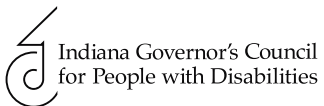


ignite thoughts into action

spark



may/june 2013
volume 3 number 3

taking a look back
RETROSPECTIVE



Independence



Equality



Empowerment

taking a look back
RETROSPECTIVE

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spark is a bi-monthly publication of the Indiana Governor’s Council for People with Disabilities, an independent state agency that facilitates change. Our mission is to promote the independence, productivity and inclusion of people with disabilities in all aspects of society. This mission is accomplished through planning, evaluation, collaboration, education, research and advocacy.

Suellen Jackson-Boner
Executive Director

Christine Dahlberg
Deputy Director

“It is a terrible thing to see and have no vision.”

–Helen Keller

The 1987 amendments to the Developmental Disability Assistance and Bill of Rights Act mandated state disabilities councils throughout the U.S. and respective territories, including the Indiana Governor’s Council, engage in a monumental task to develop a 1990 report, a Disability Policy Analysis, which would provide recommendations to the governor, the legislature and the people of Indiana, as well as the federal government.

The information was collected on a scientific basis with the goal of developing a national database to create a vision to drive and inspire the advancement of public policy relevant to people with disabilities. This unprecedented effort created a clear vision for the lives of people with disabilities in Indiana and nationwide for years to come.

After more than 23 years, it’s reassuring to know our vision has remained constant. We have aspired for public policy to advance:

- **Independence** – The ability to make choices and exercise control over one’s life.
- **Productivity** – The opportunity to work and make a contribution.
- **Integration/Inclusion** – Participation in the richness of life within society, not apart from it.


Although we have made strides, we were indeed humbled after realizing we face many of the same barriers today.

- **Housing** – The sparseness of funding alternatives.
- **Education** – The need for early intervention and adult life transition support.
- **Work** – The lack of paid employment.
- **Transportation** – One of the top unmet needs, then and now.

In the following pages of this retrospective issue of Spark, I invite you to join me in taking a renewed look at this vision, as well as trends, data and information that reveal progress.

I hope you’ll develop a better understanding of where we’ve been, and where our focus and our fight need to be in the next 20 years.

Sincerely,



Suellen Jackson-Boner
Executive Director



Disability Policy Discussion: Then and Now

Over the last few weeks, the Governor's Council spoke with two Hoosiers who have lived with disabilities, yet learned how their experiences could move public policy and perception forward. They've seen trials and victories on the state and national levels, and they understand the influence their disabilities have had on their communities. In this roundtable discussion, Karen Vaughn (KV), a disability advocate from Indianapolis, and Gary May (GM), associate professor of social work at the University of Southern Indiana, share their thoughts on the issues people with disabilities face, putting into perspective the path we've taken and where it has led us.

What do you think is the disability community's greatest legislative accomplishment in the past few decades?

KV: If referring to a national level policy, the ADA is significant because it is the biggest civil rights legislation

passed for people with disabilities. Of course, there have been victories at the state level that have brought us to where we are now.

GM: In Indiana, I think one of the most significant accomplishments would be the partial separation from sheltered workshop models for rehabilitating people with disabilities, which happened around 1995. This was a shift from vocational rehabilitation providing financial support for people in segregated work settings to community employment. It's significant because Indiana was finally getting this legislation to move us out of an institution-based model and into the world where people actually lived.

Several sources claim that since the ADA, disability policy is now mostly reactive. Would you agree or disagree?

GM: The net benefit has been very positive, but I think it's unfortunate

that ADA enforcement has become complaint-driven. You can bring attention to one deficiency in one area of accessibility that frequently evolves into a correction, but it's hard to see that correction or attitude generalize. And, there seems to be no positive sentiment to be proactive in avoiding these problems. For the third time, I'm battling an invitation by a university dean to come to his inaccessible home to listen to a guest speaker.

Also, the legal community has not really been our ally as much as it could be. A few years ago, I was getting notifications about a law firm targeting businesses to let them know they could help them avoid ADA compliance and not be detected. The legal community has embellished the opportunity to work around the ADA, and this reinforces the mindset in businesses that government regulation is all bad.

KV: Nothing is proactive, that's my opinion. Just because a person gains a right, it doesn't automatically take effect in Indiana or across the country – that's just not the way it is. I had to sue the state of Indiana on discrimination policies, and I lost! I also worked to get legislation called MED Works passed, which allowed Indiana residents with disabilities to receive Medicaid coverage and earn up to \$32,000 a year before benefits were affected. We got that legislation passed in one year, which was incredible, but it was another way we stayed reactive. Also, after ADA, IDEA and other legislation passed, folks had to go around the state and teach people what the laws even meant.

Do you feel there is a momentum in creating employment opportunities for people with disabilities? What advocacy and policy work still need to be accomplished for the employment rate to improve?

GM: I don't think I've seen anything above or beyond rhetoric. Bubbles come up in the local media about businesses who have hired a worker with a disability and the wonderful experience they're having, but these stories aren't scalable. For several presidencies, I haven't seen the real results of White House announcements about big initiatives to hire people with disabilities. And, people also talk about the monetary benefits of hiring people with disabilities until they're blue in the face. But, real change has been very muted. I think business people or chambers of commerce need to get serious about hiring. We should try to shame businesses into hiring

people with disabilities – to carry out the collective social obligation we all have to our fellow man. The largely ineffective stances aren't going to help unless it's something that can prick social consciousness.

KV: Unfortunately, the state of Indiana still sees sheltered workshops as employment. I do not, and I don't think they're a good thing. It's amazing to see the lack of knowledge that folks have on this topic. Right now, to keep the CHOICE home care services program running, it costs \$48.8 million. But they're taking \$20 million out of the program to support waivers. If you can't support CHOICE, there's no hope for it. And, there is fragmentation in the disability community that segregates us and keeps us from getting broader policy work for the disability community accomplished. Public education is key to all of this.

In your opinion, what are the positive advances the disability community has made in the realm of health care and health services?

KV: I think the Olmstead Decision was the most positive. [Olmstead was a Supreme Court decision stating it is a violation of the ADA to send people with disabilities to institutions, or keep them there, when their needs could be met through home- and community-based services.] In reality, if you are very well versed on the laws or can use other people as a resource to educate yourself on the laws, having that knowledge is a positive thing.

GM: There is greater awareness of this issue overall, and it's

largely expressed by the new physical accommodations so that all people have access to services. Also, the sensitivity to privacy and confidentiality has been noticeably changed too, probably because of HIPAA (Health Insurance Portability and Accountability Act).

If you could change public attitude and perceptions on one area of disability, what issue would you choose and why?

GM: I would want to adopt the attitude that we are all equal citizens. We should be held equally accountable for contributing to the benefit and welfare of a community. I'm not asking for a pass for contributing to my community because I have a disability. But, I also won't tolerate the short shrift that I might get because I have a disability.

KV: I would change the perception of those who have a mindset that people with disabilities can't accomplish what others can, yet be surprised when they do something unexpected. If people could change that one mindset, people with disabilities will be seen as even more productive and worthwhile.

As a disability advocate and leader in Indiana, what have you learned from your experiences that you could help others understand?

KV: I think when people realize it is their right to experience their life just like everyone else – even if it means filing appeals or being a stickler with your health care provider – and knowing there are other advocates who

(continued on page 19)



Independence

The overarching message of the 1990 Americans with Disabilities Act (ADA) was “Independence” – independence through fully inclusive and supportive communities, independence through appropriate supports and assistance, and independence through meaningful education and job opportunities.

In the years since the ADA’s passage, public discourse and advocacy have continued to influence national and state policy to enhance people with disabilities’ options for living and working within their communities. However, economic crises and other setbacks have dealt heavy blows to affordable housing, supports and services, and other critical components needed to ensure Indiana communities are livable for everyone.

Livable communities

“Too many people who need assistance with the activities of everyday life face a difficult choice: move into a nursing home and face safety and quality of care problems or risk injury or death by staying in the community without adequate services to address personal needs.” This statement from the White House website (whitehouse.gov/issues/disabilities) clearly depicts an unfortunate dilemma that could be avoided by creating livable communities – an initiative discussed in recent issues of Spark and at the Governor’s Council’s 2012 Conference.

Livability means greater access, such as walkable destinations for health care, employment and entertainment. It means more affordable options for housing, goods and services. And, it means more opportunities for citizens to

become involved, engaged, and to receive the services they need in their home and community. To build livable communities, we must focus our attention on key areas that create a fully inclusive and accessible society.

Housing

The 2010 Priced Out report, published regularly by the Technical Assistance Collaborative (TAC) and the Consortium for Citizens with Disabilities (CCD), revealed the housing affordability gap for people with disabilities nearly doubled over a 12-year period.

One stride made toward providing more affordable housing options came in 2010 when the U.S. Department of Housing and Urban Development’s (HUD) Section 811 program – which develops and subsidizes rental housing for very low-income people with

disabilities – was made stronger by the Frank Melville Supportive Housing Investment Act. This law authorizes and provides incentives for more integrated, supportive housing units within affordable housing developments, and also includes strong language emphasizing the goal of community integration for people with disabilities.

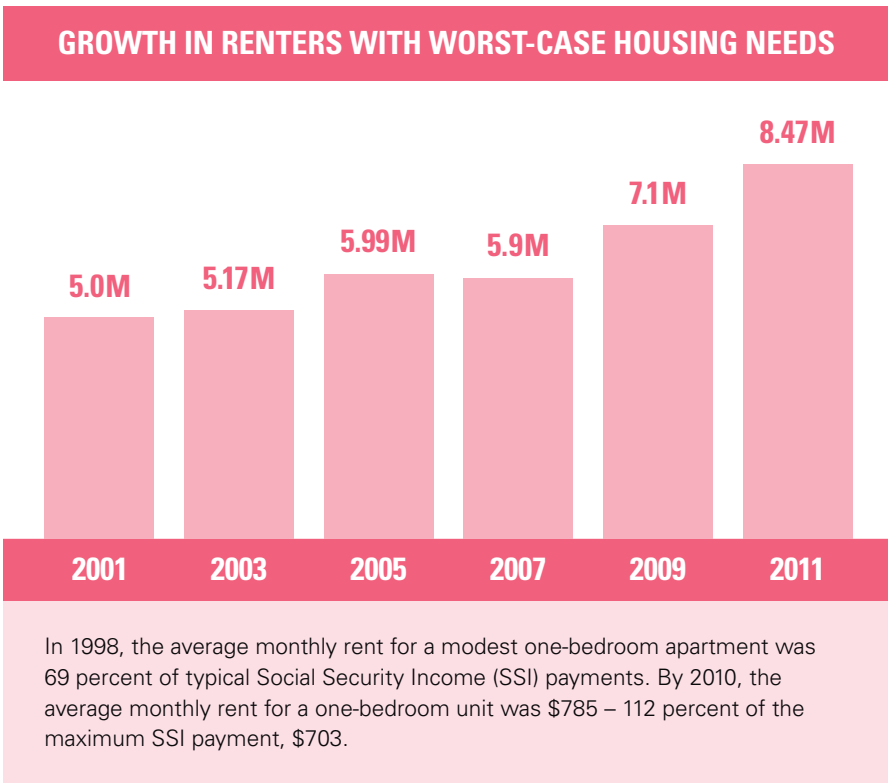
Still, the 2011 Annual Disability Statistics Compendium reported 28.6 percent of people with disabilities ages 18 to 64 living in the community live in poverty, whereas only 13.7 percent of people without disabilities in the same age range live in poverty – a 15 percent gap. In a news release dated February 2013, HUD announced that more and more individuals and families – nearly 8.5 million in 2011 – are facing worst-case housing needs. “Worst case” is defined as renters with very low incomes (below half the median in their area) who do not receive government housing assistance and who either pay more than half their monthly incomes in rent, live in severely substandard conditions, or both. This is up from 7.1 million households in 2009, a 19 percent increase, and up 43 percent from 2007.

Furthermore, HUD reports that one in six renters with worst-case needs in 2011 were households with at least one non-elderly person with disabilities. That’s 1.31 million households, up from 990,000 reported in 2009.

According to Priced Out, however, HUD’s data source for determining worst-case housing needs – the American Housing Survey – excludes individuals

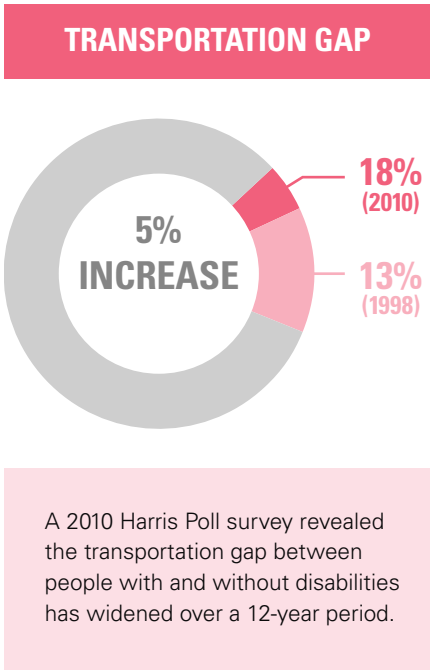
living in nursing homes, health care facilities, homeless shelters or other group quarters. TAC and CCD feel these individuals must be

accounted for in survey data, as they could live in their communities if affordable housing and supportive services were available.



Mobility

Accessible public transportation is a significant missing link in many communities – limiting people with disabilities’ opportunities for employment, education, adequate health care and community involvement. Finding and securing meaningful employment is significantly affected by transportation. According to a 2010 NOD-Harris Interactive poll, 45 percent of all the people with disabilities who reported that access to transportation was a major problem had annual incomes below \$35,000, and transportation problems decreased as incomes increased.



NUMBER OF INDIVIDUALS IN WAIVER SERVICES

AS OF 9.30.2012 13,168

2011 12,774

2010 12,316

2009 11,988

2008 10,927

2007 10,247

Supports and assistance

In the 1990 report addressed to the governor and state legislature, the Indiana Governor's Council included a hopeful vision that people in both rural and metropolitan areas of the state would have access to a system of support services that enables them to function as independently as possible. Unfortunately, survey data revealed respondents with disabilities had little familiarity or experience with state or federal support programs, and three out of four of those respondents did not affiliate with any advocacy or support group.

Indiana's Family and Social Services Administration (FSSA) administers various home- and community-based services (HCBS) waivers that can assist people

with disabilities and help them stay in or transition back into community life.

- Family Supports Waiver
- Aged and Disabled Waiver
- Traumatic Brain Injury Waiver
- Community Integration and Habilitation Waiver
- Money Follows the Person (MFP) Grant
- CHOICE (community and home options)

Although multiple waivers are offered, a consistent problem is growing waiting lists to obtain services. However, as of September 2012, more than 13,100 Hoosiers were receiving Medicaid waiver services, and the number served has continued to grow since 2008. For more information about Indiana's supports, visit in.gov/fssa.

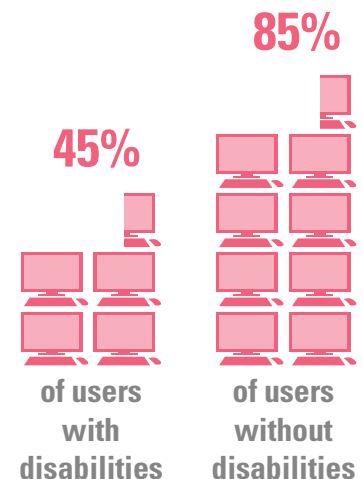
Technology

A critical area for people with disabilities that has likely seen the most advancements over the last decade is assistive technology. More sophisticated supportive devices for communication, mobility and personal care have emerged to help people with disabilities perform daily functions with greater confidence and ease. Furthermore, legislative actions have lent support to states and federal programs for making technology more accessible to people with disabilities. Recognized as the legislation that most directly supports assistive technology, the Assistive Technology Act of 1998, which replaced a 1988 law and was

reauthorized in 2004, provides states with support for promoting access to and awareness of assistive technology among people with disabilities.

However, in addition to supportive devices and other technology specifically built to assist people with disabilities, it's equally important that technology in general – phones, tablets, the Internet and more – accommodates all users. Since 1997, the World Wide Web Consortium's Web Accessibility Initiative (w3.org/WAI) has worked to improve web page accessibility. And Indiana's Easter Seals Crossroads has provided assistive technology solutions to Hoosiers since 1979. *

TECHNOLOGY GAP



Percentage of people with and without disabilities who are accessing the Internet, 2010.



Equality

During the signing of the ADA in 1990, President George H. W. Bush proclaimed, “Together, we must remove the physical barriers we have created and the social barriers that we have accepted. For ours will never be a truly prosperous nation until all within it prosper.”

The president’s call for the betterment of all affirms that each American is a full-fledged, rightful

citizen. Has our nation echoed the president’s call and fully executed these ideals? Not entirely.

As displayed in the timeline below, we’ve witnessed a major transformation in defining what it means to have a disability, moving from a medical model to a social model. We’ve pushed through attitudinal barriers and freed people with disabilities from institutions, created access

to sidewalks and buildings, and provided high-quality, inclusive education.

A great deal of work remains if we are to bring increased funding to effective community-based solutions. And, we must fight to change the attitudes of educators and employers toward people with disabilities and their capabilities and contributions.

1817

The American School for the Deaf, the first school in the Western Hemisphere for children with disabilities, founded in Hartford, Conn.

1848

The Perkins Institution opens in Boston as the first residential institution for people with developmental disabilities

1864

Congress authorizes Columbia Institution for the Deaf & Dumb & Blind, world’s first college established for people with disabilities

1883

Eugenics, a term coined by Sir Francis Galton in his book *Essays in Eugenics*, spawns a movement resulting in a proliferation of literature linking disability with immorality; laws are enacted to prevent people with disabilities from moving to the U.S., marrying or having children; institutionalization; and forced sterilization of adults and children with disabilities. Indiana was the first state to pass eugenics laws

1918

The Smith-Sears Veterans Rehab Act promotes vocational rehab and return to civil employment for disabled persons discharged from U.S. military

PROGRESS AND PERSPECTIVE: A DISABILITY RIGHTS TIMELINE

Employment

In our 1990 report, Americans knew the next century would bring more high-skilled jobs to the workforce, thereby forcing out certain employees with disabilities. It was imperative that jobs, which could easily be accommodating, were available for people with disabilities. Twenty years after, regardless of how many jobs we reserved, the economic climate changed for everyone. Even though the ADA stipulates employers should allow for “reasonable accommodation” to make a functional workplace, many felt this language created the stigma of an “additional price tag” when hiring people with disabilities.

As of February 2013, labor force participation of people with disabilities jumped 4.6 percent from last year, totaling an employment rate of 31.8 percent. By today’s standards, this increase is significant; however, according to the chart at the right, the rate still sits well below past years’ numbers. In truth, according to the Center for An Accessible Society, the employment rate for people with disabilities has hovered around 35 percent since World War II.

ADVANCING EMPLOYMENT: BY THE NUMBERS

A 2013 study by the Conference Board revealed:

33% 

Number of human resources managers who said employees with disabilities have a lower rate of turnover

85% 

Number of people who said they would prefer to give their business to companies that employ people with disabilities

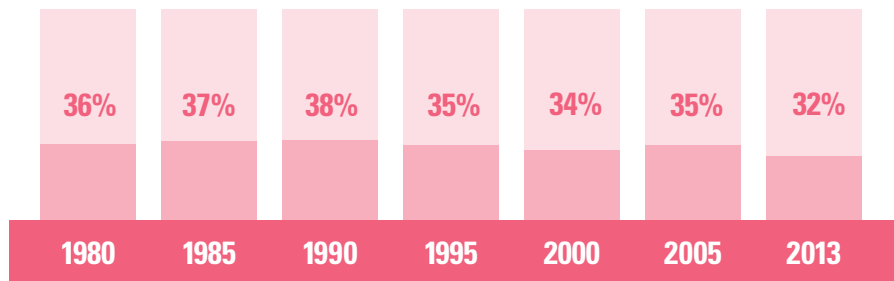
\$0 (FREE)

Cost to employers of nearly half of accessibility accommodations

\$25 

Median cost of accessibility accommodations

YEARLY EMPLOYMENT RATE OF THOSE REPORTING WORK LIMITATIONS (PERCENTAGES)



1935

The Social Security Act creates federally funded old-age benefits and provides funds to assist blind individuals, disabled children and existing vocational rehab programs

1940

The National Federation of the Blind forms and advocates for legislation preserving equality for blind people; The American Federation of the Physically Handicapped becomes first cross-disability national political organization

1961

President Kennedy appoints a special President’s Panel on Mental Retardation; American National Standards Institute sets first minimum standards for making buildings accessible

1970

The Developmental Disabilities Services and Facilities Construction Act (replaces the 1963 Mental Retardation Facilities Construction Act) becomes the Developmental Disabilities Assistance and Bill of Rights Act

1973

Rehabilitation Act promotes vocational rehabilitation for individuals with severe disabilities, provides civil rights protections and creates the Architectural and Transportation Compliance Board to set accessibility standards

1975

Education for All Handicapped Children Act requires free, appropriate public education for children with disabilities and authorizes financial incentives to promote compliance

AFFORDABLE CARE ACT – CHANGES TAKING EFFECT 2011-2014

2011	2012	2013	2014
Offer home- and community-based services to individuals with disabilities through Medicaid.	Voluntarily enroll in a long-term care insurance program.		<p>Tax credits will be available.</p> <p>Insurers cannot deny coverage to any individual due to a pre-existing condition.</p>
			<p>Medicaid will expand.</p> <p>Health Insurance Exchange will be established.</p>

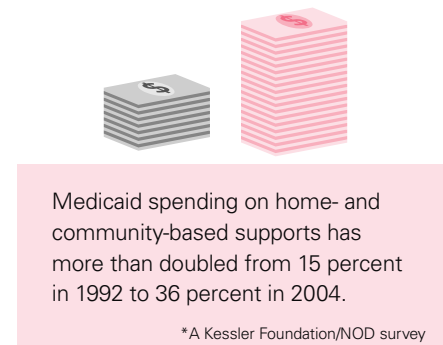
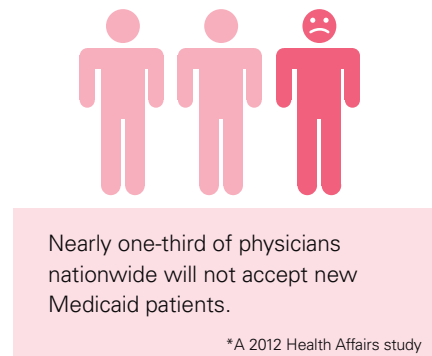
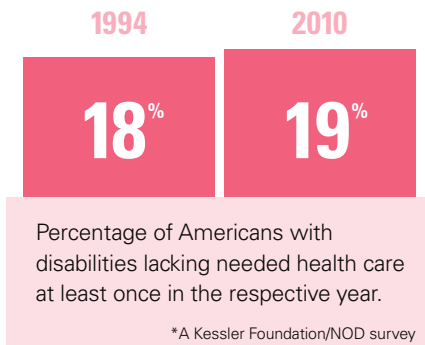
Health care

According to the 1984 Survey of Income and Program Participation, 85.9 percent of people with disabilities had some type of health insurance. In 2004, it was 82.7 percent. By 2014, the Obama administration hopes with the passage of the Affordable Care Act that 100 percent of people with disabilities will have access to coverage. However, these policy changes create challenges, and

the question remains: Where will dependable coverage come from?

Over the last two decades, people with disabilities have continued to have to mix public and private health insurance to meet their needs, and we've lost funding for effective community-based alternatives to predominantly federal- and state-funded Medicaid supports. In addition, billions of taxpayer dollars continue to fuel high-level federal programs.

It has always been the position of the Council to support quality, affordable and accessible health-related services – public or private – that meet the needs and choices of people with disabilities. Whether it's services for primary, rehabilitative or preventive care, people with disabilities should have access to appropriate and expert health management programs to help them maintain their livelihoods without service limitations, waiting lists and hefty price tags.



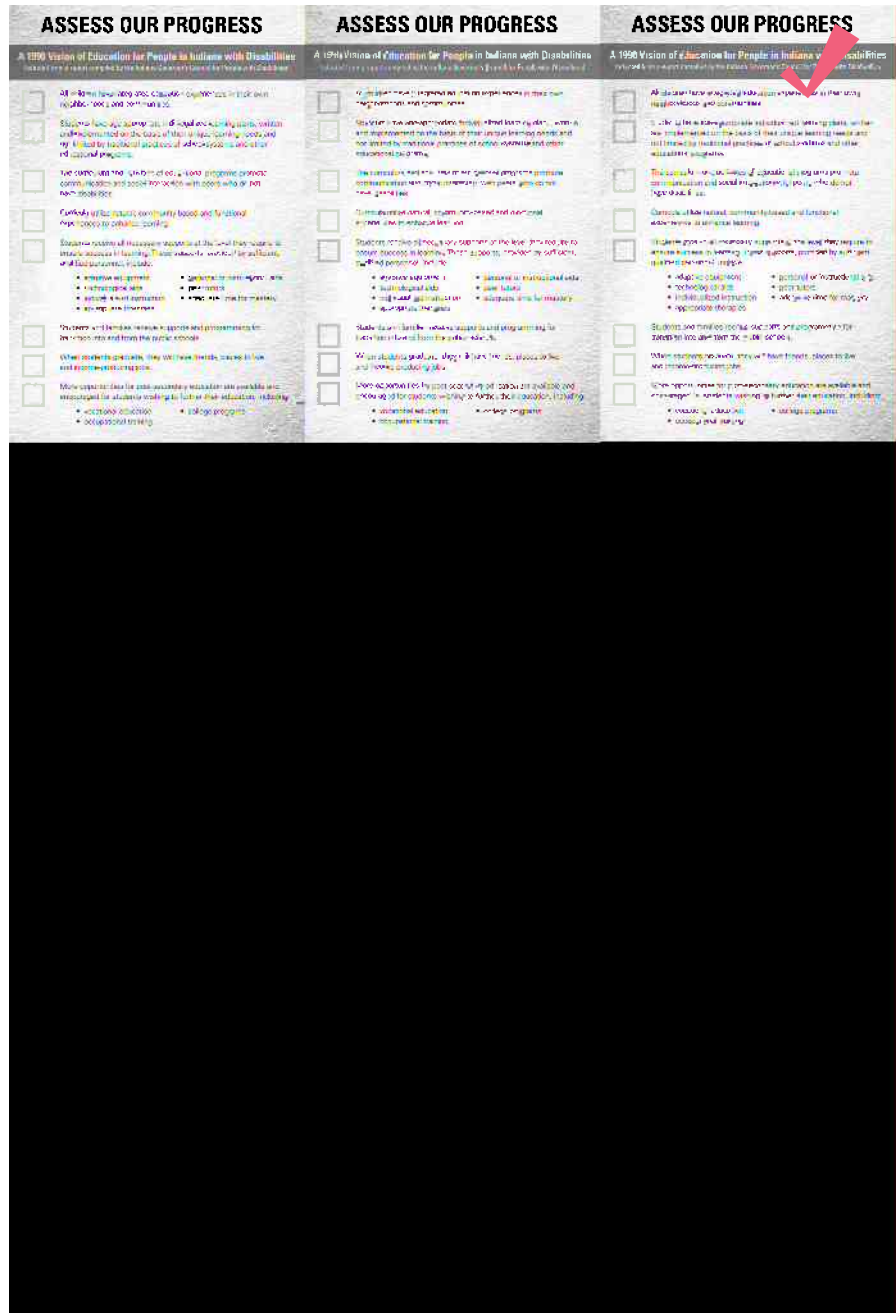
1984 Voting Accessibility for the Elderly and Handicapped Act passes	1986 Air Carrier Access Act passes	1988 Technology-Related Assistance for Individuals with Disabilities Act provides state grants to promote assistive technology	1990 Americans with Disabilities Act passes	1996 Telecommunications Act requires broadcast and cable television to provide closed captioning	1999 Ticket to Work and Work Incentives Improvement Act provides health benefits and other non-cash benefits for people to work; the Olmstead decision upholds the right of individuals with disabilities to live and obtain supports within a community setting
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Education

Like most landmark legislation, we have a reason to celebrate the passage of the Individuals with Disabilities Education Act (IDEA). What started as the Education for All Handicapped Children Act in 1975, this law supports states in ensuring students with disabilities have a free, appropriate public education in the least restrictive environment, just like other children. In 2010, the disability community celebrated 35 years of IDEA.

Today, 57 percent of students with disabilities are in general education classrooms for 80 percent or more of their school day. Early intervention services are now provided to nearly 350,000 infants and toddlers with disabilities and their families, and more than 6.6 million children and youth receive special education and related services designed to meet their individual needs.

Although the National Dropout Prevention Center for Students with Disabilities reported a dropout rate of 14.5 percent in 2010, the Council continues to promote its 1990 vision for education: strive for adequate funding of special education programs and fill the demand for qualified teachers. *



2001

Alabama v. Garrett rules that people with disabilities who are employed by a state may not sue the state for employment discrimination, thus limiting the scope of the ADA

2002

Toyota Motor Manufacturing v. Williams narrows the definition of disability, making it more difficult for people with disabilities to win ADA-related lawsuits; Help America Vote Act requires polling places to be accessible and guarantees the right to cast a secret ballot

2004

Tennessee v. Lane rules people with disabilities can sue states to remedy inaccessible judicial facilities and services, reaffirming an essential component of the ADA

2009

The Matthew Shepard and James Byrd Jr. Hate Crimes Prevention Act expands the 1969 U.S. federal hate-crime law to include crimes motivated by a victim's actual or perceived gender, sexual orientation, gender identity or disability

2013

The U.S. Department of Education issues a mandate requiring schools to provide sports for children with disabilities



Empowerment

The cornerstone of the entire disability rights movement has been the unwavering determination of people with disabilities and other advocates. The Architectural Barriers Act, the Individuals with Disabilities Education Act, the National Voter Registration Act, the Help America Vote Act, the Air Carrier Access Act, the Fair Housing Act and the Americans with Disabilities Act all became law because of the empowerment of people with disabilities.

Thomas Jefferson said, “I am not an advocate for frequent changes in laws and constitutions, but laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered and manners and opinions change, with the change of circumstances,

institutions must advance also to keep pace with the times.”

Our political, economic, community and educational institutions have indeed become more accepting and accessible thanks to our advocates, allies and change agents who helped shape and develop the rights people with disabilities enjoy today. But now is not the time to rest on our laurels. We must continue to find and fight for improvements.

The disability community continues to impact the lives

“Laws and institutions must go hand in hand with the progress of the human mind.”

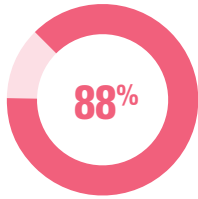
—Thomas Jefferson

of every American. Especially with the passage of the Americans with Disabilities Act Amendments Act (ADAAA), signed into law Sept. 25, 2008, we now have a broadened definition of disability that spills over into employment, education and housing policy.

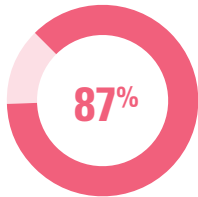
The National Academy of Sciences’ report, “The Future of Disability in America,” agrees that with the more expansive definition, the future of disability in America can no longer be described as a minority issue. More than 57 million Americans are people with disabilities, and we’ve earned a “place at the table,” to shape the laws of tomorrow.

Looking back at the empowerment witnessed throughout history, it’s reassuring to know the disability community has always steadily moved forward to create necessary change.

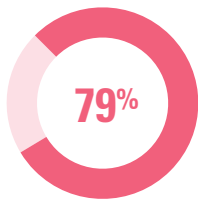
SUPPORT FOR THE ADA



Believe in non-discriminatory public places



Agree with making public transit accessible



Support making reasonable accommodations in companies with 15 or more employees

American support of disability issues

Today, Americans are split on whether the U.S. government is making advances in policies and programs to help people with disabilities. In a national study conducted by Greenberg, Quinlan, Rosner Research in September 2012, 46 percent of Americans feel the government is doing enough and 44 percent believe they are not. The survey also revealed 55 percent of voting Americans said that it would make no difference to their vote if a candidate commits himself or herself to making disability issues a priority. In other words, there is no downside for political candidates to support policies for people with disabilities, but that also means those candidates – depending on

their constituent demographics – may not feel compelled to support disability rights legislation.

Back in 2003, a National Organization on Disability/Harris survey showed strong support from Americans for the ADA – roughly 88 percent believed in non-discriminatory public places, 87 percent agreed with making public transit accessible and 79 percent supported making reasonable accommodations for people with disabilities working in companies with 15 or more employees. No recent survey has provided updated results, but it's reasonable to believe support remains strong.

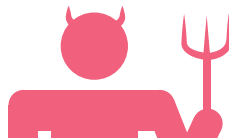
Legislation

Throughout the years, perspectives on disability legislation have experienced cycles. Early policies helped provide income support to those who couldn't work and afford basic life needs. Throughout the 1960s, Medicare, Medicaid and the first accessibility laws foreshadowing the ADA were established. Going into the 1970s, the disability community embraced civil rights movements, which spurred the goal of equality. Today, advocates focus on “interpreting, refining, and fully implementing existing policies related to disability,” as stated by the National Academy of Sciences. Advocates work to protect people with disabilities from policy changes or interpretations that could directly or indirectly threaten their rights.

FOUR IDEOLOGICAL MODELS OF DISABILITY

Dating back to the early 1800s, these perspectives on disability have shaped legislators' views on disability policy.

MORAL MODEL



Disability is the result of sin.

MEDICAL MODEL



Disability is a defect or sickness that must be cured through medical intervention.

REHABILITATION MODEL



Disability is a deficiency that must be fixed by a rehabilitation professional.

SOCIAL MODEL



Disability is a normal aspect of life, defined by the physical and attitudinal barriers in society.

Civic engagement

Voting

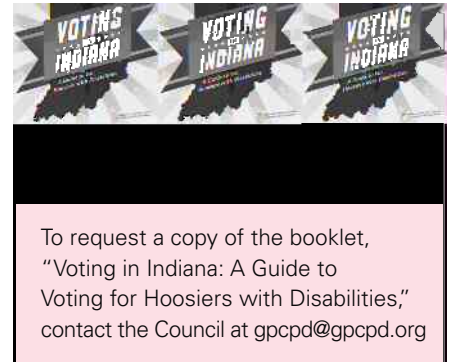
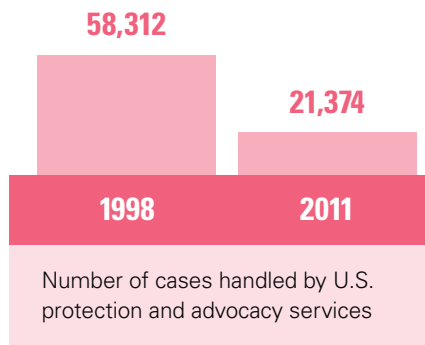
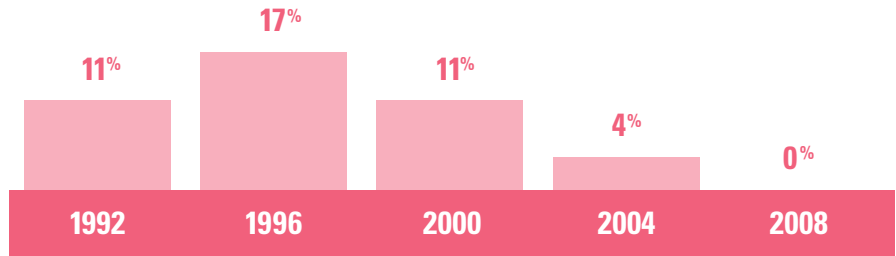
A 2010 Harris Poll/NOD report found the voting gap between people with and without disabilities was eliminated – 59 percent of each population voted. After the election, a statewide poll of voters with disabilities still revealed a main reason for not voting was limited access to polling locations. But, Indiana has remained proactive about fixing these issues. With the Council's Count Us IN initiative supported by Indiana Protection and Advocacy Services (IPAS) and the Indiana Secretary of State, and the implementation of the Help America Vote Act, poll accessibility has improved.

Advocacy Groups

Although the disability rights movement was said to start in the mid 1960s, there were many forerunners of the cause – some dating back to the late 1800s. The chart to the right shows a sampling of the hundreds of organizations that exist to support disability causes.

As more private advocacy groups assembled, people with disabilities have also relied on statewide protection and advocacy agencies since the passage of the Developmentally Disabled Assistance and Bill of Rights Act. In 2012, IPAS handled 549 cases related to abuse, neglect, health, special education, employment, voting and privacy. In addition, 2,132 individuals received information and referral services from IPAS in 2012, empowering them to self-advocate. And, 98 percent of these callers said they would call IPAS again, if needed.

VOTING GAP BETWEEN PWD AND NON-PWD



A HISTORY OF ADVOCACY GROUPS

- 1876** American Association on Intellectual and Developmental Disabilities
- 1880** National Association of the Deaf
- 1909** Mental Health America
- 1916** Easter Seals
- 1920** Disabled American Veterans
- 1921** American Foundation for the Blind
- 1922** Rehabilitation International
- 1940** National Federation of the Blind
- 1946** United Spinal Association
- 1946** Paralyzed Veterans of America
- 1949** United Cerebral Palsy
- 1950** The Arc
- 1950** Muscular Dystrophy Association
- 1960** Post-Polio Health International
- 1961** American Council of the Blind
- 1968** Special Olympics
- 1970** Disabled in Action
- 1972** Center for Independent Living
- 1973** Consortium for Citizens with Disabilities
- 1973** National Down Syndrome Congress
- 1975** TASH
- 1978** National Council on Disability
- 1979** National Alliance on Mental Illness
- 1979** Disability Rights Education and Defense Fund
- 1980** National Disability Rights Network
- 1982** National Organization on Disability
- 1982** National Council on Independent Living
- 1983** Americans Disabled for Accessible Public Transit (ADAPT)
- 1990** Autism National Committee
- 1990** Self Advocates Becoming Empowered
- 1993** International Disability and Development Consortium
- 1995** American Association of People with Disabilities
- 2006** Autistic Self Advocacy Network

Justin Dart

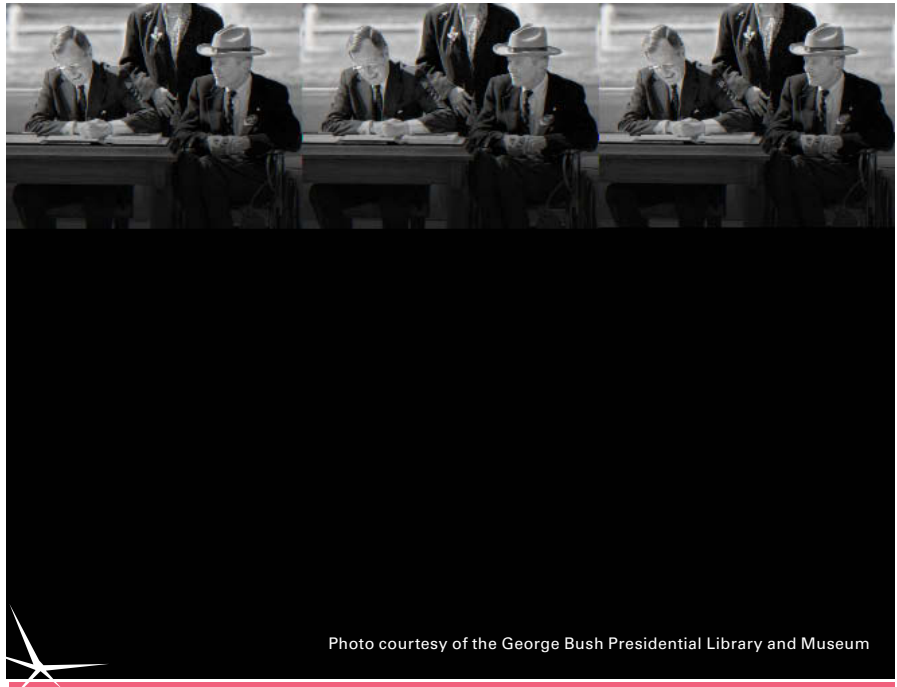
Justin Dart, known as the “father of the ADA,” has long been known as the Martin Luther King Jr. of civil rights for people with disabilities. Dart, who began using a wheelchair after contracting polio in 1948, was inspired by the philosophy of Gandhi. He whole-heartedly believed in this teaching – “find your own truth, and then live it.”

Dart became a successful businessman in Japan, but it was after a visit to a polio camp in war-torn Vietnam that he became serious about human and disability rights. He returned to Texas and engrossed himself in disability advocacy, working tirelessly with grassroots organizations and national committees. President Ronald Reagan appointed Dart as Vice-Chair of the National Council of Disability in 1981. His work there would eventually become the ADA.

In 1989, President George H. W. Bush appointed him to the President’s Committee on the Employment of People with Disabilities and as chair of the Congressional Task Force on the Rights and Empowerment of Americans with Disabilities. Unwavering in his efforts, Dart visited every congressional office and met with activists in every

“Our lives, our children’s lives, the quality of the lives of billions in future generations hangs in the balance. I cry out to you from the depths of my being. Humanity needs you! Lead! Lead! Lead the revolution of empowerment!”

- Justin Dart, disability advocate



Justin Dart, wearing his signature ADA Cowboy hat, watches President George H.W. Bush sign the ADA into law.

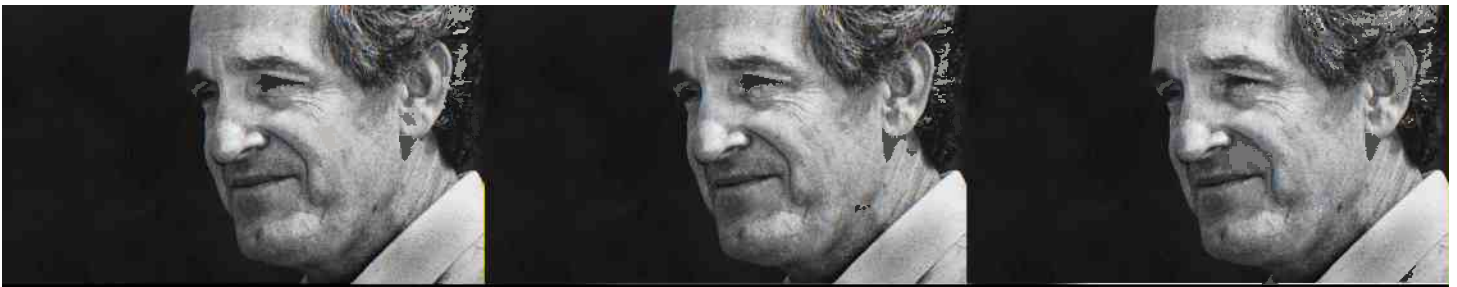
state explaining the necessity of the ADA. And, he was honored to be with President Bush when the ADA was signed into law.

As backlash grew against disability rights in the mid-1990s, Dart toured the nation and became a “full-time citizen soldier in the trenches of justice.” He testified, presided over meetings, corrected distortions in the media, and inspired thousands of grassroots groups to fight for full civil rights for people with disabilities. In 1998, Dart received the nation’s highest civilian award,

the Presidential Medal of Freedom. He never forgot his advocacy allies and friends from all walks of life, always urging solidarity and the “politics of inclusion.”

Even after suffering a series of heart attacks in 1997, Dart continued to lobby Congress and attended numerous rallies and demonstrations fighting “like his life depended on it.”

Before his death in 2002, Dart authored a political manifesto for all those willing to take on the hard task of gaining rights for people with disabilities across the world. In it, he states: “Beloved colleagues in struggle, listen to the heart of this old soldier. Our lives, our children’s lives, the quality of the lives of billions in future generations hangs in the balance. I cry out to you from the depths of my being. Humanity needs you! Lead! Lead! Lead the revolution of empowerment!” *



Sen. Tom Harkin on the future of disability policy

More than 25 years ago, U.S. Senator Tom Harkin (D-IA) outlined his goals and ideas for the advancement of people with disabilities to the Indiana Governor's Council and its advocates in a 1988 publication produced by the Council known as "Vision."

We're honored to have another opportunity to hear his thoughts on the future of disability policy before he leaves Congress in 2014. We hope this interview encourages you, our advocates, as well as educates Indiana policymakers and community leaders.

Council: Since the late 1980s, many areas of disability laws have improved and in others, they have not. Looking ahead, which disability laws are you most concerned with?

Sen. Harkin: One of my major priorities in my remaining years in the Senate is to work toward

ensuring that people with disabilities have job opportunities – and not just any job, but one that is equal to their interests and talents and pays accordingly. As part of that effort, my work will include access to the training and supports necessary for those individuals to be successful. We will have opportunities to promote these goals in the Workforce Investment Act, the Elementary and Secondary Education Act, the Higher Education Act, and the Individuals with Disabilities Education Act, all of which are under the jurisdiction of the Senate HELP Committee (Health Education, Labor and Pensions), which I chair.

It's important that individuals with disabilities have the option to receive care and services in their homes and communities. As Chairman of HELP, I am continuing to look at what states are doing to comply with their

obligations to offer people long-term services and supports in integrated settings under the ADA. We made progress on this front with the health reform law – I pushed to include a provision known as the Community First Choice (CFC) option, which allows individuals to receive these services outside of a hospital or nursing home. Several states have chosen to implement the CFC option, and I'm optimistic that more states will continue to follow suit.

Council: Has 20 years of the ADA changed Congress' perspective on disability rights? Do newcomers understand its legacy?

Sen. Harkin: Working on the passage of the ADA, I heard stories of individuals who had to crawl on their hands and knees to go up a flight of stairs. Stories of individuals who couldn't ride on a bus because there wasn't a lift and

stories of individuals who couldn't go to concerts or ballgames because there was no accessible seating. Many young people today don't remember a time before these sorts of accessibility measures. It's always been a part of the world they grew up in.

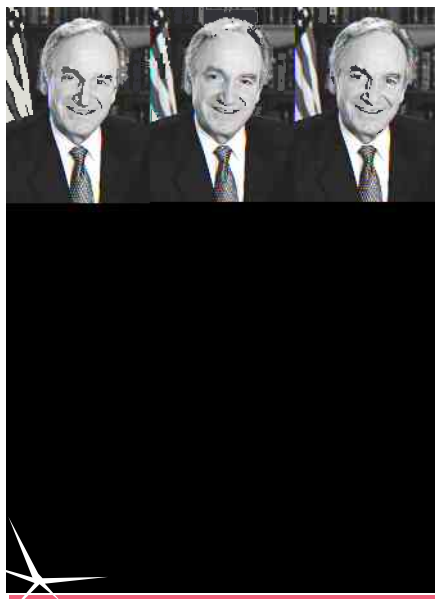
Thanks, in part, to the ADA, today we recognize that disability is a natural part of the human experience and that children and adults with disabilities have a right to make choices, pursue meaningful careers, live independently and participate fully in their communities. I think newcomers to Congress may not always recall our country's history of discrimination, segregation and exclusion, but I think there continues to be bipartisan support for the tenets of the ADA.

Council: Where should our focus be in the years ahead to advance disability causes?

Sen. Harkin: We must make more progress on increasing employment for people with disabilities, and I am troubled that we still have an institutional bias in the Medicaid program. These are issues that will continue to be a priority for me in my final two years in the Senate. For working-age people with disabilities who use long-term services and supports, these two issues are connected. I believe that increasing labor force participation is the key to increasing economic self-sufficiency for people with disabilities. That is why I have set a goal to increase the size of the disability labor force by more than 20 percent, from just over 4.9 million to 6 million workers, by 2015.

Similarly, when we give people a real choice in the community and they can count on the supports they need to live independently, finding a job and building a career is much more of a possibility.

Finally, I believe the Senate should ratify the U.N. Convention on the Rights of Persons with Disabilities (CRPD). Officials from the United States shared our nation's experience and expertise when the U.N. was drafting the Convention on the Rights of Persons with Disabilities, and we should



Sen. Tom Harkin

be at the table with the other state parties to the Convention as they work to enact and implement disability rights laws in their countries. We live in an increasingly global economy, and Americans with disabilities should be able to work, study and travel abroad without having to worry about whether they will be able to access buildings, transportation and technology outside the U.S.

While I was disappointed by the Senate's failure to ratify the CRPD last Congress, I am committed to working hard to get the 67 votes we need in the Senate to support ratification during this session of Congress.

Council: Do people with disabilities and disability advocates still hold the same unity and vigor since the passage of the ADA? Has this voice become stronger or weaker?

Sen. Harkin: There is no question in my mind that people with disabilities and disability advocates played a critical role in the passage of the ADA, and we have worked together on many pieces of legislation since then: Section 255 of the 1996 Telecommunications Act; the ADA Amendments Act of 2008; and the 2010 21st Century Communications and Video Accessibility Act, and the push to ratify the CRPD, to name a few.

I think the disability advocacy community needs to continue to find issues that bring people together and find ways to resolve differences of opinion "within the family" wherever possible. The more united the community is, the harder it is for elected officials to overlook their priorities. I am encouraged by groups like the National Disability Leadership Alliance that bring together cross-disability consumer organizations, and I believe the disability community will only grow in power and influence over time.

Council: As we move closer to 2020, can you share your best piece of advice for disability

advocates working at the state level?

Sen. Harkin: My best advice is for people to work together, grow and organize the community, and build long-term relationships with local, state, and federal elected officials and policymakers. One of our greatest assets as a community is the fact that disability affects people and families across the political spectrum, so I think it's important for advocates to be always looking for new allies and never make assumptions that someone might be against them without taking the time to discuss the issue.

Council: Who have you empowered for the future, at the federal level, to continue your work?

Sen. Harkin: The important thing to remember is that passage of the ADA – and virtually any piece of disability rights legislation – has been a bipartisan team effort. As chief sponsor of the ADA in the Senate, I worked very closely with people on both sides of the aisle, both in Congress and in the

Administration. Sen. Bob Dole was an indispensable ally. We received invaluable support from President George H. W. Bush and key members of his administration, including White House counsel Boyden Gray and Attorney General Dick Thornburgh. And there were so many others – Justin Dart, Tony Coelho, Steny Hoyer, Steve Bartlett, advocates, other members of Congress and the administration – whose commitment and support were instrumental in helping get the ADA passed.

I have many colleagues on both sides of the aisle, in both the House and the Senate today, who are still doing good work on behalf of people with disabilities, and the disability advocacy community is playing a large part in ensuring that their voices continue to be heard.

I fully expect long-time champions like Steny Hoyer and Ed Markey to continue to lead on these issues, and I am confident that they will be joined by younger members like Jim Langevin, Tammy Duckworth, Cathy McMorris

Rodgers, Pete Sessions, Elizabeth Warren, and many others with and without disabilities who will take up this cause for many years to come. I am also encouraged by the leadership demonstrated by my fellow HELP Committee members Patty Murray, Bob Casey, Al Franken and Mark Kirk.

Council: Do you have any parting thoughts to share in regards to advancing policies and laws impacting people with disabilities?

Sen. Harkin: I want my friends in the disability community to know what an honor and a joy it is to work with you, and to know that I expect that work to continue for the next two years and long after I leave the Senate. What we have accomplished together has been central to my mission as a House member and a Senator, and none of it would have been possible without the advocacy of grassroots disability activists around the country. Fundamentally, I want the disability community to know that I love them and that our country needs them to keep pushing for justice and freedom. To quote Justin Dart, "Lead on!" *

"If Americans retain their ability to empathize with those who have disabilities, if they continue to elect such informed and principled members of Congress as are on the Subcommittee on the Handicapped, and if people with disabilities, family members and professionals retain their overall unity and vigor, I believe that all of the shortcomings [...] can be – and will be – overcome."

- Sen. Tom Harkin in a 1988 article titled "Where will developmental disabilities laws be in the year 2000?"

Disability Policy Discussion: Then and Now

(continued from page 4)

have lived out in the community independently... I can't even express how much that can mean. And make sure you're more involved, because the more you give, the more you're going to receive.

GM: Speaking up counts – especially for advocates who have disabilities! We get socialized into a model that causes us to be apologetic or shameful for our lives. I think this causes us to hold back as entitled, equal citizens of our community. Much of the socialization process is

to hide, pass or make do rather than celebrate a disability. But, advocates work best when they speak out – people with disabilities are the world's foremost experts on the topic. I'm also a strong believer of using letters to the editors and appearing on TV to resonate a message.

What has been the highlight of your career championing disability issues?

KV: I was fortunate to participate on the 317 Taskforce, a bill that supported people with disabilities living independently instead of supporting institutions. Legislators heard individuals talk about their lives, and it ultimately helped people get out of institutions. About \$34.4 million dollars

of new funding was allocated towards services for people with developmental disabilities, and we did it in one year – that was awesome!

GM: My career isn't over yet so there's probably a giant lemon that's still out there! One I do recognize is an increasing level of awareness. As an educator, I have the pleasure of seeing former students out and about in the community. They often tell me they can relate back to what I said in the classroom, which includes a narrative on disability, since I make consistent connections with my life as a person with a disability and as a professional social worker, clinician and educator. *

Resources

Lives Worth Living: A PBS Independent Lens documentary

pbs.org/independentlens/lives-worth-living

This documentary, produced by Storyline Motion Pictures, LLC, showcases the development, courage and determination behind the Disability Rights Movement in the United States using interviews from the time period's heroes and footage from across the decades. Visit the website to order the DVD and view an interactive multi-media timeline with video excerpts.

The Indiana Disability History Project

is.gd/indisabilityhistoryproject
museumoftheperson.org
staffor@indiana.edu
(812) 855-2163

The Governor's Council and The Center on Aging and Community at the Indiana Institute on Disability and Community have undertaken an exciting initiative to document historical highlights of disability in Indiana and improve understanding of the experiences and contributions of Hoosiers with disabilities.

Using video, audio and digital technology to record and preserve memories of movement leaders and pioneers, the Indiana Disability History Project will document the evolution of cultural attitudes toward people with disabilities over time and the concerted efforts of disability advocates in influencing developments in policy, legislation and service provision.

The project is currently gathering historic records, photographs, personal interviews and artifacts from Indiana residents. You can view stories by Indiana disability advocates at youtube.com/cacvoices, or learn how to share your story online at museumoftheperson.org.

ignite thoughts into action

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We welcome your suggestions
for newsletter content and
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Bicentennial 2016: The Next Indiana



Join your community in preparing for Indiana's next 200 years! These four communities have been selected to host a "Community Conversation," led by Indiana Humanities and the Bowen Center for Public Affairs and sponsored in part by the Governor's Council.

The City of Evansville

Historic Southern Indiana, a heritage-based program out of the University of Southern Indiana, will examine the city's history and work with cross-disciplinary groups to revitalize center-city neighborhoods.

Hamilton County

The Hamilton County Convention and Visitors Bureau seeks to lead a meaningful cross-county conversation about how Hamilton County's heritage can be preserved and presented in the future.

The City of La Porte

The La Porte Historic Preservation Commission will discuss best practices for revitalizing historic towns in the 21st century.

Lawrence County

The Lawrence County Economic Growth Council will lead a conversation to celebrate its past and identify its path to the future.