the accepted custom of the social system that the culture has developed. Chapters 6 and 7, and particularly chapters 8 and 9 of the ICF, give extensive examples of organized activities that are representations of various components of participation via role elements. But even the area of mobility would provide an example which would be the management of a motor vehicle or the use of public transportation. Personal use of a motor vehicle requires coordination of visual and physical activities, and necessary attention to laws about stopping and starting to move the vehicle and geographic familiarity with the area in order to maneuver the vehicle from point A to point B.

Ascertaining that an individual is capable of completing a willful action gives no information about their ability to participate in an organized activity, but participation in an organized activity does imply that the person was capable of some form of willful action and specific task completion, so the levels of measurement identified here do reflect a crude hierarchy.

There is one further piece of information that can be derived from survey measurement that will shed light on categories of the concept of Participation elaborated in Chapters 8 and 9 of the ICF. General censuses and surveys frequently collect data on role behavior such as whether one holds a job, is seeking a job, has left a job and the nature of that work, part time or full time, remuneration and in some instances the type of work and characteristics of the organization . They also identify whether or not the individual is

married, lives with their spouse, has separated or divorced their spouse and whether they have parented children and currently care for them. This information, which can be considered indication of participation, is part of the general information from censuses and surveys that is used to describe the total population sampled, not just those who are identified as impaired or disabled. As such it is a fourth type of measure available for use in censuses and surveys that can be sued to express an element of the ICF model.

Glossary Additions –Measurement Based

[8] **Willful Action –** Based on either performance or capacity, action reflects the individual's will to carry out basic volitional bodily operations at the level of the organism (whole person). Examples include walking, climbing steps, reading, communicating, etc. It is distinct from body functions[5] (ICF) which are "physiological functions of body systems" rather than functions of the whole person. When combined, multiple actions can result in performance of tasks (Nordenfelt, 2002).[g] In the ICF, actions are included in the domain of activity defined as "the execution of a task or action by an individual, representing the individual perspective of functioning". (ICF short version, p.190) The ICF does not differentiate actions and tasks.

[9] **Specific Task –** The execution of a group of willful actions by an individual. It is an indicator of a series of related or more complicated actions necessary to accomplish an objective, which is a central component of role behavior. Examples include bathing, dressing, and feeding which are central elements of self-care, or driving a car and planning a meeting, which can be central elements of employment. In the ICF, tasks are included in the domain of activity defined as "the execution of a task or action by an individual, representing the individual perspective of functioning". (ICF short version, p.190) The ICF does not differentiate actions and tasks.

[10] **Organized Activity -** Represents the accomplishment of a variety of specific tasks and willful actions in order to complete an activity that is socially recognized or defined in a culture. An example would be going out to dinner which entails making reservations, getting dressed appropriately, finding transportation, engaging with friends, reading a menu, ordering, paying the bill, leaving a tip and other details.

[11] **Role Participation –** Represents the accomplishment, through willful actions, specific tasks and organized activities, of enough elements of a social role to claim that form of role participation as represented in a particular culture or society.

[g] Nordenfelt L: Disability, action theory and ICF. Newsletter on the WHO-FIC 2003;1(1):13-15