David B. Gray was a professor, a researcher and a public official who shaped the landscape of disability research and U.S. healthcare policy. He also was paralyzed and used a wheelchair, but that only made him a more persuasive force in his efforts to make the world a more accessible place for people with disabilities.

Gray, Ph.D., believed that people, no matter their injuries or physical limitations, could do or achieve anything they wanted if the environment didn’t stop them or slow them down. His life was a testament to that, say his colleagues around the country.

Gray, who spent two decades teaching and conducting research at Washington University in St. Louis, was still working when he died of a heart attack Feb. 12 at the age of 71.

“He knew what the issues were. He knew what the issues were. He knew what the issues were.”

Finally, we honor and remember our dear friend, Dr. David Gray, who died this year. We are happy to have worked alongside him, sharing the passion and significance of his life’s work.

For more information about our projects and educational opportunities, please visit our webpage at www.ric.org/cror. And don’t forget to “like” us on Facebook!

Allen Heinemann, Director
Neal Michalik: Working With Children is His Calling

Neal Michalik found his calling on the pediatric floor of the Rehabilitation Institute of Chicago. While a graduate student studying Disability and Human Development at the University of Illinois at Chicago, he worked as a rehab aide at the renowned rehabilitation hospital on Chicago’s North Side in the mid-2000s. There, he was an extra set of hands for RIC’s occupational and physical therapists. Frequently, though, Michalik found himself distracting children and cheering them up during the often draining therapy sessions when recovering from a serious injury.

“A child with a spinal cord injury would work on tolerating standing. He would be put in a standing frame and I would play cards or video games with him,” Michalik said. “It was the daily challenge of engaging kids in their therapy sessions. You have to be creative and sometimes firm with adolescents. You have to say, ‘No, you can’t go back to sleep. You have to get out of bed—we’re doing this today.’

Michalik spent two years as a pediatric aide before moving on to other positions at RIC, but that first job convinced Michalik he wanted to work directly with people, not with hardware such as wheelchairs and communication devices. These days, he works as the business support manager at the Center for Rehabilitation Outcomes Research (CROR) at RIC while going to nursing school at night and on weekends. He is part of an accelerated 18-month program at Resurrection University in Chicago and will finish his Bachelor of Science in Nursing degree in December.

The 33-year-old had considered becoming a high school math teacher as a way to return to working with children but the Chicago teachers’ strike of 2012 and directive advice from a RIC executive caused him to change paths. “My boss, Pat Murphy, said, ‘Nurses get to teach, too.’ She frequently reiterated the various roles that nurses fulfill outside of the clinical role. She had mentioned a few times that she thought I would be a good nurse.”

Patricia Murphy, Associate Chief Nurse at RIC, says Michalik’s intelligence and understated demeanor makes him a natural for the evolving field of nursing. “He is very quiet and soft spoken. He has a terrific sense of humor. I saw in him a kindness and quiet presence. You know if you were a patient you would find him extremely supportive.”

By choosing nursing as a career, Michalik is following in his mother’s footsteps. While raising her family in the Jefferson Park neighborhood of Chicago, Michalik’s mother renewed her nursing license and went back to work as a nurse; his father worked in sales and warehouse management. Nearly a quarter of a century later, his mother retired from the job she loved and she passed the proverbial torch to Michalik by way of her stethoscope.

Between his job and school, Michalik doesn’t have much time for fun—except when it comes to his wife and two dogs, Lenny and Jimbo, German Shepherd/Pit Bull Terrier mixes. The 60-pound puppies are in training to become certified therapy dogs so that they can visit people at libraries, hospitals, and schools. They are learning behaviors such as “bowling” by knocking over pins with their noses or just sitting still while a child reads them a book. There’s a cup game where the dogs find the hidden treat. “It’s little ways to trick children into learning,” Michalik said. Michalik and his wife are also being trained so they can become the dogs’ certified handlers. Once they have all graduated, they will be able to sign up for visits to hospitals and other settings that have requested visits by therapy dogs.

These visits also will have a larger purpose, he believes: changing society’s negative misperceptions of pit bulls as vicious dogs that can’t be trusted around people. “I feel like an advocate for these dogs. I would never want to own any other breed.”
Noelle Carlozzi

Noelle Carlozzi was exasperated when her Long Island, N.Y., high school required her class to take a career aptitude test. Carlozzi already knew she wanted to be a psychologist so she didn’t see the point. The test itself irked her even more. Which did she like more—hamburgers or hotdogs? How could a question like that reflect on a career choice, she wondered. When the same question came up later but reversed—hotdogs or hamburgers—she decided to rebel. Every time a redundant question came up, she answered inconsistently. The school’s guidance counselors were flummoxed by her results. “Because I had contradicted myself so many times, they couldn’t get a valid measure,” she remembers. “I was very proud of myself.”

Carlozzi, Ph.D., now knows the irritating questions were validity items designed to assess whether test takers were being consistent in their answers. Ironically, perhaps, she has ended up devoting her career to improving measurement instruments for people with a range of disabilities and diseases. And in doing so, she has found a way to combine her interest in psychology and neuroscience as a researcher and associate professor in the University of Michigan’s Department of Physical Medicine and Rehabilitation. Carlozzi is also the Director of the Center for Clinical Outcomes Development and Application (CODA), which provides guidance on measurement instruments to clinicians in the university’s medical school.

Instead of psychology, Carlozzi decided to focus on neuropsychological research, which brought her to Indiana University in Bloomington in the mid-2000s for a research position focused on detecting early signs of Huntington’s disease, a genetically transmitted brain disorder that causes severe neurological impairment and eventually death. Carlozzi was looking for the best measures to detect the earliest stages of neurological decline when medical interventions would be most effective. “It’s much more complicated than giving something to someone with an active disease,” she said. “As a result of the study, we had a better understanding of when symptoms occurred and when it’s best to administer a drug.”

When her advisor and mentor moved to Australia, Carlozzi accepted a job in 2008 at the Kessler Foundation in New Jersey working for David Tulsky, an expert in outcomes assessment who was developing measures for the NIH Toolbox (see cover story). The pair moved to the University of Michigan in 2010. Tulsky encouraged Carlozzi to submit a grant proposal to explore quality of life measures for people with Huntington’s and another for caregivers of people with traumatic brain injury. To Carlozzi’s surprise, both of the National Institutes of Health (NIH) grants were funded in the same year.

“She is incredibly tenacious and efficient. She manages to get a lot of things done,” said Julie Stout, Ph.D., Carlozzi’s postdoctoral supervisor at Indiana and now a professor at Monash University in Melbourne, Australia. “There are lots of big projects on Huntington’s disease but no one had done work in the category of patient-reported outcomes. Noelle developed the project, got the funding and did this huge data collection. Her determination has gotten her to the point where she is now.”

When Tulsky left Michigan for the East Coast two years ago, Carlozzi decided to stay put. She loves living on the outskirts of Ann Arbor, where she and her husband, a pianist and organist, have an acre of land and a pumpkin farm across the street. Having a balance between work and home has become even more important now that Carlozzi is the mother of a toddler. “It’s very different. I used to work all the time and stay until things got done. Now I have to pick him up from daycare so you have to leave. My husband has a flexible schedule so that helps. It’s hard in many ways but now I’m more focused when I’m working.”
with each other. With this set of tools researchers are able to keep a person in a study for multiple years with comparable scores and, because it is free, there is an incentive to keep using it.” The NIH got what it wanted in October 2012 when the Toolbox was launched – a multidimensional set of brief measures assessing cognitive, emotional, motor and sensory function, calibrated with input from more than 200 scientific experts. Since then, the number of researchers making use of the Toolbox has grown dramatically. It was used in 378 studies in 2014 and that number is expected to double in 2015.

Yet the number of clinicians using the Toolbox in private practice, where both cost and time savings would be significant, remains small. That concerns Allen Heinemann, Ph.D., Director of the Center for Rehabilitation Outcomes Research (CROR) at the Rehabilitation Institute of Chicago (RIC).

“The original intended purpose was for research applications, but the Toolbox can also be used in direct patient care. You can compare results across patients, clinics, states and regions,” Heinemann said. “You can talk about benchmarks or improvement you might expect during a course of an intervention because you used a standard assessment.”

One reason the Toolbox is so useful is that many of the tests are administered through computer-adaptive testing, which bases subsequent questions on a subject’s previous responses. Traditional vocabulary tests, for example, can take 20 minutes or more because they include dozens of questions outside of the range of a subject’s word knowledge. The Toolbox vocabulary measure has more than 300 items, but the typical subject only answers 25 questions before it comes up with an accurate score, Gershon said. The process usually takes no more than five minutes.

Similarly, a traditional neuropsychological evaluation routinely takes two or three hours and then has to be scored. The toolbox cognition evaluation takes only 30 minutes and is scored in real time. All told, a full battery of the 45 tests included in the Toolbox can now be completed in under two hours.

“The levels of reliability are comparable to the ‘gold standard’ tests,” Gershon said. “We can often get the same reliability in half the time as these longer instruments because we’ve designed them to be computer driven. We don’t have to give people a lot of test content that’s not relevant.” Also increasing the Toolbox’s utility is its normative values for the general population, which were developed by administering the Toolbox instruments to thousands of people. When a test is nationally normed, it means the test can be used to show the performance of a person relative to the U.S. population (for example, a person scored higher or lower than 50 percent of the general population). That allows the Toolbox’s instruments to measure deficits as well as exceptional performances. The norms are age-based but can be refined further by ethnicity, education level and gender. The Toolbox’s Spanish-language version also has been normed.

“You have the best norms available for any test anywhere,” asserts Robert Heaton, Ph.D., Professor of Psychiatry at the University of California, San Diego, who helped develop the Toolbox’s norms. “For most cognitive tests, you have different tests for different ages. When someone goes from 15 to 16, you have to use a different IQ test. That’s not the case with the Toolbox.”

Still, many clinicians aren’t in a hurry to make the Toolbox part of their practice. Jennifer Moore, a Clinical Practice Leader in neurological clinical therapy at RIC, says she is aware of how and why the NIH Toolbox was put together but she is not yet using it. “I think there’s a lot of confusion about whether it’s ready for clinical practice,” she said.

A big part of Moore’s job is to select and implement evidence-based assessments at RIC. When she is looking for a measure, she looks to online resources such as the Rehabilitation Measures Database, a compendium of measures for people...Continued on Page 5
NIH Toolbox (Continued from page 4)

with spinal cord injuries, traumatic brain injuries and stroke, which she helped develop.

Her go-to measures come with metrics that help her interpret the results, including standard error of measurement, minimum detectable change and minimum clinically important difference.

All Toolbox measures come with standard error of measurements, Gershon says, and many have values for minimally important difference. But it doesn’t surprise Gershon that many clinicians prefer measures that have worked for them in the past. “Historically new instruments are slower to be adopted than new versions of older instruments. It’s an uphill battle,” he said. “People tend to use the instruments they used in school or early in their career. We’re a lot of years away from that happening with the Toolbox.”

One factor that may have slowed adoption of the Toolbox by private practitioners, Gershon says, was the initial complexity of its setup. Its first iteration required a laptop and a standalone screen, and clinicians needed training to use it. That changed in August when a new version was released that can be administered on an Apple iPad. Toolbox instruments are now available through the iTunes Store for a low subscription cost designed to cover distribution, maintenance and upgrade expenses. To ensure that those administering and interpreting the tests are trained properly, users must be preapproved to access the Toolbox’s cognition measures.

The Toolbox’s advantages will become more widely known and more commonly used as researchers incorporate it into their research proposals, conduct studies and write articles about their results, Gershon believes. “We’re still a baby,” he concedes. “The current median user of the Toolbox is five years or more away from publishing an article, but I can sleep well at night knowing the potential impact on research, health and education of the hundreds of studies already in progress.” Although the battery is still in its relative infancy, there are already more than 50 peer-reviewed articles about the use of the NIH Toolbox that have appeared in the medical literature.

Next year the NIH will take a large step in promoting wider adoption of the Toolbox by encouraging its 300,000-sponsored researchers to use it. Meanwhile, Gershon and his team will be getting the word out about the Toolbox’s advantages to medical schools and neuropsychology programs. They also will be reaching out to state boards of education, which could use the Toolbox to supplement or replace longer, more expensive assessments for students. “We are going to all of these groups and saying, ‘The government has paid for this incredible set of instruments and they’re available to you royalty free. We’d like you to try them.”

In Memoriam: David Gray (Continued from page 1)

the barriers were. He knew how people’s lives could be facilitated by good environments,” said Carolyn Baum, Ph.D., Director of the Occupational Therapy program at Washington University and the person who recruited Gray to the department in 1995. “He set about in his career to study those things, to make it visible and conscious for everybody that people don’t have to be disabled if they have the right environment. Nothing stopped him unless it was the environment.”

Gray’s path to becoming an internationally known advocate for people with disabilities began in 1976 when he fell off a ladder at his Minnesota home and broke his neck. Gray, then a 32-year-old behavioral geneticist, nearly died and then spent six weeks in intensive care. A year of intensive rehabilitation at the Mayo Clinic followed.

The same day Gray was injured, his grant application to study the genetics of multiple sclerosis was approved. “They thought I couldn’t do any research so they took it away,” Gray said in an interview with CROR Outcomes in 2014. He never forgot that experience or the following years when he applied for dozens of teaching jobs and got nowhere. Then a friend told him about an opening at the National Institutes of Health (NIH). He applied and was hired. Gray’s family moved to Washington, D.C. so he could pursue his second career as a health research administrator.

At NIH, Gray mastered the system for reviewing grant applications and funding research. Through his work, Gray met the leaders of the disability movement, who considered access to public places and services such as mass transportation a civil rights issue. He took up the cause. “It was an amazing time to be in D.C. and to be a part of what was happening in the world around us,” Gray said in an interview with Washington University’s O.T. Link newsletter shortly before his death. “Regardless of how you get around in society, whether you roll along the sidewalks in a chair or otherwise, you have a right to be heard and treated equally.”

In 1986, Gray was tapped by President Ronald Reagan to be the Director of what is now known as the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the U.S. Department of Education. After a year, Gray was back at NIH where he worked with divisions concerned with developmental disabilities, human learning, and behavior.

Three years later, the disability movement
Help Grow the Rehabilitation Measures Database!

We are excited to be adding Trudy Mallinson, Associate Professor at the George Washington University Department of Clinical Research and Leadership, to our thriving list of educational collaborations. This dually beneficial collaboration between the Rehabilitation Measures Database (RMD) and post-professional Occupational Therapy Doctorate students allows us to simultaneously grow the library of instrument summaries in the RMD while helping clinicians integrate evidence based practices into their daily therapies, giving patients the best chance of improved outcomes. These relationships allow students to have an informal publication on the RMD website, along with an opportunity for formal publication in one of several rehabilitation journals that has teamed with the RMD. These collaborations have been developed to create tear sheets and case studies related to instrument summaries already active in the RMD.

Don’t miss out on an opportunity to be an integral part of the RMD database, which receives 130,000 monthly hits and is the home of more than 330 instrument summaries. For more information, contact the RMD Project Coordinator, Jill Smiley, at jsmiley@ric.org.

Increase in RMD Website Traffic

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Acknowledgements

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In October, collaborators on the Rehabilitation Research and Training Center on Improving Measurement of Medical Rehabilitation Outcomes presented at the International Society for Quality of Life Research in Vancouver BC:

  Elizabeth Hahn, MA, Feinberg School of Medicine Northwestern University, Chicago, IL, United States

- New Patient Reported Outcomes Scales to Measure Economic Quality of Life
  David S. Tulsky, PhD, University of Delaware, Newark, DE, United States

- Finding a Focus for Social Aspects of Quality of Life with Neurological Disorders: Cognitive, Emotional, Physical, and Environmental Factors
  Alex Wong, PhD, Washington University School of Medicine, St. Louis, MO, United States

- Familiar Models, New Measures of Environmental Factors Influencing Quality of Life
  Allen W. Heinemann, PhD, Rehabilitation Institute of Chicago, Chicago, IL, United States

- Reasonable Accommodations Affect the Validity of Scores on the NIH Toolbox Cognition Battery Among People with Neurological Disabilities
  Susan Magasi, PhD, University of Illinois at Chicago, Chicago, IL, United States

- Health Disparities in Health-Related Quality of Life Among Individuals with Disabilities
  Noelle Carlozzi, PhD, University of Michigan, Ann Arbor, MI, United States

In Memoriam: David Gray (Continued from page 5)

David Gray was deeply committed to the development and improvement of healthcare outcomes for individuals with disabilities. Throughout his career, he pursued research that aimed to enhance the independence and quality of life for people with physical disabilities.

Gray was instrumental in the drafting and signing of the American with Disabilities Act, which provided protection from discrimination for individuals with disabilities and required employers to provide “reasonable accommodations” so they could remain part of the workforce. Gray traveled the world with President George Bush, wielding the pen. That same year, he moved on again to become the acting deputy director of the newly created National Center for Medical Rehabilitation Research (NCMRR). The agency was dedicated to advancing scientific knowledge to improve the health, independence, and quality of life for people with physical disabilities.

Through his work at NCMRR, Gray met Washington University’s Baum, whom he had helped select as one of the agency’s first board members. She was so impressed, “I told him he should stop being a bureaucrat and start testing his ideas and building science around them.”

Gray accepted Baum’s challenge and moved to St. Louis in 1995. He had approved hundreds of grant requests but never written one. Among all the topics he could have pursued, Gray decided to focus his research on the effect of the physical environment on the independence and quality of life for individuals with mobility impairments. “His talents were effectively deployed finding evidence for social change,” said Allen Heinemann, Director of the Center for Rehabilitation Outcomes Research (CROR), who brought Gray on board as a collaborator on several projects. “Working with him was a rewarding experience because of his broad perspective and the experience of living with a spinal cord injury as well as his in-depth knowledge of models of the environment and how they affect participation. It’s the environment that determines the range of possible activities and participation.” Few people knew better than Gray how to deal with the environmental barriers he encountered. Gray traveled the world with the help of a personal assistant, attending conferences and advising the World Health Organization (WHO) with revising its International Classification of Functioning, Disability and Health (ICF). Along the way, he patiently tutored everyone from flight attendants to fellow passengers to hotel workers about the right way to deal with someone in a wheelchair. “He was good at getting his needs met and educating people about disabilities,” said Jessica Dashner, a Washington University Instructor in Occupational Therapy who worked for him as a research assistant for more than a decade. “He could get mad if he needed to.”

No one worked harder than Gray, she says. “It wasn’t unusual for him to arrive at the airport and go straight to the office. He liked the adrenaline rush of going down to the wire to meet a deadline,” Dashner said. “Sometimes we pulled all-nighters. You’d look around the office and see that the entire group was still there. He didn’t have to ask. It was something that you wanted to do. He drew you in.”

Despite his absence, Gray’s work will go on at Washington University where Dashner has picked up the work on all of his grants. And it also will be carried on by the more than 100 occupational therapy students he mentored over the years who are now practicing around the world. “He was a very wonderful man who knew what it would take to move a field forward,” Baum said. “And he did.”