

CROR Outcomes: Spring 2019

Welcome to the Spring Issue of the Center for Rehabilitation Outcomes Research (CROR) Outcomes newsletter. This newsletter gives you an inside look at the work we are doing as well as the studies on which we collaborate. This issue's cover story focuses on the new CROR research grant that aims to help people with disabilities maintain employment and features key collaborators both onsite and off site.

On page 2, we share a profile highlight of Sherri LaVela, Ph.D, who is helping people with mobility issues improve their quality of life as well as her Department of Defense-funded study in collaboration with CROR- looking at barriers faced by people with SCIs who are trying to lose weight or maintain it.

Check out a study that aims to enhance measurement tools and outcomes for

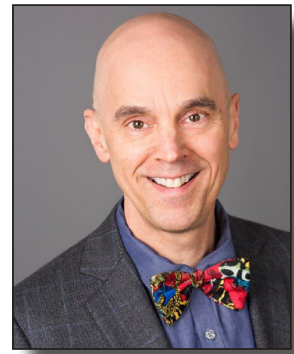
people with foot and ankle orthoses with Nicole Soltys and CROR.

Finally, we provide updates on CROR's social media page as well as knowledge translation activities.

Please see page 7 for details.

For more information about CROR's projects and educational opportunities, please visit our webpage at <https://www.sralab.org/research/labs/center-rehabilitation-outcomes-research-cror>. And don't forget to "like us" on Facebook!

Allen Heinemann, Director



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New CROR Grant Seeks to Help People with Disabilities Maintain Employment

The Center for Rehabilitation Outcomes Research (CROR) has been awarded a five-year \$4.3 million grant by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) to fund research into barriers limiting people with disabilities from maintaining employment.

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Study Focuses on Helping to Enhance Measurement Tools and Outcomes for People with Custom Ankle Foot Orthoses

Lots of people end up wearing an ankle-and-foot brace during some period of their life. If someone breaks a bone in their foot or ankle, they may need an ankle/foot orthosis (AFO) to help the bones heal. People who have had strokes or spinal cord injuries may experience a gait abnormality known as "foot drop," which requires a different type of AFO. AFOs may also be worn by individuals with traumatic brain injuries or cerebral palsy, which can cause spasticity or contractures in ankle and foot muscles. Some of those patients will need their AFO for the rest of their lives.

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Sherri LaVela, PhD: Helping People with Mobility Issues Improve Their Quality of Life



Growing up in the Chicago suburb of Oak Lawn, Sherri LaVela observed her grandparents' challenges. Her grandmother lived with the effects of polio and had balance and gait problems and her grandfather, a military man, had been forced into early retirement when he was diagnosed with multiple sclerosis in his mid 30s. "From my earliest memories he was in a wheelchair," says LaVela, Ph.D., MPH, MBA, a Research Health Scientist at the U.S. Department of Veteran Affairs and a Research Associate Professor of Physical Medicine and Rehabilitation at Northwestern University's Feinberg School of Medicine. "He was a tall thin man and my grandma, who was five feet one, struggled to help him with transfers. It affected him. I recognized that it was hard for him to need help from other people. He never wanted pity." Even as a child, LaVela remembers wondering why there wasn't better equipment available that would help people like her grandfather retain their autonomy and independence.

She also became fascinated by the interplay of biology and psychology. It was no surprise when she chose to major in biology at Saint Xavier University in Chicago. Initially interested in becoming a physical therapist, she volunteered at social service agencies that provided services to children with disabilities. Through that work, she saw the connections between mind and body and decided to double major in psychology. "So many functional disorders could benefit from interventions that touch both fields," she says. As things turned out, LaVela didn't pursue the physical therapy route. Instead her interest turned to public health in the hope of helping people and solving problems on a much larger scale. After graduating she became a researcher at the Edward Hines Jr. Veterans Administration Hospital in Hines, Illinois, where she studied clinical and rehabilitation outcomes and quality-of-life issues for individuals with spinal cord injuries (SCIs) and other disorders.

As she worked with geriatric patients, she saw that lots of people were aging with medical issues such as traumatic brain injury, multiple sclerosis and post-traumatic stress disorder. She wanted to make their lives better, and to do that she needed to be able to get funding for her own research studies. While working full-time, LaVela went back to school to pursue a joint master's degree in public health and business at the University of Illinois at Chicago. She had a flexible schedule so when classes were only available during the day, she would attend in Chicago and then head to work at Hines in the evening.

That dedication and sleep deprivation paid off in 2002 when LaVela received two master's degrees in less than two years. "The master's in public health really molded my ability to design research studies and it improved my awareness of public health problems and how to view them at a population level," LaVela says. "It filled my head with a lot of intervention ideas that I could bring back to my work as a research scientist." These days, she is juggling research for four grants that are united by their focus on clinical and quality-of-life issues.

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Helping People with Mobility Issues Improve Their Quality of Life

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In one of those, LaVela invited colleagues at the Center for Rehabilitation Outcomes Research and the Shirley Ryan AbilityLab to partner with her on a Department of Defense-funded study looking at barriers faced by people with SCI who are trying to lose weight or maintain it. Weight gain after a spinal cord injury is a prevalent problem for people who are dealing with decreased mobility. It's also serious--the extra weight contributes to higher rates of diabetes and heart problems among people with spinal cord injuries. By talking with SCI patients, their informal care givers and healthcare providers, LaVela wants to identify barriers to healthy weight maintenance and suggest ways to overcome them.

While her job doesn't give her much time for outside pursuits, LaVela makes time to keep strong and agile by hitting the gym, hiking, doing Pilates and practicing yoga. She has been lifting weights since she was 17 and enjoys the surprised looks on the faces of muscular gym members when she "lifts heavy," such as doing curls with a large dumbbell. "I can lift a lot of weight for my body size. I find it mind clearing," LaVela says. "I like to be independent, and in all aspects of my life, it's good to be able to get things done without needing someone to help me." One thing she hasn't had time to pursue yet but is thinking about doing alongside her research is getting certified as a personal trainer for people with mobility conditions and disabilities: "There's a big need. There is a lack of trainers who know how to work with people with disabilities. I'd love to do that in mainstream gyms."

New CROR Grant Aims to Help People with Disabilities Maintain Employment

Only about 10 percent of people with disabilities who want to work actually hold jobs. That means they typically rely on publicly funded Social Security Disability insurance or Supplemental Security Income and Medicare or Medicaid for health insurance. The personal and financial costs to people who must leave the workforce because of injury or chronic illness are difficult to calculate.

"Whatever we can do to reduce barriers to employment and support independent living is a great good for those individuals—and the public," said Allen Heinemann, Ph.D., Director of CROR, which is part of the Shirley Ryan AbilityLab. "Our former Medical Director Henry Betts hammered home to us that it's not enough just to provide our patients with medical rehabilitation. The ultimate goal is to get people back to their roles. For most adults working is a major part of their lives."

The grant designates the AbilityLab as one of NIDILRR's national Rehabilitation Research and Training Centers (RRTC's). In applying for the funding, CROR partnered with two outside institutions with strong track records of research in the field of disability and employment—the University of Washington (UW) in Seattle and the University of Illinois at Chicago (UIC). Both universities are home to Americans with Disabilities Act (ADA) Centers, which work to increase awareness and knowledge about people with disabilities in order to help them live freely and equally. The RRTC will support four major research projects running the gamut from developing strategies to help people successfully request reasonable accommodations from their employers to identifying beneficial employment interventions for people with Parkinson's disease, a neurological condition that causes many to retire early.

Reducing Chronic Lower Back Pain's Impact on Work

One of the most common health-related reasons people quit their jobs or are absent from work is chronic pain. Some soldier on using opioids to dull the pain. Others resort to surgery. Dawn Ehde, Ph.D., professor of Psychology and Rehabilitation Medicine at UW, wants to find out if people who are working with chronic back pain can be helped by cognitive behavioral therapy (CBT), an evidence-based pain treatment delivered by "telehealth" to improve access and convenience.



Dawn Ehde, Ph.D

“Few people with disabilities and chronic pain have access to evidence-based behavioral interventions for pain. When those people are in work settings, it’s even harder for them to access those resources,” says Ehde, a clinical psychologist and expert in pain self-management. Ehde will be conducting a randomized controlled trial to see if CBT delivered by live video or audio on computers, mobile phones or tablets is effective in reducing participants’ pain interference, including at work. Other outcomes including pain severity also will be assessed. People eligible include those with spinal cord injuries, amputations, multiple sclerosis, neuromuscular diseases, traumatic brain injury and stroke, among others.

Ehde is planning to enroll 200 people, 100 at UW and 100 at the Shirley Ryan AbilityLab. Half will receive the intervention, which will consist of eight 45-minute sessions designed to teach participants pain management skills such as relaxation that have been adapted for use in a work setting. The control group will be wait-listed and receive the same intervention nine months later.

“We’ve shown in a number of studies that one-third to a half of people who learn these pain management skills report statistically significant and clinically meaningful reduction in their pain,” Ehde says. “That reduces how much pain gets in the way of mood activities, work, family relationships and sleep.”

If the new study shows the intervention reduces pain, the plan is to create a therapist’s guide that would be available to clinicians around the country who work with people who experience pain. Because the therapy is delivered remotely, it could be used by anyone.

Helping People with Parkinson’s Stay Employed

Research shows that people who are diagnosed with Parkinson’s leave the workforce five to seven years earlier than they would have otherwise. With 60 years old the average age of a Parkinson’s diagnosis, that means people are missing out on some of their highest earnings years, which also cuts into their retirement savings and ends their access to employer-paid health coverage. Miriam Rafferty, DPT, Ph.D., a research scientist



Miriam Rafferty, DPT, Ph.D.

at the Shirley Ryan AbilityLab who focuses on neurological disorders, will be studying ways to help people with Parkinson’s continue to work. Parkinson’s affects both people’s physical abilities as well as their cognitive functioning so it could cause difficulties no matter what kind of work someone does. “Nobody has done any intervention studies to see if we can ameliorate the problem,” says Rafferty.

The first phase is a qualitative study and needs assessment that will involve focus groups of people with Parkinson’s and experts in the field such as rehabilitation counselors and occupational therapists, among others. The goal is to develop tools and an intervention pathway to help people with Parkinson’s know when to inform their employers of their diagnosis and seek reasonable accommodations so they can continue to work.

In the implementation phase, the intervention will be introduced to a group of 60 people—20 in Chicago and 40 elsewhere. The researchers will then track how people use the tools that have been developed. “We will be letting people do what they feel is best for them and then tracking the results,” Rafferty says. “The goal is to provide better resources for people with Parkinson’s and disseminate them around the country.”

Strategies to Successfully Seek Accommodations from Employers

The ADA requires that employers make reasonable accommodations for employees or potential hires who have disabilities. But since the law was passed in 1990, the level of people with disabilities in the workforce has barely budged. There are likely many factors at play, but Mark Harniss, Ph.D., researcher at UW, thinks issues surrounding asking for accommodations is one of them.

“There’s a lot of information out there about your rights under the law and things you should think about,” says Harniss. “But there aren’t many tools that walk you through the process. Do I need an accommodation? What should I ask for? What should I disclose? How should I approach Human Resources or my employer?” He adds that many of the currently available tools don’t acknowledge how frightening and personal these decisions can be. He also believes that an individual’s feelings about self worth and his or her value to the organization may play a role. Harniss is heading a project focused on developing decisional support tools to help people make requests for accommodations whether they are currently employed or seeking a job. His team—which includes Robin Ann Jones, Director of the Great Lakes ADA Center at UIC, and Kathe Matrone, Ph.D., Principal Investigator at UW’s Northwest ADA Center—will hold a series of focus groups with people with disabilities, family members, employers and community service providers.



Mark Harniss, Ph.D

They hope to include people with both visible and invisible disabilities, and they want the groups to reflect diversity of ethnicity, gender and income levels.

Once they have gathered the input, they will create a paper-based prototype of a decision support process. The prototype will be reviewed by experts in both decision aids and user interface design. It will then be tested by people from the stakeholder groups. After it’s refined, the tool will become digital. “We’ll build a personalized interface that guides people through a set of questions leading to a confident decision. We want it to be both highly usable and accessible,” Harniss says.

The team will then recruit a sample of 50 people to test the tool, some independently and some with the aid of rehabilitation counselors. The ultimate goal is to disseminate a tool that helps people access accommodations that support them in finding or keeping a job. “These decision guides won’t make the environment more accommodating, but hopefully they will help people think through the negative and positive consequences of accommodation requests and help them feel confident in their decisions,” Harniss says.

Employers’ Best Practices

Many employers are apprehensive when an employee asks for workplace accommodations related to a disability. Will the worker be less productive? Will the changes be costly? But some employers have embraced the idea that a truly diverse workforce includes people with disabilities. Managers at those companies have worked successfully with their employees to create conditions that allow them to continue work after a disability—or be hired in the first place. Heinemann along with Pamela Capraro, Shirley Ryan AbilityLab Manager of Vocational Rehabilitation, and Robert Trierweiler, a Shirley Ryan AbilityLab Certified Rehabilitation Counselor, and Deborah Crown, CROR Project Manager, want to identify what those “best practices” are. The team will identify and interview employers of workers with disabilities to find out how they successfully handled accommodation requests.

They also will survey employees with disabilities, many of whom found work through a large network of employers in the Chicago area cultivated by Capraro and Trierweiler.

Based on the responses they gather, the researchers will revise the survey questions and administer it to employers and employees across the country. The big-picture goal is to identify barriers to job retention but also find out what factors facilitate continued employment for people with disabilities. Helping those people find and retain jobs will not only improve their lives but also will benefit employers who will be able to find and keep valuable workers at minimal cost, Heinemann says.

Meet the team members:



Deborah Crown, CROR Project Manager



Pamela Capraro, Shirley Ryan AbilityLab Manager of Vocational Rehabilitation



Robert Trierweiler, an Shirley Ryan AbilityLab Certified Rehabilitation Counselor

Study Aims to Enhance Measurement Tools and Outcomes for People using Custom Ankle Foot Orthoses

Most orthotics are custom made for individual patients. The orthotist takes a cast of the person's ankle and foot, and then fabricates a device that is precisely calibrated to the needed angle of correction. If the orthotic device is not made properly, it can rub the skin and cause wounds that may become infected. If it's too heavy or uncomfortable, a patient may not use it, increasing their chance of falling.

Nicole Soltys, a Certified Prosthetist and Clinical Operations Manager of Prosthetics and Orthotics at the Shirley Ryan AbilityLab, is part of a study at the Center for Rehabilitation Outcomes Research (CROR) looking at ways to measure and enhance the quality of orthotic services. "We are trying to get the best outcome for patients, and we want to enhance the quality of orthotic services by identifying how to measure that," Soltys said. "Orthotic care is so multi-faceted. It's not just about the skill of the individual orthotist. We're also talking about the quality of the facility, the communication between care providers and the quality of follow-up care."

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Study Aims to Enhance Measurement Tools and Outcomes for People using Ankle Foot Orthoses Continued...



Nicole Soltys, a Certified Prosthetist and Clinical Operations Manager of Prosthetics and Orthotics at the Shirley Ryan AbilityLab

After a year of protocol planning and focus groups with patients, orthotists and therapists, the research team is ready to start collecting data. The researchers are currently recruiting patients at the Shirley Ryan AbilityLab, and colleagues are recruiting patients at the Edward Hines Jr. Veterans Administration Hospital in Hines, Illinois, and the Minneapolis Veterans Administration Health Care System in Minnesota. The study, which is funded by the U.S. Department of Defense, will include military veterans who use custom foot-and-ankle orthoses, too.

One cohort of patients will be using a custom ankle-foot orthotic that they have had for at least six months. They will come in twice to do walking tests and fill out patient-reported measures about their care. “For patients using their devices for a long time, we want to show that the tests are reliable,” Soltys says. “If we’re measuring a steady state, the outcomes shouldn’t change. We’re expecting the results to be the same at both visits.”

A second group of patients will be receiving a custom orthosis for the first time. They will be tested three times—before they are fitted with the device, after they receive it and at a later date. The researchers will spend three hours with each subject per visit administering a wide variety of measures.

They are expecting to see improvement in this group and will be watching to see if the patients’ progress continues or plateaus.

“We’re trying to find the best measures that can be done in the shortest amount of time,” Soltys says. Through the Prosthetics & Orthotics department at the Shirley Ryan AbilityLab, Soltys and her team already have at least 20 former patients who may be good candidates for the study. She is hoping to recruit 50 subjects at the Shirley Ryan AbilityLab, 25 at Hines and another 25 in Minneapolis. Shirley Ryan AbilityLab staff will be videotaping participants when they take walking tests so that the researchers can score the quality of the patients’ gait. Orthotists see a high volume of patients each day and need every minute to evaluate, cast, measure, fit and adjust their devices. Additional time is taken by ordering components, filling out fabrication work orders and documenting each visit. That leaves little time to do additional outcome assessments, Soltys says. Once the data are collected and analyzed, the research team plans to share the study’s findings with orthotists, physical therapists and physicians through published papers and by speaking at conferences around the country.

The study is an example of translational research, applying knowledge gained from clinical trials to techniques and tools that address important medical needs to improve health outcomes. “This project builds on our collaboration with Shirley Ryan AbilityLab’s prosthetists and orthotists,” says Allen Heinemann, Ph.D., Director of CROR. “Clinicians provided valuable insights and contributed to data collection when we developed an assessment tool, the Orthotics Prosthetics Users Survey, which is gaining widespread recognition. Our current project will help advance our understanding of patient outcomes in this area of rehabilitation.”

CROR Scholarly Activities Highlights

Publications

Botticello, A. L., Tulsy, D., Heinemann, A., Charlifue, S., Kalpakjian, C., Slavin, M., Rohrbach, T. (2018). Contextualizing disability: a cross-sectional analysis of the association between the built environment and functioning among people living with spinal cord injury in the United States. *Spinal Cord*. doi: 10.1038/s41393-018-0186-8

Pellegrini, C. A., Powell, S. M., Mook, N., DeVivo, K., & Ehrlich-Jones, L. (2018). Use of Physical Activity Monitors in Rheumatic Populations. *Curr Rheumatol Rep*, 20(12), 73. doi: 10.1007/s11926-018-0786-5

Ketchum, Jessica M., Cuthbert, Jeffrey P., Deutsch, Anne, Chen, Yuying, Charlifue, Susan, Chen, David, Whiteneck, Gale G. (2018). Representativeness of the Spinal Cord Injury Model Systems National Database. *Spinal Cord*, 56(2), 126-132. doi: 10.1038/s41393-017-0010-x

Check Out CROR on Social Media

CROR is now on Facebook and Twitter! Both pages offer fascinating content including project updates, staff highlights, and social events for you to stay as connected as possible to CROR and its latest developments.

Our social media platforms serve as a link directly to CROR for patients and health professionals alike to observe the benefits of outcomes research in real time and how it affects the care individuals receive.

Visit our Facebook (<https://www.facebook.com/RehabOutcomes/>) and Twitter (<https://twitter.com/RehabMeasures>) pages and click “Like” or “Follow.” We look forward to bringing you great content and keeping in touch. We hope you comment on our posts and feel free to ask questions or share content with friends and family who would benefit from the information.

Acknowledgements

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