Oversight Hearing on "The Americans with Disabilities Act: Sixteen Years Later"
Testimony before the Senate Judiciary Committee,
Subcommittee on the Constitution
Statement by the Honorable Tony Coelho, Chair, Epilepsy Foundation
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Good Afternoon. I am Tony Coelho, Chair of the Board of the Epilepsy Foundation, Secretary of the Board of the American Association of People with Disabilities, businessman and former Member of Congress. As you may know, I was the original author of the Americans with Disabilities Act and introduced the bill in 1986 – together with Senator Lowell Weicker - when I served in the US House of Representatives; we introduced the bill together, in order to ensure the ADA was both bicameral and bipartisan. It is a pleasure today to be back here and speaking to you, Chairman Sensenbrenner, Mr. Conyers, Chairman Chabot and Mr. Nadler and other distinguished Members of this Committee and Subcommittee. I want to thank you all for holding this oversight hearing today and for offering us the opportunity to talk about the ADA – its successes and challenges for the future.

Sixteen years ago we made a lot of promises when we signed the Americans with Disabilities Act into law. Through the passage of the ADA we promised our fellow Americans who have disabilities the right to share in our country's greatest strengths -- our capacity for progress and advancement.

I believe that prosperity and justice are not meant to be hoarded but shared; that when the American dream is available to ever-greater numbers of us, that itself is the well-spring of our national security and prosperity.

For generations of Americans, the right and ability to work at a trade or profession was the key to individual realization of that dream, and the national prosperity that followed.

But, as I learned when my epilepsy was discovered, and legalized bigotry left me unemployed and unemployable, work means much more than financial stability.
My passion for expanding job opportunities for Americans with disabilities is rooted in my life – in the pain and personal failure I felt when I was prevented from working – and in the confidence and ability to contribute I rediscovered when I was finally able to find work once again

I have always been outspoken about my disability. I believe that if you want to change people's perceptions, particularly of hidden and stigmatized disabilities like epilepsy, you have to be outspoken about it. People have to see that any one of us could be affected by disability, that people with disabilities are not somehow "other" than those without. When I was in Congress, I was a primary sponsor of the Americans with Disabilities Act because I knew firsthand how a person could be qualified to do a job, but still be

excluded from employment because of others' misunderstanding and fears. I knew then, as now, that people with disabilities may be discriminated against because their condition is a disability, or because the employer thinks it is a disability even if it is not in fact substantially disabling, and sometimes, just because someone has a past history of a disability.

Even though my epilepsy did not interfere with my ability to work or participate in other daily activities, I was unfairly denied many opportunities simply because of the stigma associated with my health condition and the ignorance of others. Stigma and ignorance about epilepsy persists today and still results in the denial of equal opportunity to many. There is similar stigma and ignorance about a whole range of other disabilities which may be "controlled" to a certain extent such as mental illness and diabetes -- which likewise may effectively rob many others of their part of the American dream.

As the author of the ADA, I absolutely intended the legislation to cover people with disabilities who took medication or used a corrective device to alleviate their condition but were nonetheless denied employment or fired from employment because of their disability. I absolutely intended it to cover people whose conditions did not actually interfere with daily living, but who were treated by others as having a disability. I believe that everyone in Congress who voted to pass the bill understood that it applied to people like me. I intended this bill to apply to the discrimination that I faced in my family, my church, and my government because of my epilepsy.

The ADA has now become a model for anti-disability discrimination legislation around the world, as more and more countries adopt civil rights protections that promote the full integration of people with disabilities and the protection of their civil rights. America and Congress when it passed the ADA, proposed a true model to the rest of the world – because of our goal and dedication to the full inclusion of all Americans into the mainstream of life. This includes our understanding and belief that people who have disabilities are fully capable of working in competitive employment and being productive members of society. Sometimes a reasonable accommodation, one that is not unduly burdensome, is needed; often it isn't. The support for the ADA was bipartisan, bicameral and complete; we all understood that if we do not integrate people with disabilities, we not only cause them and ourselves to suffer, we also expend enormous resources to support people who actually want and are capable of supporting themselves. That is a far different attitude and goal than many other countries have; rather, attitudes of paternalism, caretaking, and exclusion are the norm. Though we have a long way to go internationally, I am very proud of what we – what you in Congress, have done in passing the ADA. You have been able to produce a model for people in over 50 countries, to guide our world to a better place.

Since the ADA was enacted, there have been many positive changes for which you in Congress must be recognized. For example, there has been a noteworthy reduction in physical barriers – everywhere one sees signs of a more accessible world, and that is rapidly getting better as new office buildings and businesses are built in compliance with the law. All of us have benefited from these changes in our physical and environmental

space, and the attitude of inclusion that accompanies those changes. Curb cuts and ramps designed to allow access for people with wheelchairs help parents with baby carriages, delivery people, mail carriers making their rounds, and elderly people.

You in Congress also changed lives by passing the ADA in the area of access to information through technology usable by people with disabilities. Thanks to the ADA's clear call to equal access to the goods and services offered by public accommodations, people with disabilities are, more than ever before, finding it easier to privately and independently make purchases at retail stores (such as pharmacies) with accessible point of sale machines. More and more automated teller machines provide accessible controls and audible output for people with vision loss.

When the law was passed, we heard fears from the business community that compliance with the ADA might be too costly, too burdensome. That has not proven to be the case. The average business faces only minor costs in complying with the ADA. In fact, businesses and the service industry now increasingly recognize that far from being a burden, being accessible to people with disabilities actually provides more business opportunities and income for the business. It makes economic good sense for business to be fully accessible and inclusive.

There are other benefits that have accrued to all of us as a result of Congress' passage of the ADA. Today, when you apply for a job, you do not need to reveal whether you have a physical condition or disability – you simply need to indicate whether you can safely perform the work, with or without an accommodation. The law precludes questions about disability before an employment offer is made, and so now helps to identify and route out covert discrimination based upon stigma and attitude. This has not only increased opportunities for people with disabilities to contribute to the workforce and to society, but has also enriched the lives of those who work alongside them and learn from them as well as those who reap the benefits of their work.

These are all examples of the real and significant progress for people who have been too often locked out of everyday life, forced to rely upon government handouts and charity because they cannot get a job or participate in society.

We have much more to do, however. We have not gotten very far on our goal of protecting the civil rights of all people with disabilities, and promoting equal opportunity for all. Too many Americans with disabilities can still not participate in the same range of activities that the average citizen has available. Sixteen years after the ADA, despite the mandate of Congress and the Administration, too many areas of business and commerce open to the general public, including virtual (e.g., internet) goods and services, remain inaccessible to people with disabilities. Today, and despite clear congressional intent and agency guidance, it still is not the standard in this country that commercial websites provide to people with disabilities the same ease of access, scope and reliability of information, and independence to transact business as is provided to other customers.

The employment situation for people with disabilities is especially bleak. Too many American businesses still fail to employ people with disabilities. Unemployment and

underemployment rates for people with disabilities remain as high as they were when the ADA was passed; in fact, in some sectors, notably the federal government, the rate of employment of people with disabilities is actually lower now than it was over the last decade or so.[1]

Too many people with disabilities continue to sit at home or languish in institutions, isolated from the rest of the community. Waiting lists for services in the community for people with severe disabilities are long and getting longer. Gainful employment remains an unfulfilled dream. Serious attitudinal barriers to hiring people with disabilities remain the norm; while many employers recognize the ideal of integration and full employment, fear and concern about liability and costs continue to make others shy away from hiring people with disabilities. For the many adults and children with disabilities who remain warehoused unnecessarily in institutions, opportunities to work, learn, and to participate in family, social and cultural activities are severely curtailed, as the Supreme Court has recognized.

What has happened in the last sixteen years? Why has more progress not occurred? While there are a number of areas of concern, and many reasons for this state of affairs, I would like to focus specifically on the employment area. Unfortunately, there has been a concerted effort by lawyers for employers, supported by a federal judiciary that does not understand the ADA and what Congress meant when it passed the ADA. As a result, there has been a tendency to try to limit the scope and coverage of the law. As has now been amply recognized and described in numerous law reviews, articles, and other publications,[2] in the years since the ADA's enactment,

> the federal courts have chipped away at the law's protected class by adopting overly narrow rules for the analysis of who meets the statutory definition of "disability." As a result of a string of Supreme Court decisions and hundreds of cases in the lower federal courts, it has become very difficult for individuals with certain health conditions to establish that they have a disability for purposes of the ADA. …People with epilepsy, diabetes, cancer, psychiatric diagnoses, and other conditions that are well controlled with medications or other disease management strategies are routinely dismissed as outside the protection of the statute. With the definition of disability dramatically contracted, millions of Americans who continue to experience disability discrimination are barred from challenging these abuses in the courts. Further, win or lose, many employment discrimination victims are now subjected to irrelevant questions about their personal lives and private health information that have nothing to do with the merits of their discrimination case.[3]

Even people with severe complications from these diseases such as amputation and nerve damage – have been told they are not “disabled enough” to bring a discrimination claim. And this has been the case even when the employer has explicitly said that an employment opportunity is being denied *because of* the medical condition.

Today, as a result of the Supreme Court's opinion in a trilogy of cases decided in 1999,[4] and other subsequent ADA employment cases,[5] there is a very good chance that if you have a disability such as epilepsy, diabetes, cancer, multiple sclerosis, or mental illness, you are likely to discover, should you attempt to press a discrimination charge on the basis of your disability, that you are not protected from unfair discrimination. If you have your disability controlled in whole or in part by medication, or other intervention (known as a mitigating measure), you are going to be found not disabled enough to have the benefit of the law, and therefore not protected by the ADA. If your disability is episodic – it only has an actual impact on you periodically or briefly – you are going to be found not disabled enough to be covered by the law. If an employer admits that he REGARDED you as having a disability and refused to hire you as a result, it is highly likely that a court review of that decision will find that because the employer can produce a simple statement that he only regarded you as unable to do this particular job, and not any job in the workplace, you are not protected by the ADA.

So, as the state of the law now stands, you can get fired or not hired because you have a physical or mental condition that may or may not pose an actual barrier to your ability to do a particular job – but you have no recourse under the law as it's being interpreted, because courts focus on who is covered or not, rather than on whether illegal discrimination has occurred! That is not what we envisioned when the ADA was crafted and passed. It ignores common sense, clear Congressional intent, and explicit federal regulations interpreting the ADA. It also ignores experience and history with the ADA's predecessor laws, including Section 504 of the Rehabilitation Act of 1973 and state anti-discrimination laws that allowed people to sue for unfair discrimination based upon a broad definition.

Very briefly, the ADA's definition of who has a disability, based upon the Rehabilitation Act of 1973 definition of disability, says that three groups of people are covered by the law. That is, a person with a physical or mental impairment that substantially limits one or more major life activities, a person who is regarded as having such a mental or physical impairment, or a person who has a history of such a mental or physical impairment (that is, one that substantially limits one or more major life activities) is covered by the law.[6] This definition requires courts to determine at least three things. First, the court must determine that a condition, such as epilepsy, is a physical or mental impairment. Second, the court must determine that a major life activity is involved. Major life activities include activities such as working, sleeping, walking, caring for oneself and reproduction. Third, the court must determine that the condition substantially limits the person's ability to participate in or to perform the major life activity.

Once those decisions are made, the substantive question of whether there has been illegal discrimination is raised. A person must show that he or she is able to carry out the essential functions of a job, with or without a reasonable accommodation to the disability, that is, that one is qualified for the job at hand. The individual must also show that he or she suffered an adverse employment action *because of* the disability. Was a person with a disability who could do the job kept from doing the job because of prejudice based on

that person's medical condition? Instead, today, *most* times the question of qualification is never dealt with by the courts. Instead, the focus of time, energy, and resources of both the employer and the employee or applicant, is on a determination of who has a disability under the law. A recent review of cases in the area of epilepsy shows that in 32 out of 42 cases, the federal courts have found that the individual does not have a disability under the ADA. Thus, people are being thrown out of court before there is ever a determination of qualification to do the job.

While the Supreme Court has not ruled on an epilepsy case, many lower courts have with disastrous results. For example, a woman with uncontrolled nocturnal seizures, who could not do rotating shift work without some accommodation, is not disabled and therefore not protected by the ADA, according to the 4th Circuit.[7] A warehouse worker whose breakthrough seizures, brought on by a temporary illness, caused him to miss work, was not substantially disabled, and therefore, not protected by the ADA, according to a federal court in Texas. The judge who wrote the opinion said he wanted to rule in favor of coverage for the worker, but felt he could not, given the Supreme Court's mandate.[8] A firefighter whose medical condition was completely controlled but who was denied employment because of a rule that said no one with epilepsy can be hired for his job, was found not protected by the ADA.[9] The cases go on and on, and similar decisions closing the door of the ADA have been reached in cases concerning other disabilities.

I focus on epilepsy and seizures in particular because so many of the negative cases concern this condition, and Congress clearly intended to cover such individuals. It seems to me, if you cannot get a job because of your medical condition, or if you lose a job because of your medical condition, you should be within the ADA's intended protection. You should be permitted to demonstrate whether or not you can perform the essential functions of a job. This doesn't mean that every person with a disability in entitled to the job of his or her choice. But at least you should be within the law's coverage. Instead, federal courts, relying upon the Supreme Court's failure to carry out Congressional intent, misapplication and misunderstanding of the ADA have so narrowly construed the ADA as to have effectively written people like me out of my own bill!

What can be done to correct this state of affairs? First, we look to the Administration to continue to assist with the implementation and aggressive enforcement of the mandates of the ADA. We appreciate the support that has come from the Justice Department and from the Equal Employment Opportunity Commission and other implementing agencies on the range of issues that people with disabilities face. We will continue to need support from these agencies, and increased vigor in their technical assistance, education, and enforcement would only help. In areas other than employment, obviously, there has been litigation to enforce the requirements of the ADA, and decisions have been both positive and negative. It is unfortunate that litigation is necessary to implement the law's mandate, but that is the state of affairs, and the disability community will continue to work to shape legal opinion through the courts in line with Congressional mandate when it passed the ADA. As an increasing number of public accommodations move to the Internet as a significant, if not the exclusive, commercial means for offering their goods

and services, it will be imperative to ensure that the ADA's promise of nondiscrimination and equal access is implemented in a way that ensures that people with disabilities have ready access to all goods and services. In this and other areas, including full inclusion of Americans into their community, it is possible that we will need to return to Congress to seek assistance in carrying out the ADA's intent and mandate.

But to address the specific problem of the exclusion from coverage of individuals that Congress fully intended to be protected by the ADA, I firmly believe we must take legislative action now. We look to Congress to restore the coverage of people with disabilities, undo the restrictions placed by the Supreme Court on the classes of people protected by the law, and reopen the remedies available to those who successfully prove ADA violations. We must restore responsibility for employers to comply with the requirement for meaningful accommodations. We must reverse the Court's decisions that permit people with diabetes, heart conditions, cancer and epilepsy to lose their legal rights, because medications make them "too functional" to be protected under the law.

There are a number of ways to restore the promise of the ADA. Congress would be well served to begin its consideration with the 2004 report of the National Council on Disability, "Righting the ADA," which contains an analysis of all the Supreme Court's erroneous interpretations of the ADA and Congressional intent, and includes proposed legislative solutions. It should be noted that, in keeping with a law that had full bipartisan support, the NCD is composed of Republican appointees. For those who would like to see the position of some Democratic members, I would highlight the Washington Post article Minority Whip Steny Hoyer wrote in 2002,[10] and his speech at New York Law School a couple of years ago on restoring the ADA and its intent.[11] For reassurance on the wisdom of ensuring that ADA coverage is broadly construed, one could also look to the experience of states which have adopted a broad coverage approach to disability discrimination.[12]

I firmly believe that the time is right to propose a restoration of the ADA to its original intent and meaning. I want to see the promise of the ADA fulfilled, the intent of Congress restored in my lifetime. Among the materials that are available for your consideration is a set of principles that I believe every member of the House and Senate can and should endorse.[13]

As a society, I believe we are ready to embrace the idea that people should be employed based upon whether they can do the job – perform the job requirements – NOT based upon whether they have a physical or mental condition, or how it is described or quantified by others. In addition, I believe our society values the right of the individual to privacy, including the privacy of their medical records, and neither employers nor employees are well served by detailed delving into one's private medical histories and how the individual and their physician have determined to treat a medical condition simply to determine if the employee is "sick enough" to be afforded protection from blatant discrimination.

Congress intended to ensure that people with disabilities had these opportunities and rights, to be treated with the dignity and respect of any American, and to not be denied a job simply because one had a disability – including one like epilepsy that has stigma and fear attached, when it passed the ADA. I ask for your help and leadership again to ensure that our society operates as you intended. America can continue to serve as a model to the world for full equality and inclusion if we work now to ensure that the original mandate of Congress when it passed the ADA is carried out.

Thank you for the opportunity to present this testimony.

Endnotes

[1] Shockingly, in a recent report, the Equal Employment Opportunity Commission (EEOC) found that "Over the past 20 years, the federal government's efforts to improve the participation rate [in the federal work force] of employees with targeted disabilities have failed to result in any significant progress." See EEOC Annual Report of the Federal Work Force, Fiscal Year 2004, EEOC, available at http://www.eeoc.gov/federal/fsp2004/index.html. (The targeted disabilities include "convulsive disorders," along with deafness, blindness, missing extremities, partial paralysis, complete paralysis, mental retardation, and mental illness.) Just this past July, EEOC acknowledged that people with targeted disabilities have dropped to less than one percent of the permanent federal workforce, continuing a long-term decline. See EEOC press release of 6/28/06, available at http://www.eeoc.gov/press/6-28-06.html.

[2] See, e.g., Claudia Center and Andrew J. Imparato, *Redefining "Disability" Discrimination: A Proposal to Restore Civil Rights Protections for All Workers*, 14 Stanford Law School Law & Policy Review, 321 (2003) (Center Article); Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?, 21* Berkeley J. Emp. & Lab. L. 91, 154 (2000); *Righting the Americans with Disabilities Act*, National Council on Disability Report (2004) (containing NCD's legislative proposal intended to restore the protections of the Americans with Disabilities Act that have been restricted by several U.S. Supreme Court decisions over the past few years), available at http://www.ncd.gov/newsroom/publications/2004/publications.htm; Steny H. Hoyer, *Not Exactly What We Intended, Justice O'Connor*, Wash. Post, Jan. 20, 2002, at B01

[3] Center Article at 322.

[4] Sutton v. United Airlines, 527 U.S. 471 (1999); Murphy v. United Parcel Service, 527 U.S. 516 (1999); Albertson's v. Kirkingburg, 527 U.S. 555 (1999).

[5] See, e.g., Toyota v. Williams, 534 U.S. 184 (2002); Chenoweth v. Hillsborough County, 250 F.3d 1328 (11th Cir. 2001).

[6] 42 U.S.C. § 12102(2).

[7] EEOC. v. Sara Lee Corp., 237 F.3d 349 (4th Cir. 2001).

[8] Todd v. Academy Corp., 57 F. Supp. 2d 448 (S.D. Tex. 1999).

[9] Arnold v. City of Appleton, Wisconsin., 97 F. Supp. 2d 937 (E.D.Wisc. 2000).

[10] Steny H. Hoyer, *Not Exactly What We Intended, Justice O'Connor*, Wash. Post, Jan. 20, 2002, at B01.

[11] Congressman Hoyer's speech is available at http://www.nyls.edu/pages/2786.asp.

[12] Katherine Hsu Hagmann-Borenstein, *Much to Ado About Nothing: Has the U.S. Supreme Court's Sutton Decision Thwarted a Flood of Frivolous Litigation?*, 37 Conn. L. Rev. 1121 (2005). This commentator notes that "it appears that the relatively liberal California and Massachusetts state laws have had little negative effect, while they have greatly enhanced the protections afforded to the states' disabled populations. Plaintiffs with legitimate claims who sue under the state statutes are much less likely to be thrown out of court based on the definition of 'disability.' Yet courts in California and Massachusetts retain many methods to dismiss frivolous suits. In sum, these states have achieved a better balance between plaintiffs' and defendants' rights than exists under federal law." *Id*. at 1124-25.

[13] CCD Principles Underlying Proposed Legislation Prohibiting Discrimination in Employment Against Persons with Fully or Partially Correctable and/or Episodic Conditions, July 2005, attached.