In Memoriam: An Appreciation of Stephen M. Haley, PT, PhD, FAPTA

STEPHEN M. HALEY, Professor of Health Policy and Management and Associate Director of the Health & Disability Research Institute at Boston University’s School of Public Health, died on July 16, 2011 after a long battle with a debilitating illness. Dr. Haley had a remarkable career as a pediatric physical therapist, researcher, educator, and mentor.

A native of Ohio, Dr. Haley received his BS in Psychology and Certificate in Physical Therapy from Ohio State University, becoming a fervent and life-long Buckeyes football fan. He received a MS in Education from the University of Kentucky and a PhD in Educational Psychology from the University of Washington.

From 1983 to 1986, Dr. Haley was Assistant Professor of Physical Therapy at Boston University’s Sargent College of Health & Rehabilitation Sciences where he returned from 1996 to 200 to serve as the college’s first Associate Dean for Research. In that capacity, he played a leading role in creating a research infrastructure that supported a major expansion of the faculty’s research and cofounded the college’s Center for Rehabilitation Effectiveness, which he directed from 1997 to 2004. In 1999, Dr. Haley collaborated with colleagues at CARF International to develop an international professional education course called Transforming Outcomes Data into Management Information. This 3-day course has been offered twice yearly and has attracted a large international, multidisciplinary audience. Dr. Haley’s desire to share his expertise combined with his wit and humor were critical to the ongoing success of the course.

In the late 1980s and early 1990s, Dr. Haley was a researcher in the Medical Rehabilitation Research & Training Center on Rehabilitation and Childhood Trauma and was Research Associate Professor in the Department of Rehabilitation Medicine at Tufts University School of Medicine. There he led a team that developed the Pediatric Evaluation of Disability Inventory (PEDI), a clinical and research assessment instrument, first published in 1991, that has become the preferred measure used worldwide to evaluate the functioning of children with disabilities. Prior to the PEDI, most pediatric assessments were guided by a developmental model that focused on the extent to which children with disabilities did or did not attain motor, cognitive, and social developmental milestones at the expected age. The PEDI changed pediatric measurement by providing rehabilitation specialists a way to measure functional abilities in children and to track their progress over time. An innovation of the original PEDI was the use of the Rasch item response theory methods for item scaling that eventually became the standard for other pediatric outcome measures. From 2004 to 2009, Dr. Haley was awarded a prestigious K02 Independent Scientist Award from the National Center for Medical Rehabilitation Research/National Institutes of Health to further develop his capacity to design and deliver computer adaptive test (CAT) applications for the assessment of functional status. During this period, Dr. Haley and colleagues applied these methodologies to create a CAT version of the PEDI instrument (PEDI-CAT), which is being disseminated worldwide. This newer PEDI-CAT provides rehabilitation professionals with a more efficient way of assessing functional abilities in children and youth from birth to 21 years.

As Research Associate at The Health Institute at New England Medical Center in 1992 to 1993, Dr. Haley led a team of researchers that published groundbreaking articles examining the hierarchical structure, unidimensionality, and reproducibility of items included within the Medical Outcomes Study 36-Item Short-Form Health Survey health-related quality of life scales, using Rasch item theory response methodology. This methodology has since become the standard in the rehabilitation field for constructing and evaluating health outcome instruments.

From 1999 to 2004, as Director of Research in the Rehabilitation Research & Training Center for Measuring Rehabilitation Outcomes at Boston University, Dr. Haley and colleagues pioneered the innovative combination of IRT and CAT methodologies to create the Activity Measure for Post-Acute Care (AM-PAC). The CAT version of the AM-PAC (AM-PAC-CAT) instrument, which has been translated in over 20 languages, is the first functional outcome instrument designed to assess patient outcomes across an entire episode of postacute care, regardless of the setting where care is received. Using the AM-PAC, Dr. Haley and colleagues published innovative re-
search illustrating how IRT methods could be employed to replenish CAT assessment instruments and how to create functional stages to assist in the interpretation of quantitative outcome scores.

In 1998, Dr. Haley began serving as the Director of Research at the Franciscan Hospital for Children, a pediatric rehabilitation hospital located in Boston, MA. Dr. Haley hoped to link the efforts and expertise of academic researchers with clinicians to promote advances in rehabilitative care for children with disabilities. For 13 years, Dr. Haley guided clinicians and researchers in developing competitive grant proposals to support the work of Franciscan’s Research Center for Children with Special Health Care Needs. He worked with staff to develop intervention studies in the areas of physical fitness and aquatic physical therapy and to develop outcome studies in the area of inpatient rehabilitation, primarily for children with brain injuries. He instructed the hospital staff in effective ways to measure outcomes for individual patients as well as for overall hospital programs and was instrumental in the creation of the Specialized Pediatric Applied Research Collaborative, a multisite clinical research consortium of postacute pediatric rehabilitation hospitals created to respond to the need to establish clinical outcome data for the development of program standards, monitor and improve quality of care, and communicate realistic expectations to children and families.

For over a decade, Dr. Haley worked with colleagues at the Shriners Hospitals for Children on developing and testing CAT platforms for physical functioning, activity, and participation. As a result of this collaboration, 10 large item banks have been developed and calibrated on children and parents with cerebral palsy, spinal cord injury, and birth brachial plexus injuries. At the time of Dr. Haley’s death, work was just completed on calibrating the items on over 200 idea typically developing children and their parents. The influence of Dr. Haley’s work on the Shriners Hospitals for Children is only in its infancy. His legacy will live on permanently as the studies he co-led will continue to completion and new studies, which he helped design, will be implemented. Collectively, Dr. Haley’s work will create a complete transformation in the method in which the Shriners Organization will be able to monitor outcomes across their 22 hospitals and will provide Shriners and other pediatric health care centers with a robust and efficient system to measure important outcomes from the perspectives of children and their parents.

As Dr. Mulcahey, Director Rehabilitation Services and Clinical Research at Shriners Hospitals For Children noted, “while Steve’s intellectual and academic contributions to Shriners Hospitals for Children have been pivotal and transformational, it was Steve’s unique personality, unforgettable wit, unassuming sarcasm, and love for meaningful relationships that will forever be remembered. Frequently during serious and difficult discussions about funding, enrollment targets, and research timelines, Steve would interject simple but quite sarcastic or witty comments that lightened the conversation and rebalanced emotions; frequently, sarcastic comments about a Boston sports team would be offered, particularly during times when Philadelphia teams were on top. Steve’s mentorship for many research staff within the Shriners organization will be sorely missed but it is the gift of friendship and professional partner that Steve gave so compassionately that is an irreplaceable loss and that will be remembered most.”

Dr. Dave Cella, Professor and Chair of the Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, summarized Dr. Haley’s impact on the field of outcome measurement as follows: “the past 2 decades have been transformative in the patient-reported outcomes (PRO) measurement field. The 2 most important advances in PRO measurement since 1990 have been the introduction and application of item response theory into health measurement, and the production of accessible, interpretable instrumentation for the end-user who doesn’t specialize in PRO measurement. Steve Haley has been a true leader in both of these areas. Always ahead of the pack, Steve was writing about IRT measurement and developing practical applications for rehabilitation settings in both pediatric and adult settings. Steve was modest about his accomplishments. He was not a showman, but those of us who read his work saw that he was out in front of so many others, scientifically and practically. Conversations with Steve never went very far before he was making it clear that his passion was about helping people make the best of their lives as they live with chronic illness or disability. Steve did the very same thing with his own illness. The article written by Steve in this very issue is an example of his leadership, which we will miss. This paper, linking Neuro-QOL, AM-PAC, and PROMIS, is one of the first such linking papers published in health outcomes, and the first one published linking these 3 conceptually related works. Again, out in front.”

Throughout his career, Dr. Haley was a teacher and mentor to many doctoral, postdoctoral, and junior investigators. He was a gifted speaker and highly skilled teacher who generously shared his knowledge with his students. His passion for improving the lives of children with disabilities by improving the quality of rehabilitation research was an inspiration to the students and mentees who worked with him. Dr. Haley received numerous awards for his research and scholarship including, in 1993, the Golden Pen Award for contributions to the Physical Therapy Journal and, in 2006, the Helen Hislop Award for Outstanding Contributions to the Professional Literature in Physical Therapy. In 2009, he was elected as a Catherine Worthingham Fellow of the American Physical Therapy Association.

Dr. Haley is survived by his wife, Karen Paterson Haley, of Reading, MA; his daughter Emily Marino Larsen, her husband Jason Larsen, and their daughter, Abigail Mary Larsen of Bothell, WA; his daughter Bethany Marino Haley of Reading, MA; his stepchildren W. Tyler Paterson of Chicago, IL, and Jessica Paterson of Reading, MA; his sister Mary Flores of Roselle, IL; and his nephews, Tony and Tom Flores of Roselle, IL.

Dr. Haley was a world-renowned innovator in pediatric and adult outcome measurement. As Dr. Scott Ward, President of the American Physical Therapy Profession, affirmed, “our profession has lost a great thinker, mentor, pioneer, and friend.”

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