

**Subcommittee on Populations  
National Committee on Vital and Health Statistics (NCVHS)**

## **CLASSIFYING AND REPORTING FUNCTIONAL STATUS**

Information on functional status is becoming increasingly essential for fostering healthy people and a healthy population. Achieving optimal health and well-being for Americans requires an understanding across the life span of the effects of people's health conditions on their ability to do basic activities and participate in life situations—in other words, their functional status.

Some clinical professionals routinely use functional status information to care for their patients, but the information is often missing from physicians' notes for acute hospital care and routine outpatient medical visits. And even when the information is present in medical records, it only rarely becomes part of administrative records. This prevents a host of possible beneficial uses of the information for management, research, public health, and policy purposes.

This report is the result of an 18-month-long review by the Subcommittee on Populations of the National Committee on Vital and Health Statistics (NCVHS), concerning the feasibility of including functional status data in administrative records. NCVHS advises the Department of Health and Human Services on national health information policy.<sup>1</sup> The Populations Subcommittee consulted with 27 clinicians, researchers, and other data users from the U.S., Canada, and the World Health Organization at three NCVHS hearings in 2000. The presenters were unanimous in stressing that health care and health policy must go beyond a narrow disease-based focus to a broader approach that emphasizes people's health and well-being, with a goal of minimizing future loss of function.

This report has two major purposes: to put functional status solidly on the radar screens of those responsible for health information policy, and to begin laying the groundwork for greater use of functional status information in and beyond clinical care. It stems from the belief that while the International Classification of Diseases (ICD) has served us well for more than a century in characterizing diagnoses, it is now time to complement it with a parallel system for characterizing functional status.

The report begins by surveying the current and potential uses of functional status information, and then discusses the importance of including this information in clinical and administrative records to support optimal decision-making for health. The World Health Organization's newly-revised International Classification of Functioning, Disability and Health (ICF) is described as a promising approach to coding functional status information. The Committee believes that a coding system that specifies the

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<sup>1</sup> Further information about NCVHS and its work in areas related to this report is contained in Appendix 5.

elements of functioning is an appropriate place to start dealing with the issues of measurement and interpretation of functional status. Further, the Committee believes that the ICF deserves careful study, under the direction of the Department of Health and Human Services, as a potential codeset for reporting this information. The report concludes with a series of recommendations on the ICF and related topics.<sup>2</sup>

## FUNCTIONAL STATUS INFORMATION

### Definitions

Functional status is variously defined in the health field, by clinicians with different emphases as well as in different policy contexts. This NCVHS project uses a broad view of functional status that covers both the individual carrying out activities of daily living and the individual participating in life situations and society. These two broad areas include 1) basic physical and cognitive activities such as walking or reaching, focusing attention, and communicating, as well as the routine activities of daily living, including eating, bathing, dressing, transferring, and toileting; and 2) life situations such as school or play for children and, for adults, work outside the home or maintaining a household.

Functional limitations occur when a person's capacity to carry out such activities or performance of such activities is compromised due to a health condition or injury and is not compensated by environmental factors (including physical, social, and attitudinal factors). Functional status is affected by physical, developmental, behavioral, emotional, social, and environmental conditions. This conception encompasses the whole person, as engaged in his or her physical and social environment. It applies across the lifespan, although interpretation of functional status differs for different age groups.

### Current and Potential Uses of Functional Status Measurement

*We must have a way to study our interventions in order to treat the right conditions at the right time and in the right manner.<sup>3</sup>*



*We waste a lot of time and an enormous amount of effort in the transition between services [for children] because we don't have a common language.<sup>4</sup>*



*Functional status is among the most predictive elements in terms of utilization as well as outcomes.<sup>5</sup>*

<sup>2</sup>Quotes used throughout this report were part of testimony given in the January, April, and July 2000 Subcommittee hearings. All presenters are listed in Appendix 2.

<sup>3</sup> Judy Hawley, P.T. (July)

<sup>4</sup> Rune Simeonsson, M.D. (April)

<sup>5</sup> Robert Kane, M.D. (January)

Functional status assessment is carried out through professional observation, testing, and/or self-report by the patient or a proxy. Some functional status instruments are generic, such as the SF-36, while others are disease-specific, such as the Activities of Daily Vision Scale. Instruments addressing the activities of daily living (ADLs) include the Functional Independence Measure (FIM), the Minimum Data Set (MDS), the MDS for Post-Acute Care (MDS-PAC), and the Outcome and Assessment Information Set (OASIS). Hundreds of specialized instruments have been developed to assist practice in such areas as geriatrics, psychiatry, and nursing practice.

The information generated by these assessments can be used not only in clinical care but also for health care management, quality assurance, public health planning and practice, policy development, and research. At present, the most developed uses of the information are in clinical care; the others remain largely potentialities, to be realized once a standardized way has been found to include the data in administrative records and related data sets.

The concept of functional status is integral to all health care and applies to every person, regardless of age, physical or mental condition, or other characteristic. Two individuals with the same diagnosis—for example, cerebral palsy, bipolar disorder, or arthritis—can have very different levels of functioning, and their actual health status could be either better or worse than assumed. Even those who at certain times in their lives have no functional limitations should have this information included in their medical records at appropriate intervals along with other routinely-recorded clinical findings, to complement the information on diagnosis and health condition. Research is needed on such questions as frequency, coding, self-report and provider assessment.

Functional status information is commonly used in rehabilitative medicine, physical and occupational therapy, and nursing home and home care. The information is used to guide therapy in areas such as hearing, speech, vision, cognition, and mobility. It also is used to design and coordinate services for children with special needs and to monitor the well-being of people with various chronic conditions. Depending on the person and condition, health care providers can use functional status information to determine people's needs, develop interventions to restore or maintain function or prevent or minimize its decline, and prevent secondary disabilities. They also can track changes and follow people across settings and monitor quality and outcomes. Using functional status information, health care providers can help their patients maximize their abilities—arguably the purpose of all health care.

The Committee does not recommend imposing a single measurement instrument or methodology on clinical practice; rather, it recommends the use of a uniform code set so that health care providers can consistently report on their findings across the continuum of care, for clinical and administrative purposes.<sup>6</sup>

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<sup>6</sup> A code set is any set of codes used for encoding data elements, such as tables of terms, medical concepts, medical diagnosis codes, or medical procedure codes. The International Classification of Diseases and the National Drug Codes are examples of code sets.

Functional status information could serve the **management** needs of health care providers and payers in such areas as financial management, utilization review and quality assurance. The information is used, or could be used, to evaluate outcomes, compare treatment modalities, and predict costs. Knowing and tracking people's functional status could help health care organizations predict service utilization and resource use. The information is useful for risk adjustment and for documenting medical necessity, both of which are needed for payment and other purposes. Payers could use functional status information to adjust payment levels and capitation rates. Eligibility determination for some public programs requires information on function.

Information in administrative records on people's functional status and changes in it over time could strengthen efforts to evaluate health care performance, compare treatment modalities, and tie inputs to outcomes for **quality assurance** purposes. Quality assurance activities often start with administrative data, which are more readily available than clinical data. Such assessments are of interest not only to public and private payers, but also to policy makers, bodies such as the National Committee on Quality Assurance, and health care providers themselves. The President's Advisory Commission on Consumer Protection and Quality explicitly discussed the importance of functional status information in its 1998 report. HCFA, the largest public-sector payer, is supporting several quality improvement initiatives in managed care and fee-for-service environments. A major thrust is the development of standardized data collection and reporting tools to enhance the utility of regularly collected information, potentially including functional status information. Of course, functional status information could be used not only to assess quality of care but also to improve it, for the reasons noted in the preceding section.

Functional status information could help **public health practitioners** monitor and evaluate the health of the entire population and its component groups. Some of the most compelling needs for the information relate to Healthy People 2010. The two overarching goals for Healthy People 2010—increasing quality and years of healthy life and eliminating population health disparities—depend on functional status assessment. Also, the specific 2010 objectives for disabilities and secondary conditions (section 6) cannot be measured, much less met, without functional status information. Many other objectives also require it. Currently, some state and federal surveys collect this information on samples of the population, which can complement missing administrative data. The samples used in surveys do not have broad enough coverage, however, to give confidence that functional status within the population is accurately represented. A major contribution of surveys is to provide valid and reliable depth about specific areas of functional status; administrative data are needed for breadth.

Several potential **policy** applications of functional status information have already been mentioned. These include helping decision-makers set research and policy priorities, predict costs, prioritize federal, state and local health care and public health initiatives, and develop programs for priority populations. Ongoing surveillance data may be used to monitor changes and evaluate the effect of interventions.

Finally, **researchers** need functional status information not only to investigate clinical subjects but also for research in the areas of health care management, public health practice, and policy.

*If we are going to assess characteristics of people, we want to know something more about what is going to contribute to their health and well being. Knowledge of limitations and personal activities will provide the most useful additional information for understanding the individual, as well as aggregated information describing health needs and possible resources required.<sup>7</sup>*



*We have to have a way to reduce the potential for future loss of function, particularly in the 10 or 15 percent of the population that use most of our health care dollars and are most vulnerable to loss of function.<sup>8</sup>*

## The Challenges of Measuring and Reporting Functional Status

*Little attention is being paid to the cumulative impact of childhood impairment over the lifetime.... So although it seems like these are very complicated issues, it is very important that we deal with them, and that we include functioning.<sup>9</sup>*

Although there is growing recognition of the importance of functional status information, assessment, measurement and interpretation still involve many challenges. These include the existence of different conceptual bases as well as technical and methodological problems with the tools themselves, lack of proper validation studies in some cases, issues with how they are administered, complications stemming from the multiplicity of tools, and a host of external issues related to institutional barriers, cost, time constraints, training needs, and conceptual barriers.

Measuring functional status is particularly difficult with persons with cognitive limitations, either because cognitive capacity has not yet developed (as in very young children) or because it is impaired. The need to use proxies in these cases raises questions about the validity of the findings. In addition, it often is not possible to assess children's inherent capacity to do something because their physical and cognitive skills are undeveloped. Children must be assessed in terms of both their current and potential functioning in order to develop appropriate interventions. Pediatrician Ruth Stein noted "four Ds of childhood" that distinguish children from adults and pose challenges for interpreting functional differences: "developmental change, dependency on parents and other adults, differential epidemiology, and difference in demographic patterns."<sup>10</sup>

As with all health information, privacy issues must be taken into consideration in the disclosure and use of functional status information for people of all ages (although some experts view the privacy concerns in this area as no more serious than in others). Another issue is that because functional status affects such things as disabil-

<sup>7</sup> Donald Lollar, Ed.D. (January)

<sup>8</sup> Gretchen Swanson, Ph.D. (January)

<sup>9</sup> Ruth Stein, M.D. (January)

<sup>10</sup> (January)

ity benefits and payment based on medical necessity, patients or proxies and providers have a perverse incentive to modulate reporting, making measurement subject to conscious as well as unconscious bias.

In all, discussions during the NCVHS hearings made it abundantly clear that the science of functional status measurement is still under development and that no consensus yet exists on how to define and measure this complex phenomenon. At the same time, it was also clear that dozens of workable generic and disease-specific instruments are available and in use, with many still undergoing further testing and yet others being newly developed.

The Subcommittee concluded that reviewing functional status measurement was beyond its scope and purview, except to note that much more work is needed in developing suitable instruments for infants and children. The decision to focus on the feasibility of incorporating functional status information into standardized clinical and administrative records stemmed in part from the expectation that a uniform coding instrument could mitigate some of the challenges related to functional status measurement, especially those related to the multiplicity of tools and definitions. Furthermore, by essentially defining concepts in operational terms, a code set makes it possible to deal with both measurement and interpretation issues more intelligently and efficiently.

## FUNCTIONAL STATUS IN ADMINISTRATIVE RECORDS

*If the purpose of the health care claim is to submit information in order to be paid appropriately for service rendered, [then] the more accurate the information, the more appropriately the claim is paid. . . . If a physical therapist could code what they are treating—for instance, gait dysfunction—the picture created for the insurance company would be more accurate and complete.<sup>11</sup>*

The point has already been made that administrative data generally do not include information on functional status.<sup>12</sup> The significance of this fact is that information on this dimension of health—increasingly the *sine qua non* for understanding health—is not available to the health care system (e.g., insurers and health plans), nor to the researchers, public health workers, and policy makers who depend on administrative data. What is needed, therefore, is a standardized code set that will enable providers, with minimal burden, to include functional status information in administrative data. For this reason, the NCVHS Subcommittee on Populations focused its study on the feasibility of including functional status information in administrative data, including a beginning look at how the information could be coded and transmitted.

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<sup>11</sup>Judy Hawley, P.T. (July)

<sup>12</sup> The best-known exceptions to this rule are the Minimum Data Set (MDS), collected quarterly in nursing homes; the Outcome and Assessment Information Set (OASIS), collected during home health visits; and collection by rehabilitation hospitals using various approaches. Medicare requires the use of MDS and OASIS with Medicare beneficiaries, and includes this information in its administrative data. However, these “enriched” administrative data represent only small, non-random populations, mostly seniors.

Administrative data are compiled from the enrollment process and health care encounters. Resulting claims or encounter records are submitted by providers to payers and health plans so they can be reimbursed for their services (in non-capitated programs) and service utilization and aspects of quality can be monitored. Thus, payment and financial management are the first order of business for administrative data. They serve other equally important purposes, however. Administrative data complement surveys as an essential source of health statistics used to identify people with potentially disabling conditions, monitor the population's health, target interventions, evaluate health care quality, predict costs, design and track the results of health policy, and conduct health services research.

Although they have many limitations, administrative data offer a number of important advantages. First, they already exist, are relatively inexpensive to acquire, and are computer-readable. Second, they can include large groups of people, thus enhancing the utility of information for management purposes. Third, for some population subgroups (primarily Medicare beneficiaries at present), longitudinal, person-level administrative databases can track study subjects over time and across settings of care. And finally, the large number of cases in aggregated data bases helps hide individual identities.

It must be acknowledged that a major problem with administrative data is that with some exceptions, they exclude the uninsured. For those with administrative records, however, the chief limitations of current data stem from their reliance on diagnostic codes, which are regarded as having questionable accuracy, completeness, clinical scope, and meaningfulness. Most diagnoses alone convey little about their effects on people's daily activities or the impact of people's social or physical environments. Diagnosis does not reveal or predict function—and function has an enormous effect on utilization rates and is a good indicator of quality of care, among other things.

Without functional status information, the researchers, policy makers, and others who are already using administrative data have at best a rough idea of how people, individually and collectively, are doing—and at worst they are making erroneous assumptions and decisions. The addition of this information would make administrative records far more useful for the purposes for which they are already used, as well as for the many other potential applications discussed above. For example, the information is critically needed to support DHHS initiatives to design and modify prospective payment systems under Medicaid and Medicare. And Dr. Gregg Meyer, Director of the Center for Quality Measurement and Improvement for the Agency for Healthcare Research and Quality, told the Committee in June 1999 that functional status information was one of his top “wishes” for administrative data for use in assessing quality of care.

In short, the institutions responsible for payment, public health, and policy need this information, along with information about diagnoses and health conditions, to make the best possible decisions in their domains.

The passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996 introduced another powerful vector into the dynamics of this issue. When the

first standards become mandatory in October 2002, providers will no longer contend with dozens of different claim forms, definitions, and sets of instructions. National standards are developed in consultation with Standards Development Organizations (SDOs). By agreement with the federal government, recommended changes in claims and transaction standards are the purview of Designated SDOs and Data Content Committees, known collectively as Designated Standards Maintenance Organizations, or DSMOs. The law's administrative simplification provisions impose stringent requirements for changing or enhancing the standards, necessitating the support of the healthcare industry based on a strong business case. However, they also represent active federal support for standardizing administrative data, code sets, and transactions.

There are other signs of growing interest in standardization. Of particular note is a recent congressional requirement, enacted as part of the Medicare, Medicaid, and SCHIP Benefits Improvement Act of 2000, calling for the HHS Secretary to submit to several congressional committees by January 1, 2005 a report on the development of standard instruments for the assessment of the health and functional status of beneficiaries for whom a wide array of Medicare services are provided. This legislative requirement was foreshadowed in January, 2000, when Sally Kaplan, Ph.D., of the Medicare Payment Advisory Commission (MedPac) told the Subcommittee on Populations,

We strongly believe that it would be extremely useful, to say the least, to have standardization of functional status measures at least in post-acute care so that if similar patients are treated in different post-acute settings, or if patients are treated in successive post-acute care settings, that we would have a means of measuring them.... It would expand the utility of regularly collected information.<sup>13</sup>

Subsequently, in a March 2001 report to Congress, MedPac advised that HCFA have a single tool for functional status measurement and reporting.

In sum, there seems to be considerable momentum toward standardizing definitions and terminology related to functional status so that it is possible to track people across settings and to communicate across disciplines.

## ICF: CANDIDATE FOR THE CODE SET

*The ICDH-2 provides a solid conceptual framework for clinical assessment and provides strong support for all that we do as rehabilitation service providers, clinicians, researchers and teachers.<sup>14</sup>*

Based on its extensive hearings and deliberations over a period of 18 months, the Subcommittee on Populations concluded that a promising candidate as a code set—and the only viable one at present—is the International Classification of Func-

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<sup>13</sup> The National Committee had made similar observations in a July 3, 1997 letter to the HHS Data Council (see NCVHS web site).

<sup>14</sup> Gloriajean Wallace, Ph.D. (July)



tioning, Disability and Health (ICF<sup>15</sup>). This newly revised classification was created in 1980 (and then called the International Classification of Impairments, Disabilities, and Handicaps, or ICIDH) by the World Health Organization (WHO) to provide a unifying framework for classifying the consequences of disease. The classification complements WHO's International Classification of Diseases (ICD), which contains information on diagnosis and health condition but not on functional status.

## A Brief Description

The ICF provides a framework and classification scheme for describing a wide range of information about health. It is structured around two broad components — 1) body functions and structure and 2) activities (related to tasks and actions by an individual) and participation (involvement in a life situation) — with additional information on severity and environmental factors. Functioning and disability are viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors. The picture produced by this combination of factors and dimensions is of “the person in his or her world.” The classification treats these dimensions as interactive and dynamic rather than linear or static. It allows for an assessment of the degree of disability, although it is not a measurement instrument. It is applicable to all people, whatever their health condition. The language of the ICF is neutral as to etiology, placing the emphasis on function rather than condition or disease. It also is carefully designed to be relevant across cultures as well as age groups and genders, making it highly appropriate for the heterogeneous population of the United States. An example of the use of the ICF to classify a case study is contained in Appendix 4; a WHO description of the classification is in Appendix 3.<sup>16</sup>

Many who spoke at the Subcommittee's hearings described the conceptual framework of the ICF as solid and useful. Some recommended that the classification be piloted and further tested to determine its appropriateness as a standardized set for coding functional status data. Others who testified said their organizations have already started to use it for this and other purposes (see examples below). On the strength of these recommendations, the National Committee has concluded that the ICF is worthy of consideration as a possible standardized format for coding functional status information, following testing, piloting, and perhaps further modification.

## Development of ICIDH/ICF

The exhaustive revision process that resulted in the ICF took nearly a decade and involved comments from more than 80 countries and field tests in 42 countries, as well as input from scientists, non-governmental organizations, and others. The process, which was explicitly guided by the needs of users, resulted in a version that was approved by the WHO Executive Board in January 2001 and given final approval by the World Health Assembly in May 2001.

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<sup>15</sup> Also sometimes called ICIDH-2.

<sup>16</sup> This example captures all components of ICF, while routine collection of functional status in administrative records might be more limited and focused on functional limitations.

The United States played a major role in the revision, which involved not only federal agencies but also consumer advocacy groups, professional organizations, private sector disability insurance companies, and mental health and disability researchers. Early in the revision process, NCVHS hosted a hearing on the ICIDH in 1993, hearing from consumer advocates, scientists, data users, clinicians, and administrators about their hopes for the revision process. All of these groups had further opportunities to provide input into the process. The WHO Collaborating Center for the Classification of Diseases for North America, housed at the National Center for Health Statistics (and informally called the North American Collaborating Center), coordinated the participation of the U.S. and Canada. Americans had leadership roles in the International Mental Health Task Force, which achieved one of the major changes in the second edition, giving mental functioning parity with physical functioning. North Americans also had leadership roles in the International Children's Task Force and the International Environmental Task Force.

The revised version, the ICF, is widely regarded as a significant conceptual and practical advance over the first one, making it more flexible and useful. The revision process also instituted a process for updating the classification. Dr. Raymond Seltser has noted that the issues with ICIDH that were outlined by Dr. Saad Nagi in a 1991 Institute of Medicine Committee report do not apply to the ICF.<sup>17</sup> Efforts were made to make the ICF relevant to children, and the new version can be used to classify their functioning. The International Children's Task Force is working on a children's version, which is expected in about two years.

Steps to advance the ICF and its use in the U.S. and abroad are being spearheaded by WHO and various stakeholders including the North American Collaborating Center, HHS, and the following professional organizations: the American Speech, Language and Hearing Association; the American Occupational Therapy Association; and the American Psychological Association (APA). A wide range of educational, training, and pilot-testing efforts are also planned or underway. In addition to building awareness of the classification among clinicians, APA is working collaboratively with WHO, other professional organizations, and business and government stakeholders to develop a standard functional assessment procedure manual based on the ICF. In another arena, the ICF was used as a conceptual base for the development of WHO's Disability Assessment Schedule II, in collaboration with three Institutes from the National Institutes of Health. It is now being used in national surveys in the U.S. as well as in international studies.<sup>18</sup>

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<sup>17</sup> Saad Nagi, "Disability Concepts Revisited: Implications for Prevention," Appendix A of IOM's *Disability in America* (1991). Dr. Seltser's comments were made at the July hearing.

<sup>18</sup> More information on ICF is available on the WHO website, <http://www.who.int/icidh>

## Comments on the Classification's Merits and Drawbacks

*[The ICF model] addresses the outcome measure of individual performance across disciplines. This hasn't been done before in our medical system. It is also a model which explicitly recognizes the contribution of the environment on the performance of people who have disabilities, and we hope it will eliminate language barriers between professions. As the pressure for accountability increases and the evidence of clinical effectiveness becomes a requirement for reimbursement, this model may become a clear measure to determine if the appropriate clinical outcomes have been achieved. This model would help payers recognize the performance gains in therapy.<sup>19</sup>*

The panelists in the April and July hearings offered opinions on the ICF that ranged from qualified support tempered by caveats, on the one hand, to enthusiastic endorsement and reports of arenas in which clinicians, educators, and researchers are already using the classification, on the other. A few representative comments from the July 2000 meeting, which was devoted to the ICF, are summarized below. (It is worth noting that the classification has undergone significant additional development since then.)

In the policy area, John Crews of the Centers for Disease Control and Prevention observed that the ICF creates a method for linking broad public policy (e.g., on transportation and employment) with disability policy. Dr. Raymond Seltser of the University of Pittsburgh stressed the unprecedented ability of the classification to unify disparate fields, make encounter forms more meaningful, and enable the health-care delivery system to help people maximize their abilities.

The American Psychological Association, which values the etiological neutrality of the classification, believes the ICF would be an appropriate way to capture functional status information on health care claims and that this can be done in a relatively simple, methodologically sound manner. So reported Christopher McLaughlin of APA.

Dr. Travis Threats of St. Louis University and the American Speech, Language, and Hearing Association said the Schwab Rehabilitation Center, affiliated with the University of Chicago Hospital, has adopted the ICF as a rehabilitation model.

Dr. Susan Stark of Washington University School of Medicine reported that the American Occupational Therapy's practice guide for occupational therapists uses the ICF as a model for understanding the relationships between person, environment, and outcome factors. AOTA views the classification as a "language neutralizer" that facilitates communication between disciplines. Dr. Stark cited institutions that are using the ICF for education and training of OTs, and she stated that the classification can guide assessment, help show clinical effectiveness, and track performance.

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<sup>19</sup> Susan Stark, Ph.D., OTR/L (July)

Judy Hawley, P.T., of the Minnesota chapter of the American Physical Therapy Association (APTA) reported that this state chapter intends to incorporate the ICF into the Minnesota Outcome Study and use it to capture activity and activity limitation.

The Minnesota chapter is not representative of the parent body, however. Dr. Andrew Guccione of APTA expressed concerns about the validity of the ICF, particularly in the area of participation and the way it addresses the environment. Nevertheless, he noted the potential value of the classification for crosswalking to different assessments and for developing computerized documentation systems. Perhaps the greatest concern of APTA is that the ICF is not compatible with the current requirements of insurance companies and payers.

Two other presenters, Michael Wolfson and Alexander Ruggieri, raised questions about the conceptual design as well as operational issues. Dr. Wolfson, who is Assistant Chief Statistician at Statistics Canada and an active partner in the WHO Collaborating Center for the Classification of Diseases for North America, discussed many of the potential contributions of the ICF but also raised concerns about aspects of its conceptual framework. He advised caution, pointing out that even unanimity on the importance of functional status on the encounter form would not necessarily mean that the ICF is the appropriate mechanism for it.

Dr. Ruggieri, of the Mayo Foundation, called the ICF “a promising conceptual tool” but also noted the need for a rigorous modeling effort. In addition, he commented on the problems in establishing any new data field on administrative forms. He called for studies to evaluate how well the ICF serves informational needs in various clinical settings before considering its appropriateness as a functional status data field on health care claims.

During the July hearing, the Subcommittee also elicited comments on a possible process for achieving the inclusion of functional status information in clinical and administrative records. Dr. Seltser commented on the change in thinking and practice this calls for: “Something has to be done to reverse this situation where the physicians don’t think functional assessment is important because the ICD is the driving force. The disease model is being perpetuated by the encounter form.” He added, “The journey of 1,000 miles begins with a single step. And what you are asking us to consider in terms of the incorporation of a functional assessment element into the encounter forms, administrative records, is to me the first step in a journey of 1,000 miles.” On testing the ICF as a tool for that purpose, Dr. Jayne Lux, a former WHO staff member, took a similarly long-term view, saying that a pilot of coding functional status on administrative records using the ICF could roll out in “a couple of years.”

Several speakers at the hearings offered specific suggestions on strategy. Dr. Seltser advocated raising awareness among those on the business side of health care about the potential economic benefits of functional status information. Robert Griss suggested the initiation of demonstration projects in managed care, and Dr. Wallace stressed the importance of minimizing the burden of collecting and coding the information. Dr. Iezzoni advised that alliances be formed with the physician groups most likely to be sympathetic, such as physical medicine, geriatrics, rheumatology, and pediatrics. Mr. McLaughlin described the collaborative process to which the American Psychological Association has already committed considerable time and resources.

The net effect of this array of expert, experience-based observation, then, is not only to affirm the critical uses of functional status information but also to portray the ICF as a possible code set for including the information in standardized clinical and administrative records. The National Committee believes the ICF is a worthwhile subject of rigorous examination and testing in this regard.

## NCVHS RECOMMENDATIONS

The following NCVHS recommendations are intended to help bring about three basic and necessary steps, which are likely to take several years: first, broad agreement on the importance of collecting functional status information; second, selection of a code set for functional status data in standardized records, including electronic patient records and claims and encounter records; and third, selection and testing of a code set for these purposes. The Committee believes that the ICF should be evaluated for use in coding functional status information in both electronic patient records and administrative data. This research should begin as soon as possible, under the leadership of HHS, with the intention of readying a code set for use when broader agreement has been reached that it is needed. More specifically, the Committee recommends the following:

1. Functional status information is integral to understanding health and should be included in patient records (computerized and otherwise) in the range of settings where care is provided. (The Committee is not recommending any particular functional status measures or instruments.)
2. Because of its importance for both health practice and such policy-related functions as quality assurance and monitoring progress toward Healthy People 2010 objectives, functional status information should be reported at appropriate intervals in standardized data sets, as well as in computerized patient records.
3. The concepts and conceptual framework of the ICF have promise as a code set for reporting functional status information in administrative records and computerized medical records. In the Committee's view, the ICF is the only existing classification system that could be used to code functional status across the age span.
4. Before any recommendations are made about widespread implementation of the ICF in administrative records and computerized medical records, thorough work is needed by means of research, analysis, testing, and demonstration projects to examine issues such as the following:
  - the classification's adequacy across the lifespan
  - where the gaps are in the testing of the ICF done to date
  - the feasibility of extracting functional status information from patient records in different settings
  - the training required for personnel
  - the time required to ascertain and code functional status information

- the cost of extracting functional status information
  - the appropriate interval at which to collect the information in medical records
  - the value of the resulting information
  - the reliability and validity of the information
5. Gaps in the availability of instruments for assessing functional status, appropriate to the population as well as the clinical context, should be identified and addressed. The lack of accepted tools for measuring the functional status of children is of particular concern.
  6. Any special privacy issues surrounding collection and reporting of functional status information need continuing review.
  7. Efforts should be made to increase awareness of functional status assessment and the ICF among policy makers, professional organizations, government organizations, researchers, and other relevant parties.
  8. The Department of Health and Human Services is encouraged to take the lead in the activities recommended above. In addition, HHS should provide resources within the Department and to WHO to support work, nationally and internationally, on the classification—in particular, demonstration, testing, maintenance, and updating.
  9. The designated standards maintenance organizations (DSMOs) should be alerted that NCVHS and the Department have a strong interest in the coding of functional status information in administrative records and computerized medical records.

## CONCLUSION

There are many signs that agreement is emerging on the importance of functional status information for the optimal carrying out of clinical care, public health practice, policy, and administration. The next task is to find an effective way to get this information into standardized records, and to evaluate the ICF as a possible mechanism for that purpose. The National Committee urges the Department of Health and Human Services to exercise leadership in this effort and to give it the priority it deserves, in continued collaboration with the World Health Organization. The Committee would welcome annual status reports from the Department on this project, beginning in 2002. The standards community is encouraged to begin looking at this issue and possible solutions. Finally, the Committee offers its advice and enthusiastic support for all efforts aimed at enriching clinical and administrative data with functional status information.

## APPENDIX 1

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APPENDIX 2

## Hearing Participants and Agendas

### **JANUARY 24, 2000** (Chair: Lisa Iezzoni, M.D., M.S.)

#### Overview of Functional Assessment and Health Status: Issue Identification

Robert L. Kane, M.D., University of Minnesota

William Braithwaite, M.D., ASPE

#### Functional Assessment and Health Status: Lessons Learned

Donald Lollar, Ed.D., CDC

Nancy Whitelaw, Ph.D., National Council on the Aging

#### Functional Assessment: Risk Adjustment and Rehabilitation Focus

Gretchen Swanson, Ph.D., Western University of Health Sciences

Dr. Jinnet Fowles, HealthSystem, Minnesota

Dr. Margaret Stineman, University of Pennsylvania

#### Functional Assessment: Selected Focus Areas

Ruth Stein, M.D., Albert Einstein College of Medicine

Dr. Alice Kroliczak, HRSA

Dr. Sally Kaplan, Medicare Payment Advisory Commission

### **APRIL 13, 2000** (Chair: Lisa Iezzoni, M.D., M.S.)

#### Proxy, Disability, and ICIDH:

Donald Lollar, Ed.D., CDC

Michele Adler, SSA

#### Overview of ICIDH

Gerry Hendershot, Ph.D., NCHS

#### Functional Assessment and ICIDH

Margo Holm, University of Pittsburgh

Rune Simeonsson, M.D., University of North Carolina

Allan Meyers, Boston University

#### NHIS: Functional Assessment

Jennifer Madans, Ph.D., NCHS

Else Pamuk, NCHS

#### Recap of the Day and Discussion

**JULY 17, 2000** (Chair: Lisa Iezzoni, M.D., M.S.)

International Standards and Applications

Michael Wolfson, Ph.D., Statistics Canada  
Jayne Lux, M.S., CCC/SLP, former World Health Organization  
Yerker Andersson, Ph.D., National Council on Disability

ICIDH-2 Training and Testing Activities

Gerry Hendershot, Ph.D., NCHS  
Paul Placek, Ph.D., NCHS  
Judy Hawley, P.T., Minnesota APTA  
Gloria Jean Wallace, Ph.D., University of Cincinnati

Considerations in Possible Uses of ICIDH-2

Nora Wells, MSED, Family Voices  
Robert Griss, Center on Disability and Health  
John Crews, DPA, CDC  
Raymond Seltser, M.D., M.P.H. University of Pittsburgh

ICIDH-2 Revision and Applications

T. Bedirhan Ustun, M.D., World Health Organization

Logistical Considerations in Applications of ICIDH-2

Christopher McLaughlin, American Psychological Association  
Travis Threats, Ph.D., Saint Louis University  
Andrew Guccione, P.T., Ph.D., FAPTA American Physical Therapy Association  
Susy Stark, Ph.D., ORT/L Washington University School of Medicine (AOTA)

Conceptual Clarity and Comparable Measures

Alexander P. Ruggieri, M.D., Mayo Foundation  
Elena Andresen, Ph.D., Saint Louis University School of Public Health