

They Did It Themselves

By Gary Karp



Expert Forum



The current process of people with disabilities dramatically emerging into society didn't happen thanks to the charitable generosity of others. It didn't happen because enlightened policymakers saw the value of investing in accessibility and civil rights. It didn't happen because business saw an untapped talent pool or a market of unspent disposable income. It didn't happen because family members and clinicians could see firsthand that people were being unnecessarily denied their quality of life.

The current process of people with disabilities dramatically emerging into society didn't happen thanks to the charitable generosity of others. It didn't happen because enlightened policymakers saw the value of investing in accessibility and civil rights. It didn't happen because business saw an untapped talent pool or a market of unspent disposable income. It didn't happen because family members and clinicians could see firsthand that people were being unnecessarily denied their quality of life.

People with disabilities did it themselves.

I'll never forget a comment from the late Dr. Doug Martin, who I interviewed for a profile in *New Mobility* magazine. Doug was a man with an Urban Design degree (and a significant disability since birth) who accomplished some stunning accessibility solutions at UCLA. He said to me, "When you put obstacles in people's way, you bring out the militant in them."

That's exactly what happened. People got really tired of being told what they couldn't do. People got really tired of being kept from what they clearly knew was possible; tired of being cast in the medical/sympathy model of disability. They had a clear vision of lives of greater independence and accomplishment – kept just beyond reach.

Ed Roberts was quadriplegic with post-polio. When UC Berkeley denied him admittance in the sixties, he successfully took the school to court – and the State of California which was refusing to pay his tuition through Vocational Rehabilitation. They said he'd never work.

While Roberts earned his degree in political science, he and other students with disabilities began providing services to expand access to the university. They were also responsible for the first curb cuts in the U.S., right there in Berkeley. Soon

They Did It Themselves

By Gary Karp



Expert Forum

people around the country were looking to their model to provide similar services – at schools and in the general public.

Thus was born the independent living movement – and an entire modern disability movement.

The true poetry of Roberts' story: in 1975 he was appointed director of the California Department of Vocational Rehabilitation. He'll never work, eh? Judy Heumann earned a teaching degree, but was denied a certificate. Her wheelchair, they said, rendered her unsafe in the classroom. She fought and won, too. Judy is now at the U.S. State Department, fostering disability awareness and independence globally.

There are many, many, many more notable names and stories, but hopefully you're getting the idea here. A substantial cohort of highly educated people with disabilities like Doug, Ed, and Judy, successfully dealt with the upper echelons of power and society, skilled in advocacy and negotiation, finessing the political system to forward an enlightened disability agenda.

All of which leads directly to the signing of the Americans with Disabilities Act in 1990 (thanks to some other heroes of the movement: the late Justin Dart, and his wife Yoshiko who's still out there fighting the good fight).

It has sometimes taken more than sophisticated advocacy. Disability leaders like Bob Kafka and Stephanie Thomas of ADAPT were more than happy to take things to the next level and lead people to chain themselves to buses or occupy offices when talk wasn't getting anywhere. That's how Greyhound was forced to start buying accessible buses – which they were refusing to do despite an agreement that granted them extra time following passage of the ADA.

In 1973 people with disabilities occupied the Health and Human Services offices in San Francisco to force signing of the Section 504 regulations which made discrimination against people with disabilities illegal in the Federal government and its contractors, already approved by Congress, but delayed by the Carter Administration. It remains the longest occupation of a federal building on record to this day – and the regulations were signed without revision.

I owe the custom-built titanium wheelchair I'm sitting in now to the likes of Rory Cooper, Marilyn Hamilton, Peter Axelson, and Ralf Hotchkiss, who found themselves paralyzed and assigned the standard-issue chrome folders of the day,

They Did It Themselves

By Gary Karp



Expert Forum

knowing they could do better. So they did. The lead designers – and business entrepreneurs – of today’s extremely sophisticated mobility tools are largely chair users themselves.

Thanks to such people, what it means to have a disability (and my own life) has been utterly transformed. Yet the work continues. While mobility, public accessibility, technology, and civil rights protections have unleashed a huge population of people who are contributing in every level of society, access to housing is still extremely limited, people are still forced into institutions by simple matters of policy language, and rehabilitation benefits have been severely cut back. The disability community is still hard at work making change.

Of course, many people without disability had meaningful supporting roles in the process. The recently-retired Senator Tom Harkin, D-IA is one notable example.

But they didn’t initiate or energize this radical, historic change that has been occurring around us. People with disabilities did that. Themselves. Here’s the great irony of all of this: society still tends to see people with disabilities as dependent and limited, believing that decisions should be made on their behalf by presumably well-meaning able-bodied folk who are supposed to take care of “the disabled.”

But when you look at what really happened, it is the very proof that people with disabilities are absolutely capable of the kinds of hard work, innovation, leadership, and vision that serves our society so well – in their families, their communities, and in the workplace.

In fighting for the right to inclusion, they have more than proven their fitness to contribute. For real.

It’s time we got the story straight.