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Gerry E. Hendershot:
Survey Measurement of Disability: A Review of International Activities and Recommendations

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Prepared for the United Nations Statistical Division

by

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Abstract

Several international and supranational organizations have undertaken efforts to improve and standardize the measurement of disability in population-based surveys. Among these are the Organization for Economic Cooperation and Development, the Statistical Office of the European Commission, the World Health Organization Regional Office for Europe, the World Health Organization, and Reséau sur l'Esperance de Vie en Santé Européennes. The activities and recommendations of these organizations are reviewed, examined from the viewpoint of the International Classification of Functioning, and analyzed with respect to overlaps and gaps.

Survey Measurement of Disability: A Review of International Activities and Recommendations

I. International and Supranational Activities and Recommendations

This section of the review examines activities and recommendations of five international and supranational organizations: the Organization for Economic Cooperation and Development (OECD), the Statistical Office of the European Commission (EuroStat), the World Health Organization Regional Office for Europe (EuroWHO), the World Health Organization (WHO), and Reséau sur l'Esperance de Vie en Santé Européennes (REVES). Each of these organizations has recently published significant reports on disability measurement in surveys, and those reports that are the primary basis for this review. Readers are referred to those reports and the literature they cite for additional details.

The reports on which the first two subsections are based, those attributed to OECD and EuroStat, are primarily inventories—listings, descriptions, and comparisons of national disability-related surveys. They make few, if any, recommendations. (Except, perhaps, by implication—it could be argued that questions that are widely used in national disability-related surveys are, for that reason alone, candidates for inclusion in other surveys.) The reports on which the last three subsections are based, those attributed to EuroWHO, WHO, and REVES, are at least partially based on inventories, but they are more explicitly directive: that is, they make explicit recommendations about what should be done to measure disability in future national surveys. Following the summary presentations of the recent reports of these five international and supranational organization, this review makes a summary analysis of the relationships of their recommendations (implicit and explicit) to the ICF (ICIDH-2).

Organization for Economic Co-operation and Development (OECD)

The OECD is an organization of 30 nations who cooperate to create and sustain economic growth in their own countries and in the world. Member states share a commitment to an open market economy, democratic pluralism, and human rights. The forerunner of the OECD was the international organization formed after World War II to administer the "Marshall Plan" for the economic redevelopment of Europe. In 1961 it became the OECD with 20 member states, including most West European nations, plus the United States of America and Canada. It has since admitted another 10 nations to membership, including Japan, Korea, and Australia.

One of the functions of OECD is to monitor trends in member countries that are related to economic growth and human rights. Because health costs are an important part of the economies of OECD countries, the organization has an active health statistics program. Of particular interest in the field of health is the aging of populations, and resulting changes in health and disability. Disability is also of interest because of OECD's commitment to the human rights of persons with disabilities.

Because of its interest in disability in its member nations, the OECD was an early proponent of internationally standardized disability measures. In the late 1970's, as part of a broad effort to develop social indicators, OECD produced a questionnaire on longterm disabilities (McWhinney, 1982). The questionnaire was used in 8-10 OECD nations and is used in some nations even today.

Inventory of Health and Disability Related Surveys

In 1999 an OECD expert meeting on aging and disability noted that policy discussions "are seriously hampered by the lack of internationally comparable data." Whereas many OECD countries had national surveys that included questions on health and disability, there was so little comparability that few international comparisons could be made. In response to that observation, OECD undertook a more careful study of the comparability of national survey data on disability in member countries (Gudex and Lafortune, 2000).

Of the 30 OECD countries, 23 were found to have had a recent national survey that measured health and disability. The 30 countries are listed below, and those with national surveys on health and disability are underlined. For countries that had more than one national survey, the number of surveys is show in parentheses. A total of 30 national surveys were included in the inventory.

OECD Nations

<u>Australia (2)</u>
<u>Austria</u>
<u>Belgium</u>
<u>Canada (2)</u>
<u>Czech Republic</u>
<u>Denmark</u>
<u>Finland</u>
<u>France(2)</u>
<u>Germany</u>
<u>Greece</u>
Hungary
<u>Iceland</u>
<u>Ireland</u>
<u>Italy</u>
<u>Japan</u>
<u>Korea</u>
Luxembourg
Mexico
<u>Netherlands</u>
<u>New Zealand(2)</u>
<u>Norway</u>
Poland
<u>Portugal</u>
Slovak Republic
<u>Spain</u>
<u>Sweden</u>
Switzerland
Turkey
<u>United Kingdom(3)*</u>
<u>United States(2)</u>

*One survey each covering England, Great Britain, and the United Kingdom
Note: Nations with health surveys are underlined

The questionnaires for each of the surveys were obtained and analyzed with respect to their properties: definitions of disabilities, domains of activity, etc. Summaries were prepared showing the extent of comparability among survey with respect to particular properties and in general. Finally, recommendations were made for improving international comparability of disability survey data.

The OECD inventory found that the 30 surveys were generally "consistent with the 1980 ICIDH definition of disability." The OECD report characterizes the ICIDH definition as "activity limitation," and notes that even with that definition, it remains to define the specific activities to be included. The report identifies two broad approaches to the operational definition of "activities" in the surveys studied. Many surveys define activity as "activities of daily living," sometimes referred to as "functional limitations." Activities of daily living include simple activities, such as walking, and may also include more complex activities, such as preparing meals. A smaller number of surveys define activity in terms of broader, more complex activities, such as work or even unspecified "usual activities." In a few surveys, the two approaches have been combined to produce a unified operational definition of disability. The OECD notes that each of these broad approaches will yield different estimates of the prevalence of disability in a country; indeed, even the particular activities selected within either of the broad approaches will

1980 ICIDH definition of disability:

"A disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p. 143).

affect estimates. It is important, therefore, to be intentional and explicit about the definition of disability by a survey, both at the conceptual and the operational levels.

Another question implied by defining disability as "activity limitation," is how to define "limitation." Several dimensions of limitation are identified in the surveys studied by OECD, including duration and severity. Surveys generally regard disability as relatively long-lasting and relatively severe, but they differ significantly in the particular cut-points of duration and severity they use to distinguish between persons with and without disability.

For purposes of its study of national health surveys, OECD chose to focus on "chronic" health conditions and activity limitations. Health conditions domains included specific conditions (such as arthritis), unspecified chronic conditions, mental health (including emotional and psychological well-being, and cognition), and pain. The activities domains were self-care, mobility, communications (including sensory impairments), activities associated with independent living (such as preparing meals), work and social activities, and "usual" activities that are not specified or only broadly specified (such as "work").

OECD health domains

-Chronic conditions, general
-Chronic conditions, specific
-Mental health (psych/cognitive)
-Pain

OECD activity domains

-Self-care
-Mobility
-Communication/ sensory
-Independence
-Work/social
-Usual activity (general item)

Each of the 30 survey questionnaires was rated for the presence or absence of questions in each of the 10 health and activity domains. Based on a simple count of the number of questionnaires that did include questions in each domain, the domains can be ranked with respect to the extent of their coverage across the 30 surveys. By this measure, the best-covered health domains were specific chronic conditions and mental health, followed by pain and general prevalence of chronic conditions. The best-covered activity domains were self-care and mobility, followed by communications/sensory, usual activity, work/social, and activities associated with independent living. The combined ranking of all domains is shown at right.

Domains ranked by number of surveys covering each

1. *Self care*
2. *Mobility*
3. *Communications/sensory*
4. *Chronic conditions, specific*
5. *Mental (psych./cognitive)*
6. *Pain*
7. *Usual activity (general item)*
8. *Work/social*
9. *Independence*
10. *Chronic conditions, general*

Coverage across surveys is very good for self-care and mobility: 27 of the 30 surveys had questions in those domains of activity. Coverage is nearly as good for the communication/sensory activity domain and the specific chronic condition health domain: each of those domains was covered in 24 of the 30 surveys. If the goal is to compare disability across nations using data already collected, these domains show promise. Similarly, if the goal is to increase international comparability by including in the surveys of additional nations those domains already best-covered, these same domains show promise.

However, the utility of the best-covered general domains for international comparability, present or future, depends in part on the comparability of their specific content. That is, for national surveys that include questions in the same domain, how comparable are the questions? The OECD report attempts to answer that question for each of its 10 health and activity domains. Because of its focus on disability, this summary will cover only the three activity domains that are “best-covered” by the 30 surveys studied by OECD.

Among surveys that included questions on self-care, the number of specific types of self care about which questions were asked varied from 2 to 6. The types of self-care about which questions were most commonly asked were bathing one's self, dressing one’s self, and feeding one’s self. Among the 25 surveys that included at least one of those activities, twenty-four included dressing, twenty-three included washing, and 18 included feeding.

In the activity domain of mobility, the subdomains about which questions were most often asked were climbing stairs, walking, and getting in and out of bed (or transferring). Twenty-four countries asked about one or more of those activities, with climbing being most frequent (21 surveys) and walking and getting in and out of bed somewhat less frequent (19 surveys). In the communication/sensory activity domain, twenty surveys asked questions, included questions about seeing (18 surveys), hearing (16 surveys), or speaking (12 surveys).

Best-covered activity subdomains (by rank within domains)

Self-care	*Mobility*	*Communication*
Dressing	*Climbing*	*Seeing*
Bathing	*Walking*	*Hearing*
Feeding	*Transferring*	*Speaking*

That there is as much agreement as there is among the surveys studied by OECD reflects the fact that they stand within the same tradition of conceptualizing and measuring disability. All of the best-covered subdomains of self-care and mobility just listed were among the domains identified as important in the early work of Sidney Katz (1963) and Saad Nagi (1976). Another powerful force toward convergence has been the development and promotion of several standardized instruments, themselves based in part on the work of Katz and Nagi. They include the Medical Outcome Study Short Forms Scales (SF-36), the European Quality of Life 5-Dimensional health status questionnaire (EuroQol-5D), and the Health Utilities Index, version 3 (HUI-3). Many of the surveys in the OECD inventory have adopted all or part of one or more of these instruments.

Statistical Office of the European Commission (Eurostat)

Survey Data on Disability

Through its Task Force on Health and Health-related Survey Data, the Statistical Office of the European Commission (Eurostat) supported a Danish National Institute of Public Health (NIPH) survey of disability data collected in the European Union (EU). The survey covered 16 national surveys from 11 EU member states. The countries represented are listed below with the number of surveys from each shown in parentheses (if more than 1).

Austria (3)
Belgium
Germany
Denmark
Spain
France (2)
Finland (2)
Netherlands
Portugal
Sweden
United Kingdom (2)

Questions from each survey were classified by general topic in the following categories: chronic problems, acute problems, limited daily activities, physical and sensory functioning, work participation, occupational status, educational level, and employment status. The questions in each category were compared across surveys with respect to format, wording, and meaning, and judgements were made about the comparability of questions and categories across countries.

Of the question categories considered in the NIPH study, limited daily activities and physical and sensory functioning are most relevant to the purposes of this review. “Limited daily activities” refers to health-related limitations of “usual” or “normal” day-to-day activities, without further specification. In Denmark, for instance, the question asked is “Within the last two weeks, has illness, injury, or ailment made it difficult or impossible for you to carry out your usual daily activities?” This type of question is a global activity limitation indicator” or GALI, and is discussed at greater length elsewhere in this review. The NIPH researchers found questions from nine surveys that fell into this category, but determined that only six countries had questions sufficiently similar to warrant international comparisons.

“Physical and sensory functioning” is a broad category covering many different types of functioning. A list of activities about which comparable questions are asked in at least two of the EU countries is shown below; in parentheses is the number of countries for which the questions were comparable, and the activities are ranked by that number.

Climbing stairs (7)
Running or walking (6)
Lie down and get up (6)
Bend forward or kneel (6)
Confined to house (6)
Use the toilet (6)
Dress or undress (6)
Speaking difficulties (6)
Feed yourself (6)
Recognize face 4 meters (5)
Sit down and get up (5)
Wash hands and face (5)
Carry 5 kilograms (4)
Close reading (4)
Hear normal conversation (4)
Confined to a bed (4)
Confined to a chair (3)
Move around inside (3)
Bathe or shower (3)
Hear TV with volume up (3)
Go shopping (2)

The purpose of the NIPH study was to determine the comparability of disability-related questions asked in EU surveys. In that regard, the study concludes:

> "Overall, comparability is low between surveys and there are no surveys which could be compared on all or most questions. For most of the disability-related indicators, however, there are some comparisons which may be useful, where there are approximately 6-8 surveys asking a similar question."

While the NIPH report does not make recommendations about which questions should be asked in future surveys, it might be suggested that one strategy for improving international comparability of disability data is to encourage national surveys to adopt questions that are already used by a large number of other national surveys.

> "Overall, comparability is low between surveys … however, there are some comparisons which may be useful."

World Health Organization Regional Office for Europe

Harmonization of European Health Interview Surveys

In the late 1980s and early 1990s, the World Health Organization Regional Office for Europe (EuroWHO) and Statistics Netherlands undertook a series of consultations with representatives of European national health interview surveys. The project went under the name EuroHIS, for European Health Interview Surveys. The goal of EuroHIS was to harmonize European health interview survey measures of health targets in WHO's "Health for All" program. Three consultations were held (1988, 1990, and 1992), leading to the publication of "Health Interview Surveys: Towards international harmonization of methods and instruments" (deBruin *et al.*, 1996). In the area of long-term disability, EuroHIS explicitly adopted the ICIDH-1 framework, and even provided ICIDH code values for the disability questions it recommended, which are shown on page 10.

In the area of mental health, EuroHIS concluded that it is not possible in a general health interview survey to measure the full range of conditions adequately. Instead a selection of conditions must be made and instruments appropriate to those conditions should be used. Among the instruments recommended by EuroHIS is the General Health Index, 12-Item Version, discussed in the section of this paper on Euro-REVES.

In 1998 the World Health Organization Regional Office for Europe was joined by the BIOMED2 Program of the European Commission as a co-sponsor of EUROHIS. In its current form, EUROHIS has two objectives, much like those with which it began:

- to develop recommended common survey instruments and to promote their use in national health interview surveys
- to collate and adjust data already collected by countries and to determine their potential for international comparison

In the current phase of its work, EUROHIS aims to develop common instruments in these areas:

Chronic physical conditions
Mental disability
Alcohol consumption
Physical activity
Use of curative medical services
Use of medicines
Use of preventive health care
Health-related quality of life

Of these, mental disability and health-related quality of life are relevant to this review. In November 2000 EUROHIS held a mid-term review of its work. Twenty-seven European countries, the OECD, and WHO were represented. At that point, common instruments had been developed and tested for all but one of the eight indicators. Work on mental disability was behind schedule because of a change in leadership of the network responsible for that indicator.

Long-term Disability Questions Recommended by EuroHIS

Handicap items (ICIDH-1)

"The following questions refer to what you are normally capable of doing. Temporary complaints should be ignored.

"Are you permanently confined to bed even though there may be help to get you up?"
Yes, No.

"Do you sit in a chair (not a wheelchair) all day even though there may be help for you to walk?"
Yes, No.

"Are you confined to your household and garden?" Yes, No.

Disability items (ICIDH-1)

"What is the farthest you can walk on your own without stopping and without severe discomfort?
Only a few steps, More than a few steps but less than 200 meters, 200 meters or more.

"Can you get in and out of bed on your own?"
Without difficulty, With some difficulty, Only with someone to help you.
"Can you get in and out of a chair on your own?" (Same answer categories.)
"Can you dress and undress yourself on your own?" (Same answer categories.)
"Can you wash your hands and face on your own?" (Same answer categories.)
"Can you feed yourself, including cutting up food?" (Same answer categories.)
"Can you get to and use the toilet on your own?" (Same answer categories.)

"Do you ever lose control of your bladder? Yes, No."

IF YES: "Do you lose control of your bladder at least once a week, less than once a week but at least once a month, or less than once a month?"

"Is your hearing good enough (with a hearing aid if necessary) to follow a TV program at a volume others find acceptable?" Yes, No.

IF NO: "Can you follow a TV program with the volume turned up (with a hearing aid if necessary)?" Yes, No.

"Can you see well enough (with glasses or contact lenses if necessary) to recognize a friend at a distance of four meters (across a road)?" Yes, No.

IF NO: "Can you see well enough (with glasses or contact lenses if necessary) to recognize a friend at a distance of one meter (at arm's length)?" Yes, No.

Optional disability items

"Can you walk up and down a flight of 12 stairs without resting?" Yes, No.

IF NO: "Can you do this if you hold on and take rests?" Yes, No.

"Can you (when standing) bend down and pick up a shoe from the floor?" Yes, No.

"Can you speak without difficulty?" Yes, No.

The Network on Quality of Life had reviewed several popular measures used in European countries: the Medical Outcomes Study Short Form 36 (SF-36), the World Health Organization Quality of Life measure (WHOQOL), and the European Quality of Life measure (EuroQOL). The Network chose the WHOQOL as the basis for further development by EUROHIS. Beginning with the 26-item WHOQOL, the Network developed an 8-item EUROHIS-QOL that includes “satisfaction with ability to perform daily living activities.” The instrument was tested as part of the EUROHIS pretest with generally positive results. Although EUROHIS has more work to do before making its final report, it appears that it will recommend satisfaction with ability to perform daily living activities as part of its standard quality of life measure.

World Health Organization

Disability Assessment Schedule

The World Health Organization Disability Assessment Schedule II (WHODAS II) is being developed by the Assessment, Classification, and Epidemiology group (ACE), a unit in the Global Programme on Evidence for Health Policy (GPE) at the World Health Organization headquarters in Geneva, Switzerland. The CAS group is also responsible for the ICF and the International Classification of Diseases (ICD).

The direct antecedent of WHODAS II was the World Health Organization Psychiatric Disability Schedule (WHO/DAS) published in 1988. WHO/DAS was used to assess disability in psychiatric patients in a number of dimensions of behavior. In the dimension of "Social role performance," for instance, there was an assessment of "participation in household activities," including such activities as "participation in common activities of the household" and "participation in decision-making concerning the household." Patients were rated at six levels of dysfunction: none, minimum, obvious, serious, very serious, and maximum.

WHODAS II is a complete revision of WHO/DAS. It was undertaken with several objectives in mind. First, it was intended to be compatible with the revised ICIDH, now the ICF. There were obstacles to achieving this objective, including the different sponsorship and schedules of the WHODAS and ICIDH development processes. Second, it was intended to be cross-culturally applicable; that is, it was intended to be useful in places that differ in language, history, and custom. Toward this end, a series of Cross Cultural Applicability (CAR) studies were undertaken in many countries to identify and solve problems of comparability. Third, it was intended to treat all disorders at parity; that is, WHODAS II was intended to be useful when evaluating disabilities of all kinds: mental, physical, sensory, and so on. This objective was based on the assumption, common to the ICF as well, that functioning is an important measure of outcomes, regardless of its determinants.

WHODAS II is still in development, with publication expected in 2001. Testing of various versions and aspects of the instrument has taken place at 31 research centres in 21 countries in Europe, Asia, Africa, North America, and South America. In the current round of field trials, two aspects of WHODAS II performance are being evaluated: its ability to detect change in functioning following an intervention; and its ability to predict objectively-observed functional status.

WHODAS II DOMAINS

- ☐ Understanding and communicating
- ☐ Getting around
- ☐ Self-care
- ☐ Getting along with others
- ☐ Household and work
- ☐ Participation in society

In its current version, WHODAS II assesses functioning in six domains: understanding and communicating, getting around, self care, getting along with others, household and work activities, and participation in society. In each domain 4-6 questions are asked about the person's difficulty in doing specific types of behavior; for instance, in the domain of self-care, questions may be asked about washing and eating. For each type of behavior for which difficulty is reported, information is obtained on the frequency of that difficulty by asking on how many days (in the last 30 days) the difficulty occurred.

In its first test version, WHODAS II had 89 items. After analyzing test results, a 36-item version was developed for further testing. WHO recommends that the 36-item version be used, administered by an interviewer in a face-to-face interview with the person whose function is being assessed. Realizing, however, that in some practical circumstances face-to-face administration may not be possible, WHO offers 36-item versions for *self*-administration by the subject and for self-administration by a *proxy* for the subject. There is also a 36-item version designed for administration by an interviewer to a proxy respondent. The 36-item instruments produce an overall measure of functions and specific measures for each of the six domains.

For circumstances in which 36 items are too numerous, there are 12-item versions for interviewer- and self-administration, and 6-item versions for administration by proxies and clinicians. The 12- and 6- item versions produce an overall measure of function but not domain-specific measures. WHO estimates that the 36-item versions can be administered in 20 minutes, and the 12-item versions in 5 minutes. No time estimate is given for the 6-item versions.

WHODAS II versions by number of items and mode of administration

Items/Mode	Interviewer	Subject	Proxy	Clinician
36 item	**X**	**X**	**X**	
12 item	**X**	**X**		
6 item			**X**	**X**

The complete WHODAS II instrument (dated February 2000) is attached to this review. It may be useful, however, to illustrate the main features of the instrument at this point. The "Preamble" to the questions on functioning is reproduced in the accompanying box. The "flashcards" mentioned in the preamble simply give the respondent a visual reminder of instructions in the preamble.

Following the preamble, there are six blocks of questions, one for each of the WHODAS II domains listed above. Each block consists of a series of questions about specific activities in the domain, asking how much difficulty the respondent had with the activity in the last 30 days, and if there was any difficulty, on how many days there was difficulty. Each block ends with a global question about reported difficulties in that domain: "How much did these difficulties interfere with your life?"

WHODAS II

PREAMBLE TO QUESTIONS ON LIMITATIONS OF ACTIVITY

SAY TO RESPONDENT:

The interview is about difficulties people have because of health conditions.**(HAND *FLASHCARD #-I TO RESPONDENT).*** By health condition I mean diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs.

I remind you to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about ***(POINT TO FLASHCARD #1)***

- Increased effort
- Discomfort or Pain
- Slowness
- Changes in the way you do the activity

(POINT TO FLASHCARD #1). When answering, I'd like you to think back over the last 30 days. I also would like you to answer these questions thinking about how much difficulty you have, on average over the past 30 days, while doing the activity as you usually do it.

(HAND FLASHCARD #2 TO RESPONDENT). Use this scale when responding. **(*READ SCALE ALOUD):*** None, mild, moderate, severe, extreme or cannot do.

(FLASHCARDS #1 AND #2 SHOULD REMAIN VISIBLE TO THE RESPONDENT THROUGHOUT THE INTERVIEW. CARD #3 IS TO BE USED WHEN THE RESPONDENT PROVIDES THE NUMBER OF DAYS DIFFICULTY WAS EXPERIENCED).

Survey on Health and Health System Responsiveness

In its annual report for the year 2000, The World Health Report 2000, the World Health Organization presented the methods for and results of a system for measuring the performance of national health systems. According to the report, five things must be measured to assess a population's health system: level of health, equality of health, level of responsiveness, equality of responsiveness, and equality of financing. For each of these aspects of a health system, methods were proposed for calculating a numerical score, and such scores were calculated for WHO member states. The scores for the five aspects were combined in a weighted overall score for each national health system.

While all of the five aspects are important in the WHO assessment system, the aspect relevant to this review is health. One half (50%) of the overall score comprised "level of health" (25%) and "equality of health "(25%). With respect to both level and equality, "health" is measured by Disability Adjusted Life Expectancy (DALE), a summary measure of population health or "health expectancy." Thus, the level of health for a health system is the Disability Adjusted Life Expectancy for the population it serves, and the equality of health is a statistic measuring the evenness of distribution of DALE across socioeconomic subgroups of that population.

Like other summary measures of population health, to calculate a DALE requires data on population mortality and morbidity (and for DALE , a measure of the value of a year of life lived with a non-fatal health outcome.) Whereas comparable data on mortality are available for many nations, internationally comparable data on non-fatal health outcomes are harder to come by, as has been frequently noted in this review. While it made do with what was available for its Year 2000 report, WHO staff subsequently noted that "First, no single instrument appears to be commonly used internationally," and "Second . . . no instrument has proven cross-population comparability (WHO, September 2000)." It was recommended, therefore, that the "WHO Secretariat should orchestrate the development and periodic implementation of a common survey instrument for measuring health states."

> " First, no single instrument appears to be commonly used internationally
>
> …Second, … no instrument has proven cross-population comparability…"
>
> *WHO, September 2000*

According to WHO, a common survey instrument should be reliable, valid, cross-culturally applicable, and consistent within a culture (with respect to item response scales). In addition to these psychometric properties, the instrument should have cross-population comparability; that is, the end-points and cut-points of a scale should correspond to identical population health conditions regardless of the population in which it is administered. For instance, a response that is scored as "excellent health" in one population should correspond to the same true general health condition as a response that is scored as "excellent health" in another population. This is said to be the most important problem in international comparability at this time: that different populations have different expectations about health, and therefore respond differently to questions that may otherwise be reliable, valid, cross-culturally applicable, and intra-culturally consistent.

WHO proposes three approaches to achieving cross-population comparability. First, comparing survey measures with authoritative objective measures; for instance, comparing survey reports of seeing limitations with standard clinical tests of vision for the same persons or populations ("calibration tests"). WHO proposes beginning with calibration tests in the domains of vision, mobility, and cognition, domains for which internationally applied, authoritative, and objective tests already exist. Second, using coding rules for survey measures to code standardized descriptions of the health of individual persons ("standard case vignettes"). Third, administering the survey instrument to populations whose health is known to be very good ("reference cases").

In the documents supporting its proposal, WHO proposes that the health state domains to be measured by the standard survey instrument be selected from the revised ICIDH-2, now known as the ICF, arguing that the ICF encompasses most health and health-related states. Seventeen ICF health domains and 4 ICF "health-related" domains are proposed, as listed below:

Proposed Domains for A Common Instrument on Health States

Health Domains

1. Vision
2. Hearing
3. Speech
4. Digestion
5. Bodily excretion
6. Fertility
7. Sexual activity
8. Skin and disfigurement
9. Breathing
10. Pain
11. Affect
12. Sleep
13. Energy/vitality
14. Cognition
15. Communication
16. Mobility
17. Dexterity

Health Related Domains

18. Self-care
19. Usual activities
20. Interpersonal relations
21. Social functioning

A draft survey instrument has been developed and is under test by WHO in a number of different nations. The instrument includes questions to measure health states in each of the domains listed above. It also includes questions to measure the value of life lived in various health states (necessary to the calculation of DALE), and household-administered tests to calibrate vision, mobility, and cognition. In addition, it includes questions on the responsiveness of health systems, the other major component of health systems assessment.

Many of the questions in the WHO draft questionnaire about the health and health related domains are identical to WHODAS II questions, and nearly all are framed like the WHODAS II questions; that is, they focus on difficulty in performing activities in the usual way during the last 30 days.

Comparative Analyses of Surveys

As part of its work in developing a survey instrument, WHO undertook statistical analyses of data from a large number of household health surveys (Sadana *et al.*, 2000). In contrast to much of the other work reviewed here, this study was not concerned so much with the conceptual content of the questions asked by the surveys, but with the cross-population comparability of the estimates of health states produced from the surveys. Cross-population comparability, called by the authors “X-comparability,” would exist if reporting of health states were unbiased: that is, if different populations had the same end-points, low and high, on an underlying scale of health states, and the same cut-points between meaningful levels along that scale. The analyses assumed that whatever the particular questions asked in different surveys, all surveys were measuring the same underlying scale of health status. A measure of health status was calculated from each survey, and the measures were standardized statistically to make them as comparable as possible. This procedure is called by the authors “post-harmonization,” by which they mean harmonization of health measures *ex post facto,* or after-the-fact. It is to be contrasted with efforts at harmonization that attempt to achieve comparability across populations by standardizing the questions asked in surveys.

Because post-harmonization is the subject of another paper in the conference for which this review was prepared, the work by Sadana *et al.* will not be discussed further here, except to note its main finding: “Even where the survey methodologies and data collection approaches are standardized, biases in the self-report of health status prevent a meaningful comparison of non-fatal health status across populations.”

> “… biases in the self-report of health status prevent a meaningful comparison of non-fatal health status across populations.”

Reséau sur l'Esperance de Vie en Santé Européennes (Euro-REVES)

With support from the Health Monitoring Program of the Commission of European Communities (EC), Euro-REVES undertook to review international recommendations and practices in survey measurement of health, and tp propose standard measures for use by surveys in European Union. They reported the results of that activity in "Selection of a Coherent Set of Health Indicators: A First Step Towards a User's Guide to Health Expectancies for the European Union." As the title suggests, the project was undertaken with the long run goal of standardizing measures of "health expectancies," the defining interest of REVES.

Health expectancy is one kind of "summary measure of population health," or SMPH. SMPH typically combine population statistics on demography, health, and mortality, into a single statistic that summarizes the health of the population. Some people regard such measures as useful for tracking trends and evaluating policy options. They are also regarded as useful for international comparisons because they statistically "control" for some differences between national populations that might otherwise mask true health differences.

International comparability of SMPH is limited, however, by the extent to which nations use the same or similar survey measures of health. The Euro-REVES study was undertaken to assess that similarity and to propose standard survey questions on health, which, if widely adopted by national surveys, would increase the comparability of health expectancies.

The study focuses on five aspects of health: physical and sensory limitations, activity restrictions in daily life, limitations in usual activities, perceived health, and mental health. As conceptualized by Euro-REVES, all of these domains except perceived health are relevant to the purposes of this paper. The questions Euro-REVES proposed for each of the four relevant aspects of health will be reviewed here.

Physical and sensory limitations. These are conceived as being at the level of the person; that is, they are limitations in functional activities undertaken by the whole person. Such activities are conceptually divided into sensory and physical functions, although these tend to be combined in many kinds of activities about which survey questions can be asked. Thirteen activities are proposed for measurement, listed in the accompanying box.

Proposed physical and sensory abilities

Seeing newspaper print
Keeping balance
Speaking to others
Grasping a small object
Lifting, carrying 5 kilos
Seeing a face at 4 meters
Walking 500 meters
Biting, chewing firm food
Turning a tap
Hearing another person
Climbing 12 stairs
Shaking someone's hand
Bending or kneeling

At the time of the Euro-REVES report, the wording of questions for all of these abilities had not yet been developed, but illustrative wording was provided for vision and hearing. The wordings, one for face-to-face interviews and one for self-administered questionnaires, are shown in the boxes below.

Illustrative question about vision (face to face interview)

"Think about situations you may face in daily life. Please ignore temporary problems:

Can you see clearly newspaper print without glasses or contact lenses?"

Yes, No.

IF NO: "And with your glasses or contact lenses, can you see clearly newspaper print?"

Yes, No, Have no glasses or contact lenses

Illustrative question about hearing (self-administered questionnaire)

"Think about situations you may face in daily life. Please ignore temporary problems:

Can you hear distinctly what is said in a conversation with one person without a hearing aid?" (only tick one box)

☐ Yes, I can hear distinctly without a hearing aid
☐ No, but I can hear distinctly with my hearing aid
☐ No, and I can not hear distinctly even with my hearing aid
☐ I cannot hear at all

Activity restrictions in daily life.

In the language of the Euro-REVES study, activity restrictions refer to activities that are necessary for minimal independence, as defined by social roles. Usually two levels of complexity in activity restriction are recognized, the simpler "activities of daily living" (ADL) and the more complex "instrumental activities of daily living" (IADL). After reviewing the development and current practice of survey measures of activity restriction, Euro-REVES proposes that five activities of daily life be included: feeding (yourself), transferring (from bed to chair), dressing (and undressing), using a toilet, and bathing (or showering).

Activities of Daily Life

Feeding
Transferring
Dressing
Using toilet
Bathing

For each activity of daily life, Euro-REVES proposes that questions be asked that establish whether or not the person actually performs the activity without difficulty and without the help of a person or special equipment. For people who have difficulty or use help, additional questions would determine if they use the help of another person or special equipment to perform the activity. A measure of the severity of the restriction would be constructed from answers to all of these questions, reflecting the kind of aid used, if any.

An illustrative question wording is given for the activity “feeding yourself” (see box).

“Think about your activities in everyday life. Please ignore temporary problems:

1. Do you, usually, feed yourself without any difficulty, on your own and without special aid?” Yes, No.

IF YES, go to question 2.
IF NO, go to 1a.

1a. “Do you use someone’s help to feed yourself?” Yes, No.
1b. “Do you [also] use special aid or appropriate equipment?” Yes, No.

IF YES to 1a or 1b:

1c. “Do you still have problems to feed yourself?” Yes, No.

Mental Health

The Euro-REVES study notes that mental health is an important component of health for purposes of calculating summary measures of population health. It also notes that mental health presents some special problems for survey measurement. In the Chapter on mental health, the Euro-REVES report proposes the General Health Questionnaire, 12-item version (GHQ-12) as the standard for survey measurement of mental health, because of its measurement properties and its ease of administration by survey interviewers untrained in clinical psychology. The GHQ-12 is a checklist of mental and emotional symptoms (see box). The respondent indicates the frequency of each symptom in the past few weeks relative to their usual experience. The measure is reported to do well in measuring depression and anxiety, and is also an indicator of certain other disorders.

**General Health Questionnaire,
12-item version**

List of mental health symptoms

Lost sleep over worry

Felt constantly under strain

Been able to concentrate on what you were doing

Felt that you are playing a useful part in things

Been able to face up to your problems

Felt capable of making decisions about things

Felt you couldn’t overcome your difficulties

Been feeling happy, all things considered

Been able to enjoy normal day-to-day activities

Been feeling unhappy and depressed

Been losing confidence in yourself

Been thinking of yourself as a useless person

The checklist is designed to be self-administered but could also be administered by an interviewer in a face-to-face interview. In the case of a self-administered questionnaire, the wording of the question that precedes the list of symptoms would read as follows (see box).

"We would like to know if you have had any medical complaints and how your health has been, in general, over the past few weeks. Please answer ALL the questions simply by underlining which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you have had in the past. Have you recently . . .

Lost much sleep over worry?" ☐ Not at all ☐ No more than usual ☐ Less than usual ☐ Rather more than usual ☐ Much more than usual

[continue with other checklist items]

Limitations in usual activities (global indicators).

Working within REVES, Lois Verbrugge and colleagues argued in a series of papers, conceptual and empirical, that it is both desirable and feasible to measure disability by a very small number of survey questions, possibly only one question, which they refer to as a "global indicator" or disability. They argue that a global indicator is useful for describing disability, explaining disability, and screening for disability. It is useful for describing disability because an indicator based on one or a few questions is inherently easier to understand and communicate than an indicator based on many questions. It is useful for explaining disability because it can be used as a predictor or an outcome variable in causal models, and it can be transported across a variety of research settings and disciplines, adding to the scope of information that can be related to disability. It is useful in screening for disability in situations in which it is desirable to first determine efficiently if a person has a disability before asking a series of additional questions pertaining to disability.

Verbrugge distinguishes between parsimony in data collection and parsimony in data analysis, both of which are desirable. Parsimony in analysis can be achieved by summarizing in one measure the responses to many questions about disability. Parsimony in data collection requires that a small number of questions be asked to begin with. It is parsimony in the latter sense, in data collection, that is most desirable, because parsimony in data collection necessarily leads to parsimony in data analysis, but parsimony in data analysis does not require parsimony in data collection.

Three types of global indicator question format were identified. In the first format, a question is asked about chronic health conditions, followed by a question about functional consequences of the conditions. In the second format, a question about function is asked first, followed by a question about its underlying health conditions. In the third format, a prefatory statement instructs the respondent to focus on long lasting health conditions, and then a question is asked about functional consequences of such conditions. In consultations with international disability survey specialists, some of them REVES members and some not, Verbrugge found that the third format was preferred.

Verbrugge also asked her consultants to assess several proposed wordings of questions for a global indicator. The proposals were selected from an inventory of such questions that had been undertaken earlier. The most promising of the questions in the inventory were modified and formatted to improve their comparability and utility. The candidate questions preferred by Verbrugge's consultants are shown in the boxes below.

Global Indicator, Candidate 1

"Is there anything about your health that makes it hard for you to do your usual activities."

Yes, No.

IF YES: "Has the difficulty with your activities lasted 6 months or more, or do you expect it to last that long?"

Yes, No.

IF YES TO 6+ MONTHS: "What are the activities you have trouble doing because of health?" [Interviewer records answers.]

"Would you say your difficulty doing these activities is a little, some, or a lot?"

A little, Some, A lot.

Global Indicator, Candidate 2

"Because of a physical, mental, or emotional condition, are you limited in doing your daily activities like personal hygiene, house or yard care, shopping, your work, or other things that you *need to do*?"

Yes, No.

IF YES: "Has the limitation lasted for at least 6 months or do you expect it to last that long?"

Yes, No.

IF YES TO 6+ MONTHS: "Are you limited just a little, somewhat, or a great deal in your daily activities?"

Just a little,
Somewhat,
A great deal.

Global Indicator, Candidate 4

After questions about presence of specific physical, cognitive, or emotional problems, IF YES TO ANY:]

"During the past 12 months, did any of these problems interfere with your ability to work or attend school or manage your day-to-day activities?"

Yes, No.

IF YES: "Did they interfere with those activities a little, some, or a lot?"

A little, Some, A lot.

Global Indicator, Candidate 5

***Note*: A preface statement or overall health context is required before this question.**

"Would you describe your overall level of functioning in your home, work, and leisure activities as excellent, very good, good, fair, or poor?"

Excellent
Very good
Good
Fair
Poor

In the subsequent work by Euro-REVES (2000), specific wording for a global indicator question was proposed and re-named the Global Activity Limitations Indicator, or GALI (see box).

Global Activity Limitations Indicator (GALI)

"For the past 6 months or more have you been limited in activities people usually do because of a health problem?"

Yes, strongly limited/Yes, limited/No, not limited

Recommendations

II. Comparison to the International Classification of Functioning

Cross-population Comparability: End points and cut points

The major finding of the work by Sadana *et al.* (2000) is very important for the future of survey measurement of disability. They assumed that there is a true non-fatal health status that is comparable across populations; however, the health status *perceived* by a person may be different from the true health state, and the health status *reported* by that person may be different from both. What surveys measure, of course, is reported health status, not true health status nor even perceived health status. The question asked by Sadana et al. was: are survey self reports of non-fatal health status biased (that is, systematically different) from population to population. Their answer, based on analyses of data from more than 50 household surveys, is yes. And because of these biases, they conclude that survey measures of non-fatal health, including survey measures of disability, are not comparable across populations, even when survey questions and survey methods are standardized.

There may be several ways to deal with this unsettling conclusion. First, the particular statistical analyses undertaken by Sadana *et al.*, could be examined and possibly replicated by others, perhaps leading to different conclusions. Second, the basic assumption that there is a true health status that has cross-population comparability could be examined; perhaps what is meant by “health”or “disability” is necessarily subjective and therefore subject to “biases” in reporting across populations. Third, cross-population comparisons could be based on health examination surveys instead of health interview surveys, thus avoiding the biases of self-reporting. Finally, and this is the approach recommended by WHO, some objective tests should be incorporated in health interview surveys to “anchor” self-reports to true health states within populations. These true health states could then be used to calibrate the self-reports to a standard scale of non-fatal health with cross-population comparability.

Activity and Participation

The ICF makes a distinction between activity and participation. During most of the revision process these were conceptualized as “dimensions” or “levels” of disability, corresponding in a general sense to the “disability” and “handicap” dimensions of ICIDH 1980. Activity was conceived to refer to the person level of disability, and participation to the social or societal level. Further, it was conceived that within each dimension there were plural “domains,” broad categories of personal activities and societal participation, and that within those broad categories were many specific activities and types of participation that comprised the detailed classes of the classification system.

Toward the end of the revision process, however, it became clear that a consensus could not be achieved on which domains should be included in Activity and which should be included in Participation. To a large extent the lack of consensus resulted from disagreement among revision participants about the definitions of personal and social: what was clearly "personal activity" to one participant was just as clearly "social participation" to another participant, and *vice versa*.

Eventually the deadlock was broken by *fiat*: WHO declared that all domains were <u>both</u> personal and social, and that users could code them as Activity, or Participation, or both Activity <u>and</u> Participation. One list of domains and detailed classes within domains was to be used which ever was being coded. The same code number was to be assigned to a detailed class whether it was coded as Activity, or Participation, or both. A literal prefix would indicate which was being coded, "a" for Activity and "p" for Participation; or if the user chose not to make the distinction between A and P, the generic prefix "d" (for disability) could be substituted. Thus, for instance, in a study of housing and disability, "acquiring a place to live" could be assigned ICF code **a**610 if the focus were on the person level (reading newspaper advertisements, talking to realtors, etc.) or **p**610 if the focus were on the societal level (discriminatory housing practices, business cycles, etc.) Or if the emphasis were on both or neither, it could be coded **d**610.

Given the history of this issue in the ICIDH revision, it is interesting to examine how it is handled in the recommendations. The EuroHIS recommendation on longterm disability explicitly adopted the ICIDH 1980 framework of three "planes of experience" in the consequences of disease: impairments, disabilities, and handicaps, which correspond, respectively to effects on the body, the person, and the society. More specifically, Handicap refers to a disadvantage in the performance of a social role, a departure from the behavior normally expected of persons occupying that role. Therefore, the questions recommended by EuroHIS are explicitly labeled as pertaining to Handicap (3 questions on mobility) or Disability (10 questions on self-care, continence, hearing, and seeing). They are also assigned ICIDH 1980 code values.

The EuroREVES document also distinguishes between levels of disability, using a scheme first presented by Philip Wood (1975). The pertinent levels of the scheme for EuroREVES are "functional limitations" and "activity restriction," which Wood saw as cause and effect, respectively. Functional limitation is conceived by EuroREVES to be a person-level dimension of disability, whereas activity restriction is conceived to be at the social level. The domains of functional limitation include seeing, hearing, balance, mobility, agility, and strength and endurance. Whereas activity limitation might encompass a variety of different social roles, EuroREVES chooses to focus on one: independent self care, which it proposes to measure with questions about feeding, transferring, dressing, toileting, and bathing. The distinction between functional limitations and activity restriction is said to be important for policy purposes, because the choice of a preventive intervention may be conditioned by the causal relationship between the two levels of disability.

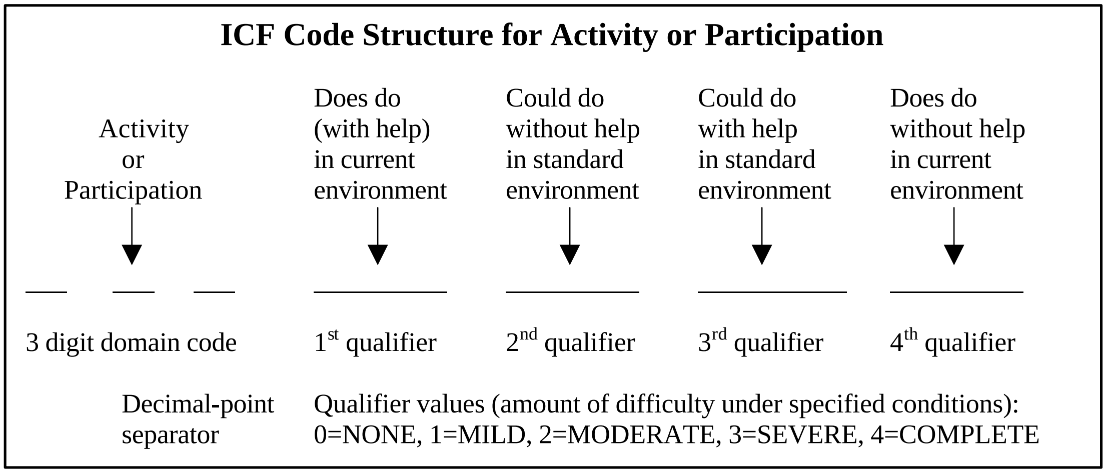
WHODAS II was developed and began testing during a phase of the IDIDH revision in which a distinction was still being made between Activity and Participation as being at the person and societal level, respectively, and comprising different, although sometimes overlapping, domains. WHODAS II assesses disability in six "domains" which include what were, at the time of its development, both Activities and Participation domains. The structure of the questions is the same across all of the domains measured, and they have been shown to empirically distinct. The domains are treated, in effect, as undifferentiated with respect the levels they represent, anticipating the ultimate WHO position on the ICF: with respect to their content, there is no necessary distinction between Activity domains and Participation domains.

In summary, the position now taken by WHO in the ICF is apparently at odds with the positions taken by EuroHIS and EuroREVES. The latter regard a distinction between the person and social levels as being scientifically correct and practically useful, whereas the former regards the distinction as unnecessary, potentially confusing, and at best an optional.

Performance and Capacity

Another late innovation to the ICF was incorporation of the distinction between “performance” and “capacity.” During most of the revision process, the emphasis had been placed on what people can be observed to do, whether as individuals (Activity) or as participants in social life (Participation). A complication of this approach was recognized: what a person does may depend on their use or nonuse of personal assistance and special equipment. To address this complication, it was proposed that the coding scheme allow for noting whether the assessment was made with or without personal assistance or special equipment.

The ultimate ICF retained that feature and adds a new feature, which allows for assessing function in the person’s actual environment, called “Performance,” and in a “standardized” environment, called “Capacity.” Combining the two environmental conditions (actual and standardized) and the two assistance conditions (with and without personal or technological help), there are four sets of conditions for assessing function.



ICF Code Structure for Activity or Participation

In the coding scheme, a specific digital position is reserved for each set of assessment conditions, following the three-digit domain code and a decimal-point divider. The numeric entry in each place indicates the extent of difficulty in performing the activity or participation under the specified conditions of environment and assistance, with values from 0 (no difficulty) to 4 (complete difficulty).

The ICF coding scheme for Activity and Participation allows a rich body of information to be recorded in a simple and direct manner. It should accommodate many applications in a variety of settings. To take full advantage of the coding scheme however, requires that a large amount of information be collected: information about Activity or Participation in sufficient detail to assign ICF domain codes, information about the use of personal assistance and assistive technology, and assessments of five levels of difficulty in both a current environment and a standardized environment.

None of the question sets currently recommended by international organizations would provide all of this information. The accompanying table shows the ICF information

requirements--two environmental conditions (columns2-3) and two assistance conditions (columns 4-5), the four qualifiers constructed from those conditions (columns 6-9), and the five levels of severity to be assessed (cell entries in columns 6-9). Below the ICF row are rows for each of the major internationally recommended disability questionnaires. Cell entries indicate whether or not the ICF-required information is available from the recommended questions, and the levels of severity available.

All of the recommended questionnaires ask about performance in the current environment, making it possible for them to assess qualifier 1. There is some ambiguity, however, in the EuroHIS questions with respect to the environmental condition. The preamble to the questions specifies that they refer "to what you are normally <u>capable</u> of doing," and the questions about specific activities begin "<u>Can</u> you…." The words "capable" and "can" may connote in English an implied "standardized environment" that is different from the actual current environment, but that was probably not intended.

Because none of the recommended questionnaires inquires about performance in standardized environments (with the possible exception of EuroHIS, as just noted), none is able to assess qualifiers 2 and 3. Also, because WHODAS II does not ask explicitly about performance without assistance, it cannot assess qualifier 4. The EuroHIS and EuroREVES recommended questions would support assessment of qualifier 4, because both ask explicitly about performance with and without assistance.

Clearly there is more work to be done in the areas of measuring standardized environments and the use of personal assistance and assistive technology if full advantage is to be taken of the ICF potential for assessing Activity and Participation under a variety of conditions.

ICF Activity and Participation codes compared to recommended survey questions

Measurement reccomenda-tion (1)	Performance (current environment) (2)	Capacity (standard environment) (3)	Without Assistance (person or equipment) (4)	With assistance (person or equipment) (5)	Does do (with help, if needed) in current environment (6)	Could do without help in standard environment (7)	Could do with help in standard Environment (8)	Does do without help in current environment (9)
ICF	YES	YES	YES	YES	No Mild Moderate Severe Complete	No Mild Moderate Severe Complete	No Mild Moderate Severe Complete	No Mild Moderate Severe Complete
EuroHIS	YES?	NO	YES	YES (personal assistance only)	None Lower Higher Unable	NO	NO	None Lower Unable
EuroREVES	YES	NO	YES	YES	None Light Moderate Severe	NO	NO	YES
WHODAS-II	YES	NO	NO	NO	None Mild Moderate Severe Extreme/can not do	NO	NO	NO

Long forms, short forms, and global indicators

A good case has been made that short forms of questionnaires on functioning are needed for a variety of purposes. Most importantly, perhaps, functioning is a very general aspect of human life, and is therefore relevant to many fields of study. It is therefore desirable to measures of functioning available in data sets covering a wide range of human experiences, such as labor force participation, medical encounters, criminal victimization, etc. However, specialists in each of these broad fields of human experience have their own data needs, and given typical limitations on resources (including respondent burden), they cannot afford to collect much data on functioning. The only realistic hope for obtaining functional information in these diverse fields is reducing the amount of such information collected to an absolute minimum, perhaps even to a single question.

This need has been recognized by EuroREVES and by WHODAS II. EuroREVES recommends a Global Indicator of Activity Limitation (GALI), and WHODAS II offers a 12-item short form of its recommended 36-item questionnaire. EuroHIS does not currently offer a short form, although it should be noted that its full set of recommended questions is not very long to begin with. The work by Verbrugge cited above offers several other short sets of questions as candidates for a global indicator of disability. In another effort, the U.S. Centers for Disease Control and Prevention had developed a two-item disability screener that is now used in surveys conducted in each of the 50 States. While these efforts are worthwhile and should be continued, there is a need to link them more closely to the ICF. In terms of ICF concepts, domains, and categories, what are these short form questionnaire and global indicators measuring? Do they measure impairments, activity limitations, participation restrictions, or something else?

Domains of Activity and Participation

Nomenclature

By now the idea that disability has several dimensions or levels is almost universally accepted, at least among those who give much thought to such matters. It almost as universally accepted that the dimensions or levels correspond in some way to aspects of the body, the person, and the person-in-society. There are still legitimate differences of agreement about the specific definitions of these levels, particularly in the factors that distinguish one dimension or level from another. Those differences probably will be worked out through a process of research, discussion, and consensus-building, activities in which the international organizations have had a leading role, a role they should continue to exercise. That process may take some years to be fully resolved, but it could begin now with agreement on standard nomenclature, based on the ICF. Let us name body-level domains “body structure” and “body function.” Let us name person-level domains “activity,” and societal-level domains “participation.” The parallel negative terms at each level will be “impairments,” “activity limitations,” and “participation restrictions.”