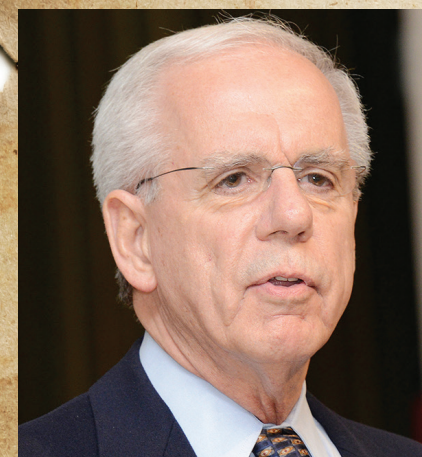




POWER

to the People

BY MARIA HESS
PHOTOS BY SUSAN GREGG



Tony Coelho, one of the original authors of the Americans with Disabilities Act, is arguably the nation's most tireless advocate for people with disabilities. So why is he frustrated?

Tony Coelho was 16 when he had the accident on his family dairy farm in California. He had blacked out, so he didn't have much of an explanation about his head injury or the run-in with the pickup truck. He didn't see a doctor.

But a year later, while milking cows, he passed out again. This time, he woke on a bed, with a doctor glaring at him. He didn't remember his brother carrying him into the house. And he couldn't speak.

He was unaware that the doctor had told his parents he'd had a seizure, and that the pickup accident could have been related to his mysterious disease — except no one told Coelho what that mysterious disease was.

"If you had epilepsy," says Coelho, "people thought you were possessed by the devil and that God was punishing the family for something."

So his parents guarded the secret, despite visits with three doctors — and even a few witch doctors. Coelho suffered seizures for years. He took no medications. And he remained ignorant of his diagnosis.

Coelho did well in high school, then left the farm for Los Angeles, where he attended and in 1964, graduated from Loyola University (now Loyola Marymount University). He joined a fraternity and in his senior year became student body president.

Loyola was and is a Catholic university grounded in Jesuit and Marymount traditions. While there, Coelho became deeply religious and grew fascinated by the teachings of the church. He said goodbye to his girlfriend of five years — as well as his fraternity brothers — and entered the seminary. It was only after taking the required physical that he learned of his epilepsy. That was the first shock.

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Rita M. Landgraf, Secretary of Delaware's Department of Health and Social Services; Tony Coelho; U.S. Sen. Tom Carper; Wilmington University President Dr. Jack P. Varsalona



Coelho chats with attorney Santino Ceccotti after Coelho's presentation at WilmU in March.

The second came from the church. In 1965, the world — and those running the Church — was very different.

Epilepsy was so misunderstood that Canon Law prohibited anyone afflicted by it from becoming a priest. There was still a notion that the relatively common condition had demonic implications.

So the priesthood was out. The government wasn't particularly accepting of Coelho's challenges either. Once word of his diagnosis spread, Coelho was stripped of his driver's license and health insurance. When his disability forced him to ignore *the call*, Coelho found himself at a crossroads.

While his devoutly Catholic parents knew about the epilepsy, they maintained the façade, possibly to avoid complications with the church. But their son couldn't land a job. They didn't realize that in addition to being unemployed, he had started drinking and had become suicidal.

"Then one day," Coelho says, "I'm in Griffith Park in Los Angeles, and I'm on top of a hill, and all of a sudden I hear music. I hear happy kids. I looked down and there was a merry-go-round. I decided at that very moment that I wanted to be happy, too. I was never going to let anyone or anything stop me from believing in myself again."

He's been clean and sober since.

Politics and Beyond

Coelho had found inner peace, but he was still unemployed. As politically incorrect as it sounds now, companies were permitted to legally reject people with disabilities. Shortly after his epiphany at the park, Coelho visited a priest who held a leadership role at Loyola. The priest told him this his friend Bob Hope — yes, *the* Bob Hope — was looking for someone to live with his family and manage various chores. Coelho lived

with the Hope family for a year, and grew close to the comedian.

After being rejected groundlessly all his life and suffering a kind of disappointment few can understand, Coelho finally found a crusader. It was Hope who saw the politician within Coelho. Hope knew that Coelho had the guts to act with passion, and that one way to change the world was through politics.

So after securing a job with Congressman Bernie Sisk of California, Coelho did as he was advised. He then created what he calls "a political ministry."

Coelho, a Democrat, was elected to Congress in 1978. For six terms he served the Agriculture, Interior, Veterans Affairs, and Administration committees. In 1986 he was elected House Majority Whip and was the chief organizer of votes for his party. It's no surprise that he specialized in rights for people with disabilities.

Coelho knew what it felt like to be stripped of his dignity. He'd been shunned by most of the people he cared about, simply because of his disability. He knew he had to change the way Americans viewed people like him. And he did that in an ambitious and political way.

Coelho became the original author of the Americans with Disabilities Act, which was signed into law by President George H.W. Bush in 1990. (The ADA went through numerous drafts and amendments since the first version was introduced in 1988. Coelho, along with Sen. Lowell Weicker, introduced that version of the ADA in April 1988 in the 100th Congress.)

To say that the ADA changed lives would not sufficiently describe its merit, but numbers don't lie. By 1994, approximately 800,000 more people with severe disabilities had found employment than before the bipartisan legislation was



Coelho appeared as part of Wilmington University's Speaker Series in March.

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first enacted. Today, 24 years later, the legislation supports millions of Americans living with disabilities.

Authoring the bill earned Coelho credibility, such as being asked by President Bill Clinton to serve as chairman of the President's Committee on Employment of People with Disabilities, or serving as vice chair of the National Task Force on Employment of Adults with Disabilities, or being appointed as United States Commissioner General at the 1998 World Expo in Portugal. One leadership role led to another.

Coelho also played a large role in securing rights for people with disabilities at the federal level. It took 25 years, he says, but he had to work with others to first create a definition for disabilities, then to get the right questions in place for the U.S. Census Bureau to ask in its questionnaires.

"There's no way you could propose the executive order without knowing how many disabled there were in each area," says Coelho, adding that he worked with the agencies involved, and when Obama was elected, Coelho "worked the White House hard."

This year, President Obama issued an executive order to have federal contractors and subcontractors hire individuals with disabilities, which was in compliance with Section 503 of the Rehabilitation Act of 1973.

There was still work to be done in terms of the ADA's international reach. When Bush signed the ADA, he said his presentation came three weeks after Independence Day, but that the passing of the ADA meant real independence for the



Coelho with Sen. Carper at Wilmington University

then 43 million Americans with disabilities. He also proclaimed the following:

"This historic act is the world's first comprehensive declaration of equality for people with disabilities – the first. Its passage has made the United States the international leader on this human rights issue. Already, leaders of several other countries, including Sweden, Japan, the Soviet Union and all 12 members of the EEC have announced that they hope to enact now similar legislation."

Indeed, an ADA-type of legislation has been adopted in more than 50 countries, says Coelho. Now he's working to ratify Treaty 503: The Convention on the Rights of Persons With Disabilities.

According to a 2012 letter published in The Wichita Eagle by Coelho and Bob Dole – the former Senate Majority Leader and chairman of the Senate Finance Committee whose World War II battle injuries left him permanently disabled – the treaty does basically the same thing the ADA did, except on an international scale.

The United Nations estimates that 650 million people worldwide are disabled.

Treaty 503 has garnered support from many disability and veterans organizations, as well as religious and interfaith groups. Its ratification doesn't require changes to American laws, nor would it mandate new budget costs. But as Dole and Coelho wrote, "Ratification would signal to the world that the U.S. is committed to international standards for disability rights and will play a leadership role in implementation of the treaty obligations."

Bureaucratic red tape can stifle nearly any agreement,

and the treaty is no exception. It was actually presented to George W. Bush, who first sent in the declaration to be signed. (Each country ratifies it.)

Obama did submit the treaty to the Senate, but it was met with opposition from Republicans – though some GOP advocates like Senator John McCain consider it bipartisan. The tea party is opposed.

According to an article by the Associated Press in 2012, the opposition was led by tea party favorite Sen. Mike Lee of Utah, who argued that "the treaty by its very nature threatened U.S. sovereignty." Lee expressed concerns that the "treaty could lead to the state, rather than parents, determining what was in the best interest of disabled children in such areas as home schooling, and that language in the treaty guaranteeing the disabled equal rights to reproductive health care could lead to abortions." Lee concluded that parents will "raise their children with the constant looming threat of state interference."

Coelho is confused by Lee's interpretations of the treaty. "Why would anyone oppose this?" he says. "They're saying that if you adopt this treaty, the United Nations has a right to go to your home, see if it's ADA compliant, and if not, they could take your child away."

In truth, the UN can't come to your home. Your home does not have to be ADA compliant. And most important, says Coelho, "the UN has no right to take your child."

Commanding the Podium

Coelho has earned countless accolades. He is arguably one of the nation's most tireless advocates for people with disabilities. But he's frustrated.

He's been wrapped in red tape for most of his adult life. So he makes no apologies for taking the podium when he has the chance. He's had his say with commanders-in-chief and other luminaries. He's even confronted a higher power.

While working as a Whip in 1987, Coelho traveled to the Vatican, where

he got a private audience with Pope John Paul II.

"The pope walks in," says Coelho. "We all stand up. I go to the podium to give my boring speech that's been pre-approved. I then say, 'Your Holiness, I need to tell you something personal. As a young man, I decided to become a Catholic priest. I was kicked out because I had epilepsy. I think that was very un-Christian of our church and I think you ought to look into it.'"

The politicians and minions were speechless. "As we're leaving," Coelho says, "the pope turns to my wife and blesses her. He turns to me and does not bless me. But he did say: 'I heard your comments.' And he walked away."

Canon Law was changed two years later. Coelho does not take credit for tweaking what's been in place since A.D. 400. "But I can say I made the plea," he says. "By not blessing me, the pope was very direct and very sincere. Ultimately it was the greatest blessing he could have given me."

A faithful Catholic still, Coelho calls his life blessed. "I thank God for my epilepsy," he says. "It gave me a strong sense of conviction. It made me a better Christian. And I have an obligation to do good."

Coelho took his first epilepsy meds at age 21. Every day he wakes not knowing if he'll have a seizure. He knows there are lots of people worse off than he is. And, he says, he likes to pay taxes, because paying taxes means he's employed.

That's all Coelho wants employers worldwide to do: to hire the right people for the job, regardless of their disabilities. "If they can't do the job, fire them," he says. "But give them the right to fail." [WU](#)



Landgraf introduces Coelho at his speaking engagement at WilmU.

THE ADA AND HIGHER ED

When University Vice President Dr. LaVerne T. Harmon established Wilmington University's

Office of Disability Services in 2000, the Americans with Disabilities Act provided clear direction for compliance by identifying learning styles and illnesses that qualify as disabilities, and by defining reasonable accommodations, says Harmon. "It has made it possible for students with special needs to receive fair treatment and become active, productive citizens."

Modifications were made to physical facilities to make them wheelchair or handicap accessible, and Harmon and her team educated faculty and staff on the law, as well as university policies and procedures.

"That was crucial to our ability to successfully implement services for students with special needs," says Harmon, adding that the goal was and is to provide all students with services that give them the opportunity to reach the same level of achievement, and to succeed without lowering standards."

Indeed, the ADA has made it possible for Wilmington University students with special needs to receive fair treatment and become active, productive citizens. While WilmU offers a wide variety of accommodations for students with disabilities, each is treated individually based on his or her needs, says Christyn Rudolf, manager of disability services.

"This is a special school that is open enrollment," Rudolf says. "Some students have such a difficult time testing, in terms of the grueling application processes at other schools, and that can be a real deterrent. They don't have to go through that here. We offer them a four-year degree, and with that comes a family-friendly culture."