

Equal Access: The Ongoing Struggle for Disability Rights The Rev. Dr. J. Carl Gregg

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This year marks the **25th anniversary of the Americans with Disabilities Act** (ADA). The ADA is estimated to have improved the lives of 43 million U.S. citizens at the time of its passage (Nielson 180). Today approximately 20% of the U.S. population are people living with disabilities: "Some disabilities like diabetes, muscular sclerosis, and depression, can be invisible. Others, like deafness or vision loss, are not immediately noticeable. Some chronic illnesses, like hepatitis C or HIV, aren't apparent to other people" (Davis xi).

Upon passage of the ADA, for the first time in the history of the United States Senate, a Senator, in this case Tom Harkin, spoke entirely in sign language without verbal speech. After signing, he translated orally: "I just wanted to say to my [Deaf] brother Frank that today was my proudest day in sixteen years of Congress, that today Congress opens the doors to all Americans with disabilities. That today we say no to fear, no to prejudice, and no to ignorance." In his signed speech, he added something that he didn't translate into spoken English, something only for his Deaf audience, which included his brother: "...Today the United States Senate will say that the days of segregation, the days of inequality, are finished. By winning your full civil rights you strengthen ours" (218).

Much was accomplished with the passage of the ADA, and much remains to be done in the struggle for human rights and dignity for people with disabilities. Disability comes in many forms and can depend on context. Kim Nelson, in her book <u>A Disability History of the United</u>

States, tells of being at a conference in Montreal with a colleague who is blind. She writes, "Waiters and cab drivers always looked to me to take the lead. [But] I don't speak French. Luckily, my colleague is fluent in French. In that context, my linguistic deficiencies became far more of an impediment, far more of a disability, than her blindness" (xv). The Americans with Disabilities Act of 1990 changed the context of our country for the better, although much work remains to be done.

Growing-up, I didn't think much about disabilities. In contrast, my wife Magin's mother was born with Type-I Diabetes, which had an increasingly disabling effect on her health and eventually led to her death when Magin was only twenty-one. And for the 80% of Americans who currently do not have a disability, none of us know what the future holds. My sophomore year in college, my friend Greg who lived a few doors down from me was with a group of four other of our friends for a short drive downtown to a cafe — a trip we made hundreds of times — when they were hit by another car, who ran a red light. Four of the five of them escaped with minor abrasions, as did the other driver. But Greg was thrown through the front windshield, leaving him legally blind, partially deaf, and in a wheelchair.

Not long after that accident, I read the political philosopher John Rawls's landmark book A Theory of Justice. In that book, Rawls invites us to think through what it means to seek justice. One of his core ideas that has stuck with me, especially in the wake of Greg's accident, is a thought experiment in which you imagine that you, in some hypothetical pre-birth "original position, are standing behind a "veil of ignorance" regarding the advantages and disadvantages with which you will be born, and must choose "the principles of justice" that would structure the society you would live in. Behind this imagined veil, "No one knows their [future] place in society, class position or social status, nor does anyone know their fortune in the distribution of natural assets and abilities, intelligence, strength, and the like" Rawls assumes that most people in such a position would choose to structure society in such a way that even the most vulnerable among us would have their basic needs met. Rawls's theory of justice challenges us to fight for the same accommodation and dignity for others that we would want if we were in their situation.

Along those lines, the argument could be made that the wheelchair ramp at the front of

our sanctuary is not the most aesthetically attractive feature of the room — although from a perspective of mobility impairment, it could be perceived as one of the most beautiful and welcoming features. And although houses of worship are excluded form ADA accommodation requirements, many religious communities hold accessibility as a core commitment. Some of you who have been a part of UUCF since the 1970s may remember that on a Sunday morning many years before this building was constructed when we were renting space, "An invited minister came to speak — in a wheelchair. The meeting room was not accessible, and he had to be carried downstairs and back upstairs." That awkward and embarrassing experience increased the awareness of many members of this congregation as to the importance of meeting in space that is as accessible as possible to all.

To give you a few more difficult examples, in dialoguing with disability rights activists, one of the ways I've been challenged is to become more aware of "Ableist language": the ways in which our language has evolved to have negative associations related to disabilities — for example, using the phrase "that's lame" to express derision. Even if not intended to be offensive, such phrases are often experienced differently depending on one's situation in life. As the saying goes, "Intent does not equal impact."

Here's a more complicated example. This past December, the Unitarian Universalist Association posted a holiday image on its Facebook page that said, "We already possess all the gifts we need; we've already received our presents: ears to hear music, eyes to behold lights, hands to build true peace on earth and to hold each other tight in love." In an increasingly commercialized holiday season in which too many people go into debt buying presents, the message's intent was to encourage gratitude from the simple pleasures of listening to music, seeing beautiful sights, and extending a helping hand. But some people were offended at a perception of ableist language that seemed oblivious that some people are unable to see or hear or do not have hands.

To give an even more complex example, there are critics who perceive our "Standing on the Side of Love" campaign as *unloving* toward those who are unable to stand. The other side of that debate is understanding that slogan in the sense of "taking a stand," not of literally needing to stand. And at our best, we must seek to balance increasing our sensitivity to

differences with the need to be able to express ourselves with imperfect, finite language and perception. In the words of one of my colleagues:

If our mission is perfection, we are doomed to fail.... Instead, I believe our mission is to love the hell out of the world. This means being in relationship with the world. It means constantly expanding who "we" are. It means challenging ourselves to listen more and put down our need to be right all the time. It does not mean we will always agree – we won't – but it means we will stay in conversation without trying to convince the other person we are right. We will stay in conversation because we will want to hear more about their story.

To be part of a diverse, pluralistic community seeking to build the Beloved Community means that we must seek to stay in right relationship with one another across our differences.

And in regard to "constantly expanding who 'we' are," studying the history of how the meaning of "disability" has changed over time can give us hope that definitions, perceptions, and experiences of disability can and will continue to become more inclusive. To consider only a few historical examples, the <u>U.S. Constitution</u> originally counted enslaved people as only "three-fifths" of a person in regard to "We, the people." Such racial inferiority myths created a perception of disability to justify slavery as a "positive good" for a group of people falsely depicted as 'lesser-than' (Nielsen 42).

Similar tropes of disability were used to keep women as second-class citizens. In 1873, for instance, we have records of a respected professor at Harvard Medical School publicly warning against the dangers of increasing numbers of white women seeking higher education. According to his 'research,' "higher education... could and had 'permanently disabled' [respectable white women].... No woman, he warned, could simultaneously use 'a good brain' and 'a good reproductive system that should serve the race.' It was simply too much for the female body" (Nielsen 94). That was a Harvard professor less than 150 years ago teaching that women were too intellectually disabled to pursue higher education.

And just as African-Americans and women had to overcome racist and sexist structures in society, Leonard Davis, who has written a book titled Enabling Acts about the history of the Americans with Disabilities Act, reminds us of what the world was like for many people

with disabilities in this country until quite recently, as they faced a society structured only for certain bodies. For Davis's parents, who were both deaf:

There were no telecommunication devices that allowed their friends or family to call them and arrange to meet up. Every visit required that a postcard be sent and another one returned with place, date, and time arranged. They couldn't call a doctor to make an appointment or a travel agent to book a flight.... There were no sign language interpreters available for doctor visits, hospital stays, or court dates. [They] couldn't go to religious services, because there was no way they could follow what was going on.... Movies had no captions....

If you had a mobility impairment, you could not use local public transportation.... Since automobiles were't yet equally equipped with hand controls, you were essentially confined to your house.... With no curb cuts or ramps, most streets were impossible to navigate and most buildings were inaccessible....

If you were a person with Down syndrome, autism, or other cognitive disabilities, unless you had a lot of family money, you would be shipped off to a nightmarish institution.... (ix - xi)

In some instances in those institutions, "As few as 1 to 3 men were in charge of as many as 350 patients, including those individuals with the most severe disabilities" (Nielson 144). **Dorothea Dix** (1802 - 1887) is one of our Unitarian forebears who lobbied fiercely for desperately needed reforms.

And through the first half of the twentieth-century, we see even prominent figures such as President Franklin D. Roosevelt hiding from the general public that he was paralyzed from the waist down due to polio (139). **One turning point was parents "coming out of the closet," so to speak, on behalf of their children with disabilities.** Just as people telling their personal truth has changed the hearts and minds of the majority of the American public about the inherent worth and dignity of Lesbian, Gay, Bisexual, and Transgender people, so too the Pulitzer Prize and Nobel Prize winning author Pearl Buck's 1950 book <u>The Child Who Never Grew</u> described Carol, her daughter with cognitive disabilities, "not as shameful, but as an innocent and joyful

child" (142-143).

Similarly, regarding Rosemarie Kennedy, the cognitively-disabled sister of President John F. Kennedy:

In 1962 Eunice Shriver Kennedy, another Kennedy sister, wrote in *The Saturday Evening Post*, "Mental retardation can happen in any family. It *has* happened in the families of the poor and the rich, of governors, senators, Nobel prizewinners, doctors, lawyers, writers, men of genius, presidents of corporations — the president of the United States. (143)

That piece was published a decade before Rawls published his *A Theory of Justice*. But knowing that disabilities and differences can happen to every family should incline us to work to build a world that is as accessible as possible for all.

As it became more acceptable to be public about disabilities, a coalition of politicians with personal stakes in disability rights reached across the aisle of political parities to advocate for the passage of the ADA:

- Republican Senator Bob Dole spent two years in bed recovering from injuries in
 World War II, and one of his arms was permanently injured.
- Democratic Senator Ted Kennedy "always had in mind his older sister Rosemary.... Ted Kennedy himself had various physical ailments, as did his brother John." And Ted Kennedy's own son Teddy's treatment for bone cancer at age twelve required that his leg be amputated above the knee.
- Democratic Senator Tom Harkin's "older brother was born deaf. And Harkin spent his childhood with his sibling, learning sign language in the process. The senator also had a nephew...who became paraplegic in an accident when he was in the U.S. Army....
- From here in Maryland, Democratic Representative Steny Hoyer's wife was epileptic.
- Republican Senator Orrin Hatch's brother-in-law "contracted both types of polio when he was a college student."
- Also crucially, Republican President Herbert Walker Bush, who would sign the

bill into law, "had an uncle...who had polio. One of Bush's brothers had been born with only one eye, Bush's son Neil had severe learning disabilities, and another son, Marvin, had had a colostomy. The president had also lost a daughter, Robin, to leukemia when she was almost four years old. (Davis 4-5) In some ways, that list both is and isn't surprising, since 20% of the U.S. population are people with disabilities. Together that coalition of legislators helped make our country a more humane place to live.

Among other iconic moments that contributed to the ADA, perhaps the most unforgettable came on March 12, 1990, when activists with various mobility impairments crawled with great difficulty up the steps of the U.S. Capitol Building to drawn attention to protest Congress's slow pace in considering the legislation (191-193). Another vitally important contribution was the agreement among activists from the beginning that, "No single group — blind, Deaf, mobility impaired, affectively or cognitively disabled, HIV positive — would be sacrificed. No one would be thrown under the bus" to achieve justice for some rather than for all (211).

As a result, there have been many positive changes in our society in the last twenty-five years since the passage of the ADA, but the greatest gap in the bill is that the ADA is "an anti-discrimination bill not an employment bill" (243). Tragically, employment numbers have worsened in the last 25 years: "According to the Employment and Disability Institute at Cornell University, 28.4 percent of disabled adults worked in 1990, compared with 14.4 percent in 2013."

If we look around the world at how we might change these numbers, **the most pragmatic solution is quotas**, which although controversial in the U.S. are precisely what has worked in other countries. For example,

In France, all companies with more than twenty workers are required to have 6 percent of the employees be people with disabilities. The average rate of unemployment of European Union workers with disabilities is about 5 percent of those who want to work.... Compare that with the 80 percent unemployment rate in the United States. (Davis 244)

The ADA is only the beginning of what is needed.

For our part, we here at UUCF have a building that is only twelve years old and our structure is all on the ground floor — so we are much more accessible than many religious structures that are decades or centuries old. And we have both hearing-amplification devices and large-print Orders of Service. However, we do not have doors that are equipped to open electrically. And even with the large Deaf population in our area, we do not have an American Sign Language interpreter. But I and others are looking into the process for potentially offering ASL interpretation. (Our 19th-century Unitarian ancestor <u>Samuel Gridley Howe</u> is another pioneer in creating schools for the blind and deaf that we can look to for inspiration, although Howe was not without his flaws.)

As we look toward building a more just future, the UUA has published a new program called Accessibility Inclusion Ministries (AIM), similar to our LGBT Welcoming program and Green Sanctuary program. Some UUCF members have already started working on a proposal for making UUCF more accessible. And I'm interested in expanding that effort through the Accessibility Inclusion Ministries program. If you are passionate about disability rights or if this sermon has left you feeling a call to help us move toward a more accessible future, I encourage you to email me about your interest in being part of a potential Accessibility Inclusion Team here at UUCF.

For now, we began this morning by singing "Come, Come, Whoever You Are," and I invite you to turn in your teal hymnals to the related song #1018, "Come and Go with Me." As we sing, I invite you to continue to reflect on how you might be called to help advocate for disability rights in the various places you have influence — so that when we sing songs like "Come, Come, Whoever You Are" and "Come and Go with Me" we might increasingly make it possible not merely for some to be able to respond, but for *all*.