



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Testimony of Jonathan M. Young, Ph.D., J.D.

Chairman, National Council on Disability (NCD)

Subcommittee on the Constitution, Civil Rights and Civil Liberties

Judiciary Committee

U.S. House of Representatives

**“Americans with Disabilities Act at 20 –
Celebrating Our Progress, Affirming Our Commitment”**

Thursday, July 22, 2010

2141 Rayburn House Office Building

2:00 P.M.

Mr. Chairman, Ranking Member, and Members of the House Judiciary Subcommittee on the Constitution, Civil Rights and Civil Liberties:

Thank you for the opportunity to submit for the record this written testimony just a few days before the 20th anniversary of the signing of the Americans with Disabilities Act (ADA). Providing testimony on the ADA is an especially profound honor for me as the Chairman of the National Council on Disability (NCD), as it completes a circle of sorts in both my personal and professional lives.

The Americans with Disabilities Act – Dawn of a New Day

There is a personal dimension to the history of the ADA and the history of the agency of which I am now Chairman – one that poignantly displays the power of the ADA. In 1996, I began work as a contractor on the *Equality of Opportunity: The Making of the Americans with Disabilities Act* report for NCD while a doctoral candidate in American history. The irony in this undertaking was that I was a person with a disability, having broken my neck in a high school wrestling match and living with partial paralysis, however, I did not identify as a person with a disability, nor did I view myself as part of a disability community. To me, disability was the enemy. I wanted to pass for “normal” as best I could.

So in 1996, ten years after my original spinal cord injury, having spiraled downward into a depression after years of internalizing social stigma about disability, and while giving serious thought to dropping out of my Ph.D. program, I found myself contracted to write a history of the ADA on contract with NCD – a project I had serious self-doubt about completing. However, through writing the ADA’s history, my life was radically transformed.

I had only been vaguely aware of the ADA when it passed in 1990—probably much like most of the 43 million people identified in the ADA’s findings who similarly lacked identity as a person with a disability and thus took little note of the ADA’s passage. However, researching the history of the ADA, and particularly interviewing many of the people who made the ADA’s enactment possible, including people gathered here today, made me rethink the meaning of disability and my own identity. I was riveted by the story of how the ADA came into existence and the gravity of the change wrought through the ADA. My preconception that disability was a debilitating weakness, an enemy to be overcome, ran headlong into the life stories of disability rights advocates whose power and pride both individually and collectively laid the foundation for passage of the ADA.

By the time NCD released *Equality of Opportunity* on July 26, 1997, I had begun to view myself as a person with a disability and as part of the disability community. I had also emerged from a deep depression and regained my self-confidence—no doubt largely because my inability to embrace my identity as a person with a disability had contributed to my depression in the first place. In retrospect, penning the closing line of *Equality of Opportunity*—“The dawn of a new day”—was as much about the impact of

the ADA on my life as the ADA itself. Identity as a person with a disability was liberating rather than stigmatizing. It gave my life new purpose and meaning.

My personal story is part and parcel of the ADA's significance in our society. The ADA is a nondiscrimination, civil rights law. However, much more than that, it is a clarion call for transforming attitudes about disability. As more people undergo the kinds of transformative experiences I and many others have had, we can build a stronger base of support for effectively implementing the ADA and other disability policies and programs.

The Identities of NCD and ADA are Intertwined

NCD has a critical role to play in preserving and strengthening the impact of ADA in our nation's policies and programs. Indeed, NCD's very identity is inextricably intertwined with the ADA and its history. NCD began as a small advisory body within the Department of Education. In 1984, Congress made NCD an independent agency and charged it with a new mandate to review all federal policies and programs. Two years later, NCD delivered on that charge with its path breaking report, *Toward Independence*, which called for enactment of the ADA. NCD later helped rally the disability community around it when NCD offered the first draft in 1988. After the ADA was signed into law, NCD's mission was amended to reflect the national disability policy goals now enshrined in the ADA.

NCD now serves a unique role among federal agencies because its mission reflects the breadth and diversity of the disability community itself. Achieving this mission requires bipartisan collaboration among diverse stakeholders. NCD will continue to seek common ground and help to identify priority issues for a diverse community that can make critical differences in the lives of millions of people with disabilities.

So with each ADA anniversary, NCD takes stock of its own history; and the 20th anniversary is no different. In fact, during my tenure as Chairman, my primary objective is to build a solid foundation for NCD to carry its work into the future, which means being able to coordinate and collaborate effectively across the Federal Government, with state and local governments, and with a variety of stakeholders within the disability community. We are at a critical juncture. There is no longer any mystery about the broad policy objectives for people with disabilities. The important uncertainties regard concrete and actionable steps toward implementing our policy objectives. Absent effective leadership and coordination, we will continue to fall short both in improving the lives of people with disabilities and in stabilizing our nation's fiscal health.

NCD will continue to identify policy priorities, but we want to ensure that we are well-positioned to shepherd those ideas and recommendations into reality in coordination with various decision-makers. Accordingly, we have undertaken a strategic planning process that will be completed over the next couple of months to determine how, within our resource constraints, we can best structure the agency to be an effective partner in delivering on the promise of the ADA. This process will strengthen the foundation of

NCD as we look to work with Congress and the Administration in evaluating possible changes to NCD's authorizing statute.

Twenty Years of Transformation

The year the ADA was signed into law was the same year that East and West Germany reunited; a first-class stamp cost \$0.25; Seinfeld debuted on NBC; unemployment averaged 5.6%; and the World Wide Web had just arrived on the scene.

Times have changed. We celebrate the 20th anniversary of the ADA well after civil rights provisions have been implemented in regulations, tested in court, and even amended by the Americans with Disabilities Act Amendments Act of 2008. We also celebrate amidst our nation's worst economic downturn since the Great Depression. Unemployment is nearly double digits. People are losing their homes. Access to health care remains elusive. And that is before we begin talking about the individual experiences of millions of people with disabilities, for whom the economic downturn only compounds longstanding disparities in living, learning, and earning.

Unfortunately, the challenges that we face together as a nation are compounded by partisan strife. Although vitriol is no stranger to the history of American politics, something is sorely missing today—the genuine and widespread willingness to set aside ideology to pursue pragmatic solutions that make critical differences in the lives of real people. The explosion in access to 24-hour Internet-based communications exacerbates this trend, even though information technologies and other technologies have provided new levels of access for people with disabilities.

Despite the fast-paced and daunting world we inhabit, tangible marks of the ADA's success surround us—not just regarding the ADA's specific nondiscrimination provisions but symbolically as well. In a 2001 Supreme Court decision's concurring opinion, Justice Anthony Kennedy wrote:

One of the undoubted achievements of statutes designed to assist those with impairments is that citizens have an incentive, flowing from a legal duty, to develop a better understanding, a more decent perspective, for accepting persons with impairments or disabilities into the larger society. The law works this way because the law can be a teacher. So I do not doubt that the Americans with Disabilities Act of 1990 will be a milestone on the path to a more decent, tolerant, progressive society.¹

The ADA is the disability community's standard bearer for the disability policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency. Some of the ADA's impact has been increasingly felt with the march of time as requirements for new and renovated construction create more livable communities, with physical and telecommunications infrastructures becoming more accessible and usable by more people with disabilities. With the ADA as a teacher, public transportation, entertainment venues, workplaces, businesses, streets and sidewalks

have all undergone physical transformations that recognize people with disabilities as whole citizens deserving of inclusion.

In other cases we see the symbolic victory of the ADA as people with disabilities assume prominent positions of leadership in government, business, and our communities and more children grow up embracing disability as a natural part of the human experience. With the ADA as a teacher, slowly but surely, American society is coming to view disability as part of a social construction rather than a biological fate or mere functional limitation. But we also know that problems abound, and the hard work of delivering on the ADA's promise still lies in front of us.

Twenty Years of History Repeating, Advancing

Disability is a natural part of the human experience, and for this reason, disability anti-discrimination laws are for everyone. Any one at any time can join the disability community, be it through birth, age, or injury. So while the societal landscape changes – largely for the better – for people with disabilities, the “new” people the law serves and protects twenty years later have much in common with the tireless leaders whom I interviewed who went before.

In a few days, NCD will convene the National Summit on Disability Policy 2010, a national gathering that will bring approximately 600 people from 46 states, Guam, Rio Di Janeiro, and the Tribal Nations to D.C. for substantive dialogue on the future of disability policy. The Summit theme is “Living, Learning, and Earning.” As we work this week to bring final Summit details to a close, I am struck by the breadth of disability experiences represented in both our Summit participant list as well as our distinguished list of panelists and speakers.

Sergeant First Class Karl Pasco is one of our morning panelists on July 27. Karl joined the Army in 1992, straight out of high school, and has served for over 17 years. While in Iraq in 2004, his vehicle ran over a 500-pound aircraft bomb converted into an IED. The blast severely injured him by shattering his right leg, breaking his upper jaw, fracturing three vertebrae, breaking ten ribs, and wounding his left arm with shrapnel. After recovering, Karl's unit redeployed to Iraq. Fourteen months into deployment, he fell victim to a roadside bomb, which tore through his upper arm and ripped apart his jaw. Karl participates in the Warrior Transition Brigade's Activities Section and facilitates outings for other Wounded Warriors. Karl has received numerous awards and medals, including two-time Purple Heart recipient, two Bronze Stars, a Meritorious Service Medal, three Army Commendation Medals, eight Army Achievement Medals, and the Combat Action Badge. Karl returned home from Iraq after both significant war injuries, likely not thinking at all about the ADA but nonetheless protected by it.

Now flash back twenty years. The signing of the ADA on July 26, 1990 was exactly a week before Iraqi troops invaded Kuwait, thus beginning what would a short time later become the Persian Gulf War. Few troops or policymakers likely thought at the time of the law's signing of the protections this great, new law afforded returning disabled

soldiers; nor could they likely imagine that on its twentieth anniversary, it would continue to protect a new round of returning war-wounded soldiers from Iraq and Afghanistan.

In 1990, baby boomers were in their 30s and 40s. Twenty years later, U.S. Census statistics suggest that hundreds of baby boomers are turning 60 every day, no doubt many of which are or will soon experience a progressive degree of mobility, hearing, or vision loss that accompanies aging. One of the enduring challenges for the disability community has been developing a greater sense of shared mission and purpose with the aging community. Both groups—seniors and people with disabilities—resist being lumped together. Seniors often don't want to be viewed as "disabled," while people with disabilities don't want to be dismissed as "old." Nevertheless, many of the challenges to fuller participation for both groups are similar. I am pleased to have Fernando Torres-Gil join me in serving on the Council. Dr. Torres-Gil was the first Assistant Secretary for the Administration on Aging. He is also a person with a disability. I am hoping his engagement and expertise can help bridge the gap so that we can improve a myriad of policies that have a dramatic impact on both people with disabilities and seniors. I am also pleased that representatives of the AARP will be participating in NCD's Summit.

Tia Holmes is another one of our Summit panelists. Tia is a 13 year old, rising eighth grader with disabilities at Martin Middle School in Raleigh, North Carolina. At school, Tia has been a member of the student council, Peer Mediators, National Junior Honor Society, Odyssey of the Mind, and has performed in two musical productions. In her community, she is Vice President of the Girl Scout Troop 1323 and volunteers with homeless families at the Caring Place. She was a participant at the National Youth Inclusion Summit here in D.C. in February, and she currently moderates the Summit's group webpage. She will also be joining the board of the Inclusion Initiative for the Pines of Carolina Girl Scout Council this fall. In her spare time, Tia enjoys hanging out with her best friends, playing Super Mario Brothers on the Wii, and listening to her iPod, just like her nondisabled peers. At 13, Tia has grown up only knowing the transformations and protections of the ADA.

However, when the ADA was signed in 1990, it had been a relatively short period of time (fifteen years) since federal law was enacted that stipulated that all children with disabilities receive a free and appropriate public education.² Before that time, scores of children lived in state institutions or other segregated facilities rather than attended school. Tia may have been such a child. As of 2007, 95 percent of 6- to 21-year old students with disabilities were in regular schools, and less than one percent were served in residential facilities, homebound or hospitals, or correctional facilities.³ More to the point, just as the Individuals with Disabilities Education Act assured freer access to learning opportunities, the ADA and other disability rights laws have continued to both bolster those opportunities as well as assure freer access to equality of opportunities in living and earning.

The ADA proclaims that all people, including people with disabilities, should participate fully in all aspects of our communities and have opportunities to take risks, to succeed, and – yes – to fail. Equality of opportunity means having a chance to live independently and become financially secure, but it is not a guarantee.

On this twentieth anniversary, our collective goal, as it was when we worked to pass the law, should be to ensure that the ADA is always a robust civil rights law, there for everyone when they need it. But more than that, we should recollect the intent, the motives we had in banding together the way we did to pass this great law, and recognize that we accomplish far more as a cooperative collective of policymakers, advocates, than we can ever hope to do as a divided sum of individual directions.

We must also remember that the ADA itself is neither unassailable nor self-sustaining. We learned, beginning in the 1990s, that courts were not interpreting critical aspects of the ADA as Congress intended. Another critical dimension is enforcement of the law. The ADA Amendments Act of 2008 addressed many of the significant problems that the ADA faced in court by overturning overly restrictive judicial decisions and clarifying the ADA's definition of disability.

However, the 2008 ADA Amendments did not address the lack of awareness that exists in many communities of what rights the ADA protects and how to make use of them. ADA enforcement is largely a complaint driven process. If people in underserved communities are not aware of what rights the ADA guarantees, they will be unable to meaningfully benefit from our nation's landmark disability civil rights law. We should therefore be vigilant in ensuring that executive agencies are vigorous in enforcement and that outreach about rights under the ADA is continued and expanded, particularly with communities that have been underserved by ADA enforcement efforts in the past.

This two decade anniversary urges us to press on with renewed and united sense of purpose to deliver on the ADA's legacy, hope, and promise. And an important part of that process is remembering from where we've come. Understanding the history of the ADA is every bit as important now as ever. Arguably, the urgency is even greater today. Achieving equality of opportunity for people with disabilities depends in large measure on individual transformative experiences like the one I had through writing the history of the ADA. Pausing as we are today from our busy schedules to remember the ADA's history and highlight its 20-year impact should remind us anew that the ADA's success depended on an unprecedented level of coordination and collaboration. The legacy, the hope, and the promise of the ADA endure, yet much more work must be done to transform law into life. Together, we can be the catalyst for our nation's continued transformation.

On behalf of the Members of NCD, thank you again for the opportunity to contribute this testimony to the written record.

¹ Board of Trustees of Univ. of Ala. v. Garrett (99-1240), 531 U.S. 356 (2001) (KENNEDY, A., concurring). In this 5-4 decision, the Supreme Court held that lawsuits for money damages by state employees in federal courts for a state's failure to comply with Title I of the ADA by the Eleventh Amendment.

² The Education for All Handicapped Children Act, PL 94-142, was enacted in 1975 and required all public schools that accepted federal funds to provide equal access to education for children with disabilities.

³ U.S. Department of Education, National Center for Education Statistics (2010). *Digest of Education Statistics, 2009* (NCES 2010-013), Chapter 2.