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BUILDING ON OUR HISTORY TOWARD THE FUTURE OF DISABILITY LAW

Tony Coelho

ABOUT THE AUTHOR

The Honorable Tony Coelho is a retired U.S. Congressman from California, a former House of Representatives Majority Whip, Democratic Congressional Campaign Committee Chairman and the principal author of the Americans with Disabilities Act. Diagnosed with epilepsy when he was twenty-two-years-old, Mr. Coelho has spent his entire adult life helping advance the lives of people with disabilities. While he calls this his “ministry,” those in the disability community call him their “voice” and “champion.” Mr. Coelho founded The Coelho Center for Disability Law, Policy and Innovation at Loyola Marymount University.

FOREWORD

It was the uncommon strength of the disability community whose modern-day fight for disability rights, starting in the 1960s, led us to that fateful day on July 26, 1990, when President George H.W. Bush signed The Americans with Disabilities Act (ADA) into law. During the decades preceding the ADA’s passage, people with disabilities publicly redefined disability as an identity with a shared history, common need for accommodation, culture and cause. Importantly, people with disabilities rejected medicine’s dominion over the bodies, proclaimed themselves as the experts of their lives, and pushed for civil rights and inclusion in mainstream society. It was one of the greatest honors of my life to contribute to the passage of the world’s first civil rights law for people with

disabilities, which acknowledged the pervasive discrimination faced by people with disabilities and created a mandate to work toward its elimination.

The legislation was personal to me. As a congressman with epilepsy, I had experienced discrimination myself, and I knew the ADA would have a positive effect on my own life and the lives of millions of others. At the time of the writing and passage of the ADA, almost every key player involved in the Congress and Administration had an intimate connection to disability, whether they had a disability themselves or had a close family member with a disability. And it was also personal to them. Having people with disabilities in positions of power was and remains essential as we continue our fight toward a more just society. That fight for the inclusion of people with disabilities in society must include, front and center, people with disabilities, including the most marginalized among us.

I was introduced to the world of discrimination and stigma against people with disabilities as a teenager after a car accident left me with epilepsy. In my family, I was rejected by my Catholic parents who would not accept a son with epilepsy because of our faith. According to the Church, epilepsy was a form of possession. As a college student, becoming a Catholic priest had been my dream; but canon law prohibited me from realizing it. Trying to move on from this, I applied to numerous jobs and had to check a box indicating that I had epilepsy. Even though I had been a high-achieving student and leader in college, those employers never called me back. Despite my drive and potential, I felt hopeless as

I confronted these barriers and fell into the deep depression that I know many people with disabilities confront.

In the midst of this depression, while at Griffith Park in Los Angeles, I considered completing suicide.¹ But a group of children on a merry-go-round caught my attention. Their laughing and playing made me realize that just like a little kid, I would no longer let anything or anybody stop me from believing in myself. On that fateful day, I made the decision to fight for my life, and I have not looked back since.

As a result of the leadership roles and relationships developed during college, I was very lucky to have met the film actor Bob Hope who became a mentor to me. He explained that a ministry to “do good” in the world did not need to be confined to the priesthood, and my commitment might be more suited to a ministry in politics. I am privileged to have found relationships that have encouraged me to grow and to lead. Too many individuals with disabilities do not have those strong voices in their lives letting them know they can make change in the world as leaders and policymakers. Even worse, people with disabilities often hear that they cannot achieve and should not aspire for more. My own opponent in my first political race called out my disability as a weakness and attacked me for being disabled. The good people in my district rejected that type of bullying, and I won a seat in Congress.

In Congress, I brought all my experiences as a disabled person and started thinking about a bill like the ADA. Motivated by the grassroots

¹. If you or someone you know are considering suicide, please call the U.S. National Suicide Prevention Lifeline at 800-273-TALK (8255).

disability activists across the country and their experiences being denied entry on transportation, at restaurants, and at movie theatres, I knew I had to be their relentless champion with the position I held. President Reagan's disability council approached me, as did Sandy Perino from Connecticut and Roxanne Vierra from Colorado, who both had children with disabilities, and we pushed to make the ADA a reality. My constituents in California came to me with the changes they wanted made, and we reintroduced new versions of the bill. Ultimately, the ADA came to fruition because of the disability community—because of activists with disabilities, politicians with disabilities, and key players who had family members with disabilities. President Bush, a man with three children with disabilities, understood what we wanted to do and was a strong advocate, proclaiming on that fateful day: "Let the shameful wall of exclusion come tumbling down." Justin Dart, Senator Bob Dole (R), Senator Ted Kennedy (D), Senator Orrin Hatch (R), Senator Lowell Weicker (R), Senator Tom Harkin (D), Congressman Steny Hoyer (D), Congressman Steve Bartlett (R), ADAPT, NCIL, the Epilepsy Foundation and countless other individuals and disability organizations had made history before the President's signature on the ADA dried on the page.

This historic moment removed barriers for millions of people with disabilities in the United States and became a global model for doing so. Nearly thirty years later, our community now holds incredible political influence. A quarter of eligible voters identify directly as having a disability, while a broader voting block that includes family and workers with a vested interest is 60 percent of the electorate. But, despite that strength, we've still lost momentum in how the law is enforced and interpreted, with

legislation failing to keep pace with innovation and too few people with disabilities empowered to create change. Attempts to water down the ADA began as soon as it was signed, and those attempts to cut, modify and change our disability rights will always exist in an ableist system that feeds us the lie that there exists a perfect human being who is superior to individuals with disabilities.

Three decades after the ADA became law, the question we need to keep asking is whether we are willing to continue the fight for improved civil rights for people with disabilities; especially now when the rights we have are at risk of being rolled back. The last Congress tried to advance the “ADA Education and Reform Act of 2017”—and successfully moved it through the House of Representatives despite widespread opposition from our community. Bills like these and other ADA notification laws that are proposed across the country are attacks on our civil rights and disingenuous in claiming there is a lack of notice and education. The nearly three decades since the law was enacted is ample time to remedy situations that discriminate against people with disabilities.

Beyond the ADA, the disability community has played key roles in fighting for rights that affect everyone. Over the last two years, when our healthcare was at stake, the disability community was a key reason we won the battle. The Affordable Care Act prohibited private health insurance from denying health care coverage based on preexisting conditions, a fundamental challenge overwhelmingly helped people with disabilities. It also eliminated annual lifetime caps on coverage, restricted consideration of health status in setting premiums, and expanded Medicaid thereby allowing increased access to long-term services and supports

for millions who had previously been uninsured. The Affordable Care Act barred use of discriminatory metrics to determine coverage in Medicare. When it was threatened with repeal, disability advocates from across the country showed up in the halls of Congress to protect it, demonstrating the power of our voice, which became another rallying cry for us to use our vote.

Accessibility is the full experience of a person with a disability's ability to navigate all systems as an equal participant in the community. Therefore, the need to protect the civil rights of people with disabilities can be found in almost every area of policy, including healthcare, employment, transportation, housing, education, and topics not traditionally associated with our community such as the criminal justice system and immigration. In the Independent Living Movement the sound of our advocacy can be heard in the slogan "nothing about us without us," and, more aptly, when we cry out "nothing without us" because people with disabilities exist in every sector of our society.

As we seek to expand the fight for disability rights, we must continue to look to the margins for the people at the intersections of our identities. Individuals who identify as having a disability in addition to other identities based on race, gender, sexual orientation, immigration status, poverty or economic status, education level, and those who have navigated the criminal justice system are all too often overlooked and neglected in the fight for disability rights.

The political structures that have dominated the disability rights policy agenda have often been comprised of white and economically secure leaders. Now we must be willing allies and accomplices to take the

necessary steps to change this, so that our leadership is reflective of the people it seeks to help. I include myself in this responsibility because of the perception of my whiteness, even though I'm from a Portuguese, immigrant-based farming community and was a member of the Hispanic Caucus in Congress. As current, overwhelmingly white and privileged legal scholars, activists and policymakers develop new agendas and improve existing ones, they must be intentional about including intersectional leadership with a range of identities and lived experiences.

Looking toward the future, I am proud to have recently founded The Coelho Center for Disability Law, Policy and Innovation at Loyola Law School. The Coelho Center's recently commissioned poll found that the disability community has grown to make up a majority of the U.S. electorate. It also found that many in that group are so unhappy with their representation that they were willing to cross party lines in the last election. But representation has not kept pace! Bringing the resources of an entire university to bear, and fueled by the philanthropy of our supporters, The Coelho Center aims to improve the pipeline of law students with disabilities in order to increase the number of lawyers, judges and policy makers prepared to take the ADA to the next level.

The pipeline begins at the earliest stages of education where countless students with disabilities can and should be encouraged to dream of going to law school or running for office. Next, legal education itself needs to confront the barriers that exist for law students with disabilities. This is why I commend efforts such as the Disability Law Journal at the UCLA School of Law for identifying that of the thousands of legal journals

in law schools across the United States, not one is dedicated to disability rights. With this publication, that changes now!

These efforts driven by law students with disabilities are important and attention must be paid to them. In addition to providing accommodations to law students with disabilities, law schools must teach disability rights, including the ADA, to all law students. For those who make it beyond law school, high pressured environments in law firms continue to create a profession with a high percentage of attorneys with depression, anxiety, drinking problems and high suicide rates. Accessible wellbeing practices must be adopted in the legal realm.

Our disability legal history is currently being written, and both our past and our future need to be engaged. Recently, as part of the founding of The Coelho Center, I donated all of my Congressional papers and more to the Coelho Collection in the Loyola Marymount University Library. I encourage disability legal scholars to continue to critique how we arrived to the ADA and make implications for how we move forward. And as we move forward I hope that people with disabilities will be at the helm, in leadership positions, making decisions for our future. To all those involved with this first issue of the Disability Law Journal, I thank you for your work. I am confident this journal will go on to critically analyze our law and legal institutions and drive innovation in disability law.