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Polio, Devalued Bodies and Disability

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It is, perhaps, a very opportune time to be discussing devalued bodies. After all, we live in very precarious times socially and politically.

Similarly, these are also interesting times for the disability community. On the one hand, our rights and hard work for disability justice are still unfamiliar and ambiguous to many around the world. While on the other hand, academia is forging ahead into uncharted territories through the academic discipline called disability studies.

My interest in the issue of devalued bodies and the problem of what constitutes mobility and walking in contemporary society derives from my own personal experience with polio. I was diagnosed with poliomyelitis at the age of 18 months. I spent countless hours in the hospital for a multitude of reasons that included surgeries, rehabilitation, physical therapy, limb measurements, construction, fitting and walking rehearsals with new braces. As a toddler, I never felt or thought anything was different about me. Perhaps, I was naïve. Though, even as I was introduced to my first pair of braces and crutches, I still did not notice any difference.

It was not until I was about seven or eight that I first experienced an awareness of my difference—as a result of being encouraged to participate in a national crusade that came with a promise of being able to walk again. I was confused because, in my own eyes and mind, I was fine. However, the world saw me as different. This was the beginning of my political awakening. It was the beginning of my stance in defining who I was. It was the beginning of saying YES to my spiritual self—my true being. I want to publicly declare that I am DISABLED AND PROUD! I AM HAPPY WITH WHO I AM—YES, WITH MY CRUTCHES AND BRACE, I AM HAPPY. I AM HAPPY TO BE ALIVE AND TO BE HERE TODAY. I choose to challenge the myth that the polio body is not worthy or valuable due to its paralysis.

We as a society have failed to acknowledge that walking with crutches and rolling with wheelchairs are themselves forms of walking, ones that were created by rehabilitation experts. We have failed to embrace polio survivors as a people who have taught us to accept our bodies even though it might walk/roll or perform life's daily functions differently. We have failed to promote that not all forms of walking are the same.

The fact of the matter is that polio bodies have always been devalued.

Polio was one of the most misunderstood and feared diseases in the 20th century. It was sometimes referred to as infantile paralysis or “thecrippler of children,” and even the strongest of children were more susceptible to getting the disease than some of the weakest seniors. Those who managed to survive were left with twisted backs, withered limbs and bodies that no longer could run and play. It is no wonder that the “normates” are mostly afraid of these bodies. If we are to be honest, it is these kinds of bodies that are perceived as abnormal and that cause discomfort in mainstream American culture and society.

This space where disabled and/or polio bodies are threatened and devalued is where disability justice



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is greatly needed. Disability justice, as described by disability advocate Mia Mingus, is a “political understanding of disability and ableism, moving away from a rights based equality model and beyond just access, to a framework that centers justice and wholeness for all disabled people and communities.”¹

Disability justice challenges us to embrace, to love, to empathize, to be friends with, and to see people with disabilities as one of us. It is doing more than securing rights for disabled people; its aim is to challenge the status quo and the very meaning of disability. It is asking all of us to make a more just world for all of our disabled brothers and sisters, including survivors of polio.

I have spoken openly about what I believe healing means and choose to do so in this space because I want to reflect on the fifth principle of disability justice, which is recognizing wholeness.

The moral or religious model views disability as a form of punishment inflicted on a person and or his or her family. Growing up in Sierra Leone in the 1980s, I was urged to attend spiritual Christian crusades for the purpose of receiving my wholeness. I needed to stand in front of 5,000 people to receive my healing. Some of my affectionate friends and family members were convinced that with prayers and Godly intervention, I would be healed. In their eyes, because I was on crutches, I was not complete. I do not mean to devalue the power of prayer or their genuine affection for me, but only to point out that they did not see my wholeness because of how people with crutches are perceived and valued in that society. They meant well but did not understand the ramifications of their actions. Walking with crutches does not mean that you are less than. I am a human being first and foremost. I have inherent worth. Simply, I stand up against the societal notions of perfection and normalcy that devalues certain bodies that fall outside the norm.

Historically, polio survivors found a way to cope and adapt to many of the social obstacles that they encountered. Many of these survivors became the agents of the disability rights movement, the architects of the Americans with Disabilities Act and the pioneers of disability studies. They included Ed Roberts, father of the independent living movement; Judith Heumann, a former Assistant Secretary of Education under President Clinton and co-founder of the World Institute on Disability; and Justin Dart, Jr., co-founder of the American Association of People with Disabilities, and one of the instrumental figures that helped pass the American with Disabilities Act of 1990.

In spite of the devaluing of polio bodies in American society and across the globe, polio survivors and others joined forces to lobby against discrimination. “They demanded ‘equal access’ to public transportation, public accommodations and telecommunications, to school and work, to ‘independent’ or ‘congregate’ living in the community rather than in institutions.”²

The story of the emergence of the disability rights movement and its academic arm—disability studies—could not be told without acknowledging the prominence of polio survivors among the movement’s leaders. Heumann, Roberts and Dart all played central roles in the early years of the disability rights and independent living movement. Scholars and artists such as Irving Zola, Paul Longmore and Anne Finger all were instrumental in gaining recognition for a new interdisciplinary approach to disability known as Disability Studies. What all of these individuals have in common is not only a shared passion for the rights of people with disabilities, but a grounding of that passion in their personal experience with polio and its aftermath.

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The discrimination and prejudice those polio survivors and other people with disabilities faced in the middle of the twentieth century led to the struggle for change in the streets and in the law. The disability rights movement was not as visible as the civil rights movement, but it took place in the same venues where African-Americans protested, the streets and the courts.³ Lawsuits were filed, demonstrations took place, new organizations were born and a number of disability rights leaders helped pave the way for a better America.

The disability rights movement started with survivors of polio who were courageous and unafraid to challenge the status quo. In 1970, wheelchair user and polio survivor Judith Heumann filed a lawsuit against the New York City Board of Education when her application to secure a teaching certificate was denied because of her obvious impairment. The board explained that people with disabilities were perceived as fire hazards. Heumann was asked to

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demonstrate how she used the bathroom, but she told the doctor that unless it was a requirement for her to teach children, she was not going to do it.³

Through the resilience of polio bodies, we learn that all bodies matter. These bodies matter because they are worthy. They matter because polio bodies are sacred bodies that teach us about what it means to live with broken and rejected bodies. They matter because they have experiences that can instruct us in new ways of living and seeing the world. They matter because they exhibit the power of the human spirit. ■

1 Taormina-Weiss, Wendy. "In Pursuit of Disability Justice." *Disabled World*. 2013.

2 Longmore, Paul K., and Lauri Umansky, eds. *The New Disability History*. NYU Press, 2001.

3 Fleischer, Doris Zames, and Frieda Zames. *The Disability Rights Movement: From Charity to Confrontation*. Temple University Press, 2001.

Gini also realized networking could serve other goals. In 1959, she led a letter-writing campaign in support of national attendant care legislation. It was unsuccessful, but showed her the importance of collective action.

"Networking links people who share common needs or common goals," she wrote. "Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all, it is a method by which people get things done."

Anyone paying even cursory attention to the health care debate that consumed Washington for much of the year can see that this is self-evident. From the more visible protests from groups such as ADAPT to the quieter campaigns from organizations urging their members to call their congressional representatives and make their position known, disability organizations demonstrated the power of networking and collective action to advocate for our shared interests. We saw that when we band together, we amplify our voice and let others know that "WE'RE STILL HERE!"

—Brian Tiburzi, Executive Director

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