

*A Celebration of Difference*<sup>1</sup>  
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*Allen Avenue Unitarian Universalist Church*  
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This weekend we celebrate the birthday of the Rev. Dr. Martin Luther King, Jr. It is a time to reflect on the ongoing struggle for equality and justice, and to ask the question of who is included or excluded in our understandings of human dignity and human community. Today I will be exploring the celebration of difference, from a parallel struggle for equality, as expressed in the life of disability activist Connie Panzarino. Today is also a time to ask, how can we help to serve the value of equality and the celebration of difference.

*Reading:* From *The Me in the Mirror*, the autobiography of Connie Panzarino<sup>2</sup>

When I got word that the town was building a new library just a few blocks from my home, I was ecstatic. I loved to read. If there was a library so close, I could be wheeled there by a friend.

Towards the end of my first year [in high school], the new library was completed. To my dismay, there were over a dozen steps at the entrance, making it totally inaccessible to me. My disappointment quickly turned to rage, and I called the library.

“Hello, my name is Connie Panzarino. I would like to know when your next board meeting is?”

“Let’s see, oh yes, it’s on Wednesday, June 18th at 8 p.m. in the board room in the basement of the library,” replied the woman who answered the phone.

“Thank you. I would like to discuss the inaccessibility of the library at that meeting. Is there anyone I can talk with to get that arranged?”

“Yes, I will talk to the chairman and see if he can put that on the meeting agenda.”

“Also, I’d like to mention that I’m in a wheelchair, and I would like to come to the meeting with several other friends who may be in chairs too. Is there anyone who can help us in since there isn’t a ramp?”

There was a pause. “I will have to check with the chairman on that. May I have your number so he can call you back?”

...Several days later the chairman called and said that he and the other trustees would be happy to assist in carrying us downstairs to the basement.

... I got five adults in wheelchairs to go with me to the board meeting. All of them were big, heavy people, the heaviest I could find. Then I called the local newspaper and asked them to cover the meeting because it was going to deal with a very important issue.

The night of the meeting we all assembled outside the rear library door that went to the basement. ...Dad went down the stairs and came back up, followed by seven or eight middle-aged and older men in business suits. ...

“How can we help?” offered the chairman.

“Well, sir,” replied Roy, a large middle-aged man..., “we need you to carry us down the stairs, unless there’s another entrance with a ramp.”

“No problem,” said one of the other trustees. “Just show us how to do it.” He looked at my father.

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2 Connie Panzarino, *The Me In the Mirror* (Seal Press: 1994), pp. 100-102.

“Don’t look at me,” Dad replied. “I have a bad back. I can help carry [my daughter] down, ...but I’m afraid these guys are too heavy for me.” Dad winked at me and tipped me up on my back wheels and bounced me gently down the steps. The man from the local newspaper began snapping pictures.

Dad and I sat in the conference room and waited to the sound of a great deal of thumping, panting and groaning. One by one the people in wheelchairs rolled into the room. We smiled at each other and remained quiet. ...Dad leaned over to me and whispered in my ear, “Wait’ll they have to carry everybody up again.”

After about a half an hour, the trustees assembled and ran their usual business meeting. The last item on the agenda was the inaccessibility of the library.

“Is there any need to discuss the fact that we must make this library accessible, gentlemen?” the chairman addressed the other trustees.

“No,” chorused the trustees.

...Four months later, the woman from the library called. “The chairman of the Board of Trustees on the library would like to invite you to the opening of the new ramped entrance to the library.”

#### *Sermon:*

Connie Panzarino was a disabled lesbian activist, artist, art therapist and writer. I met her when we both lived in Jamaica Plain, Massachusetts. Connie was born November 26, 1947 and I was present with her when she died July 4<sup>th</sup>, 2001 at the age of fifty-three.

People with disabilities are sometimes pitied as tragic figures, or put on a pedestal as heroic examples of overcoming obstacles. I don’t want to do either of those things today, but I wouldn’t be telling you about Connie’s life if I weren’t inspired by her. I was inspired not because she overcame obstacles. I was inspired by the vision she held for transforming the world, and by the creativity with which she lived that vision, and explored its possibilities throughout her life.

Connie wrote, “No matter what I leave behind, it is my biggest wish that each of you carry in your hearts the love and appreciation of difference.” This celebration of difference was the guiding value of Connie’s life. Connie believed that every person has unique gifts and particular needs. Every gift deserves to be honored, and every need deserves to be respected. Every person is part of what makes all of us human.

Connie was born with Spinal Muscular Atrophy. It is a disease affecting the nerve connections in the spine, and control of the voluntary muscles. She was never able to walk, and eventually was unable to move her arms and hands, and needed a ventilator to help her breathe. Another common feature of Spinal Muscular Atrophy is higher than average intelligence, and Connie was a genius. At seven months, she was already talking, as she lay in her mother's arms at the doctor’s where they were trying to find out why she wasn’t beginning to crawl.

Connie began changing the world by claiming for herself the right to live a full life. She made significant contributions to gaining rights for people with disabilities. Some of these battles were fought in the public eye--such as the fight to get a ramp for her neighborhood library. Many more were quiet and behind the scenes: she had to battle for the right to attend school, for connection to friends and peers, for adequate medical treatment.

I want to tell you about one struggle in particular, because it was such an important gain for people with disabilities, and because it reveals the contradictions between the society we live in, and Connie's vision of a world in which difference is accepted and celebrated.

Like most young adults, Connie wanted to move out of her parents' home and live on her own. In the late 1960's, she became one of the first disabled students at Hofstra University. Two years after graduation, she got a job at the Department of Social Services. But once she got a job, she encountered a whole new catch-22.

Connie was a competent and creative employee. Yet, she also needed personal care attendants to lift her from her bed every morning, to bathe and dress her, to help her go to the toilet. She needed someone to help with meals, and with going to bed at night. On a social service salary, she couldn't afford to hire her own attendants, but because she was working, the government declared her no longer "disabled" and thus not eligible for benefits which would pay for her attendant needs.

Connie came up with a creative solution. She helped another disabled friend move out of a nursing home to share an apartment with her. Her friend was eligible for attendant care benefits. They supplemented these funds by offering a live-in arrangement, and the attendants they hired did personal care for both of them. Connie was always including others in her visions. She knew from necessity that together we can accomplish more than we can do alone. Both she and her friend were thus able to achieve the self-determination that every young adult desires.

The solution worked for a couple of years, but not without difficulty. The wages they were able to offer were low and it was hard to find steady attendants. Over a two year period they had eighty different aides. Eventually, her friend decided to move out on her own, and Connie no longer had a way to pay for attendant care.

At that point, she began to confront the system itself. Why should a disabled person who was working, not be eligible for attendant care funds? Certainly, it made more sense that she be able to contribute to society through her work, be able to earn wages and pay taxes, rather than not work in order to have the help she needed just to survive. She also met with another problem: now that she had been working, she was classified as "able to work," and thus would not be eligible for any assistance even if she left her job. None the less, she filled out a Medicaid application for attendant care, and when it was refused, she began an appeal process.

In the meantime, she tried finding an aide in exchange for free room and board. She got some help from friends, but also found herself up all night in her wheelchair when there was no one to help her transfer to bed. She strategized with all the activists she knew. She called the Secretary of Health, Education, and Welfare in Washington, DC. At first he reassured her that of course she could work and get attendant care. Later, a secretary called back, to say, sorry, there is no way to provide attendant care for someone who works. After a couple of weeks, her stomach ulcers acted up, she got a fever and lung congestion, and in desperation called her doctor. She explained her situation on the phone.

“Dr. Madonia, I’m pretty sick. I have 102 degree fever, but I’m afraid to take antibiotics because my ulcers are acting up. Besides, antibiotics always make me have to go to the bathroom and I don’t have an attendant right now.”

“What do you mean? When’s she coming back?”

“Well you see, I don’t have attendant care now because I’m working and I can’t share Priscilla’s attendant because she doesn’t live here anymore so some of my friends have been helping me out, but the law says even if I quit working I’m not eligible because I am able to work, and I should work, and I don’t think I can figure this out now...”

[Dr. Madonia replied,] “You are not able to work right now, you have a 102 degree fever, and I forbid you to work. You are under doctor’s orders not to work. You send someone back to Medicaid to tell them you are disabled, your doctor says so, and if they want an argument they can see me in court.”<sup>3</sup>

The next day, Connie turned in her resignation at work, applied for temporary welfare and Medicaid, and permanent Social Security Disability benefits. Within 24 hours she had an attendant, antibiotics and was in bed recovering. But that’s not the end of the story. As soon as her fever went down, she called *Newsday* and told them what had happened. They sent a photographer to document why she needed attendant care. The next day her story was on the front page of the paper. Some of the photos showed an attendant transferring her in a Hoyer mechanical lift on and off her bed.

She wrote,

Some of my friends with disabilities were appalled that I allowed myself to be shown to the able-bodied public in a vulnerable dependent position because they felt it would increase oppression by encouraging the stereotype of the “helpless cripple.” I believed that in order to have our needs met we needed to stop trying to “pass” in the able-bodied community and pretend that we were self-reliant because that fed the misconception that attendant care was a frivolity rather than a necessity for life support.<sup>4</sup>

Her friend, John Kelly, later wrote, “For Connie, needs were simply needs, and had nothing to do with the value of life.”

Her story got picked up by more and more news outlets, and the fight was on. Legislators began calling her at her home. One senator offered to write a bill just for her, as an exception to the rule, but she refused--there were many people with disabilities who could work, but needed attendant care. She and her activist friends formed a coalition called Disabled in Action of New York. During that year she helped in writing eleven local, state and federal bills and policies to attempt to rectify the situation. She also filed a lawsuit, and began a lengthy court process.

It took years, but eventually, the laws were changed. Over ten years later, in 1986, she was able to accept a position as director of the Boston Self-Help Center, and retain her attendant care, because of those earlier battles. John Kelly spoke about Connie’s political work at her memorial service. “Connie was an activist every day of her life, from her childhood to her last hospitalization. Wherever she was, she joined up with other disabled people to fight for access and rights. She was a persuasive organizer, wily tactician, and relentless advocate.”<sup>5</sup>

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3 Panzarino, p. 177.

4 Ibid., p.178.

5 From his words at Connie's memorial service. Unpublished.

He goes on,

But let's look at what her activism was about. She was up against massive massive oppression as a disabled person. From the moment of her diagnosis as an infant, she was tortured by the medical care system. First it told her she was lazy, and could walk if she only desired. Then it almost let her die by not bothering to treat an ulcer. In her frequent stays in the hospital over the last few years of her life, medical personnel continually commented on the poor quality of her life-- 'wouldn't she be better off dead?' and ignored her clear requests regarding her treatment. Over and over, she was given the message that her life was less valuable.

But Connie refused to believe that her life was less valuable than anyone else's life. Connie and other activists challenged the assumption that disability was primarily a personal or medical problem. Rather, the worst obstacle they faced was in the actions and attitudes of society toward people with disabilities. Connie wrote that oppression of people with disabilities was part of a larger oppression called ableism. While stairways and legal regulations were barriers, at the heart of the problem were the values and beliefs that cause people to hate what is different. "Ableism says that those who are more 'able' should have more rights, more power, and more money than those who are less 'able'."<sup>6</sup> Connie began an ongoing experiment to imagine a world without ableism.

Now, some of us might be thinking, this is all really wonderful for people with disabilities, but what does it have to do with me? What does ableism mean for people who are not disabled?

First of all, none of us can guarantee that we won't become disabled at some time in our lives. Disabled activists refer to the rest of us as "temporarily able-bodied." It is ableism which tries to create a wall between "us" and "them."

Secondly, ability and disability are on a continuum. We all have gifts and we all have limitations. How many of us think nothing of having limited eyesight, because we have the assistive technology of prescription glasses or contact lens, which enable us to read, to drive, to recognize faces and get around? Is that so different from someone who uses the assistive technology of a wheelchair? In my own case, I have allergies to paint fumes and dust. If a building is being renovated, I can't remain inside without getting sick. Might that not be a form of disability? While most of us are aware of disability as to do with personal limits, we might also look at how society itself is structured to disable. Society is structured to include or exclude people based on certain criteria, to create artificial limits on the full participation of every person.

All of us lose out when some people are excluded from our community. In this way, ableism is related to racism, and other forms of oppression. When we celebrate difference, we can welcome into our community the gifts and resources of a wide range of people. However, when society is built around ableism, all of us are stuck in a competition for value. We are measured by what we can produce, and we learn to hate ourselves when we don't measure up.

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6 Panzarino, p. 259.

Connie says, “We need to stop committing ableism amongst ourselves. Each time you look in the mirror and say to yourself, ‘I’m too fat,’ or ‘my skin is ugly,’ or ‘I’m too skinny,’ you are committing ableism. Be proud of your difference. What would a forest be like if every single tree and leaf were identical? I have seen some very beautiful trees with twisted or broken branches.”<sup>7</sup>

In the early 1980’s, Connie purchased a big farmhouse on land in upstate New York, with the dream to create a space where disabled lesbians could live free from homophobia and ableism, out where there was clean air to breathe, and homegrown food to eat. She named it Beechtree, after a huge double beech tree on the land.

She wrote,

As a group we were to try to eliminate ableism in our living space, our working lives, and in the world at large. [For example,] several of the women who stayed at Beechtree had epilepsy. When they started to feel that they had a seizure coming on, they got down on the floor so as not to fall down. Sometimes it passed, and they didn’t have a seizure. Some of us needed to lie down for other reasons, so we decided that each room would have either a daybed or a couch or at least a mat on the floor. Lying down became a norm, and even some of the more able-bodied women used the couches just to rest.

Abby, one of the big, strong women who lived there, had a bad back. In the fall, when she was going to put up the storm windows, Maggie offered, ‘Hey Ab, if your back seems to get tired let me know, okay? I’ll be glad to help.’ Abby just nodded. It was up to her to decide what was too much and what wasn’t. It was helpful for other women to check in with her during the day to see if she needed a hand, but confronting ableism was not about taking control for someone or setting that person’s limits...

Liza, a woman with Crohn’s disease, was having a severe exacerbation at one point and could not even get out of bed. We had all decided to go pick wild flowers. When we got back, Maggie and I collected all the vases in the house, filled them with water, and brought them to Liza’s bedside along with the flowers. Her job was to help us arrange them in the different vases. That way she took part in the activity...

Living at Beechtree was about not just accepting disability or difference, but celebrating it. It was easy to honor difference when one lived so close to nature and saw so much diversity. It became easier as we learned how valuable each of our differences and differing perspectives were.<sup>8</sup>

One of my own favorite stories from Beechtree, is when Connie volunteered to take responsibility for the seedlings which would be transplanted into their garden. She wrote, “My seedlings thrived until I had to thin them. I could not bear to pull out the straggling, smaller, slightly deformed seedlings and let the healthier ones grow. Instead, I pulled out all the healthy ones. The seedlings looked pathetic, and the women in the house were upset for fear that none of them would grow.”

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7 Ibid., p. 259.

8 Ibid., p. 229-30.

“To all of our amazement, we had very healthy plants that year. The small little ‘disabled’ seedlings grew strong and were able to survive the abundance of rain we had that year followed by intense heat.”<sup>9</sup>

What would our lives look like without ableism? Connie helped me begin to imagine the possibilities. We might have more compassion for our own limitations. We might be more aware of our interdependence, and not so afraid to ask for help when it would be helpful. We might be more respectful of each person’s right to participate in decisions that affect their lives. We might be more confident of our own right to determine our goals and make decisions for ourselves.

We might feel less afraid of being rejected or judged. We might be less concerned with external norms for beauty and appearance, and celebrate our own beauty more extravagantly. Connie always loved to wear silks and velvets, bright colors and jewelry. When Margy & I were going out with Connie we were inspired to dress up, too.

A radical celebration of diversity would remove the largest obstacles that people with disabilities face. None of us would have to be afraid that if we lost the ability to walk, we would also lose our homes, our jobs, our community, our ability to get around. We wouldn’t have to be afraid that if we became ill, we would also lose our ability to make money, to have a partner, to go to the beach, to read a book: in short, to be alive and contributing and valued in our world.

Disability is a part of life. Connie taught me to cherish all aspects of life, with its surprises and its limits and its never ending miracles.

### *Meditation*

I invite each of you now to take some time to honor and celebrate your own unique difference.

Close your eyes if that feels comfortable for you, focus inwardly and be aware of your breathing... Give thanks for the breath that links you to all life...

Pay attention to your body and your mind and your heart... remember what they do well and the joy they give you...

Be aware of the ways that they feel pain or distress, and hold them with compassion...

Be aware of the judgements you pass, the things you may hate about how you look, or the needs and limits you experience, and just for a moment, try to let go of that judgement, to really embrace the whole of yourself...

In this world of our imagination—with no ableism—every part of you is just right...  
silently say to yourself: my face is just right,... my hands are just right, ...  
my legs are just right, my belly is just right, ...  
my hair is just right, my shape is just right, ...  
my memory is just right, my sexuality is just right,  
my feelings are just right, my needs are just right...

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9 P. 231-32.

Now you may be hearing another little voice—or maybe its a big voice—inside, saying, no, no, no, ...your body isn't just right...and your shape isn't just right...and on and on...

But you don't have to judge yourself for that voice either...that's just the way we were taught... that's why we need each other to help make a change...

When you hear that little voice, just answer right back, calmly and with conviction  
my face is just right, my shape is just right,  
my voice is just right, my skin is just right,...

And the next time you talk to someone you love, tell them, too:  
you are exactly right, ...your body is just right,  
your mind is just right, your feelings are just right...  
Each of us alive is a perfect gift from the universe...

When you are ready, open your eyes if they are closed,  
and return your attention to those around you,  
Let us regard each other with deeper awareness:  
we are surrounded by perfect treasures to explore and cherish.  
Blessed be.

#### *Closing Words*

As we go forward today, let us remember to notice and appreciate difference, in ourselves, and in those around us, and in those who are far away.