

INside the OUTcomes: A Rehabilitation Research Podcast

Episode 1: Introduction with Allen Heinemann, PhD, Director, Center for rehabilitation Outcomes Research

SHARON PARMET, HOST:

Welcome to INside the OUTcomes: A Rehabilitation Research Podcast of the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. I'm your host, Sharon Parmet.

On this podcast, I'll speak with researchers from the Center for Rehabilitation Outcomes Research as well as with leading experts in the field of rehabilitation research.

Today for our very first episode, I thought we'd start by speaking with Dr. Allen Heinemann, Director of the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. Dr. Heinemann conducts health services research with a focus on developing and applying outcome measures in rehabilitation care. He is also a professor in the departments of physical medicine and rehabilitation, emergency medicine and medical social sciences at Northwestern University's Feinberg School of Medicine. Dr. Heinemann is also co-editor-in-chief of the Archives of Physical Medicine and Rehabilitation. Welcome, Dr. Heinemann.

DR. HEINEMANN:

Thank you, Sharon. Good to be here today.

SHARON:

Glad to have you. You are the director of the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. Can you tell me a little bit about what rehabilitation is and why we study rehabilitation outcomes?

DR. HEINEMANN:

Well, medical rehabilitation refers to a broad array of services provided by physicians, rehabilitation nurses, allied health therapists and others to help people who've incurred physical disability or chronic illness to live their lives as independent and independently and as fully as possible. That happens in inpatient rehabilitation hospitals, such as Shirley Ryan AbilityLab. People typically transition to day rehabilitation programs or receive outpatient services, such as physical or occupational or speech-language services. And the research that focuses on rehabilitation historically has focused on the outcomes that patients achieve trying to understand both how to measure those services, patients' access to those services, what kinds of treatment components are effective in improving quality of life and functional status. For years, the focus has been on function, what can people do for themselves? How much assistance do they need? And what kind of modifications to the environment are needed to help people live as independently as possible?

SHARON:

Can you tell me a little bit about how services are delivered at the Shirley Ryan AbilityLab and how the Center for Rehabilitation Outcomes Research fits into the larger environment of research that is embedded at Shirley Ryan AbilityLab.

DR. HEINEMANN:

Shirley Ryan AbilityLab is licensed as an inpatient rehabilitation facility. It's one of several kinds of what the Centers for Medicare and Medicaid Services call post-acute services, other settings or skilled nursing facilities, for example, long-term acute care hospitals, home health services.

We have a partnership with several other hospitals across the state of Illinois that also provide services with whom we consult on providing rehabilitation services. But it's not just an inpatient operation. We have extensive outpatient services not just at the flagship hospital at 355, East Erie Street in Chicago, but several other sites throughout the city and suburban communities. This is an intensive outpatient sort of program where patients typically receive at least three hours of services per day, but they don't need close monitoring by physicians and nurses to achieve the

rehabilitation goals. We also offer outpatient services downtown and a variety of other facilities including our former site at the Rehabilitation Institute of Chicago at 345 East Superior with a pain management program. We offer outpatient services there, and also nearby our vocational rehabilitation services just to give you a flavor of the breadth of services that we offer.

SHARON:

Thank you for that overview of Shirley Ryan AbilityLab. Can you tell us a little bit about how the Center for Rehabilitation Outcomes Research fits into the AbilityLab?

DR. HEINEMANN:

Sure, the AbilityLab has a mission to integrate research into clinical care so as to provide the best and most cutting-edge services to help our patients' independence and quality of life. To that end, we've dedicated a lot of space to various labs within the larger organization. Some of these focus on mobility, some focus on upper extremity functions. Some focus on speaking and cognition. The Center for Rehabilitation Outcomes Research focuses on the whole person rather than just a particular body system. Thus, we are interested in patients who have sustained strokes, traumatic brain injury, spinal cord injury, Parkinson's disease and other neurologic disorders and also children who've incurred disabilities and or have a chronic illness.

Our research is mostly externally funded. The National Institute on Disability, Independent Living, and Rehabilitation Research that you mentioned earlier, is the primary funder of our research. But we've also had funding from the US Department of Defense, Craig H. Nielsen Foundation, Paralyzed Veterans of America, National Institutes of Health, among many other funding sources, both federal and private foundations. We also have an internal focus on our research, as well as an external one, we try to address issues that are important to patients that we serve major ones being stroke, spinal cord injury, traumatic brain injury, and children. So you'll see a lot of focus on quality of life and increasing function for those populations.

SHARON:

So you've told us a little bit about how research is embedded directly into the care that patients receive at Shirley Ryan AbilityLab. Can you tell me a little bit more about the Center for Rehabilitation Outcomes Research or give us a tour of the kinds of research that is going on within that lab at Shirley Ryan AbilityLab.

DR. HEINEMANN:

Happy to do so. Well, in addition to myself, director of the center, the associate director is Linda Ehrlich-Jones. She has a nursing background and has expertise in motivational interviewing. And she is a research scientist who has deep policy experience and also has a rehabilitation nursing background as well. Alex Wong is a research scientist and an occupational therapist and rehab counselor by training focused on use of technology to better monitor patients' progress in rehabilitation. We have a full-time biostatistician. We have two full-time project managers. We have a number of project coordinators and research assistants who help get to funded work done.

Just to highlight a couple of major projects. We have a Rehabilitation and Research and Training Center on Employment for People with Physical Disabilities. That's a NIDILRR funded, it's a five-year center. We also have another Research and Training Center focused on home and community-based services. These are the services that people get in addition to rehabilitation, typically in community settings, that help them live as independently as possible. We have a number of other long-term projects, perhaps the longest of which is the Midwest Regional Spinal Cord Injury Model System. We're one of 18 centers across the country that are models of care for spinal cord injury, we conduct a number of research projects. Perhaps the most important component is a national database of current and former patients. Some patients who are now coming up on their 50th-anniversary post SCI, whom we interview every five years. This is an invaluable resource that lets us track the long-term outcomes of patients who sustain SCI, both in terms of independent living employment, need for health services and other issues.

SHARON:

So Dr. Heinemann, you are Director of the Center for Rehabilitation Outcomes Research. How did you first get interested in this field?

DR. HEINEMANN:

My graduate training is in rehabilitation psychology from the University of Kansas after completing my internship, my first job was at the Illinois Institute of Technology in the psychology department, primarily a teaching position, but they also expected research productivity, just a few miles away was the Rehabilitation Institute of Chicago. I developed a collaborative relationship with a couple of physician-scientists at the hospital. The early work focused on alcohol and drug use issues experienced by people with spinal cord injuries that in short order led to an offer of a position at what was then the Rehabilitation Institute of Chicago and I've been there ever since. The opportunities to pursue funded research and to have excellent, challenging opportunities within the organization and wonderful colleagues with whom to work has kept me there for all of those years.

SHARON:

Can you tell us a little bit about what are we going to talk about on the podcast going forward?

DR. HEINEMANN:

Well, I know a couple of ideas. The first is with one of our scientists Miriam Rafferty, who's a physical therapist, by clinical background and completed a neuroscience doctoral degree was one of our postdoctoral fellows at Northwestern University a few years back. She focuses on implementation issues within rehabilitation, that is the process by which you implement new therapies and procedures and evaluate those outcomes. She has a particular interest and expertise in Parkinson's disease and has a funded project as part of our Research and Training Center on Employment for People with Physical Disabilities, focused on enhancing employment of people with Parkinson's disease. She's identified one of the research participants, a person who has lived experience with Parkinson's disease with whom she'll be talking about the challenges of maintaining employment and strategies that work.

I know we'll also be highlighting the Rehabilitation Measures Database. This is a website that's been underway now for more than a decade. The idea came from one of our research scientists, Trudy Mallinson, she's now at George Washington University but appreciated the incredible value of that internal resource available to therapists that Shirley Ryan AbilityLab – a summary of outcome measures that are suitable for use with our clinical populations. These summaries are a distillation of the literature on the measurement properties of commonly used tests, such as a Timed Up and Go, Six-Minute Walk Test. Those are used widely by physical therapists, for example. Therapists benefit from knowing whether the test results for an individual patient are working within a normal range or particularly high or low, and also interested in the amount of change that occurs over time and whether that change is clinically important. Without a compilation of that information, one would spend an awful lot of time digging through the literature and therapists at RIC had already compiled that information. Trudy had the vision of making that available internationally. And that's why the Rehabilitation Measures Database is a searchable website. It has over 500 instrument summaries curated there. Linda Ehrlich-Jones oversees this activity and works with academic partners across the country to add to and update that information. Routinely, the site gets thousands of hits a day, we get feedback on how valuable the resources in fact, one of our former postdocs, Allan Kozlowski, was just at the physical therapy meeting in California and leading a session on outcome measurement and asked for a show of hands of how many people were familiar with the Rehabilitation Measures Database. He said virtually everybody raised their hand instantly and were very enthusiastic about the resource. So we want to tell our listeners more about that resource in a future session.

SHARON:

For sure. I'm also looking forward to introducing everybody to the other researchers in the Center for Rehabilitation Outcomes Research. Thank you, Dr. Heinemann, I want to thank you for being on the podcast. It has been a pleasure speaking with you.

DR. HEINEMANN:

Well, you're very welcome and I look forward to listening to future podcasts.

SHARON:

This has been INSIDE the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported in part by the National Institute on Disability, Independent Living, and Rehabilitation Research. You can learn more about the Center for Rehabilitation Outcomes Research by visiting our website at SRAlab.org. Forward slash research forward slash

labs forward slash C R O R. Be sure to follow us on Facebook at rehaboutcomes all one word or on Twitter at rehab underscore outcomes. This is your host Sharon Parmet. Signing off. I hope you'll join us for the next episode.