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Being Heumann

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October is Disability History Month, an annual opportunity to reflect on the history of the disability rights movement and honor the achievements of people with disabilities. Since I knew I was planning to preach about disability justice this month, I finally made time a few weeks ago to watch the documentary [Crip Camp](#). I had heard good things about it, including that Barak and Michelle Obama were executive producers, but I was still blown away by how powerful and compelling it was.

The film combines two of my great loves: summer camp and social justice. *Crip Camp* is the affectionate and subversive nickname for Camp Jened, a summer camp for young people with disabilities that was founded in 1951 in the Catskill Mountains of New York—and which came to be strongly shaped by the hippie counterculture of the 1960s and 70s. Young people with disabilities who were often isolated much of the year found themselves immersed each summer in this temporary utopian community of a summer camp that compassionately and joyfully *centered* the needs of people with disabilities instead of marginalizing them. And the film shows how these early formative experiences at Camp Jened helped shape and empower many future activists in the disability rights movement.

One among many people featured in the film was Judy Heumann, who attended Camp Jened every summer from ages 9 to 18, and later become a major leader in the disability rights movement. Her starring role in the film made me even more excited than I had been previously to read her excellent memoir, published this year by our own

Beacon Press. But before I tell you more about her, I want to take the time to show you a short video about the film *Crip Camp*. It's only about two minutes, and it will give you a better glimpse into what I'm talking about.

As you may be able to tell from even that short clip, *Crip Camp* is a remarkable and inspiring film about disability justice. So much progress has been made, even as much work remains to be done to create a more accessible and equitable world for all.

A few years ago, I preached a sermon on the 25th anniversary of The Americans with Disabilities Act of 1990, often referred to by its abbreviation (ADA). That bill was and continues to be transformative for the millions of Americans living with disabilities. And it is remarkable and inspiring to learn more about the activists who made the ADA possible—especially when you remember that those disabilities rights activists did not yet have, of course, the support of ADA-based assistance. There were so many hurdles that had to be overcome to secure basic human rights for citizens of this country living with disabilities.

And on this Sunday in Disability History Month, I want to share with you a little more about Judy Heumann in particular. She was born in 1947, and became a quadriplegic after having polio at the age of 18 months (4). That means she lived more than four decades of her life without the support of legislation like the ADA. We know now that she is brilliant, inspiring, charismatic, and more. But when she was two years old, her family doctor recommended that she be institutionalized due to her disability. Heumann writes that she bears no ill will toward that doctor who was simply given the standard medical advice of the time, but fortunately for her and for the world, institutionalization was not an option her parents considered (xi).

Looking back on how she was able to break through so many barriers in her life, she writes, **“I simply refused to accept what I was told about who I could be. And I was willing to make a fuss about it”** (3). I'll give you a few examples from her life.

The first was access to education. Although a basic education has been compulsory in this country since 1918, significant discrimination remained against anyone with a disability (21). And Judy Heumann was told that she couldn't attend public school because her wheelchair was a fire hazard (8). But both she and her

parents persisted for years and eventually were able to secure her access to public school.

In college, she lived away from her parents for the first time. This was the late 1960s—again, decades before the ADA—so the two steps up into her dormitory and the one step up into the bathroom were significant hurdles that her electric wheelchair could not overcome. She writes that:

Every day, every time I had to go to the bathroom, or into my dorm, or to class, I had to ask somebody to help me up the steps.... The bigger challenge...was in the morning and at night, when I needed help getting my braces on and off, getting dressed or undressed, and in and out of bed. (39)

Many times her roommate was around to help, but not all the time.

These are just a handful of the times that it would have been so much easier in the short run for her to just give up. But her life is a consummate example of “Nevertheless, she persisted.” And learning more about her life repeatedly made me think of our UU Seventh Principle, “Respect for the interdependent web of all existence of which we are a part.” We often talk about that principle in terms of environmental justice (and I fully support that), but it’s also helpful to consider our Seventh Principle from a disability justice perspective. Heumann lived such an existential, embodied example of *interdependence*: of being forced to ask for help from others and, in turn, of working together with others to create systemic change. The disability rights movement challenges us to ask not only what do *I* need, but also, through a lens of the interdependent web, to ask, “What do *all of us* need to survive?”

The most dramatic action that Judy Heumann helped champion was the Section 504 Protest in 1977. This episode is covered in depth in the film *Crip Camp*. But I’ll give you a few of the highlights. Section 504 of Title V of the 1973 Rehabilitation Act was a law that prohibited discrimination against people with disabilities in institutions and programs receiving federal funding. That sounds good, but it wasn’t being enforced (95).

When Judy and a delegation of other disability rights activists—many of them friends since Camp Jened—visited the Federal Department of Health, Education, and

Welfare to advocate for the law to be followed, the Regional Director attempted to stonewall them. In response, they refused to leave. More than a hundred people with disabilities occupied that federal building for twenty-four days until finally the enabling regulations were signed (146).

There's so much more to say about Judy Heumann's remarkable life, and how she has continued to break barriers. From 1993 to 2001, she was Assistant Secretary of the Office of Special Education and Rehabilitation Services at the US Department of Education (176). From 2002 to 2006, she worked as the World Bank Group's first Advisor on Disability and Development (185). And from 2010 to 2017 she was the Special Advisor on International Disability Rights for the U.S. State Department. Most recently, she served as a Senior Fellow at the Ford Foundation to help advance the inclusion of disability in the Foundation's work.

As Unitarian Universalists, our living tradition draws from Six Sources. Of these six sources, the second is the "Words and deeds of prophetic people which challenge us to confront powers and structures of evil with justice, compassion, and the transforming power of love." Judy Heumann is one of those prophetic people.

We live in a time when the systems and structures of this world are too often being shaped by injustice, cruelty, and hate. But the example of activists like Judy Heumann can encourage and embolden us to continue working together for justice, compassion, and love. As we continue to hold in our hearts the call to create a more accessible and equitable world—an interdependent world that includes all of us—***let's sing together "How Could Anyone."***