

# North American Collaborating Center

## ICF Newsletter

Issue Number 1, 2012

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- 1) [\*\*\*World Health Organization and World Bank Released the World Report on Disability, with Recommendation to “Adopt the ICF”\*\*\*](#)

The World Report on Disability is a seminal document. Read about its description of and advocacy for adopting the ICF.

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This important new textbook, edited and authored by several ICF pioneers, incorporates ICF into the Public Health curriculum.

- 3) [\*\*\*Honoring the Contributions of Stephen M. Haley, PhD, FAPTA, Professor at Boston University School of Public Health\*\*\*](#)

We honor Professor Haley’s contributions to the ICF literature and the rehabilitation sciences, and mourn his passing.

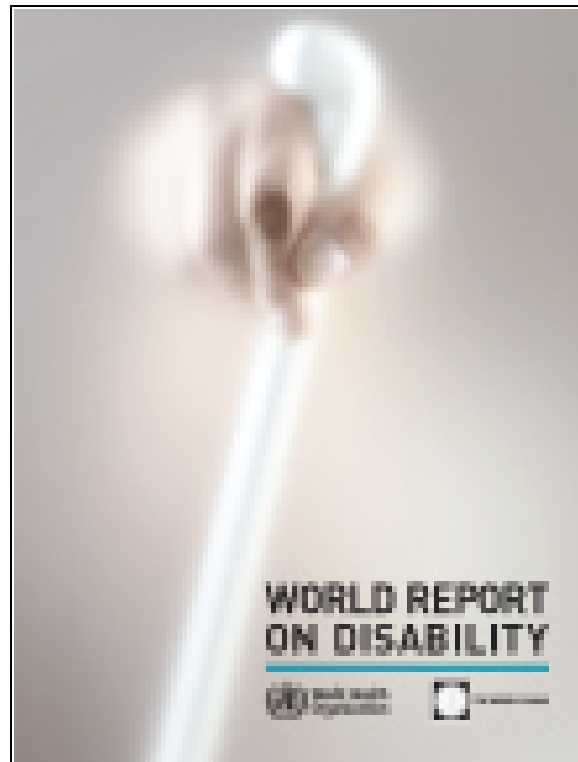
- 4) [\*\*\*Coder’s Corner\*\*\*](#)

*Coder's Corner* is our educational feature to help build and enhance your skills as an ICF Coder. In this edition, we feature coded photographs of the Canadian marathon runner, Terry Fox.

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1) ***World Health Organization and World Bank Released the World Report on Disability, with Recommendation to “Adopt the ICF”***

The **World Report on Disability** is a seminal document. Read about its description of and advocacy for adopting the ICF.



Readers of this ICF Newsletter will want to take stock of the new [World Report on Disability](#), released in June, 2011 by the World Health Organization (WHO) and the World Bank.

The World Report includes many references to the ICF, particularly in its Chapter 2, “Disability: A Global Picture.” In fact, the World Report provides a straightforward recommendation: “Adopt the ICF.”

The content of the World Report is vast: it is more than 350 pages long, and a world-class team of experts and editors from many countries and non-governmental organizations needed four years to prepare it.

This excerpt from the June 9, 2011 WHO-World Bank [Press Release](#) summarizes the World Report nicely:

“WHO and the World Bank [that date] revealed new global estimates that more than one billion people experience some form of disability. They urged governments to step up efforts to enable access to mainstream services and to invest in specialized programmes to unlock the vast potential of people with disabilities. The first-ever *World Report on Disability* provides the first global estimates of persons with disabilities in 40 years and an overview of the status of disability in the world.

New research shows that almost one-fifth of the estimated global total of persons living with disabilities, or between 110-190 million, encounter significant difficulties. The report stresses that few countries have adequate mechanisms in place to respond to the needs of people with disabilities. Barriers include stigma and discrimination, lack of adequate health care and rehabilitation services; and inaccessible transport, buildings and information and communication technologies. As a result, people with disabilities experience poorer health, lower educational achievements, fewer economic opportunities and higher rates of poverty than people without disabilities.

‘Disability is part of the human condition,’ says WHO Director-General Dr. Margaret Chan. ‘Almost every one of us will be permanently or temporarily disabled at some point in life. We must do more to break the barriers which segregate people with disabilities, in many cases forcing them to the margins of society.’

‘Addressing the health, education, employment, and other development needs of people living with disabilities is fundamental to achieving the Millennium Development Goals,’

says Robert B. Zoellick, President of The World Bank Group. 'We need to help people with disabilities to gain equitable access to opportunities to participate and contribute to their communities. They have much to offer if given a fair chance to do so.'

Welcoming the report, renowned theoretical physicist Professor Stephen Hawking said, 'We have a moral duty to remove the barriers to participation for people with disabilities, and to invest sufficient funding and expertise to unlock their vast potential. It is my hope this century will mark a turning point for inclusion of people with disabilities in the lives of their societies.'

Nearly 150 countries and regional organizations have signed the Convention on the Rights of Persons with Disabilities (CRPD), and 100 have ratified it, committing them to removing barriers so that people with disabilities may participate fully in their societies. The *World Report on Disability*, developed with contributions from over 380 experts, will be a key resource for countries implementing the CRPD."

The key findings and recommendations within the World Report are thorough and robust. For example, the World Report recommends utilizing the short set of census questions developed by the Washington Group on Disability Statistics. Let's take a brief look at some of the descriptions of the ICF that are found in Chapter 2 of the World Report.

"Data gathered need to be relevant at the national level and comparable at the global level – both of which can be achieved by basing design on international standards, like the *International Classification of Functioning, Disability and Health* (ICF). International frameworks and resources are important in these efforts. Policy frameworks and agreed principles are set out in the CRPD. Information-related standards are provided by the ICF." (2011, pg. 24).

"Adopt the ICF: Using the ICF, as a universal framework for disability data collection related to policy goals of participation,

inclusion, and health will help create better data design and also ensure that different sources of data relate well to each other. The ICF is neither a measurement tool nor a survey instrument – it is a classification that can provide a standard for health and disability statistics and help in the difficult task of harmonizing approaches across sources of disability data. To achieve this, countries can:

- Base definitions and national data standards on the ICF.
- Ensure that data collection cover the broad array of ICF domains – impairments, activity limitations and participation restrictions, related health condition, environmental factors – even if a minimal set of data items is to be selected.” (2011, pg. 45).

In the same section of the World Report in which it recommends adopting the ICF, these other salient recommendations are provided, here summarized in bullet form but explicated in great detail within the Report:

- “Improve national disability statistics;
- Improve the comparability of data; and
- Develop appropriate tools and fill the research gaps” (2011, pp. 45-47, summarized)

The World Report provided an outstanding example of how the ICF might be utilized in disability prevalence estimation activities within countries. “Box 2.4” (2011, pg. 38) is entitled “Measuring the effect of environment on disability.” Summarizing data collected and reported on by the European Union-funded initiative known as “Measuring Health and Disability in Europe” (MHADIE), Box 2.4 helpfully described the application of ICF concepts and codes in an international prevalence estimation effort.

### **“Measuring the effect of environment on disability**

The ICF model of disability provides a tool for measuring the effect of changes in the environment on the prevalence and severity of disability. It uses capacity and performance to assess the influence of the environment on disability. These constructs are as follows:

**Capacity** indicates what a person can do in a standardized environment, often a clinical setting, without the barriers or facilitators of the person's usual environment;

**Performance** indicates what a person does in the current or usual environment, with all barriers and facilitators in place.

Using these notions provides one way of identifying the effect of the environment and judging how a person's performance might be improved by modifying the environment.

Data were collected from a range of settings (research, primary care, rehabilitation) in the Czech Republic, Germany, Italy, Slovenia, and Spain on 1,200 individuals with bipolar disorder, depression, low back pain, migraine, multiple sclerosis, other musculoskeletal conditions (including chronic widespread pain, rheumatoid arthritis and osteoarthritis), osteoporosis, Parkinson disease, stroke, or traumatic brain injury. Participants were rated on a five-point scale by interviewers using the ICF checklist recording levels of problems across all dimensions. Activity and participation items were scored using both the capacity and the performance constructs. Data were reported using a 0–100 score, with higher scores representing greater difficulties, and a composite score was created (see accompanying figure).

Capacity scores were worst in people with stroke, depression, and Parkinson disease, while individuals with osteoporosis had the fewest limitations. Performance scores tended to be better than capacity scores, except for individuals with bipolar disorder or traumatic brain injury. This suggests that most individuals had supportive environments that promoted their functioning at or above the level of their intrinsic ability – something that applied particularly for multiple sclerosis and Parkinson disease.

For people with conditions such as bipolar disorder and traumatic brain injury, the environmental factors hindered optimal performance. The data suggest that it is possible in

clinical settings to disentangle aspects of disability that are particular to the individual (the capacity score) from the effects of a person's physical environment (the difference between capacity and performance)." (2011, pg. 38)

At least five Commentaries have also appeared, describing the World Report and also referring to its emphasis on the ICF. Click on the hypertext links to view either the Abstract or the complete copy of each article.

Bickenbach J. The World Report on Disability. *Disability and Society* 2011 (August 1); 26(5):655-658.  
[\[Publisher's Abstract\]](#)

Krahn GL. WHO World Report on Disability: A review. *Disability and Health Journal* 2011 (July); 4(3):141-142.  
[PMID: 21723520](#)

Shakespeare T, Officer A. World Report on Disability. Editorial. *Disability and Rehabilitation* 2011; 33(17-18):1491-1492.  
[PMID: 21780912](#)

Von Groote PM, Bickenbach JE, Gutenbrunner C. The World Report on Disability: Implications, perspectives and opportunities for physical and rehabilitation medicine (PRM). *Journal of Rehabilitation Medicine* 2011 (October); 43(10):869-875.  
[PMID: 21915583](#)  
Open Access .PDF copy available at:  
<http://www.medicaljournals.se/jrm/content/?doi=10.2340/16501977-0872>

World Report on Disability. Editorial. *The Lancet* 2011 (June 11); 377(9782):197.  
[PMID: 21665020](#)

You can also view a video interview about the World Report at the following CNN International website:

“WHO Report: Society and Disabilities.” Video interview between *World Report* Co-Executive Editor Dr. Tom Shakespeare and CNN International Correspondent Errol Barnett, on the occasion of the release of the *World Report* at the United Nations on June 9, 2011. Duration: 5 minutes, 40 seconds.

<http://edition.cnn.com/video/#/video/health/2011/06/09/who.disability.report.cnn?iref=allsearch>

The full citation for the World Report is as follows:

World Health Organization. *World Report on Disability*. Geneva: WHO Press, 2011. ISBN 978-92-4-156418-2.

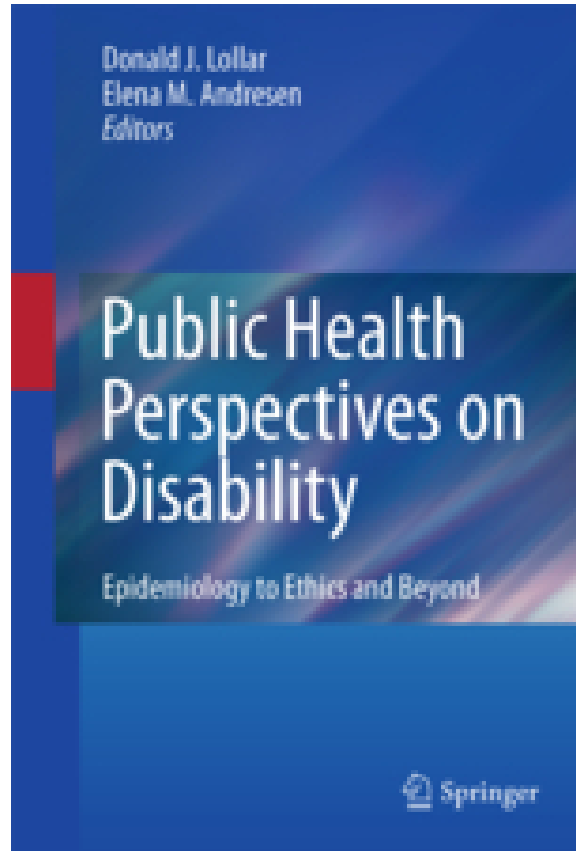
We encourage Readers to become familiar with the entire World Report on Disability. You can view all the contents and download a copy of the World Report in .PDF format at this WHO website:

[http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html)



2) **“Public Health Perspectives on Disability: Epidemiology to Ethics and Beyond” (Lollar and Andresen, editors, 2010)**

**This important new textbook, edited and authored by several ICF pioneers, incorporates ICF into the Public Health curriculum.**



Readers of this NACC ICF Newsletter will welcome a new textbook on the intersection of disability and Public Health. This new book features a robust treatment of ICF, with the authors and editors expressing mostly support for implementing the ICF, but also delivering an honest appraisal of its weaknesses in relation to its strengths.

Designed for use by instructors in graduate schools, but accessible enough for mainstream readers, this new textbook is entitled *Public Health Perspectives on Disability: Epidemiology to Ethics and Beyond*. It was released in November, 2010 by Springer Publishing Company.

The editors are probably familiar to many readers of this NACC ICF Newsletter: Professors Donald J. Lollar and Elena M. Andresen, now both affiliated with Oregon Health and Science University (OHSU) in Portland. Over two decades, both Don and Elena have made many contributions to the development of the ICF, both in the U.S. and internationally.

According to the publisher, *Public Health Perspectives on Disability*

- “Examines disability through diverse and multidisciplinary perspectives;
- Represents all the major fields within public health study: epidemiology, environmental health, maternal and child health, etc.; [and]
- [Is] designed to be used in planning for any core course in the public health curriculum.”

Additionally, the publisher described the orientation of the chapters:

“Each chapter applies awareness and understanding of disabled persons’ experience to one of the core curriculum areas, including:

- Health services administration;
- Environmental health science and occupational health;
- Health law and ethics;
- The school as physical setting;
- Maternal, child, and family health; [and]
- Disasters and disability.

In *Public Health Perspectives on Disability*, faculty, researchers, administrators, and students in graduate schools of public health throughout the U.S. will find a worthy classroom text and a robust source of welcome—and much needed—change.”

In their Dedication, the editors justifiably credited the originating vision for this textbook to the late Professor Allan Meyers, from the Boston

University School of Public Health, who initiated the concept and convened the original authorship team for this textbook in the late 1990s. They wrote:

“This volume would not have come to be except for the vision and will of Allan Meyers. . . . He was adamant about the need to immerse public health students in disability sensitivity and literacy, whether or not disability was their primary academic focus. He also envisioned a specific disability concentration within the public health curriculum. . . . We hope this book provides some semblance of the product Allan envisioned so that public health students and professionals of the future will be better prepared to address the public health needs of all people, including those with disabilities” (2010, pg. v).

(Professor Meyers was indeed a pioneer, and an early contributor to our North American Collaborating Center during the ICIDH-ICF revision. Testimony to his stature in the disability sciences is provided to this day in a fitting memorial to Professor Meyers. Since 2001, each year the Disability Section of the American Public Health Association has selected one or more recipients for the Section’s Allan Meyers Award, “presented to a person who has combined excellence across the areas of research, teaching and advocacy to improve the health and quality of life for people with disabilities.” Some of the best-known scholars and advocates in the contemporary disability sciences have received this award, including Harlan Hahn, David Pfieffer, Bobby Silverstein, Elizabeth DePoy and Stephen Gilson, David Braddock, Jim Rimmer, Tom Seekins, Professor Andresen, and Professor Meyers himself, posthumously.)

The chapters that really focus on the ICF are those authored by Lollar and Andresen in their Introduction, by Andresen on “Epidemiology and Biostatistics,” and by Mary Chamie on “Disability and International Health.”

In their Introduction, the editors described the ICF and wrote:

“With the growing need to consider not just acute but chronic conditions, with the aging of the population, and with improved medical interventions, it is difficult to overstate the importance of incorporating functioning, operationalized by the ICF into the public health armamentarium. Disability, a crosscutting public

health field most dramatically defined by the ICF, provides a practice and theoretical foundation for future public health students to understand the integrated nature of environment, and human health and functioning. ICF conceptual dimensions distinguish among body functions and structures, person-level limitations of activities, and participation in society. Environment is included in the ICF as a factor affecting all the other dimensions. In this regard, the ICF disability and IOM [Institute of Medicine, referring to *The Future of the Public's Health in the 21<sup>st</sup> Century* (2003)] public health models begin to converge. The future of public health data for disability is closely tied with the use of the ICF system. As public health expands in response to a changing world, disability has the capacity to provide relevant concepts and data for that expansion" (2010, pg. 8)

In her chapter on "Epidemiology and Biostatistics," Andresen wrote:

"Questionnaires that are substantially longer than usual surveillance tools have been developed for classifying people according to the ICF. The WHO has tested a comprehensive tool for measuring disability and the environment, the WHODAS II. This instrument provides a profile of functioning across six activity domains, as well as a general disability score. . . . To date, applications of the WHODAS II are very limited in the United States, although it is used more frequently in Canada and Western Europe. Other applied survey methods which use the ICF to code results have been developed, including the Craig Hospital Instrument of Environmental Factors. . . . In general, however, given the complexity and training issues for even clinical applications, the research applications of the full ICF are likely to remain in clinical rehabilitation and outcomes arenas, and not surveillance surveys" (2010, pg. 24).

In her chapter on "Disability and International Health," Chamie provided a thorough overview of the ICF conceptual framework, using "seeing" functions as an ICF-oriented case example. Chamie's overall theme had been that the ICF enhances any classification activity involving not only basic human functioning, but also inclusion and participation.

Chamie devoted a portion of her chapter to stigmatization among persons with disabilities around the world, such that invoking ICF concepts could be considered a practical “lever” used to minimize stigmatization in case-counting activities. Chamie wrote:

“ICF is proving useful for a wide range of purposes. It is important to note that an earlier draft of ICF (WHO, 1980) [referring to ICIDH] has been used to assess outcomes of services by such sectors as insurance, social security, labor, education, economics, social policy and legislation; it has also served to guide environmental modification. It is not sufficient, for example, to simply know that rehabilitation services have been received; or whether ramps have been provided; it is also important to learn whether this has changed the proportion of the population that can get dressed in the morning, or who enter the building unassisted” (2010, pp. 193-194).

Other chapter authors include:

- Debbie Allen from the Boston Public Health Commission;
- Jerome Bickenbach from Swiss Paraplegic Research in Nottwil, Switzerland;
- Erin DeFries Bouldin from the University of Florida;
- Charlie Bullock from San Jose State University;
- John Crews from the Centers for Disease Control and Prevention;
- Paul Devereaux from the University of Nevada;
- Dennis Heaphy from the Disability Policy Consortium of Massachusetts;
- Monika Mitra from the University of Massachusetts Medical School;
- Carol Tobias from the Boston University School of Public Health; and
- Deborah Klein Walker from Abt Associates.

You can read a short description of *Public Health Perspectives on Disability* on this web page provided by the publisher:

<http://www.springer.com/public+health/book/978-1-4419-7340-5>

From that web page, or directly from the links below, courtesy of the publisher, Springer Publishing Company, you can read and even download .PDF copies of three components of the new textbook.

Table of Contents:

[http://www.springer.com/cda/content/document/cda\\_downloaddocument/9781441973405-t1.pdf?SGWID=0-0-45-1070478-p174027166](http://www.springer.com/cda/content/document/cda_downloaddocument/9781441973405-t1.pdf?SGWID=0-0-45-1070478-p174027166)

Preface (Lollar and Andresen)

[http://www.springer.com/cda/content/document/cda\\_downloaddocument/9781441973405-p1.pdf?SGWID=0-0-45-1070461-p174027166](http://www.springer.com/cda/content/document/cda_downloaddocument/9781441973405-p1.pdf?SGWID=0-0-45-1070461-p174027166)

“Sample Pages,” which are all 39 pages in the chapter entitled “Epidemiology and Biostatistics” by Andresen:

[http://www.springer.com/cda/content/document/cda\\_downloaddocument/9781441973405-c1.pdf?SGWID=0-0-45-1070443-p174027166](http://www.springer.com/cda/content/document/cda_downloaddocument/9781441973405-c1.pdf?SGWID=0-0-45-1070443-p174027166)

Through the courtesy of the publisher, you can also read most of the content online, without downloading. Point your browser to this web page:

<http://www.springerlink.com/content/978-1-4419-7341-2>

There you can find online versions of all 260 pages in the textbook, although with the front and back matter. This will enable readers to appreciate the depth and breadth of this new textbook.

The ISBN for the new textbook is: ISBN 978-1-4419-7340-5.

For more information, please contact the editors directly:

- Elena Andresen [andresee@ohsu.edu](mailto:andresee@ohsu.edu)
- Don Lollar [Lollar@ohsu.edu](mailto:Lollar@ohsu.edu) .

Our North American Collaborating Center applauds these editors and authors for their comprehensive contribution to the literature on Public Health and disability, particularly in reference to the ICF.

3) ***Honoring the Contributions of Stephen M. Haley, PhD, FAPTA,  
Professor at Boston University School of Public Health***

**We honor Professor Haley's contributions to the ICF literature and the rehabilitation sciences, and mourn his passing.**



Readers of this ICF Newsletter, and participants in the North American Collaborating Center at large, will join in sadness upon learning about the passing of Professor Stephen M. Haley from Boston University.

Stephen M. Haley, Ph.D., P.T., F.A.P.T.A., had been Professor of Health Policy and Management, and Associate Director of the Health and Disability Research Institute, at Boston University's School of Public Health. Professor Haley's clinical background was in pediatric physical therapy. His research interests were broad and diverse, but mainly focused on outcomes measurement in the rehabilitation sciences. He had a prolific publication record, and he contributed to many different sciences.

Within our Collaborating Center, we remember Steve for his many presentations over the years during our series of ICF Conferences. For example, Professor Haley contributed the following:

2004, Halifax: "Sensitivity to Change: The Activity Measure for Post-Acute Care," with co-authors Alan Jette and Wendy Coster.

2006, Vancouver: "Blending Activity and Participation: Evidence for Five Major Factors Underlying Disability and Function," with co-authors Alan Jette and Wei Tao.

2007, Niagara Falls: "Developing Meaningful Measurements of the ICF Activity Domain," with co-authors Wei Tao and Anna Norweg.

Professor Haley also contributed to the pioneering Supplement to the then-titled *Health Care Financing Review* journal issue that featured an introduction to the ICF and its potential alignment with rehabilitation systems in the U.S.

Jette AM, Haley SM, Ni P. Comparison of functional status tools used in post-acute care. *Health Care Financing Review* 2003 (Spring); 24(3):13-24

Professor Haley contributed substantially to the development and validation of the assessment instrument known as the Activity Measure for Post-Acute Care (AM-PAC), an ICF-oriented instrument that summarized outcomes from the Activities & Participation Domain. In recent years, he served as Co-Principal Investigator on an important project within the "Patient Reported Outcomes Measurement Information System" (PROMIS) network of studies, funded by the U.S. National Institutes of Health and based on computer adaptive testing methods, entitled "Patient Reported Outcomes for Children and Young Adults with Disabilities," collaborating with Professor David Tulskey at the University of Michigan.

You can read more thorough, very touching and warmhearted Appreciations for Professor Haley from his colleagues in physical therapy and rehabilitation medicine, and at Boston University, at the following journal and university websites.



Craik RL. In tribute: Steve Haley. *Physical Therapy* 2011 (September); 91(9):1294-1295. doi: 10.2522/ptj.2011.91.9.1294.

Through the courtesy of the publisher, a free copy is available at:  
<http://ptjournal.apta.org/content/91/9/1294.full>

[PMID: 21885450](#)

Jette AM. In memoriam: An appreciation of Stephen M. Haley, PT, PhD, FAPTA. *Archives of Physical Medicine and Rehabilitation* 2011 (October); 92(10 Suppl):S61-S62.

Through the courtesy of the Boston University School of Public Health Rehabilitation Outcomes Center, a free copy is available at:

<http://www.bu.edu/bostonroc/files/2011/09/Stephen-M.-Haley-PTJ-In-Memoriam.pdf>

Latham NK. An appreciation of Stephen M. Haley. *Physical Therapy* 2011 (December); 91(12):1712. doi: 10.2522/ptj.2011.91.12.1712.

Through the courtesy of the publisher, a free copy is available at:  
<http://ptjournal.apta.org/content/91/12/1712.long>

[PMID: 22135754](#)

Boston University School of Public Health, Rehabilitation Outcomes Center, Tribute to "Stephen M. Haley, PT, PhD, FAPTA (1951-2011)"

Available at:  
<http://www.bu.edu/bostonroc/2011/07/18/stephen-m-haley-pt-phd-fapta-1951-2011/>

#### 4) **Coder's Corner**

***Coder's Corner* is our educational feature to help build and enhance your skills as an ICF Coder. In this edition, we feature coded photographs of the Canadian marathon runner, Terry Fox.**

Welcome back to "*Coder's Corner*," [a continuing feature in our NACC ICF Newsletter](#) designed to encourage all our Readers to become proficient in ICF coding. *Coder's Corner* is where we present illustrations appended with ICF coding, to demonstrate the four domains in ICF, and the basic principles of the ICF coding structure. Our goal is to enable each Reader to build and enhance his or her skills as a full-fledged ICF Coder.

*Coder's Corner* features color or black-and-white photographs, line drawings, or generic clip art representing people with disabilities engaged in everyday activities. Learning about ICF codes and coding rules can be easier when illustrations accompany the actual codes, in addition to text.

An important characteristic of *Coder's Corner* is the respectfulness with which we approach any given coding example. Even in the abstract, or even among deceased persons, we acknowledge that our coding examples refer to real people who have serious impairments or genuine participation restrictions. We want to see the person first, not the disability.

Our goal is not to accentuate impairments, but rather to demonstrate that the ICF provides standardization to the description of such cases, by adhering to the ICF coding guidelines. Therefore we approach each example in a non-stigmatizing, humanistic, very respectful manner, and we encourage our Readers to do the same.

In each coding example we present a brief description of the image, one or more representative ICF codes that describe the case in the image, a justification for our selecting those ICF codes, and a short discussion.

Some of our coding examples are simple, others are complicated. Some don't even involve people *per se*, for example in an illustration describing an environmental barrier or facilitator. Some examples utilize ICF qualifiers, while others are simply expressed at the code-stem level.

We acknowledge that some ICF code stems are difficult to apply in practice, too, and we discuss those as well, toward our goal of explaining those codes in a manner that makes them useful to all ICF coders.

### Terry Fox and the “Marathon of Hope”

Many North Americans remember the story of Terry Fox, the young man from Port Coquitlam, British Columbia, who in 1980 bravely committed himself to completing a charity run across Canada on behalf of medical research for children with cancer. Canadians justifiably look to the models of fortitude, perseverance, and selfless charity exemplified by Terry Fox, as reflections of their collective strength and national values.

In this *Coder’s Corner*, with respectfulness, we honor the memory of Terry Fox and his courageous “Marathon of Hope” across Canada.

Unfortunately, ICF coding cannot accommodate his “fortitude, perseverance, and selfless charity.” But ICF coding easily accommodates the examples provided by this young man with a body structural impairment (an amputation), who nevertheless could participate with only moderate limitations in activities such as running and public speaking. Terry used a prosthetic right leg to assist him in running, representing an environmental facilitator in ICF terms. In fact, and in respectful memory, today Terry Fox provides us with some outstanding examples for ICF coding.

Terry’s memory and good works live on in The Terry Fox Foundation, which sponsors and coordinates thousands of the very popular “Terry Fox Runs” for charitable causes all over Canada and around the world. We thank the Foundation for the following brief description of Terry and his Marathon of Hope, and recommend that readers of this ICF Newsletter can learn more about this remarkable man on the Foundation’s website.

“Terry Fox was born in Winnipeg, Manitoba, and raised in Port Coquitlam, British Columbia, a community near Vancouver on Canada’s west coast. An active teenager involved in many sports, Terry was only 18 years old when he was diagnosed

with osteogenic sarcoma (bone cancer)<sup>1</sup> and forced to have his right leg amputated 15 centimetres (six inches) above the knee in 1977.

While in hospital, Terry was so overcome by the suffering of other cancer patients, many of them young children, that he decided to run across Canada to raise money for cancer research.

He would call his journey the *Marathon of Hope*.

*It was a journey that Canadians never forgot.*

After 18 months and running over 5,000 kilometres (3,107 miles) to prepare, Terry started his run in St. John's, Newfoundland on April 12, 1980, with little fanfare. Although it was difficult to garner attention in the beginning, enthusiasm soon grew, and the money collected along his route began to mount. He ran close to 42 kilometres (26 miles) a day through Canada's Atlantic provinces, Quebec and Ontario.

However, on September 1st, after 143 days and 5,373 kilometres (3,339 miles), Terry was forced to stop running outside of Thunder Bay, Ontario, because cancer had appeared in his lungs.

An entire nation was stunned and saddened. Terry passed away on June 28, 1981 at the age 22.

The heroic Canadian was gone, but his legacy was just beginning. To date, over \$550 million has been raised worldwide for cancer research in Terry's name through the

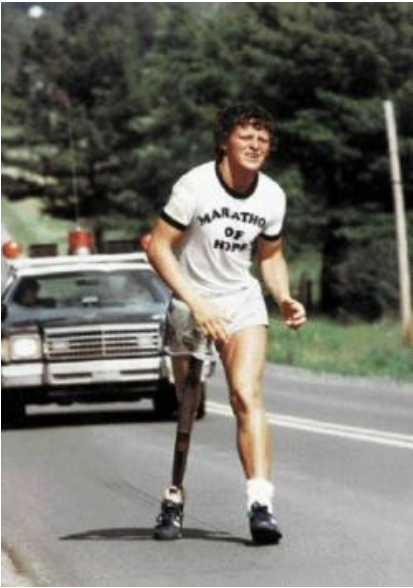
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<sup>1</sup> ICD-10: C40 - C41, Malignant neoplasm of bone and articular cartilage of limbs, and Malignant neoplasm of bone and articular cartilage of other and unspecified sites, possibly at C40.2, (Malignant neoplasm of the) Long bones of lower limb. ICD-9-CM: 170.7, Malignant neoplasm of long bones of lower limb.

annual Terry Fox Run, held across Canada and around the world.”

Source: <http://www.terryfox.org/Foundation/index.html>

Now, let's do some ICF coding, using some photographs of Terry Fox taken during the Marathon of Hope in 1980.



## Body Functions

b455.1                    Exercise tolerance functions; Mild Impairment

## Body Structures

s750.421                Structure of lower extremity; Complete impairment [4]; Partial absence [2]; Right side [1]

## Activities & Participation

d4552.2414             Running; Moderate limitation in performance with assistance [2]; Complete restriction in capacity without assistance [4]; Mild restriction in capacity with assistance [1]; Complete limitation in performance without assistance [4]

## Environmental Factors

e1151+4                Assistive products and technology for personal use in daily living; Complete Facilitator

e5458+3                Civil protection services, systems, and policies, Other specified; Substantial Facilitator.  
Specification: Policies governing the safeguarding of people and property, such as provision of police, fire, emergency and ambulance services, for a special event in which providing such services is essential for the event to be conducted, and which in turn enables the Subject to engage in the Running activity (d4552.2414).

### Description of the Images

We've presented four photographs of Terry Fox engaged in running, during the Marathon of Hope. Terry was very athletic!

Respectfully of Terry's memory, we think that one advantage of using photographs of Terry running the Marathon of Hope to illustrate ICF coding is that Terry is usually demonstrating characteristics from all four domains in the ICF at the same time: Body Functions, Body Structures, Activities & Participation, and Environmental Factors.

For simplicity and saving space here in *Coder's Corner*, we've taken these four photographs together to show typical coding in all four ICF domains, as though we were coding one composite image, rather than four.

The top left photograph shows Terry running uphill on a lonely highway, accompanied by a police automobile escorting him from behind. [This is a copyrighted image.](#)

The top right photograph is also [a copyrighted image](#). It also shows Terry running, alone on a country highway. This photograph really illustrates Terry's determination. We did not choose to use ICF coding to describe a subject's "motivation and drive functions" (e.g., **b130**, Energy and drive functions, **b1301**, Motivation), but this photograph certainly illustrates Terry's "motivation and drive." Terry was relentless in pursuing his goal in the Marathon of Hope. He exhibited "gritty determination."

The bottom left photograph is from the public domain. It was taken in Toronto on July 12, 1980, as Terry's Marathon of Hope entered the traffic in Canada's largest city. In this photo, Terry is running west on Bloor Street East, near the entrance to the Castle Frank Subway Station. This photo gives us our best visual angle to see Terry's right prosthetic leg. By today's standards in prosthetics, it appears fairly rudimentary, suggesting that Terry's running with such athleticism must have been extremely difficult.



The bottom right photograph is [a copyrighted image](#), but we thank the Library and Archives of Canada for providing it for our use in *Coder's Corner*, from its roster of "Canadian Giants." This dramatic photograph shows Terry running along a rough highway, followed by a procession of at least nine automobiles, including police vehicles and other cars driven by onlookers of the Marathon of Hope.

This photograph gives silent testimony about how newsworthy and unifying the Marathon of Hope had been during that summer of 1980. As Terry ran across Canada, many Canadians became involved and wanted to participate as much as possible along with him. In this photo, one car behind Terry bears a sign on top reading "Donations." There is even young boy accompanying everything on his bicycle. If they could not donate money, many served as volunteers who escorted Terry and his team safely on the highway by day, and fed and lodged them in homes at night.

### Justifications for Selecting the ICF Codes

As mentioned, we're coding a composite of these four photographs, because they conveniently refer to all four domains in the ICF.

In Body Functions, we selected **b455.1**, Exercise tolerance functions, Mild impairment, as an overall representation of all the body functions that are operating in any image of Terry Fox running. The exhaustive roster of all such functions would be too large to fit in our *Coder's Corner* segment.

We might ordinarily utilize **b455** to describe exercise tolerance functions associated with cardiac or respiratory functioning. An "exercise tolerance test" is a fundamental diagnostic method in the sciences of kinesiology, pulmonology and cardiology. To our knowledge, Terry Fox did not endure any primary impairments of his cardiac or respiratory functioning, although as his Foundation biographical sketch indicated, by the end of the Marathon of Hope, cancer had spread to Terry's lungs.

Instead, we selected **b455** in a more general context, referring to this elite athlete's ability to tolerate all the conditions affecting any long distance

runner: respiratory, biochemical, and endocrine demands of the high energy-utilizing human body, wide temperature fluctuations even during summer, and fatigue and diminishing endurance. Taken together, we judged Terry's degree of impairment of his overall exercise tolerance functions to be mild, represented by the qualifier digit ".1".

In Body Structures, although in these four images we cannot actually detect the extent of Terry's structural impairment because in each image he is utilizing his prosthetic right leg, we do know that he had a high-thigh amputation. Our next photograph in *Coder's Corner* shows Terry's stump and the location of his right extremity amputation. Based on knowledge about Terry in the public domain, we can describe his amputation in terms of ICF coding using Body Structures code **s750.421**, Structure of lower extremity, Complete impairment, Partial absence, Right side.

Another ICF coder legitimately might have selected the more detailed third-level code **s7500**, Structure of thigh, instead of the second-level code, **s750**, Structure of lower extremity, as the code stem. (Remember, in ICF coding a "second-level code" involves one alphabetic character and 3 digits; a "third-level code" involves one alphabetic character and 4 digits.) In that case, a coder would probably have selected "total absence" [of the thigh, qualifier digit "1"] in the Second Qualifier Position for the "nature of impairment," rather than "partial absence" [of the lower extremity, qualifier digit "2"] as we selected while using second-level code stem **s750**. In both cases, it would be a common judgment that the extent of Terry's body structural impairment had been "complete," represented by "4" in the First Qualifier Position for the "extent of impairment."

In Activities & Participation, we assigned **d4552.2414**, for Running; Moderate limitation in performance with assistance [2]; Complete restriction in capacity without assistance [4]; Mild restriction in capacity with assistance [1]; Complete limitation in performance without assistance [4]. The qualifiers really help us understand the relationship between Terry's assistive prosthetic leg and his ability to utilize his capacity to perform the activities associated with running.

In Environmental Factors, we focused on Terry's prosthetic leg, which we judged to be a Complete Facilitator. The best qualifier-modified code

for the prosthetic leg itself is **e1151+4**, for Assistive products and technology for personal use in daily living; Complete Facilitator.

We also recognized another important Environmental Factor: the fact that in order for Terry to perform the activities of running in the venues associated with The Marathon of Hope, he often needed a police escort or the accompaniment of admirers and supporters from one town to the next. We judged that support, under the short heading “police escort,” to be codeable as an Environmental Factor: **e5458+3**, for Civil protection services, systems, and policies, Other specified; Substantial Facilitator.

## Discussion

Respectfully of Terry and his memory, one of the best parts of an ICF Case Study about Terry Fox is that a few photographs of him during the Marathon of Hope clearly illustrate interactions among all four ICF Domains.

In Body Functions, we can observe Terry’s capacity to exercise and tolerate the energy drain involved with exercise, for up to the time on average to run a marathon every day. Of course, Terry’s energy expenditure was probably even greater than that of a runner with two natural legs: running a marathon with a prosthetic leg requires endurance.

In Body Structures, we observe the influence of Terry’s structural impairment. Not only is it obvious that Terry has experienced an amputation and utilizes a prosthetic leg, Terry also wanted people to see his prosthetic leg, and become comfortable with him and people like him, based on their abilities. We also recognize the several years of survival gain that Terry had because of the original surgery that yielded this structural impairment.

In Activities & Participation, of course, we have the observation of running, which is easily codeable, using A& P code stem **d4552**. We also have the advantage of photographic hindsight to be able to use Terry’s situation in photographs to make judgments about his degrees of capacity

and performance, when assisted by the Environmental Factor of his prosthetic leg.

Finally, in Environmental Factors, we have the advantage of being able to observe Terry's rudimentary prosthetic leg, and make judgments about the degree of facilitation it provides. Of course, considering the enormity of The Marathon of Hope, it was an easy coding decision for the ICF Coder: that prosthetic leg definitely warrants assigning the "+4" qualifier, representing Complete Facilitation.

Let's inspect another famous photograph of Terry in which his Body Structural impairment is a little more visible.



You don't have to do what I did – wait until you lose a leg or get some awful disease – before you can take the time to find out what kind of stuff you are made of. Start now.

## Body Structures

**s750.421**                      **Structure of lower extremity; Complete impairment [4]; Partial absence [2]; Right side [1]**

### Description of the Image

This [famous photograph is a copyrighted image](#). It has been utilized as the centerpiece of an inspirational campaign in support of persons living with cancer. This image is often enlarged to poster-size for inspirational purposes and carried by runners during Terry Fox Runs around the world.

Somewhat starkly, the image shows Terry's stump on his right extremity, clothed for his comfort while he is apparently changing clothes or at least his T-shirt. This image really gives us the idea that Terry was quite an athletic man, even before beginning The Marathon of Hope.

### Justification for Selecting the ICF Code

It is relatively easy to select this qualifier-modified code from the Body Structures Domain: it is the same Body Structures code we selected above, in the composite set of four photographs for Terry while running during The Marathon of Hope. That code is **s750.421**, for Structure of lower extremity; Complete impairment [4]; Partial absence [2]; Right side [1]

The qualifiers really are the ICF Coder's friends in the Body Structures Domain. The extent, magnitude, and location qualifier digits in the Body Structures Domain can generate an ICF summarization of an individual case that is really quite "granular," with a degree of specificity that is clear and helpful for interpretation.

### Discussion

The quote from Terry is in itself very inspirational, but not part of our ICF coding *per se*. "You don't have to do what I did -- wait until you lose a leg or get some awful disease -- before you can take the time to find out what kind of stuff you are made of. Start now." It reflects on Terry's motivation and drive, and well as his deep sense of purpose, which he probably exhibited long before beginning The Marathon of Hope.

Regarding Body Structural coding, some ICF Coders have expressed the opinion that, because some persons' structural impairments such as a stump or an amputation are easily observable, assigning such a "granular" Body Structures code might yield a disservice: making that person more easily identifiable after the necessity for the ICF coding has passed. This is probably a minimal risk, but one of which it is wise to be conscious. Just think, though: Terry's qualifier-modified Body Structures code **s750.421**, (Structure of lower extremity; Complete impairment [4]; Partial absence [2]; Right side [1]) is so specific, so "granular," that if we had access to the recording of that code, technically it would not be difficult to identify Terry Fox secondarily, say, from a medical or rehabilitation record in which that ICF code might appear, simply on the basis of that code's specificity.

In Memoriam



Today, we memorialize Terry Fox around the world, but he is especially remembered in lasting, meaningful ways by Canadians.

This montage of photographs illustrates the depth of feeling that Canadians have justifiably developed for Terry and his memory in the decades since The Marathon of Hope. We won't code these photos, they are simply here at the end of this edition of Coder's Corner to exemplify the importance of Terry Fox in so many peoples' lives, and especially in the national spirit of Canada.



On the upper left, there is a photograph of one of probably dozens of statues of Terry Fox in parks and public squares all around Canada. This bronze statue of Terry includes the inscribed quotation “Somewhere the hurting must stop,” and it is located in [Beacon Hill Park, in Victoria, B.C.](#) The photo in the lower left also shows another statue of Terry Fox, at the famous [Terry Fox Memorial in Thunder Bay, ON.](#)

On the upper right, the photograph is of the Canadian Coast Guard Ship [CCGS Terry Fox](#), a heavy icebreaker deployed to break ice and assist shipping in the Gulf of St. Lawrence, from Newfoundland to Québec including the Cabot Strait, Cape Breton Island, Prince Edward Island and New Brunswick. Of course, icebreakers are extremely important in Canada and for Canadian commerce and fisheries, hence, truly, it is a genuine honor to name an icebreaker after a countryman. In this photograph, the *Terry Fox* is shown departing Halifax Harbor.

In the center of the lower row of photographs is a snapshot of just one of dozens of elementary and secondary schools throughout Canada named for Terry Fox. This photograph represents the [Terry Fox Secondary School in Port Coquitlam, B.C.](#)

Finally, showing the worldwide influence of Terry Fox’s Marathon of Hope, the photograph in the lower right corner is a representative snapshot of one of the thousands of Terry Fox Runs conducted in Canada and around the world to raise funds for cancer research. [This Terry Fox Run occurred in Chennai, India.](#)

This concludes this edition of *Coder’s Corner*. Until next time, ICF Coders, keep on coding!

END OF NEWSLETTER