From Apprehension to Assimilation:

How the independent living movement came to infiltrate ACRM and medical rehabilitation culture and practice in the 1970s & 80s

Gerben DeJong, PhD

Photo credit: A Heinemann, PhD

A presentation
to the annual meetings of the
American Congress of Rehabilitation Medicine
in honor of its 100th Anniversary

A special past-presidents' plenary session

"From Gatsby to ChatGPT: How ACRM Shaped Rehabilitation over the Last Century"

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GEORGETOWN UNIVERSITY

ACRM AMERICAN CONGRESS OF REHABILITATION MEDICINE
Improving lives through interdisciplinary rehabilitation research

MedStar National Rehabilitation Network

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How the independent living movement came to infiltrate ACRM and medical rehabilitation's culture and practice in the 1970s & 80s

Gerben DeJong, PhD, FACRM

I want to tell you a story from ACRM's past—45 years ago in the late 1970s and early 80s.

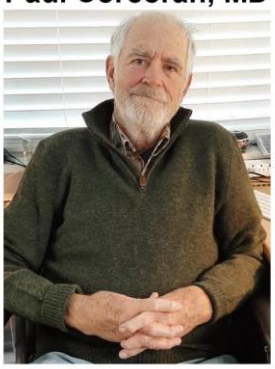
- It is a story of how the independent living movement—the precursor to the disability rights movement and the ADA, came to infiltrate medical rehabilitation back in the late 1970s and into the 1980s and gradually reshaped rehabilitation culture, practice, and research in the decades that followed.
- It is a story of the role that a professional organization and networks can have in shaping, promoting, and validating ideas that otherwise might not be heard and, in the process, enriching our own lives both professionally and personally.
- It is a story of how ACRM can greatly influence the careers of individuals like yourselves.

Just a little about myself: I trained in economics and public policy studies. I came to medical rehab through the backdoor—in 1977: I am not a physician, a therapist, a neuropsychologist, or a rehab nurse. Coming from the outside, I found a medical specialty that was struggling to secure its place in health care. Among other medical specialties, rehab was then considered a backwater specialty.

I also came to medical rehab when the independent living or IL movement was in its ascendancy—a movement of people with disabilities making their claim to full societal participation, to direct their own care, to be fully heard.

The person who sucked me into this space we call medical rehabilitation, was a rehab physician, namely, Paul Corcoran, the person to whom this presentation is dedicated. Paul headed up Boston's Tufts-New England Medical Center's 30-bed inpatient rehab center in the mid to late 1970s.

Paul Corcoran, MD



June 8, 1934 – Nov. 21, 2019

BS, Georgetown Univ.
MD, Georgetown Univ.
U.S. Navy Medical Corps
NYU Rusk Institute resident
Univ. of Washington, MS
Columbia Univ., Asst. Prof.
Boston Univ. SCI program
Tufts-New England Med Ctr, Prof. & Chief of PM&R
Harvard Univ. Founding Chief of PM&R
Spaulding Rehab. Hospital
Boston Ctr for IL, Co-founder

Paul, as it turned out, instinctively knew that physician paternalism would not mesh well with his patients, especially younger ones, who wanted to assert their independence, direct their own affairs, and take their rightful place in the life of the community. This clearly did not fit

well with an insecure physician specialty that was struggling to claim its place among the medical professions.

Paul and I met in early 1977 when I began working on a Massachusetts-sponsored study on user-directed personal assistance services for persons who, for example, had high-level spinal injuries. When the study was finished, Paul insisted that I come work with him and that he had the research funds to get me started.

More importantly, working on the personal assistance study and working with Paul, gave me a front-row spectator's seat in watching the evolution of the independent living movement in the U.S. and abroad. Within months I had met many of the movement's leaders and was quickly taken into their confidence—though I was "severely abled-bodied" at the time. In short order, I met Judy Heumann, Ed Roberts, Fred Faye, Lex Frieden, Irv Zola, Max & Colleen Starkloff, Elmer Bartels, and many more—all iconic names in the independent living and disability rights movements.

They distrusted medical rehab types and wanted to distance themselves from a rehab culture they felt disempowered them. They sensed that I was not a "rehab type"—at least not yet, i.e., one of those white-coat providers that patronized them. I had not been professionally marinated in the rehab culture of the time. I was still very naïve, a blank slate. Being naïve, there was not a whole lot I had to unlearn—and yet, there was a lot for me to learn.

I soon started crafting a monograph-length paper on what the IL movement was really all about: how it fit into various time-recognized social movements in American history, how its values contrasted with traditional medical rehabilitation values anchored in the medical paternalism of its time, and what it meant for research going forward.

ACRM Insurgents

Unknown to me, there was this organization called the American Congress of Rehabilitation Medicine. And, within its ranks were a group of insurgents—physicians, therapists, nurses, psychologists, researchers who, like Dr. Corcoran, knew that traditional white-coat standoffishness was not the wave of rehabilitation's future—and trying to figure out how ACRM and its multi-disciplinary membership should respond to an emerging consumer movement that was challenging much of rehabilitation practice and culture back then.

ACRM "insurgents"

ACRM SEAR Committee

Gary Athelstan, PhD
Paul Corcoran, MD
Jean Cole, PhD, OTR
Nancy Crew, PhD, Chair
Mary Romano, MSW
Roberta Trieshmann, Phd
Irving Zola, PhD

Insurgent sympathizers

William Spencer, MD
Thomas Anderson, MD
Henry Betts, MD
Elisabeth Sandel, MD
And others

Paul insisted that I meet these ACRM insurgents. He encouraged me to submit my newly minted paper for presentation at ACRM's annual meetings in New Orleans in November 1978.

In my ACRM audience, was a listener who some of you remember. His name was Don Galvin, the director of Michigan State University's Center for International Rehabilitation in East Lansing, Michigan—and who years later became head of CARF—and who was instrumental in the lives of two other ACRM presidents, namely Denise Tate and Deborah Wilkerson, and in the life of another ACRM laureate, Chris MacDonnell .

Donald Galvin, PhD
Nov 24, 1935-Mar 5, 2012

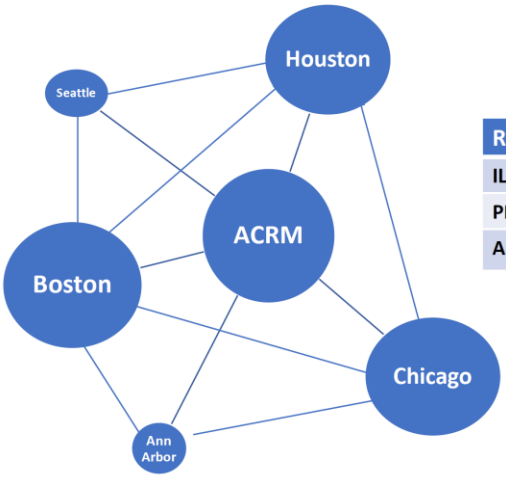
A week later, Don called me in Boston and asked if his university center could print 3,000 copies of the paper, which sold out immediately and then reprinted.

At the ACRM New Orleans meeting, I was also introduced to a whole network of people who quickly adopted me as one of their own, even though I was an outsider and had absolutely none of their clinical credentials. They had formed what was known as the SEAR Committee—the analog to what we today call an ACRM special interest group. It became the ACRM vehicle for mobilizing member interest around the issues spawned by the IL movement.

ACRM's emerging IL-medical rehabilitation network

But ACRM also sparked new IL-medical rehab collaborations at the local level, three in particular—in Houston, Boston, and later Chicago. Each location involved a similar triad of actors:

- A nationally recognized IL leader with a spinal injury,
- A nationally recognized PM&R physician "sponsor," and
- An able-bodied behind-the-scenes "enabler," if you will.



ACRM as the vital node in a deep learning IL neural network

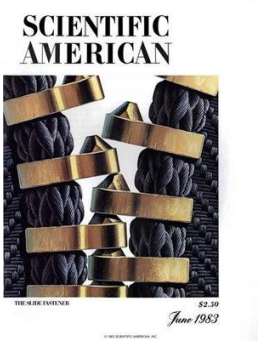
Role	Houston	Boston	Chicago
IL leader	L Frieden, MA	F Fay, PhD	M Bristo, RN
PMR doc "sponsor"	W Spencer, MD	P Corcoran, MD	H Betts, MD
Able-bodied enabler	J Cole, PhD	G DeJong, PhD	H Goodkin, BA

Seven of these 9 individuals were also ACRM members—and all 9 came into ACRM's orbit at one time or another. In short, local initiatives mirrored what was happening within ACRM at the national level and ACRM mirrored what was happening at the local level.

Later we saw additional local initiatives where ACRM members were sprinkled, such as those in Ann Arbor, MI, Seattle, WA, and many others to form an even larger network of shared interests.

How ACRM shaped one member's professional career

The ACRM insurgents—those on the SEAR Committee, decided they wanted to publish a special issue of the *Archives* on independent living in October 1979—and wanted to make my paper the lead article. But that was just the beginning. Since then, the paper has been reprinted 16 times—in multiple anthologies, foreign journals, conference proceedings; translated into 7 languages; and greatly plagiarized.



That exposure also started a wave of invited speeches throughout the country and abroad, an invitation to co-write the lead article in the June 1983 edition of *Scientific American*, and a Fulbright in the Netherlands (1984). One thing led to another. In early 1985, I was invited to become the founding Director of Research for a new rehabilitation hospital then being built in Washington, DC, namely the National Rehabilitation Hospital,[*] [†] which led to a faculty appointment to the hospital's academic affiliate, Georgetown University School of Medicine.

FULBRIGHT Scholar Program

That early start in ACRM led to a career-long engagement with ACRM, its various committees, special interest groups, the ACRM Board, and its presidency in 2006-07. And it has not stopped there.

ACRM's value proposition for today's members

Here is a thought experiment: Ask yourself:

1. What if there had been no ACRM back then?
2. What if there had been no *Archives of PMR?*

[*] National Rehabilitation Hospital is now MedStar National Rehabilitation Hospital (MNRH). Its early leaders came disproportionately from the ranks of ACRM membership: Edward Eckenhoff (President); John W. Goldschmidt, MD (Medical Director); Dorothy ("Dotty") Gordon, DNP (Vice President, Nursing); Mary Romano (Director of Social Work), Donald Galvin, PhD (Director, Outpatient Physician Services and Strategic Planning); Ruth Brannon (Research Administrator); Deborah Wilkerson (Director, Program Evaluation) and Gerben DeJong, PhD (Director of Research).

[†] Four MedStar NRH leaders have also been ACRM presidents: John W. Goldschmit, MD (1974-75); Dorothy Gordon, DNP (1989-90); Deborah Wilkerson (2002-03); and Gerben DeJong, PhD (2006-07).

3. What if there had been no ACRM-like venue for Don Galvin to attend?
4. What if there had been no ACRM networks to plug into?
5. How would one's career been different had there been no ACRM?

When we think of ACRM and the local initiatives mentioned here, it is helpful to think how all of these were but nodes in ACRM's neural network at the time. ACRM provided the synapses that linked these nodes. By being a part of ACRM, one becomes part of a very "plastic" learning network, to use a neuroscience metaphor—not just a self-serving, self-indulgent professional organization narrowly advocating for its own interests.

I want to say welcome to all of you who may be new or still relatively new to ACRM. I hope that you will find a welcoming professional network as I did 45 years ago. Today, ACRM is a vastly different organization: It is a larger, broader, more global, professional home with many different formal and informal networks to accommodate the varied interests and disciplines, that shelter under its roof.

You can say that ACRM turbo-charged my career. It can do the same for you!

In closing

This is not just story about one person's early career, but more importantly, a story of how the independent living and disability rights movements came to shape rehabilitation culture, practice, and research. Many of the things we do today, especially the manner in which rehab professionals relate to people they serve in their hospitals and clinics, were reshaped during the late 70s and into the 80s in ways we now take for granted.

The way we practice and conduct research, did not just happen: It came in response to a movement set in motion by people who no longer wanted to viewed as objects of professional beneficence, but as agents of their own betterment who were entitled to full participation in the life of the community and all that it entails.

ACRM can take pride on being on the right side of history when it mattered most.

Other past ACRM presidents also had early careers immersed in issues precipitated the IL movement. Two are noted here.

Deborah Wilkerson
ACRM president
2002-03

Deborah's early exposure to the IL movement included experiences in North Carolina, San Francisco Bay area, and later in Seattle where she had a lead role in evaluating IL programs under the auspices of the Department of Rehabilitation Medicine at the University of Washington (1979-83). Wilkerson never lost her IL consumer perspective. She brought a strong consumer commitment to outcome measurement and quality improvement.

Gary Ulicny, PhD
ACRM President
2010-11

Gary's early exposure to the IL movement was at the University of Kansas' Research & Training Center on Independent Living in the early 1980s which shaped his philosophy of providing services to people with disabilities. This carried over into his role as President and CEO of the Shepherd Center in Atlanta, GA. While president, Gary also served as board chair for the local IL Center for 10 years.

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Disclaimer: *The full story here is broader, deeper, more textured, and more nuanced. This narrative is intended to be concise and linear from the perspective of one participant in the interest of the 12 min. allotted for this presentation.*

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