

SPOTLIGHT ON DR. JOHN HOUGH

Each month we “spotlight” someone who has made a difference with the ICF. This month we focus on Dr. John Hough, who joined the Classifications and Public Health Data Standards staff under Marjorie Greenberg within CDC’s National Center on Health Statistics in October, 2005. John says: “If the *Spotlight* is designed to describe someone who has made a difference with the ICF, at this stage I can’t honestly say I’ve done much more than simply learn about the ICF, hopefully to become one of its most proficient advocates for justifiable application. Due humility is warranted. Nevertheless I’m privileged to have joined the NCHS Classifications and Public Health Data Standards Section, and this community of researchers, so as to be able to contribute more thoroughly to the development and dissemination of the ICF. As evidenced by my testimony, personal interaction and intervention have provided me with my fundamental understanding of our disability topics. I’m hoping to return the favors by providing the same kind of interaction within this growing community of investigators, and hopefully to participate in broadening this ICF ‘Big Tent’ even more.”

John is an epidemiologist who started his career in Public Health in 1984. “I’d have to say that my earliest considerations about disability in our families or in society arose during my childhood, when my maternal grandmother, an amputee as a result of diabetes, annually visited my family in Florida, and my dad would re-build a truly homemade wooden wheelchair ramp to accommodate her entry and exit from our home. It was a perfect system --- until she needed to accompany us to the supermarket, our church, or elsewhere. I recall many of our family outings being short-circuited because of our collective inability to overcome what today we would call ‘environmental barriers.’ Even though I know she meant it humorously, each time such an impediment arose, my grandmother would say something to the effect of ‘I guess they just don’t want me in there,’ which to a child in a formative period really suggested that, indeed, there were some people or places that really didn’t want disabled people to come and participate.”

“I would attribute my academic and professional interests in disability policy to three of my earliest professors at the University of California, Berkeley, School of Public Health, where I earned the Master of Public Health degree in 1984. All three are deceased now, but I want to honor them here by name: William H. Bruvold, Ph.D., M.P.H.; Frank Falkner, M.D., F.R.C.P.; and Octavio I. Romano, Ph.D.. Each of them either had a visible disability or a child with a disability. In one lesson or another, in the classroom, their faculty offices, or out in the field conducting Behavioral Science research, in retrospect I can remember many distinct lessons about disability. Once, within the rubric of a course on Evaluation Research Methods, Professor Bruvold engineered a field experiment among myself and a half-dozen other M.P.H. students at an inner city San Francisco high school, in which we were to use a Likert-scaled instrument entitled the ‘Attitudes Toward Disabled Persons Scale’ to measure whether high school students’

perceptions about disability might change after viewing a short movie about accommodation and physical barriers. Not unexpectedly, the experiment yielded no effect. Nevertheless it was a valuable experiment from the viewpoint of learning about pre- and post-test evaluation methods. But in the subsequent classroom session, Professor Bruvold said these quite memorable (though paraphrased) words: ‘Sometimes it’s the attitudes about a person with a disability, rather than the disability itself, that makes the situation worse for that person.’ That remark certainly stayed with me. Similarly, Professor Romano wrote and lectured about the somewhat philosophical theme that chronic illness or disability renders our humanity with a kind of cleansing or cathartic understanding, that even though harsh, illness should be welcomed and appreciated, and rather than avoided *per se*, illness could be seen as a necessary, desirable component of the human condition. This theme isn’t too different from that more publicly asserted by Susan Sontag in her famous book Illness As Metaphor. These ideas from faculty members surely influenced my thinking, especially in Berkeley at that time, the birthplace of the Independent Living Movement, where I met many disabled friends and from which I began to understand disability and disability policy in uniquely political economic terms.”

“My interests in disease classification arose, strangely enough, from first-hand experience with *procedure coding*, of all things! My first employment in Public Health was as a survey researcher with the California Medical Association (CMA) in San Francisco, and I landed in a position that involved the long-term revision of a seminal CMA publication entitled the California Standard Nomenclature, the CSN, which historically had been the forerunner of today’s Current Procedural Terminology (CPT) series published originally by the American Medical Association. Working with CMA physicians for nearly two years, we updated and revised the CSN, which really gave me appreciation for the breadth, exhaustiveness, and authoritativeness that are essential in procedural nomenclatures, and by analogy, in disease or disability taxonomies. I regret to report, though, that all our work on the CSN was for naught: one by one, California health insurers adopted the machine-readable CPT to align themselves with insurers nationwide, such that the CSN now resides firmly on the dustbin of history!”

After a stint as a hospital Quality Assurance Director, I returned for doctoral studies in Epidemiology and Health Policy, again at the U.C. Berkeley School of Public Health. I’m proud that my field residency experiences exposed me to working both for CDC and in health policy development settings: I served as an Association of Schools of Public Health summer intern at CDC’s NIOSH in Cincinnati, and later for a full year as a California Assembly Fellow, working as a legislative analyst for both an Assembly and the Assembly Health Committee in the lower house of the California Legislature. I earned the Doctor of Public Health degree at Berkeley, and in 1996 began a two-year post-doctoral fellowship in CDC’s Prevention Effectiveness program, through which I was assigned to the then-named Disability and Health Program, now organizationally located in CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD).”

“It wasn’t long before I met and enjoyed Drs. Don Lollar, Joe Hollowell, Mike Adams, and the late Pierre Decoufflé, all of whom contributed as CDC pioneers to the revision of the ICIDH-2 during the 1990s. I owe each of these outstanding professionals a debt of gratitude for taking the time to shepherd me into these fields, to which I had obviously had some fundamental exposure but not yet in the context of the importance of what would become the ICF. (We might all agree that it’s hard to learn about disability classification or the ICF on one’s own or simply by reading about it: having a set of personal invitations to consider these weighty topics made all the difference for me.) As a Health Scientist at NCBDDD, I was honored to be able to serve some of the most prolific contributors to the disability field, through CDC’s extramural funding program to state health departments and universities related to health promotion among populations with disabilities. Beyond Atlanta, I count myself fortunate to have been exposed to the contributions to the ICF rendered by our former NCHS colleagues Dr. Gerry Hendershot and Dr. Paul Placek (whose position I filled), and by our many academic and WHO partners, including Drs. Rune Simeonsson, Gale Whiteneck, David Gray, and Bedirhan Üstun, all of whom have had important influences on my understanding of the ICF and, perhaps more importantly, its rightful place alongside the ICD within our compendium of tools that accurately classify health-related conditions.”

Between 2002 and 2005, I served as a Health Science Administrator within the National Institutes of Health (NIH), National Institute on Alcohol Abuse and Alcoholism (NIAAA) in Bethesda, Maryland, first in its Health Services Research Branch and then in its Division of Epidemiology and Prevention Research. In that capacity, I worked as a Project Officer on a large portfolio of NIAAA extramural research grants and clinical trials, although none had anything to do with the ICF or disability classification. For enabling me to retain some currency in the ICF topics during that period, I have to applaud all our colleagues who have contributed to the development of this ICF Clearinghouse and its Newsletter, including Drs. Placek and Gray, Patricia Welch Saleeby at Washington University, Jan Valluzzi, Linda Washington, and Marjorie Greenberg at CDC, and others, all of whom have helped to generate this community of ICF researchers, under a ‘Big Tent’ large enough even to include wayward epidemiologists at NIH! I can attest that this Newsletter is worth waiting for, and provides an enormously valuable service during these early years of ICF implementation.”