SYNOPSES OF RECENT CONTRIBUTIONS TO THE ICF LITERATURE

The volume of articles involving the ICF in contemporary journals and books is unprecedented and increasing. NACC is committed to enabling its constituents to stay abreast of ICF developments in the public health literature. This document presents synopses of 14 articles published in disability, social science, public health or epidemiology journals during 2006 and 2007. This roster represents a selective literature review; it is neither exhaustive nor intended to be so. Authors and institutions from many nations are represented, but NACC's selection strategy incorporated special emphasis on contributions involving North American authors.

1) **"Developing Core Sets for Patients with Head and Neck Cancer Based on the International Classification of Functioning, Disability and Health (ICF)."**

2) **"Developing ICF Core Sets for Persons with Sleep Disorders Based on the International Classification of Functioning, Disability and Health."**

3) **"The First World Psoriasis and Psoriatic Arthritis Conference."**

4) **"The Future of Physical and Rehabilitation Medicine as a Medical Specialty in the Era of Evidence-Based Medicine"**

5) **"ICF Core Sets: How to Specify Impairment and Function in Systemic Lupus Erythematosus."**

6) **"Measuring Participation in Children with Disabilities Using the Assessment of Life Habits."**

7) **"Meeting the Criteria of a Nursing Diagnosis Classification: Evaluation of ICNP®, ICF, NANDA and ZEFP."**

8) **"Perceived Environmental Barriers to Recreational, Community, and School Participation for Children and Youth with Physical Disabilities"**

9) **"Population-Based Study of Home Accessibility Features and the Activities of Daily Living: Clinical and Policy Implications."**

10) **"Organizing Future Research and Intervention Efforts on the Impact and Effects of Gender Differences on Disability and Rehabilitation: The Usefulness of the International Classification of Functioning, Disability and Health (ICF)."**

11) **"The Potential of Virtual Reality to Assess Functional Communication in Aphasia."**

12) **"Qualitative Assessment of the International Classification of Functioning, Disability and Health with Respect to the *Desiderata for Controlled Medical Vocabularies*."**

13) **"School-aged Children with SLI: The ICF as a Framework for Collaborative Service Delivery."**

14) **"Two Steps Forward, One Step Back? A Commentary on the Disease-Specific Core Sets of the International Classification of Functioning, Disability and Health (ICF)."**

1) “Developing Core Sets for Patients with Head and Neck Cancer Based on the International Classification of Functioning, Disability and Health (ICF).”

This article had been prepared by a team of German, British and American authors familiar with the ICF, otorhinolaryngology, and the prevalence of head and neck cancers in populations. It is a helpful article for professionals in any field faced with the challenges of developing an ICF Core Set for their specific discipline or type of caseload.

A Core Set should certainly exhibit content validity. But it also should be sensitive enough in the epidemiologic meaning to capture the vast majority, if not the full complement, of patients or clients in a caseload exhibiting a particular limitation for which ICF coding and case-counting would be appropriate or valuable. In this case, in addition to the body structural and functional anomalies that head and neck cancer specialists would conventionally examine, there might be wide-ranging and variably influential factors associated with health-related quality of life among their patients, which need to be included in their Core Set because they certainly affect rehabilitation outcomes. On behalf of their head and neck cancer surgical and medical partners, these authors struggled with just such a Core Set development process, which essentially is a modified Delphi process. They invited participation from readers of this specialty journal, which has an international readership. Any classification task induces clarity, and these authors promoted the ICF-oriented consensus-building process within their profession necessary to develop such a Core Set as valuable in itself. They predicted they would conduct a consensus conference on this subject by decade’s end.

Citation: Tschiesner U, Cieza A, Rogers SN, Piccirillo J, Funk G, Stucki G, Berhaus A. Developing core sets for patients with head and neck cancer based on the International Classification of Functioning, Disability and Health (ICF). *European Archives of Otorhinolaryngology* 2007; 264:1215-1222.

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2) “Developing ICF Core Sets for Persons with Sleep Disorders Based on the International Classification of Functioning, Disability and Health.”

Five continents are represented by the authors and institutions associated with this article, for our purposes including North America: the noted sleep specialist and epidemiologist Professor Antonio Culebras, a neurologist from the Upstate Medical

University in Syracuse, New York, participated as one co-author. They reported on a workshop conducted among experts in Bangkok in February, 2007, laying the foundation for a sleep disorders Core Set. Quality of life parameters are surely part of the ICF-oriented profile of functioning among sleep-disordered persons, which must be captured in this Core Set. Soon, their efforts will require Patient Focus Groups to orient the clinicians' own perspectives on "what matters most" during and as outcomes of sleep therapy. The authors' collective timeline calls for a consensus conference on the final draft of the Core Set by the end of this decade.

This fully international complement of authors and the breadth of specialties represented among them give testimony to the influence of sleep disorders on the health of individuals and populations around the world. Moreover, their collective challenge in preparing an ICF Core Set for sleep disorders represents a tall order simply from the clinical vantage point that many different types of clinicians would observe the manifestations of sleep disorders and their effects on other forms of functioning among their patients, from nurses to pediatricians to general practitioners to psychiatrists and neurologists, among others. Many sleep disorders are masked, with uncertain effects on a person's full functioning, presenting both diagnostic and classification challenges.

Citation: Stucki A, Cieza A, Michel A, Stucki G, Bentley A, Culebras A, Tufik S, Kotchabhakdi N, Tachibana N, Üstün B, Partinen M. Developing ICF core sets for persons with sleep disorders based on the International Classification of Functioning, Disability and Health. Article in Press, Corrected Proof, accepted January 31, 2007, available online July 15, 2007, accessed January 15, 2008, *Sleep Medicine* 2007; Volume 9, doi:10.1016/j.sleep.2007.01.019 .

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3) "The First World Psoriasis and Psoriatic Arthritis Conference."

These American authors provided a Meeting Report from an international meeting on psoriasis and related conditions conducted in Stockholm in June, 2006, which referred to the ICF. They reported that this unique conference attracted nearly 700 dermatologists, rheumatologists, and others, and focused on psoriasis and psoriatic arthritis from clinical, basic research, and health services research perspectives. Pertinently, they reported that the second day of the conference was designed to emphasize Quality of Life associated with psoriasis, and quantitative approaches to measuring QoL among patients living with psoriasis, including utilizing the ICF for case-counting purposes. In fact, one of the article authors, Mease, a rheumatologist, delivered a Poster Session presentation during the conference entitled "The WHO ICF as a Framework for Understanding the Manifestations and Consequences of Psoriasis and

Psoriatic Arthritis.” Both the Meeting Report and Mease’s Poster Session Abstract are available to any reader regardless of journal subscription status.

Citations: Horn E, Gordon K, Mease P. The first world psoriasis and psoriatic arthritis conference. Meeting Report. *Journal of Investigative Dermatology* 2007 (July); 127(7):1566-1567. Available on the World Wide Web at: http://www.nature.com/jid/journal/v127/n7/pdf/5700910a.pdf

Mease P, Taylor WJ. The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) as a Framework for Understanding the Manifestations and Consequences of Psoriasis and Psoriatic Arthritis. Poster Session presentation at the First World Psoriasis and Psoriatic Arthritis Conference, Stockholm, May 31 – June 4, 2006. Abstract available on the World Wide Web at: http://www.nature.com/jid/journal/v127/n7/pdf/5700911a.pdf , specifically at Abstract # 37, page 8 of 25 document pages.

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4) "The Future of Physical Medicine and Rehabilitation Medicine as a Medical Specialty in the Era of Evidence-Based Medicine"

This Clinical Commentary presented by Austrian and German authors has international importance: the contemporary and future practice of Physical Medicine and Rehabilitation (PRM or PM&R) will be influenced by the ICF, simply because of the corollary demands and constraints on PM&R practitioners to render their medical specialty more evidence-based, particularly in relation to longer-term patient management issues and measuring outcomes. In fact, the authors contend that the fate of their specialty might depend on its ability to render itself more evidence-based, using tools like the ICF. These authors advocated for developing a PM&R workforce, among both physicians and allied health practitioners in the field, more cognizant of the ICF and its relationship to "comprehensive assessment" and whole-person case management, and to promote the use of ICF in supporting evidence-based outcomes measurement.

In support of enhancing "ICF-awareness" among members of the PM&R labor force, the authors applauded the work contributed by Professor Gerold Stucki, who had "published promising concepts that aim at developing a scientific workforce intended to promote human functioning and rehabilitation research. . . . Such concepts are based on both the framework of the ICF and a mutually rewarding, multidisciplinary relationship between MD and non-MD rehabilitation scientists" (pg. 2).

Citation: Ebenbichler G, Kerschan-Schindl K, Brockow T, Resch KL. The future of physical and rehabilitation medicine as a medical specialty in the era of evidence-based medicine. *American Journal of Physical Medicine & Rehabilitation* 2008 (January); 87(1):1-3.

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5) "ICF Core Sets: How to Specify Impairment and Function in Systemic Lupus Erythematosus."

A team of authors from German, Austrian and American medical centers contributed to this expansion of the already-robust literature on ICF Core Sets. In this case, they have developed a preliminary Core Set pertaining to systemic lupus erythematosus (SLE) and the degree of activity limitation associated with a slate of SLE symptoms. This article presents their consensus methodological approach toward the development of such an ICF Core Set. The large majority of selected ICF codes have been derived from the Body Functions and Structures domains; very few pertain to Contextual Factors associated with experiencing lupus on a daily basis. They anticipate developing separate "Brief" and "Comprehensive" Core Sets.

Citation: Aringer M, Stamm TA, Pisetsky DS, Yarboro CH, Cieza A, Smolen JS, Stucki G. ICF core sets: How to specify impairment and function in systemic lupus erythematosus. *Lupus* 2006 (April); 15(4):248-253.

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6) "Measuring Participation in Children with Disabilities Using the Assessment of Life Habits."

These Canadian authors, affiliated with the Rehabilitation Institute of Québec and the Center for Interdisciplinary Research in Rehabilitation and Social Integration at Laval University, investigated the psychometric properties of an adapted version of an assessment instrument called the "Assessment of Life Habits" (LIFE-H) scale. Pertinently, the LIFE-H had been designed in the 1990s "to assess the quality of participation on the 12 dimensions of the DCP [Disability Creation Process]" (pg. 666). The DCP had operationalized social participation according to the concept of "life habits." The authors adapted the adult LIFE-H and conducted this investigation of its properties so that it could be administered among children with disabilities between 5 and 13 yeas of age. They found that the LIFE-H "demonstrated moderate to excellent intra- and interrater reliability" (pg. 670). The LIFE-H also exhibited higher levels of convergent validity than more familiar instruments for assessing functional independence in children (e.g., PEDI and WeeFIM), on dimensions reflecting constructs associated with participation rather than functional independence *per se*.

Pertaining to the ICF, the authors wrote "Given that the ICF is relatively new, it is currently difficult to find tools that fit perfectly with its participation dimensions but LIFE-H seems to cover most of them and assesses an important construct of participation . . . without overlapping with an *activity* measure [italics included]. The ability to make this differentiation when measuring the ICF dimensions has been reported as an essential means to achieve general acceptance [of the ICF; referenced Jette, Haley and Kooyoomjian, 2003]. Moreover, an independent measure for each ICF dimension is crucial if studies are to be conducted to identify potential variables [and] constructs that contribute towards explaining the variance in participation levels observed among children with disabilities" (pg. 670).

Citation: Noreau L, Lepage C, Boissiere L, Picard R, Fougeyrollas P, Mathiew J, Desmarais G, Nadeau L. Measuring participation in children with disabilities using the Assessment of Life Habits. *Developmental Medicine and Child Neurology* 2007 (September); 49(9):666-671.

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7) **“Meeting the Criteria of a Nursing Diagnosis Classification: Evaluation of ICNP®, ICF, NANDA and ZEFP.”**

The research reported in this publication had been conducted among Swiss, Dutch and American investigators. The purpose of the study was “to identify criteria for nursing diagnosis classifications and to assess how these criteria are met by different classifications” (pg. 702). The slate of four comparative classifications they selected included the Beta 2 version of International Classification of Nursing Practice (ICNP, a product of the International Council of Nurses, which is a federation of national nursing associations based in Geneva); the ICF; the International Nursing Diagnosis Classification (NANDA, the contemporary adaptation of the terminology originally compiled by the North American Nursing Diagnosis Association); and the Nursing Diagnostic System of the Center for Nursing Development and Research at University Hospital of Zurich (ZEFP, an acronym derived from the Center’s German name, the “Zentrum flir Entwicklung and Forschung” and its system of nursing diagnoses currently used by many hospitals in German-speaking Switzerland. The authors convened a panel of Swiss nursing experts. They concluded that “NANDA should be recommended for nursing practice and electronic nursing documentation” (pg. 702). Within a roster of 17 selected “criteria for classifications of nursing diagnoses” in two broad categories of “Validity” and “Reliability and Applicability” criteria in an Assessment Matrix they presented as Table 1 (pg. 706), the authors judged the ICF to have “well-fulfilled” one criterion, “partially fulfilled” another 4 criteria, but to have “not fulfilled” their remaining 12 criteria. They cited *a priori* limitations associated with each classification that might have rendered these criteria difficult to achieve by any classification.

Citation: Müller-Staub M, Lavin MA, Needham I, van Achterberg T. Meeting the criteria of a nursing diagnosis classification: Evaluation of ICNP®, ICF, NANDA and ZEFP.” *International Journal of Nursing Studies* 2007 (July); 44(5):702-713.

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8) "Perceived Environmental Barriers to Recreational, Community, and School Participation for Children with Physical Disabilities"

These Canadian investigators, supported by research funding from the U.S. National Institutes of Health, utilized the Craig Hospital Inventory of Environmental Factors (CHIEF) to describe parents' perceptions about the environmental barriers their children face in their own everyday settings, such as recreational and school settings. The CHIEF is fundamentally based in the ICF conceptual model. Many researchers have contributed to the body of literature on validating measurements of environmental factors; this quantitative article utilized the CHIEF for that purpose, with specific reference to the new ICF-CY. It represents an important study because of the size of the sample: 427 parent-child pairs, stratified in three age cohorts and roughly equivalent among disabled boys and girls; no interventions were conducted.

One important conclusion drawn by these investigators from the CanChild Centre for Childhood Disability Research was that "Perceived environmental barriers increased with [a child's] age. Such changes occur as children move into adolescence and . . . also reflect changes in the school environment at that time, with the introduction of rotary classes and higher expectations for independent participation. With less involvement or presence of parents to mediate environmental barriers, the perceived influence of environmental factors increases" (pg. 1640).

Citation: Law M, Petrenchik T, King G, Hurley P. Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation* 2007 (December); 88:1636-1642.

Contact the Corresponding Author: Mary Law, PhD, CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada, E-Mail address: lawm@mcmaster.ca . Please note that the journal article indicates "Reprints are not available from the author."

9) "Population-Based Study of Home Accessibility Features and the Activities of Daily Living: Clinical and Policy Implications."

These American authors sought to test a new biopsychoecological model they referred to as "Health Environmental Integration" (HEI) by "showing associations between the perception of unmet need for home accessibility features and the experience of Activities of Daily Living (ADL) difficulties" (page 1165). The authors hypothesized that "ADL difficulties arise, in part, through interactions between physical limitations and the physical environment. . . . Depending on the presence of environmental barriers or the absence of facilitators, these physical limitations will reach a threshold where the performance of more complex purposeful activities, including the ADLs or IADLs, is blocked through *life space restriction*" (pg. 1166, italics added). Their data source had been the 1994-95 National Health Interview Survey Disability Followback Survey. The outcome measures included self-reported difficulty or inability dressing, eating, getting in and out of chairs, and using the bathroom. They concluded that "the perception of unmet needs for accessibility features in the home among community-dwelling adults with physical limitations was statistically and substantively associated with an increased likelihood of ADL difficulty" (pg. 1172).

Citation: Stineman MG, Ross RN, Maislin G, Gray D. Population-based study of home accessibility features and the activities of daily living: Clinical and policy implications. *Disability and Rehabilitation* 2007 (August); 29(15):1165-1175.

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10) "Organizing Future Research and Intervention Efforts on the Impact and Effects of Gender Differences on Disability and Rehabilitation: The Usefulness of the International Classification of Functioning, Disability and Health (ICF)."

Two American authors have encouraged more dialogue on the development and understanding of Personal Factors, which with Environmental Factors are considered to comprise the full complement of ICF "Contextual Factors." This Commentary serves as a preface to a special issue of this journal devoted to the contemporary emotional and social aspects of having a disability and being female. The authors argued that "the personal meaning a disability has for a woman is shaped largely by Personal Factors" (pg. 161). Moreover, they have presented an innovative Venn diagram (Figure 1) juxtaposing the Body Functions and Structures, and Activities and Participation domains, in a larger circle representing the broad range of Contextual Factors, of which Gender, a Personal Factor, is considered very important. Clinically, they advocate for "emphasizing achievements in Activities and Participation" rather than focusing on negative emotions among women with disabilities susceptible to or diagnosed with depression.

Citation: Scherer MJ, Dicowden MA. Organizing future research and intervention efforts on the impact and effects of gender differences on disability and rehabilitation: The usefulness of the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 2008; 30(3):161-165.

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11) "The Potential of Virtual Reality to Assess Functional Communication in Aphasia."

In this exploratory article, four Canadian speech-language pathologists (SLPs) relied upon the ICF conceptual model to construct a theoretical justification for utilizing various computer-generated images and technologies ("virtual reality," VR) in lieu of person-generated vignettes or role-playing activities, which are some of the conventional tools used by SLPs to assess the degree of "communication effectiveness" exhibited by persons with aphasia. The authors analogized prospective VR therapeutic activities with conventional activities that SLPs conduct today using such instruments as the "Communicative Abilities of Daily Living" test, which can be used to assess functioning in everyday language activities. They asserted that utilizing VR in clinical settings induces a therapeutic "social presence" for the person with aphasia, and that "this level of artificial encounter with a virtual human could provide . . . SLPs with some information on the user's ability to interact in communicative contexts" (pg. 276). The authors acknowledged both the ICF and the "Disability Creation Process" (DCP) model put forth by Fougeyrollas and others, as conceptual models of functioning that incorporate environmental factors affecting the functional status of persons with aphasia. In this mixed model, "interaction" among environmental factors and the person might be more influential than the factors themselves. The authors adapted the schematic model of the DCP to incorporate environmental factors elicited by either physical or virtual humans.

Citation: Garcia LJ, Rebolledo M, Metthé L, Lefebvre R. The potential of virtual reality to assess functional communication in aphasia. *Topics in Language Disorders* 2007 (July/September); 27(3):272-288.

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12) “Qualitative Assessment of the International Classification of Functioning, Disability and Health with Respect to the *Desiderata for Controlled Medical Vocabularies*.”

These American authors have evaluated the ICF for its capacity to match an existing 1998 benchmark document entitled “Desiderata for Controlled Medical Vocabularies.” They determined that the ICF satisfies 5 of the 12 *desiderata*, 5 others were not satisfied, and 2 points could not be evaluated. They asserted “The ICF is a rich source of relevant terms, concepts, and relationships, but it was not developed in consideration of requirements for formal terminologies.” They propose the ICF could serve as the foundation for a forthcoming terminology of functioning and disability, but currently does not meet their criteria for such a terminology. The 5 *desiderata* for which the ICF was judged satisfactory included "comprehensive and complete content," "concept orientation" (each concept has a single, coherent meaning), "multiple granularities," and "recognize[d] redundancy." One *desideratum* is referred to as "Evolve gracefully," referring to the evolution of a medical vocabulary, for which the judgment on the ICF was "Cannot yet be evaluated" (pg. 389-90).

Citation: Bales ME, Kukafka R, Burkhardt A, Friedman C. Qualitative assessment of the International Classification of Functioning, Disability and Health with respect to the *Desiderata for controlled medical vocabularies*. *International Journal of Medical Informatics* 2006 (May); 75(5):384-395.

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13) “School-aged Children with SLI: The ICF as a Framework for Collaborative Service Delivery.”

These Canadian Speech-Language Pathologists have authored a practice-oriented paper for professionals treating children with "specific language impairment," a form of language impairment that manifests in the absence of corollary hearing impairment or other anticipated neurological damage or cognitive delays. They explained that "the use of the word 'specific' suggests that these children's problems are restricted to language," but that that distinction is harder to maintain in contemporary practice, because children's cases often blur across diagnostic delineators. Nevertheless, in school settings, where a child's functioning might be judged more important than diagnostic information, among service providers or clinicians, the problems accurately ascertaining cases of SLI are rendered more difficult by a lack of service coordination. These authors proposed utilizing the ICF framework as the rubric for enhancing cross-disciplinary communications. They wrote that "the ICF can be used to organize coherently the broad array of disabilities that are associated with SLI, including those that are unique to SLI and those that are common across different developmental disorders" (pg. 530).

Citation: Campbell WN, Skarakis-Doyle E. School-aged children with SLI: The ICF as a framework for collaborative service delivery. *Journal of Communication Disorders* 2007; 40:513-535.

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14) "Two Steps Forward, One Step Back? A Commentary on the Disease-Specific Core Sets of the International Classification of Functioning, Disability and Health (ICF)."

Two British authors have provided an important Clinical Commentary that strikes at the heart of many practical applications of the ICF. They wrote that "the objective of this paper is to stimulate thought and discussion about the place of ICF core sets in rehabilitation practice" (pg. 1475). Their first observation is that disease-specific Core Sets probably render an important degree of "user-friendliness" to the ICF for and among its most likely users, thereby taking "two steps forward." On the other hand, generating any adaptation of the ICF that is fundamentally focused on classification according to disease category might represent "one step back" toward adherence to a model of disablement stemming only from diagnosis, rather than functional status. They have framed the debate, and encourage continuing scientific dialogue on these points. They concluded "In order to enhance the uptake of the ICF in practice, further research needs to be carried out to map its component parts to existing measures, whilst not losing the holistic nature of the ICF" (pg. 1477).

Citation: McIntyre A, Tempest S. Two steps forward, one step back? A commentary on the disease-specific core sets of the International Classification of

Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 2007 (September); 29(18):1475-1479.

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