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Max Starkloff and the Fight for Disability Rights

by Charles E. Claggett Jr. with Richard H. Weiss

Joan L. Headley, Executive Director, IVUN

Recently I attended a reading from the book, *Max Starkloff and the Fight for Disability Rights*.

After a C4-5 injury due to a car accident at age 21, he ended up in a nursing home for 12 years beginning in 1963. He received a letter from our founder, Gini Laurie, asking him, "What are you doing in a nursing home?"

Author Charles E. Claggett Jr., marketing vice president at Warson Brands, described the book as the love story between Max and a physical therapist at the facility, Colleen Kelly, who became his life-long partner in marriage and in activism. Barriers to moving out of the nursing home, adopting children, making St. Louis accessible, and more, constantly faced them. Claggett describes the book as a thriller enticing the reader to see how Max removed the next barrier.

I knew Max. He was an already-established leader of the independent living movement when I arrived in St. Louis in 1987. I was on his board (Paraquad) and he was on mine (Gazette International Networking Institute/IVUN) for years.

In the early '90s, our offices were in the same building. On days that I was frustrated with all the work

or finding money or, as he put it one day, "hoping for the time he'd not have to worry if there was toilet paper in the bathroom for staff," I would go up to his office and we'd talk philosophy. I learned from Max that the most important thing is to learn from past mistakes, even laugh about them, and to always keep looking and moving ahead bringing along as many as possible.

As a quad, he used BiPAP for years and eventually was trached. I recall a

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discussion we had about how exhausted he was when he was trying to be weaned from the vent. "I can't do my work." I queried whether being weaned was more important. "I hate the way I sound on the phone using the vent." I assured him that it would get better with practice and it did.

He continued his work for another four years, until he died in 2010. Doing for others what he said Gini had done for him. "I found myself at the table at meetings, thinking how did I get here? She had paved the way." ■

Max Starkloff and the Fight for Disability Rights is published by the Missouri History Museum and can be purchased online at <http://mohistory.org/node/9670>.

