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Toward International Comparability of Survey Statistics on Visual Impairment: The DISTAB Project

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Abstract: Using data from recent national disability surveys in Australia, Canada, France, the Netherlands, South Africa, and the United States, an international team of researchers coded indicators of several types of disability using the International Classification of Functioning, Disability, and Health. This article discusses the Disability Tabulations (DISTAB) project and presents and evaluates the estimates of the prevalence of visual impairments.

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The successful coordination of national and international policies for preventing visual impairment (blindness or low vision) and rehabilitating persons with visual impairments is complicated by differences in the procedures for estimating the prevalence of those impairments in different countries. Estimates of the prevalence of blindness and low vision may be based on population censuses or population-based sample surveys. Even assuming that the censuses and surveys are conducted competently, countries may differ in the conceptual frameworks that they use and the actual questions that they ask regarding visual problems, which makes it difficult to compare estimates of prevalence.

Attempts to make international health statistics more comparable are sometimes referred to in the literature as "harmonization." Broadly speaking, there are two types of harmonization: preharmonization and postharmonization (Nosikov & Gudex, 2003; Van Buuren, Eyres, Tennant, & Hopman-Rock, 2002). Preharmonization refers to attempts to improve comparability by the cooperative or central design of data systems so that all the researchers collect, process, and report data in similar ways. Postharmonization refers to attempts to improve comparability by the post hoc manipulation of already-collected data to render the data as comparable as possible.

In recent years, the World Health Organization (WHO) has provided leadership in efforts to harmonize international statistics on functioning, disability, and health. The staff of the WHO headquarters and its Collaborating Centers around the world have initiated a series of pre- and post-harmonization projects, among the most important of which are the World Health Survey (WHS; Üstun et al., 2001) and the International Classification of Functioning, Disability, and Health (ICF; Üstun, Chatterji, Kostansjek, & Bickenbach, 2003; WHO, 2001).

The WHS is a series of national health surveys that are planned and coordinated by WHO. These surveys use standardized interviews with representative samples of national populations to obtain information for evaluating the performance of national health systems with respect to the level of health, equity in the distribution of health, the level of responsiveness to health needs, equity in the distribution of responsiveness, and equity in health care financing. The WHS questions that are used to measure levels of health and the evaluation of the state of health generally conform to the ICF model of functioning and health.

The ICF is a revision of the previous International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was published by WHO for trial purposes in 1980 (WHO, 1980). The ICIDH was revised by a group of international disability specialists over a 10-year period, culminating in the approval of the renamed ICF by the World Health Assembly in 2001. As the international standard for the classification of function and health, the ICF joins the ICD (International Classification of Diseases), the international standard for the classification of morbidity and mortality, in the WHO family of health classifications.

Both the WHS and the ICF are examples of preharmonization--attempts to improve international comparability by the cooperative and centralized planning of data systems. Imbedded in the development of both the WHS and the ICF, however, were a number of postharmonization projects. This article reports on one such effort: an international project--Disability Tabulations (DISTAB)--that was undertaken as part of the development of the ICF (Swanson, Carrothers, & Mulhorn, 2003). The focus is on the use of the ICF in coding data on visual impairments from the nations that are represented in the DISTAB project: Australia, Canada, France, the Netherlands, South Africa, and the United States. Prior to our discussion of DISTAB, however, it is necessary to discuss the ICF conceptual framework and its codes for visual impairments.

ICF

In an earlier article published in this journal, one of the authors described the conceptual framework of the ICF (Crews & Campbell, 2001). Readers are referred to that article and the Introduction to the ICF (WHO, 2001) for a full description of the framework. A major goal of the ICF is to provide a conceptual framework and nomenclature that is cross-culturally applicable; that is, concepts and terms in the ICF are intended to have the same or nearly the same meaning when they are expressed in any language or culture. This is obviously a difficult goal to achieve, and the outcome is uncertain and far in the future. It should be noted that some in the disability community believe strongly that the ICF and similar efforts to create disability classifications are threats to the rights of persons with disabilities because such classifications can (and will) be used to deprive them of their rights (Pfeiffer, 1998). Those who are against disability classifications sometimes cite the eugenics movement, especially the racial purity theories of German National Socialism, as a historical instance in which people were defined and identified in artifical categories for purposes of controlling or eliminating them.

Briefly, the ICF conceives of function and disability as being comprised of several interacting components: (1) underlying health conditions (disease or disorder); (2) body functions and structures; (3) the individual activity of persons and their participation in community life; and the context in which the previous components are situated, including (4) the environment (physical and social) and (5) personal factors (such as age and gender).

Disability is said to exist when a health condition gives rise to an impairment of body structure or function, a limitation in personal activity, a restriction in participation in the community, or a combination of one or more of these factors. Whether an impairment, limitation, or restriction arises depends, in part, on environmental conditions and personal factors. (Although the ICF framework recognizes the importance of underlying health conditions and personal factors, it defines them to be out of the scope of the ICF for classification purposes.) It is important to note that the ICF does not posit any necessary causal relationships among health conditions, impairments, limitations, and restrictions.

The ICF framework provides a viewpoint and a language for disability that many professionals find useful. However, the ICF is not just a conceptual framework; more important, perhaps, it is a detailed classification system. It was designed to describe the full range of human functioning at the levels of the body, the person, and the community. In theory, every human function can be assigned one of several hundred ICF alphanumeric codes that identify specific human functions and describe a person's performance of that function. The code categories and the system for recording performance are contained in a 300-page WHO publication that is available in the six official United Nations (UN) languages. It may also be accessed in a machine-searchable version at an ICF web site (WHO, 2004).

The detailed codes that constitute the ICF are arranged in four components: body functions, body structure, activities and participation, and environment. Within each component, related codes are grouped in numbered chapters; within chapters, related codes are grouped in "blocks." Within blocks, each specific code has a unique identifier consisting of a letter that identifies the component and a number that identifies the function. Each specific code category has a unique verbal label and definition and may have lists of functions that should be included in or excluded from the category. The code identifying a function is followed by a separator (a decimal point); and following the separator, the user may add one or more numeric "qualifiers" that give information on a person's performance of the function. The qualifiers follow a system described in an appendix to the classification. The system allows for assessments of the level of functioning in the presence of assistance (persons or devices) and in their absence.

The ICF is not itself a measurement tool. Rather, it is a system for classifying the measurements from functional assessment tools and techniques that are currently used in statistical, administrative, and clinical settings, such as the Functional Independence measure and the Activities of Daily Living measure. It is anticipated that professionals in different settings will continue to use the tools and techniques with which they are familiar, but with an operationalized ICF, it will be possible for them to report their functional assessments in a standard, succinct language that is comprehensible across professions and nations. To achieve a fully functional ICF will require research and consensus, a process that has already begun; the American Psychological Association, for instance, in collaboration with WHO, is developing an interdisciplinary operations manual for U. S. professionals that will give them guidelines for coding the results of functional assessments that are common in their professions to ICF categories and qualifiers (Holloway, 2004).

ICF codes for visual impairment

Most codes that are specific to vision are included in the "Body Functions" component of the ICF, in which "body functions are the physiological functions of body systems." In the Body Functions component, Chapter 2, "Sensory Functions and Pain," includes a block of codes entitled, "Seeing and Related Functions." That block of codes is reproduced (with some deletions and reformatting) in Box 1. In some cases, it may be desirable to code a structural condition related to vision: the ICF component "Body Structures" ("anatomical parts of the body, such as organs, limbs, and their components") includes a chapter on "the eye, ear and related structures" that has a block of codes that are related to structures that may be important to vision (see Box 2).

In practice, the result of applying an assessment tool or technique would be matched to one of these codes for body function or body structure. Depending on the intended use and the amount of detail available, the chosen code may show the maximum detail allowed by the ICF (up to five digits) or less detail at a higher level in the hierarchy of ICF codes. To indicate the extent of problems with a function or structure, one of the following qualifiers would follow the category code (and a decimal point separator): 0 = no impairment, 1 = mild impairment, 2 = moderate impairment, 3 = severe impairment, and 4 = complete impairment.

Although the ICF regards vision as primarily a body-level phenomenon, either functional or structural, the Activity component ("activity is the execution of a task or action by an individual") does have a code (d110) for "Watching," defined as "using the sense of seeing intentionally to experience visual stimuli, such as watching a sporting event or children playing." The ICF also has codes for Activity and Participation ("involvement in a life activity") that are not specific to vision but may be affected by vision, such as d166, "Reading," and d630, "Preparing Meals." Finally, there are codes in the Environment component to describe aspects of the situation of visually impaired persons that may be important for planning or evaluating interventions, such as e1251, "Assistive products and technology for communication."

Only those components and codes that are pertinent to the practice setting would be used. In a low vision optometry practice, for instance, the Body Function codes may be the most useful, but in a rehabilitation teaching practice, Activity and Participation codes may be more relevant. While different vision-related professions may tend to use different ranges of ICF codes, the fact that they are deriving the codes from the same classification system would facilitate communication among professionals as patients move from one care setting to another.

DISTAB

In the preceding discussion of the ICF conceptual framework and its codes for visual impairments, it has been convenient to emphasize the potential clinical applications of the ICF. However, the ICF was intended to be useful in other applications, including statistical and epidemiological applications. WHO asserted that by designing population-based data systems, such as censuses and surveys, according to ICF principles or "back-coding" data from already existing data systems to ICF codes, statistics on functioning and disability could be made more comparable and, therefore, more useful.

To test this assertion, while revising the ICIDH to what became the ICF, a group of survey statisticians and epidemiologists from six countries who were involved in the process jointly undertook the task of coding data from recent disability surveys in each of their countries to ICF codes. The six countries, their surveys, and the sample sizes of each are shown in Table 1. The surveys were similar in these respects: nationally representative samples, standardized interviews, face-to-face interviews, and broad coverage of disability information. In addition, each country's survey was represented in DISTAB by one or more persons who had been involved in the international effort to revise the ICIDH and, hence, were familiar with the conceptual framework and classification system. The surveys differed in some significant ways as well: They were conducted in different languages, represented different parts of their national populations (by age and institutionalization, for instance), and used different sampling frames (census list-frame samples and area probability samples).

DISTAB focused on interview surveys and did not include surveys that collect data by means of examinations and tests of functioning. Because of their operational difficulty and expense, such surveys are less common than are interview surveys. They do, however, present opportunities for studying the measurement of disability by providing "objective" data to supplement respondents' reports. DISTAB-like studies should be considered for that type of survey as well.

The goal that DISTAB set for itself was to code data from these six different country surveys to the same, best-fitting ICF categories and to produce estimates of the prevalence of disability in these categories. In working toward this goal, DISTAB expected to confront problems in international comparability that would inform both the revision of the classification and the future design of surveys. To focus and contain the scope of the project, DISTAB limited its attention to the disability statistics that were recommended by the UN Statistical Division (UNSD) for collection and reporting by national censuses and surveys (UN, 1998). Because UNSD had explicitly used the ICIDH, the precursor to the ICF, as its framework in selecting and defining its recommended disability measures, these measures were appropriate for the DISTAB project. The UNSD disability categories numbered 14, but the number considered by DISTAB was reduced to 7 because data were not available in a sufficient number of the national surveys; the DISTAB collaborators decided to retain in the final list only variables for which data were available in at least three surveys. The final disability categories were hearing, seeing, speaking, mobility (walking), body movement, gripping (with hands), and personal care. Only the data on limitations in "seeing" are considered in this report.

Furthermore, DISTAB limited its scope to statistics for community-dwelling adults (aged 18 and older) because some of its national surveys did not include disability measures for institutionalized persons or children and youths, and all the participants agreed to make English the working language for the project, which required some DISTAB participants to make English translations of survey questionnaires and other documents. To ensure that DISTAB's work was consistent with UNSD and WHO guidelines and practices, representatives of these organizations were included on the DISTAB team.

The work of DISTAB was accomplished through electronic mail, a password-protected web site, monthly telephone conferences, and annual face-to-face meetings, usually held in conjunction with another meeting that all or many of the DISTAB researchers attended. It is worth noting, perhaps, that this kind of international collaboration, which until recently has been difficult and expensive, has now been made relatively easy and affordable by improvements in international travel and communications.

The central issue that arises in comparisons of statistics from various surveys is whether differences and similarities reflect "real" differences in the populations or are artifacts of the methods that are used. This question could not be answered statistically with the DISTAB data because there was insufficient information about sample designs in the several surveys to test hypotheses. We relied, instead, on knowledge from other sources about patterns of visual impairment and on a comparison of survey methods. Although such an analysis was often sufficient to make a judgment about the "reality" of an observed cross-national difference, it sometimes was not.

DISTAB measures of visual impairments

The UNSD recommends that national censuses and surveys report on nine types of disability, including "seeing difficulties (even with glasses, if worn)." All six DISTAB surveys included questions about such difficulties, but the questions differed significantly in form and content, as is shown in Box 3. The surveys seemed to agree that visual problems that are corrected by eyeglasses or contact lenses do not constitute a disability. Four surveys asked separate questions about problems with near vision and distant vision, but the United States and Australia did not. Two surveys (France and South Africa) asked directly about blindness, but the others did not.

In view of the variation across surveys in the information that they obtained about visual problems, the DISTAB team decided that only the most general ICF code for "seeing" could be applied to all the surveys. Therefore, the ICF code for "Seeing Functions," b210, was adopted as the reporting category (see Box 1 for the definition, inclusions, and exclusions for b210). If the answers to questions about seeing asked by a survey gave any indication of visual problems, the case was classified as having a visual impairment. Because of the variation in questions across surveys, it was decided not to attempt to assign a qualifier to indicate the extent of a visual impairment (except, of course, that the implied qualifier is greater than zero for any case that is classified as having an impairment). The lack of qualifiers is an issue for comparisons among countries because the questions and answer categories had different implied thresholds of severity. In the U.S. survey, for instance, the visual problem had to be "serious," and in the French survey it had to cause "much difficulty," but in the South African survey, "any" difficulty constituted a visual problem. Other things being equal, surveys with high thresholds would tend to produce lower prevalence rates than would surveys with low thresholds.

Table 2 presents estimates of the prevalence of visual impairments (cases per 1,000 persons) by age and gender in the six DISTAB countries. The estimates were produced independently by each survey's DISTAB representative, according to specifications that were developed collectively. Estimates were also made for subgroups of national populations that were defined by social and demographic variables, such as education and labor force participation, but those estimates are not shown here. Figure 1 shows the estimates by age for both genders combined.

In all six countries, the prevalence of visual impairments increases substantially with age (see Figure 1). Because of the well-known association between aging and the loss of visual acuity, any deviation from the observed relationship would have been reason to suspect errors in the data. Moreover, Canada, France, and the United States report remarkably similar prevalence rates by age group. This congruency would likely be expected because of the similar composition of the population and the relatively similar access to health care provided in these developed nations. In the oldest age group shown (65 years and older), the country with the lowest prevalence is South Africa; this finding was unexpected, given that South Africa is a developing country with greater health problems than the other DISTAB countries and because South Africa's next younger age group (55-64 years) has a relatively high prevalence of visual impairments. The higher prevalence of visual impairment among younger age groups may be explained by greater rates of glaucoma, untreated cataract, and trachoma in South Africa (Ballard, Fehler, Fotheringham, Sutter, & Treharne, 1983; Cook & Stulting, 1995; Rotchford & Johnson, 2002; Rotchford, Kirwin, Muller, Johnson, & Roux, 2003).

Also noteworthy are the high levels of visual impairments in the Netherlands' middle age group (35-64 years). It cannot be determined whether these apparent anomalies in the data reflect real differences or are artifacts of differences in the design and operation of the surveys; if the latter, the differences must be subtle because the DISTAB participants are not aware of any differences in the design and operations of the surveys that may account for the observed statistical anomalies. However, the 1990-93 population-based Rotterdam Study of visual impairment among people aged 55 and older revealed generally lower rates of vision loss among those aged 55-64 compared to the U.S. and other international rates and a convergence with international rates among those aged 65 and older (Klaver, Wolfs, Vingerling, Hofman, & deJong, 1998).

One subtle difference that may affect these and other international comparisons of the rates of prevalence of disability is societal differences in subjective health perceptions: Different societies may have different "cut points" on the scale of function for distinguishing between "disability" and "no disability." This measurement problem was studied by Sadana, Mathers, Lopez, Murray, and Iburg (2000), who concluded that biases in self-reports of health status prevent a meaningful cross-national comparison of the prevalence of disability, even when survey methods are standardized. It is beyond the scope of this article to consider this important issue at any length, but Sadana et al. suggested some possible solutions to the problem.

Next steps

In this article, we have briefly described the conceptual framework of the ICF; discussed the ICF code structure in the field of visual impairments; reviewed the history and operations of DISTAB, an international project that uses the ICF to improve the comparability of disability statistics; and presented estimates of the prevalence of visual impairments in the six DISTAB countries. The DISTAB experience suggests that the ICF can be a useful tool for improving the comparability of international statistics on visual impairment. By working together and using a standard classification, representatives of six national surveys--surveys that differed significantly in their operational definitions of visual impairments--were able to produce reasonably comparable statistics. However, the DISTAB process revealed that the surveys differed too much to make comparable estimates at any but the broadest ICF category of visual function. Clearly, the postharmonization of survey data on disability is crude at best.

This situation led the DISTAB participants to recommend to UNSD that an international effort be undertaken to preharmonize disability statistics from censuses and surveys. The UNSD responded by hosting the International Seminar on the Measurement of Disability in June 2001. The seminar recommended that the UN Statistical Commission authorize an ad hoc international group of experts to develop ways and means for improving the quality and comparability of national disability statistics. The commission subsequently authorized the expert group, which met for the first time in Washington, DC, in 2002. Following a UN convention for such ad hoc groups, the group was named for the city in which it first met and is now known as the Washington Group on Disability Statistics (UN, 2004).

The Washington Group is now working toward agreement on guidelines for designing census and survey questions that will cover the full range of information that is needed to describe the disability situations of national populations for all components of the ICF. Recognizing that many censuses and surveys cannot include a full set of disability questions, the Washington Group plans to recommend a shorter set of disability questions, also based on the ICF. The DISTAB group continues to meet, collaborating with the Washington Group to improve the international comparability of disability statistics.

Preharmonization--the design of statistical and clinical measures through international collaborative efforts--requires the preexistence of an internationally shared nomenclature, which now exists in the ICF. It also requires the participation of disability specialists; in the area of visual impairments, for instance, one can envision collaborations among international vision experts to reach a consensus on common measures of the ICF categories that are shown in Boxes 1 and 2.

Additional applications of the ICF to vision

It is important to recognize that although the ICF classification allows for macroanalyses of international prevalence rates, as demonstrated by the reports from Australia, Canada, France, the Netherlands, South Africa, and the United States, the coding system is sufficiently robust and detailed that it can describe multidimensional characteristics of an individual. The particular application of the ICF dictates the degree of specificity that one requires. For example, to calculate the prevalence of visual impairment, it is sufficient to use the code b210 "seeing functions" with the attendant inclusion and exclusion criteria. It is not necessary to understand the causes, severity, or multiple consequences of vision loss to inform broader policy debates. If one were concerned about the development of prevention programs, then knowing causes would be desirable. However, in a clinical application, in which interventions are designed for individuals, greater detail is required.

The purpose of the classification differs in clinical situations because the decisions of providers require greater specificity. For example, it is useful to know acuity (b2100) at near (b21002) and distance (b21000) levels. It is also useful to use severity codes to portray activity limitations in areas that are likely to be compromised by vision loss (say, walking, reading, meal preparation, and managing medications). Baseline data can be compared with exit profiles to track a person's progress and to determine the effectiveness of a rehabilitation intervention. For instance, increased acuity may occur as the result of low vision services, and the decreased severity of limitation in meal preparation may be the result of rehabilitation teaching; likewise, the decreased severity of limitation in walking may be the result of orientation and mobility services.

Similarly, the ICF coding allows for information to be aggregated to describe groups of people to determine a program's effectiveness and thus to measure rehabilitation outcomes (Crews & Long, 1997). Information that is aggregated at this level informs managerial and policy decisions (see Wood & Badley, 1980). Throughout each of these applications, the ICF allows users to employ a consistent language, one that is shared among different professions and decision makers. For many vision rehabilitation organizations and vision rehabilitation professionals, the distinctions among conditions, function, activity, and participation are made intuitively, and therefore, the ICF may be used to organize existing administrative data (Nieuwen-huijsen, Frey, & Crews, 1991; Van Hof & Looijestijn, 1995).

Finally, from a policy point of view, the aim of social policy is to improve the participation of people with disabilities. The sum of various interventions can be characterized using appropriate scales to determine the effect of a variety of rehabilitation interventions, changes in the environment, income transfer programs, and support systems. For example, work is a type of measurable participation. It may be that for a person to become successfully employed, interventions may be designed to decrease limitations on activities and to create environments (transportation, employers' attitudes, and employment policies) that are more supportive. The ICF captures these dimensions.

Conclusion

The ICF, approved by the General Assembly of WHO in 2001, is a classification system that portrays the multidimensional characteristics of human experience, including disability. Here, we reported on one application of the ICF to compare rates of prevalence of visual impairment in Australia, Canada, France, the Netherlands, South Africa, and the United States. An international project, DISTAB, coded data from national surveys using ICF categories to estimate the rates of prevalence of visual impairment. Although each country used nationally representative samples and standardized interview practices, the questions in each nation's survey differed in detail. The reported rates of visual impairment in these six nations demonstrated low rates of visual impairment among young and middle-aged adults, with substantial increases among older age groups. South Africa reported higher rates in younger age groups (perhaps because of the prevalence of diseases, such as trachoma, that are still endemic in certain areas of South Africa and other developing countries and that cause vision problems at younger ages), and the Netherlands reported substantially higher rates among people aged 35-64 than did the other five nations (the reasons for these differences are unclear). In addition to the utility of using the ICF for calculating prevalence rates, we have shown other potential applications of the ICF for practice and policy.

As we noted earlier, the DISTAB project included seven disability categories, but this article has discussed only one, vision. Although DISTAB has not undertaken a systematic study of international comparability across types of disabilities, our findings on vision do not appear to differ dramatically from the findings for other types of disabilities; that is, for other disabilities, we observed broad agreement by the DISTAB countries on trends in prevalence by age and gender but differences in the levels of prevalence for which we have no explanation.

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