

THE AMERICANS WITH DISABILITIES ACT

Perspectives on the 25th Anniversary of the ADA

The Minnesota Governor's Council on Developmental Disabilities

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The ADA Legacy Project

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For contact information, visit www.mn.gov/mnddc.

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The Minnesota Governor’s Council in Developmental Disabilities

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Foreward

July 28, 2015

The events marking the 25th anniversary of the Americans with Disabilities Act in Washington DC have ended. From the arrival of the ADA bus at the Smithsonian, to the Kennedy Center events, to the White House Champions of Change event, to the Gala to the March on Washington; the speeches have been inspirational and have set a course for the next 25 years.

Looking back, Mark Johnson from the Shepherd Center, called our Council in July 2012 and asked us to participate in the ADA Legacy Project. We said yes and began preparing monthly installments of historical events on our website, beginning in January 2013. Titled “Moments in Disability History,” our Council produced 31 segments in cooperation with Ed Preneta, former director of the Connecticut Council on Developmental Disabilities. This publication is a compilation of several Moments.

The Minnesota Department of Administration (our Council’s designated state agency) generously offered three communications experts — Alex Cole, Jake Seamans, and Adam Giorgi. They converted the Moments into this ebook, which culminates our alliance with the ADA Legacy Project. The transcripts that are included in this book place an emphasis on personal perspectives and are reproduced here in their entirety.

This book is dedicated to thousands of people whose names were not mentioned in Washington DC but whose efforts led to passage of the ADA.

Colleen Wieck, Executive Director
Minnesota Governor’s Council on Developmental Disabilities

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Introduction

The ADA Legacy Project celebrates the impact of the Americans with Disabilities Act (ADA) on disability rights, and honors the contributions of individuals with disabilities and their allies who persevered in securing the passage of this landmark civil rights legislation. To realize a world where all people are accepted and valued, it is crucial to preserve and promote the history of the ADA and the disability rights movement. We envision a world in which all people are accepted and valued for who and how they are; where all are welcomed with respect and given equal opportunities to contribute to the human experience. The mission of the ADA Legacy Project is to honor the contributions of people with disabilities and their allies by:

- Preserving and promoting the history of the disability rights movement.
- Celebrating the impact of the Americans with Disabilities Act, as well as other related disability rights legislation and accomplishments.
- Creating opportunities for inclusion, access, and equal rights for the future.

This selection of “Moments in Disability History” covers a wide range of audio and video clips, historical documents, images, and slides from over a span of decades. The chosen “moments” draw upon seminal work from the past that laid the foundation for the ADA and other disability policy. These are the “moments” every self-advocate, parent and professional advocate should know and be literate about in order to create future policy. For purposes of focus and specialization, the “moments” selected do not include activities, events, programs and projects that are about the delivery of programs and direct services. The selection of “Moments in Disability History” provides a common ground and foundation for the study of disability history. They have left an indelible mark on public policy and reflect many defining moments of the past 50 years. These are the events that have contributed to American society as we know it today. These events changed history, and their impact still resonates with us today.

People First Language in this Book

The language used to describe people with developmental disabilities has changed over the past 50 years. In the earlier decades of this time period, terms and language that are now considered disrespectful and offensive, were acceptable.

As our field and society have come to recognize and urge the use of people first language and more respectful words to describe people with disabilities in spoken and written language, terms such as “retarded,” “handicapped,” “trainable,” and “educable” have been replaced in many instances.

The remnants of what is now considered unacceptable language and terms may still be found in references to official governmental bodies (i.e. President’s Panel on Mental Retardation), organizations that were founded during these earlier years, federal laws, reports (i.e. Community Residences for Mentally Retarded Persons), case law, and quotations.

For the purpose of historical accuracy, some instances of these word, among others, have been retained when used in a direct quote. This is under the sole belief that education and reflection on historical realities births progress and advancement, and that unaltered context provides the best explanation for the changes in the reality we see today. We urge readers to be aware of this, and hope that they too may adopt people first language in their work and everyday lives.

BEFORE THE ADA

Home and Institutions: 1950–1960 History

In the 1950s, there were two major options for people with developmental disabilities—living at home with family or going to an institution. Families received little if any support from public agencies. Until 1954, no state health department offered any special services for children with developmental disabilities or their families. Public welfare services were largely directed to long-term institutional care. This meant the focus was on orphanages, mental hospitals, public and private institutions for people with developmental disabilities, and nursing homes. *Brown v. Board of Education* addressed the issue of racial segregation in the schools. This inadvertently opened the door for the recognition of the right to a free public education. Local parent groups started nursery and day care programs and sheltered workshops. The emergence of the parent movement in the late 1940s and early 1950s meant that more support was available to families, though in an indirect way.

This is not to say that families were supported adequately. Simply, the community services that began to emerge allowed more families to stay together. In the 1950s, the number of children with developmental disabilities enrolled in special educational classes doubled from the 1940s, and the number of school systems offering such services increased fourfold.¹

Rehabilitation programs for adults were increasingly available in the community. Parental counseling was offered by private physicians, clinic staffs, social workers, nurses, psychologists, and school personnel. The President’s Panel on Mental Retardation (PPMR) deemed these prospects “bright [...] for helping parents to meet their social and emotional needs”.²

Despite growing experimentation with community services, the major alternative to life in the family was institutionalization. In 1940, approximately 100,000 people lived in institutions. By 1962, the PPMR reported that approximately 200,000 children and adults lived in residential institutions, mostly at public expense.³ Some of those institutions operated programs to assist people to leave the institution. Family care situations were established, where state institutions

1 The President’s Panel on Mental Retardation, 1962, p.34

paid for the room, board, and supervision of small groups of former residents. Group residences were also established in the community. New Jersey's Vineland State School operated a group residence in Red Bank and garnered national attention.

The Birth of the Parent Movement

Beginning in the late 1940s and through the 1970s, there was a reawakening of hope and possibilities for persons with disabilities. In the fall of 1950, ninety persons from across the country came together in Minneapolis, Minnesota, to participate in the first national parent conference. Minnesota Governor Luther Youngdahl was the featured speaker.

Governor Youngdahl, a pioneer of the humane concept of care, was one of the first public officials to speak about the rights of people with disabilities and non-discrimination. Parent organizations went on and filed lawsuits to force states to recognize the civil and legal rights of their children.

Transcript:

The point is this, ladies and gentlemen, the retarded child is a human being ... And for reasons for which neither he nor his family are responsible, he is retarded. He has the same rights that children everywhere have. He has the same right to happiness, the same right to play, the right to companionship, the right to be respected, the right to develop to the fullest extent within his capacities, and the right to love and affection ... We cannot discriminate against this child, deny to this child the rights other children have because of the one thing that neither he nor his family can help, because he is retarded ... He has a right to these things and his parents have a right to know that he has these rights. For they, too, are entitled to peace of mind about what is happening to a retarded child separated from them.

Laws were passed to enforce these rights, services were established, and delivery systems were required to provide appropriate services to children and adults with disabilities. The disability rights and nondiscrimination movement was given birth.

Transcript:

Ed Skarnulis: One of the things that is true with almost any new movement is that in its early years there is a passion, an excitement, like

Rosemary described, and oftentimes there are people who emerge as leaders. In the past, say, three decades since the movement began in 1950; In fact, I think it got started in Minneapolis, Minnesota.

Dr. Gunnar Dybwad: Um-hmm. That's right. Yah.

Ed Skarnulis: In those three decades, could you tell us who you might think of as the leaders, both parent and professional in those, in those...

Dr. Gunnar Dybwad: Well, in the very early days, in the ... late 1940s and then, of course, as you say correctly, in 1950 here in Minneapolis, was the first, the founding assembly of what was then called the National Association of Parents and Friends of Mentally Retarded. There was quite a group of people, and it is hard to single out any one of them. I might say that a very active member of this group was Mr. Lindh from Minnesota. And, among the professional people in the field, again I can single out a Minnesotan, that was Mildred Thomson, who was primarily responsible in the professional field to recognize the value of an independent organization of parents. There were a good number of professionals in those days that felt that the parent movement should be an auxiliary to the professional organization. It was Mildred Thomson, herself an older professional person, that's all wrong, we need the parents as an independent body speaking for themselves, watching what we are doing. So Minnesota had really a very important role to play, and I should quickly add here, of course, Governor Youngdahl who, at this first assembly in 1950, made a speech about the rights of persons with mental retardation, particularly the rights of children with mental retardation, which was 20 years ahead of its time. Governor Youngdahl was a great leader. And so Minnesota, really, played a very important role in this. But, of course, as you say, eventually leaders grow out of such movements, and probably one of the most astounding leaders was Elizabeth Boggs, is Elizabeth Boggs, a parent of a child with profound degree of mental retardation. Herself a product of PhD from the University of Cambridge in England in mathematical chemistry, somebody who worked on the atomic energy during wartime, and who is without a doubt the most knowledgeable, the most versatile person to this day in our field. Really, one, you see that belies our silly phrase of "lay people." She is a parent and she's not a professional paid to work in our field, but to call her a lay person is silly, you see. She is far more a professional individual than many people who have a paid position. So she is a very great leader. In more recent years, we had some very interesting persons, Lotte Moise a parent in California, Ann Turnbull, who teaches special education and who with her husband, who is a lawyer and special educator, have allowed their son, who is severely multiply handicapped, to become a symbol of a modern positive approach. So

she represents the younger person in our field, which perhaps is not as dependent on the existence of the former parent association, she represents the parents' movement, but she has contributed tremendously to an understanding and has been very free to talk about her own son and what it means.

Dr. Rosemary Dybwad: I think there's someone else, another kind of person, just an ordinary housewife, perhaps, who, faced with the challenge of having a handicapped child has grown into a real professional even if she never gets paid for her voluntary work. But we've met many people like this who are quite open in saying, "I never would have believed I'm doing what I'm doing now, that I dare to go and speak to the legislators the way I can now, but I found I can." And I know people in Australia and New Zealand, in England, in Denmark who have simply been turned into different kinds of people.

The Contributions of U.S. District Court Judge Frank M. Johnson Jr.

During his 24 years as a federal district court judge in Montgomery, Alabama, Judge Frank Minis Johnson, Jr., made numerous revolutionary decisions that were the building blocks for the Americans with Disabilities Act (ADA). Between 1956 and 1966, Judge Johnson declared segregated public transportation unconstitutional; ordered the integration of public parks, interstate bus terminals, restaurants and rest rooms, and libraries and museums; required that African Americans be registered to vote; ordered Alabama Governor George Wallace to allow the civil rights march from Selma to Montgomery; ordered the first comprehensive state-wide school desegregation plan; and became the first judge to apply the equal protection clause of the Constitution to state law discriminating against women.

On July 24, 1980, nearly 10 years to the day before the signing of the ADA, Bill Moyers' interview of Judge Johnson was broadcast as "Judge: The Law and Frank Johnson" in two parts on Bill Moyers Journal by WNET/Thirteen, New York. In a segment from that interview, Judge Johnson described how litigation evolved from property rights and capitalism to human and civil rights, from divergent issues between two parties to class action lawsuits, and from redress of past wrongs to prospective relief. This evolution enabled revolutionary court decisions that provided the infrastructure leading to the Americans with Disabilities Act.

Transcript:

Bill Moyers: ... [The Federal Court] has no business running a state's prisons, tax systems, mental institutions, and schools.

Judge Frank Johnson: Well, I'll answer the last part of that question first. I do think a federal judge has no business running a state institution such as prisons and schools and mental institutions. But the state has defaulted in those areas or federal judge wouldn't find it necessary to step in. But I haven't stepped in to the point where I have run, in ... in the ... the popular sense of the word, any of the institutions. I've imposed minimum standards that it was necessary for them to comply with in order to eliminate the constitutional problems that necessitat-

ed federal court intervention to start with. Federal courts have not engaged in what I consider unwarranted judicial activism. And all of those decisions and the decisions, in the main with very few exceptions, they are discharging the constitutional duty that's imposed upon them. De Tocqueville put it in a very good way when ...

Bill Moyers: A judge always comes with his precedents

Judge Frank Johnson: He a ... (laughs) ... he wrote this. The French historian came over here and studied our constitutional system. He said, "The American judge is brought into the political arena independent of his own will. He only judges the law because he's obliged to judge a case. The political question which he's called upon to resolve is connected with the interest of the parties, and he cannot refuse to decide it without abdicating the duties of his post." And then he said this, "The peace and prosperity and the very existence of the union," talking about our union, "are invested in the hands of the judges. Without their active cooperation, the constitution would be a ... the constitution would be a dead letter. The Executive appeals to the court for assistance against encroachments of the Legislature. The Legislature demands their protection from the designs of the Executive. They defend the Union from the disobedience of the states. They defend the states from the exaggerated claims of the Union. The public interest against the interest of the private citizens." And it should be added that the courts ... the federal courts defend the interests of private citizens against the government. Bill Moyers: Well, I concede that historical, that history, Judge. It's been an argument ever since the first days, as you said. But the reason you've become controversial and judges like you — you're not alone in this — has been because you've moved into what ... into what the scholars call structural reform whereby a judge tries to reorganize a bureaucracy in the name of constitutional values which he believes have been threatened. In particular, I'm thinking of *Newman vs. Alabama*, in which you actually took over responsibility for the state prisons, and *Wyatt vs. Stickney*, in which you took over the mental hospitals. And the question is, had the constitution been so interpreted that way in the past where a federal judge actually assumes the administrative power over a state agency.

Judge Frank Johnson: We've moved from, litigation that was involved with, property rights and, capitalism to litigation that's involved with human rights and, civil rights. The, people in this country have, become conscious of the, many, many, additional governmental controls that are imposed upon them ...

Bill Moyers: A regulatory society.

Judge Frank Johnson: ... and ... and the environment and ... and every aspect of life. And they seek refuge in the federal courts. I don't mean government controls imposed just by the federal government. I mean by ... by the state government. Litigation is no longer a bipolar thing between two parties. It's class action that's brought to vindicate the rights of classes. Our federal procedures, have been changed to, recognize and even in proper circumstances, encourage class action litigation. The class action litigation such as you mentioned for the prisoners, challenging the, conditions in the Alabama prison system. The Newman case was one that, alleged the deprivation of medical, care and treatment. Pugh against James, was one that alleged Eighth Amendment violations because of the general conditions in the Alabama prison system. Wyatt against Stickney was one that alleged, on the behalf of the class of over five thousand people deprived of their liberty through civil proceedings in the State of Alabama and incarcerated in state mental institution for treatment purposes that they were not receiving treatment. And so, they raised constitutional issues, they presented them to the Federal court, and there's no way for a federal judge to discharge his oath of office if he, tells those people, "I'm going to award you some damages for the things that they've done to you in the past." That's not much solace to a prisoner that doesn't have a decent or safe environment. Award a mental patient damages for what they've done to him by depriving him of, treatment in the past, won't get him anything in the future. So the litigation has not stayed the type that asked for redress for past wrongs.

Bill Moyers: Which is the traditional way.

Judge Frank Johnson: That's right.

Bill Moyers: Two parties come together and you say, "You were wrong, pay this person accordingly."

Judge Frank Johnson: The litigation now seeks prospective relief. It seeks, ah, the elimination of conditions that exist. In, most of these cases, they aren't particularly interested in damages. You rarely ever have a claim for damages where, in the case of a suit like the prison suit, like the mental health suit.

Bill Moyers: In both ...

Judge Frank Johnson: The judge is confronted with this new type of litigation, and there's no way —and he shouldn't — attempt to dodge it.

Bill Moyers: In both cases, you said conditions in the mental institution

and conditions in the hospitals were intolerable. When you looked into them, what did you find?

Judge Frank Johnson: Well, I found that, in the Bryce facility located in the Tuscaloosa area, which is the largest for mental institutions in the State of Alabama, over five thousand people had been committed there for, treatment for their mental illness. They had been committed by the courts of the State of Alabama. They'd been deprived of their liberty for the purpose of giving them treatment. And the evidence showed that they weren't getting any treatment at all. They were being warehoused. And so the constitutional issue was presented: Were they entitled to treatment? And I held as a basic principle before we ever got into the type of relief that they may have been entitled to, I held that people that are committed through a state's civil proceedings and deprived of their liberty under the altruistic theory of giving them treatment for mental illness and then warehousing them and not giving them any treatment at all strikes at the very core of a deprivation of due process. And that they were entitled if they were deprived of their liberty for treatment purposes, then they're entitled to some treatment that is medically and minimally acceptable. They're not entitled to the best treatment, and I emphasized the word "minimally" and I used it in that.

Bill Moyers: But what criteria did you use? I remember Judge David Bazelon of the Court of Appeals ...

Judge Frank Johnson: That's exactly right.

Bill Moyers: ... In Washington had said that his criteria for intervention goes beyond just minimum standards of, of justice and fairness. And he said his test was a gut reaction to a situation in which he said, "Does it make you sick?" Now when you went into those prisons and into those mental institutions, did it make you sick?

Judge Frank Johnson: I've never been in a prison. I've never been in a mental institution. I didn't find it necessary to go there.

Bill Moyers: Well, how could you?

Judge Frank Johnson: I did not want to get a gut reaction. I did not want to base my decision on any emotional feeling I might get from visiting those places. I wanted to base it on the evidence that was presented in the court where in an adversarial proceeding where both parties had an opportunity to present evidence and be heard.

Bill Moyers: And the evidence?

Judge Frank Johnson: And the evidence in this case, in the state mental case was overwhelming that they weren't getting any treatment, they were being warehoused.

Bill Moyers: Well, how?

Judge Frank Johnson: You had sixteen hundred people out of five hundred [sic] that, wouldn't benefit from any treatment at all, that were taking space in this mental hospital. They were geriatrics. The only thing that they were suffering with was ... were the ravages of old age. They should have been in a nursing home. You had a thousand of the five thousand that weren't mentally ill at all. They were retardates that should have been in an institution for ... for retarded people and subjected to some program designed to habilitate them.

Bill Moyers: And you didn't need to go there to discover that?

Judge Frank Johnson: Absolutely not. I needed not to go there. A judge shouldn't go, visiting a place that he has under scrutiny in a lawsuit and base his decision in whole or in part on what he's observed, unless he's going to submit himself to cross-examination. He should do it on the basis of evidence that's presented during the adversarial proceeding. So I've been criticized for not going to Bryce Hospital. I've been criticized for not visiting the penitentiaries. But that's not the approach, in my judgment.

Bill Moyers: How did you determine what appropriate relief consisted of? I mean, the court order you issued from that bench was incredibly comprehensive. It covered everything from the amount of space allotted to each patient, the number of toilets, the frequency that each patient had to be bathed, down to requiring that toothbrushes be provided and toenails cut.

Judge Frank Johnson: Federal judges are trained in the law. They're not penologists, we're not psychiatrists. We're not educators that can run the schools, yet we've entered schools' orders setting forth in detail what your faculty ratio should be and what your pupil ratio should be, what kind of a facility you should have. If you had an ideal situation, you would have these cases decided by the penitentiary penologist. And the mental institutions, psychologists and psychiatrists. In the school cases, by educators. But federal judges have the job of doing it. But we have, a tremendous number of aides. We don't fly blind in these. We have experts. For instance, in the Wyatt/Stickney case, I had

experts — that's the mental health case ...

Bill Moyers: Right.

Judge Frank Johnson: ... come to this court and testify from that witness stand from all over the United States, ranging from, the, ah, Karl Menninger from Topeka, Kansas, to, psychiatrist and psychologist and mental institution expert from California to Maine. And I based my decision and I based these minimal standards on their testimony.

In his 1971 decision, *Wyatt v. Stickney* Judge Johnson established the precedent that people with mental illness or intellectual disabilities who reside in institutions have a Constitutional right to treatment. In his order issued April 13, 1972, Judge Johnson identified 35 minimum standards for adequate treatment. These standards included 14 statements of "rights." The 33-year Wyatt litigation ended on December 5, 2003.

Willowbrook Leads to New Protections of Rights

Public shock and outcry regarding abuse and neglect of residents at the Willowbrook State School on Staten Island in New York City exploded as organized parent protests and media exposés ignited mass awareness. The timing and political openness of the period led to the incorporation of the Protection and Advocacy (P&A) System in the Developmental Disabilities Assistance and Bill of Rights Act (1975); the Education For All Handicapped Children Act, P.L. 94-142 (1975); and the Civil Rights of Institutionalized Persons Act (CRIPA)(1980). The P&A and CRIPA were the early ramps of federal civil rights legislation protecting people with disabilities, and leading to the Americans with Disabilities Act (ADA).

Used as a World War II prisoner of war institution, Willowbrook was designed for 4,000 people. By 1965, it had a population of over 6,000, the largest state-run institution for people with developmental disabilities in the world. When New York Senator Robert Kennedy toured Willowbrook in 1965, the living conditions prompted the Senator, in a televised interview, to call it a “snake pit.”

In early 1972, Geraldo Rivera, an investigative reporter for WABC-TV in New York, was called by an activist physician recently fired for speaking out about the abysmal conditions at Willowbrook. Rivera’s exposé, *Willowbrook: The Last Great Disgrace*, garnered national attention, and was an indictment of institutionalization and treatment of persons with developmental disabilities.

A class-action lawsuit, filed against the State of New York in federal court on March 17, 1972, resulted in a “settlement” with the State Department of Mental Hygiene on May 5, 1975 to dismantle Willowbrook. This lawsuit gave impetus throughout the nation where other class action lawsuits were being pursued to accord persons with disabilities the rights of other citizens — developmental services, freedom from cruel and unusual punishment, and due process. Rivera’s friendship with Bernard Carabello — who spent 18 years at Willowbrook as a child, despite the fact that his cerebral palsy does not impair his mental functioning — also helped stimulate the self-advocacy movement.

William Bronston, M.D., a physician employee on the inside, illustrated condi-

tions and their causes at Willowbrook in his yet to be published book, *Public Hostage: Public Ransom — Inside Institutional America*. Many of his photo illustrations were used in the federal trial regarding Willowbrook.

Transcript:

Robert Kennedy: I think that at the state institution for the mentally retarded, and I think that particularly at Willowbrook, we have a situation that borders on a snake pit, and that the children live in filth, that many of our fellow citizens are suffering tremendously because lack of attention, lack of imagination, lack of adequate manpower. There is very little future for these children, for those who are in these institutions. Both need a tremendous overhauling. I'm not saying that those who are the attendants there, or who run the institutions, are at fault — I think all of us are at fault and I think it's just long overdue that something be done about it.

The Self-Advocacy Movement

In 1969, Dr. Bengt Nirje, Director of the Swedish Parent Association, delivered his paper, "Towards Independence," at the 11th World Congress of the International Society for Rehabilitation of the Disabled in Dublin, Ireland. The paper traced recent developments in the self-advocacy movement in Sweden that he himself had initiated. Giving individuals with developmental disabilities the opportunity to experience regular life in the community and making their own decisions was viewed as radical at the time, but a movement was gaining momentum.

Following the World Congress, parents and members of the Swedish Association planned their own first national conference in Sweden to address issues related to self-determination. These efforts then spread to England in 1972.

In 1973, Canada held its first self-advocacy conference in British Columbia. Following the Canadian conference, eight residents or former residents of Oregon's Fairview institution met on January 8, 1974 in Salem, Oregon. Five months later, the self-advocates were learning the basics about meetings. When the time came to decide on an organization name, the discussion became more energetic and heated — until a lone voice in the room shouted, "We are people first." Thus, the name "People First" became associated with self-advocacy organizations and the clarion call for the movement that was gaining strength worldwide.

Transcript:

Valerie Schaaf: I think it's cruel, I think it's terribly cruel that we are spoken of this way, labeled this way. To me, if you got to label something, label words, label jars, label streets, but don't label persons. You put them down in a hole and I'd like to see personally, for a goal for People First, is to get rid of "mentally retarded," "mentally disabled," "mentally" everything.

The emergence of self-advocacy in the 60s and 70s came at a time when individuals with developmental disabilities were moving out of large state institutions. Still, the barriers to integration were significant with family members and professionals holding on to attitudes that persist today, that individuals with develop-

mental disabilities aren't capable of learning, living, and working in the community or making decisions about their personal lives.

Regardless of these barriers, the self-advocacy movement gained strength in the 1980s. Only twenty years after its origins in Sweden, Rosemary Dybwad was photographed carrying a banner in a march with self-advocates from the gates of the Belchertown State School, a state institution in western Massachusetts, to a meeting in the town. This was one of the earliest rights demonstrations of people with developmental disabilities.

Dybwad recalls it as "a great day" when the movement finally arrived in the United States.

The momentum continued. Self-advocates began creating their own groups and organizations, planned their own conferences, conducted their own meetings, worked on their own issues, and then started joining existing organizations.

The Right of Education Based on Brown v. Board of Education

Dr. Gunnar Dybwad was a Professor of Human Development at the Florence Heller Graduate School of Brandeis University and an internationally known authority on developmental disabilities.

In 1954, early in his tenure as Executive Director of the then-named National Association for Retarded Children, Dr. Dybwad called attention to the Supreme Court's decision in *Brown v. Board of Education of Topeka, Kansas*. He suggested that what *Brown* sought to recognize and change for African American children, that "separate facilities are inherently unequal," had enormous possibilities for children with disabilities as well.

The biggest breakthrough came in 1971 when attorney Thomas K. Gilhool, representing the Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania (*PARC v. Commonwealth*), used *Brown v. Board of Education* in his arguments in a case that resulted in a landmark decision affirming the right to education at public expense and due process for children with disabilities.

The *New York Times*, on page one, quoted Dr. Dybwad: "The decision makes Pennsylvania the first state in the union to guarantee education and training to all of its children with developmental disabilities now and in the future."

Four days later, on its editorial page, The *New York Times* called on the Congress to do that for all of the states of the United States. Within two months in the House of Representatives, and another month later in the United States Senate, what became section 504 was introduced, and shortly thereafter, what became the Education for All Handicapped Children's Act of 1975, was given birth as Public Law 94-142.

In a series of videos, Dr. Dybwad discussed his work, and the effort to win recognition for the rights of children with disabilities. In this first transcript, Dr. Dybwad compares the views public officials had on the rights of people with disabilities.

Transcript:

Dybwad: ... so many of our administrators, public officials, legislators, still had this old view of the individual with mental retardation, of really not having any rights, whereas in our prisons, the rights of prisoners were very well considered. And people actually maintained conditions there so as not to conflict with these rights.

In this transcript, Dr. Dybwad discusses the contribution of the courts to winning recognition of rights for people with disabilities.

Transcript:

Voice over: Gunnar Dybwad, Professor Emeritus of Human Development, the Florence Himmler Graduate School for Advanced Studies in Social Welfare, Brandeis University, holds degrees in Law and Social Work, which have enabled him to advocate nationally and internationally on behalf of persons with mental retardation. He has served as consultant throughout Europe, Central, and South America. He has provided expert testimony in significant class action litigation involving persons with mental retardation. Dr. Dybwad served as Director of the National Association for Retarded Citizens from 1957 to 1964. He and his wife, Dr. Rosemary Dybwad, have received awards for outstanding service from the American Association on Mental Deficiency, the International League of Societies for the Mentally Handicapped and, most recently, the Kennedy International Award for Leadership in Mental Retardation.

Dr. Gunnar Dybwad: It may sound strange, but it is quite correct to say that individuals designated as mentally retarded led a lawless existence in the first half of this century in our country. That does not mean that they were criminals. Rather than sinning, they were sinned against by society by being deprived of any benefits of law. They, indeed, were lawless, without the protection of the law. And the only parallel to this we could find would be in the existence in our country of black people as slaves. They, too, were not persons but were chattel or things. We now have so firmly established tremendous progress in the field of mental retardation, whether you think of education, whether you think of social adjustment, whether you think of vocational pursuits, whether you think of lessened dependence on the behalf of others. In what all areas of human life, these individuals termed mentally retarded, indeed, have now shown to us most definitely that they are persons, that they have a humanhood just as all others of us have. Much of the progress I have just referred to, of course, has been of a particular benefit to the thousands of people in our state institutions. Those large state institutions which have been characteristic of our country, of England and of Canada. And in these institutions we have had in the past condi-

tions which really were worse than what went on in our prisons. And I can say this with certainty because both my wife and I started out in the prison field. In 1966 Burton Blatt published *Christmas in Purgatory*, which documented that these very same conditions in Massachusetts, and still in the state of Massachusetts issued in later that year a report signed by both the Commissioner of Mental Health and the Commissioner of Public Health and promulgated by the governor, the conditional institutions were not discussed, were glossed over. So this, indeed, indicates that renewal in the field of mental retardation was a very slow process because so many of our administrators, public officials, legislators still had this old view of the individual with mental retardation of really not having any rights. Whereas in our prisons, the rights of prisoners, were very well considered and people actually maintained conditions there so as not to conflict with these rights. Change, of course, did occur, and, significantly, the change in the viewpoint towards the rights of persons with mental retardation started at the very moment the National Association for Retarded Children was created in Minneapolis in 1950. The Governor of Minnesota, Luther Youngdahl, was a distinguished jurist who later served on the Federal Circuit bench in Washington. And this is what he had to say as he opened this First Congress, this founding convention of the National Association for Retarded Citizens. It is a rather stirring oratory which, as you will see, was far ahead of the time. He said, "This point is, ladies and gentleman, the retarded child is a human being. Above and beyond being a human being, he is a child. And for reasons neither he nor his family are responsible, he is retarded. He has the same rights that children everywhere have. He has the same rights to happiness, the same rights to play, the same rights to companionship, the right to be respected, the right to develop to the fullest extent within his capacities, and the right to love and affection." "He has these rights for one simple reason. He is a child. And we cannot discriminate against this child — deny to this child the rights other children have because of the one thing that neither he nor his family can help — because he's retarded. Whether he's in Minnesota — or any other state in the country or any other country in the world — he is still a child. But we have forgotten this. And with rare exceptions throughout the country the provisions we have made for him are barbaric." "The retarded child has a right to social assistance in the world in which he cannot possibly compete on equal footing. He has a right to special education." He said this in 1950. "And to special institutions for the retarded child who cannot be taken care of at home. He has a right to be provided with the most modern training in institutions that is possible, an institution marked by not only the pleasantness of its brick-and-mortar, and lawns, and play areas, and education services, and child specialty medical services, but by an atmosphere and by a group of people in attendance who will not

only give that child patient understanding, but to love and be affectionate to that child as other children get at home. He has a right to these things. And his parents have a right to know that he has these rights. For they, too, are entitled to peace of mind about what is happening to a retarded child separated from home.” That is what Luther Youngdahl, the jurist and politician, said in 1950, and nobody understood it. Not even the people in attendance at this conference understood the meaning of what he had to say. They were just nice words like a Fourth of July address. And it took a long time for this to take effect. By the way, Luther Youngdahl talked about the child because in those days, we really still felt that mental retardation was a child problem out of which you would not grow. And it was only a little later, in 1960, when I submitted a report to the 1960 White House Conference on Children and Youth that I pointed out that insufficient attention had been given in the past to the legal status of the mentally retarded child and adult, particularly with reference to the degree of legal protection required as related to the degree of mental handicap. That was 1960. And in that same year, Senator Ervin of Watergate fame, convened a session of the Senate Judiciary Committee, of which he was Chairman, in which he discussed in detail the rights of mentally ill and mentally retarded persons. And the next year, the President’s Panel on Mental Retardation, Kennedy’s contribution to our field, established a special task force on law of which Judge Bazelon and Dr. Elizabeth Boggs were the co-chairmen. I had resigned from the National Association for Retarded Children — I served as the Executive Director in 1963 — and for three years my wife and I were in Geneva, Switzerland with the International Union on Child Welfare on a special mental retardation project. In 1967, I was called back to Brandeis University to assume direction of a special doctoral program in mental retardation. And it was during that period that some people came to visit me from the Pennsylvania Association for Retarded Citizens. I had worked with them for many, many years coming there frequently as a consultant, and I had helped them with the incredible problems which then existed in Pennsylvania where thousands of children were excluded from any school attendance because of retardation and where conditions existed in the mental retardation state institutions which one really cannot discuss in polite society, they were so bad. Well, they came to us for help, and I knew what the situation was. They had made every effort up to several conferences with the governor himself — and some of them I attended — and with the Secretary of Welfare and with other high state officials to beg for changes to be made. They had been very active in the legislative field, testified, and, indeed, I arranged for some of my Scandinavian colleagues to actually come to Pennsylvania and testify before a legislative committee as to what could be done. And, in addition, we had some very excellent publicity, expose of conditions but nothing, nothing was help-

ing. And it was on that day that I said to my colleagues, "We've exhausted all these means, but there is one channel that remains open to us. We have a government that is divided into the executive, the legislative, and the judicial branch. We have never used the judicial branch. It is time to go to court." Well, we at Brandeis that afternoon quickly found agreement with my proposal. But when the proposal was brought back to the board of the Pennsylvania Association, they said, "Well, we can't do this. We could not possibly go to court and sue the Governor, sue the Secretary of Welfare. It has taken us years to be on first name basis, this is no way to do it." And for six months were stalemated until a very significant thing happened. It is an anecdote, but it is true; I was present. The institutional committee of the Pennsylvania Association made a report at the annual convention to the board of directors. Only to the board of directors. And the chairman of the institution committee, who happened to be a lawyer at that time, a Philadelphia lawyer, made a report on some recent incident that had led in one of the institutions to the death of a child. And by the way, a death that was not even reported to the mother. When a telegram addressed to her old address came back, nobody cared, and the mother came to visit and suddenly heard that her son had been dead for several weeks. The lawyer in his best courtroom manner proceeded to talk about the case. We have been able to find the body of the dead boy. It was already in a medical establishment but still kept on ice. So we were able to go to court, insist on an autopsy. The attorney very quietly, very calmly in soft voice explained the damage to this boy. He had been burned apparently and so on. And what happened was that this board of directors all of whom previously had been thinking of the secretary, of the governor, of their relationships suddenly saw that what it was all about was a little boy who had been alive and now he was dead. Why was he dead? And after that meeting the board authorized the employment of an attorney to study the possibility of a lawsuit. That was the great change. And this, you see, one has to consider when one thinks about judicial action. Burton Blatt's exciting book *Christmas in Purgatory* dealt with societal issues. But when we go to court, when we ask a federal judge for help, we go to court on behalf individual plaintiff, and we ask the court to remedy injustice that happened to these individuals. And this is what led to the employment, in this case of an attorney. It was Thomas Gilhool, who, indeed, investigated and subsequently came forth with some very good suggestions as to what the State Association for Retarded Children should do. And very wisely, he decided that we should not worry about the institution as our first step. It was too difficult for judges, for the public, for others to understand the running of an institution. He said what everybody knows is that children ought to go to school. Let's start with the denial of education for children with mental retardation. And so the famous Park case, the first

case in this judicial revolution we have had in our country, that got started in Philadelphia in the federal court house. And, of course, it resulted, significantly, in a consent agreement. Very quickly thereafter in Washington, DC, the Mills case came to the fore. And just to give you a flavor of what happened in these cases, I was asked to make a deposition and a question which the attorney for the retarded children put to me was, "Can you state an opinion as to educational sufficiency of providing only two hours of instruction per week to institutionalized adolescents labeled as dull normal and emotionally disturbed?" And I said in answer in my deposition, "The fact that a child may have to reside in an institution does not diminish his need for schooling. To the contrary, anyone acquainted with the limitations and deprivations imposed by institutional living realizes that children in institutions need the guidance and stimulation of a full-scale education program. To provide for such children or young people two hour's instruction per week can only be compared to giving a starving child two meals a week. Two meals a week do not make a diet, and two hours of instruction per week do not make an educational program." The Mills case was the first case which was solved with a judicial decision, not just a consent decree, and, as such, as gone down in history, as a very significant federal case. My next involvement with the judiciary process on behalf of persons with mental retardation was a famous Alabama case, Wyatt v. Stickney, which was a most memorable occasion because, I was privileged to get to know Judge Johnson, one of the most distinguished, most conservative judges on the federal district bench. The point I want to make is this, that at the first hearing in this case, Judge Johnson, eager to avoid a long, drawn out court case, gave the Commissioner of Mental Health of Alabama six months to come forward with a plan to remedy the conditions about which the complaint had been filed. Actually, it was seven months until the court reconvened, but the document which the executive branch had prepared through the Commissioner Stonewall Stickney in good Southern tradition — that was his name — was so inadequate that the judge refused to accept it, and we had to go to trial. I happened to be the leadoff witness in this case. And the attorney was asking me whether I thought that really what people were receiving in that institution was no more than custodial care. And I said, "Oh, no I could not say this. Because how could you speak of custodial care of custody in an institution where nobody was safe from injury, from attack, from just unspeakable conditions? So this hardly could ever be termed custodial care." This happened to impress the judge and also was an important argument in the ensuing review of the case by the Circuit Court of Appeals. One other point I want to bring in because it is not as extraneous as it may appear. Judge Johnson in this decision referred to the United Nations Declaration of the Rights of Mentally Retarded Persons. He did so to indicate that, indeed, we were dealing

with a new era, an era where the recognition of the rights of mentally retarded had not received just national but international recognition. It is interesting to say in a few words how this declaration came about. The International League of Societies for Persons with Mental Handicap, the organization of which the National Association for Retarded Children, now Citizens, is a member, convened in 1967 in Stockholm, a symposium on legal and legislative problems. And that group of international scholars — and, of course, once again New Jersey was represented by Elizabeth Boggs — came forth with a very significant section in their recommendation. And I would like to read just one paragraph from it. That section dealt with individual rights and said, “The symposium considered that no examination of the legislative aspects of the problem of mental retardation would be complete without general consideration being given to the basic rights of the mentally retarded, not only from the standpoint of their collective rights and those of their families, but only from that of the individual rights of the retarded person as a human being.” And then the ensuing recommendations were reviewed the following year by the next World Congress of the International League held in Jerusalem under a very significant title, From Charity to Rights. And the congress fashioned by general agreement a declaration of rights. That was in 1968, and nobody could have convinced me, an optimist if there ever was one, in those days that within three years the United Nations would have adopted this declaration without a dissenting vote. But that is what happened. And just as a by the way, four years later this declaration of rights of mentally retarded was extended by the United Nations as a general declaration of the rights of disabled persons in general. A rare incident where retarded people were leading the way. The question can well be raised: Was all the expense — and it was considerable expense — the disruption, the judicial encroachment on executive agencies really justified by the results obtained? Well, it would seem to me that the answer is best being given by the thousands, indeed, by now the tens of thousands of children who are now in school who previously were deprived of their education. By the thousands who faced abuse and neglect in institutions whose fate has been substantially alleviated, even though much remains to be done. They and their families will readily acknowledge the debt they owe to the judiciary. But beyond these personal long overdue gains, there are very many systemic improvements that have come to us in the wake of these court decisions to bring to this field at long last a renewal in what we call mental retardation.

In this final transcript, Dr. Dybwad speaks about the right to an education.

Transcript:

Dr. Gunnar Dybwad: In 1967, I was called back to Brandeis University to

assume direction of a special doctoral program in mental retardation. And it was during that period that some people came to visit me from the Pennsylvania Association for Retarded Citizens. I had worked with them for many, many years coming there frequently as a consultant, and I had helped them with the incredible problems which then existed in Pennsylvania where thousands of children were excluded from any school attendance because of retardation and where conditions existed in the mental retardation state institutions which one really cannot discuss in polite society, they were so bad. Well, they came to us for help, and I knew what the situation was. They had made every effort up to several conferences with the governor himself — and some of them I attended — and with the Secretary of Welfare and with other high state officials to beg for changes to be made. They had been very active in the legislative field, testified, and, indeed, I arranged for some of my Scandinavian colleagues to actually come to Pennsylvania and testify before a legislative committee as to what could be done. And, in addition, we had some very excellent publicity, expose of conditions but nothing, nothing was helping. And it was on that day that I said to my colleagues, “We’ve exhausted all these means, but there is one channel that remains open to us. We have a government that is divided into the executive, the legislative, and the judicial branch. We have never used the judicial branch. It is time to go to court.” Well, we at Brandeis that afternoon quickly found agreement with my proposal. But when the proposal was brought back to the board of the Pennsylvania Association, they said, “Well, we can’t do this. We could not possibly go to court and sue the Governor, sue the Secretary of Welfare. It has taken us years to be on first name basis, this is no way to do it.” And for six months were stalemated until a very significant thing happened. It is an anecdote, but it is true; I was present. The institutional committee of the Pennsylvania Association made a report at the annual convention to the board of directors. Only to the board of directors. And the chairman of the institution committee, who happened to be a lawyer at that time, a Philadelphia lawyer, made a report on some recent incident that had led in one of the institutions to the death of a child. And by the way, a death that was not even reported to the mother. When a telegram addressed to her old address came back, nobody cared, and the mother came to visit and suddenly heard that her son had been dead for several weeks. The lawyer in his best courtroom manner proceeded to talk about the case. We have been able to find the body of the dead boy. It was already in a medical establishment but still kept on ice. So we were able to go to court, insist on an autopsy. The attorney very quietly, very calmly in soft voice explained the damage to this boy. He had been burned apparently and so on. And what happened was that this board of directors all of whom previously had been thinking of the secretary, of the governor, of their relationships suddenly saw that what it

was all about was a little boy who had been alive and now he was dead. Why was he dead? And after that meeting the board authorized the employment of an attorney to study the possibility of a lawsuit. That was the great change. And this, you see, one has to consider when one thinks about judicial action. Burton Blatt's exciting book *Christmas in Purgatory* dealt with societal issues. But when we go to court, when we ask a federal judge for help, we go to court on behalf individual plaintiff, and we ask the court to remedy injustice that happened to these individuals. And this is what led to the employment, in this case of an attorney. It was Thomas Gilhool, who, indeed, investigated and subsequently came forth with some very good suggestions as to what the State Association for Retarded Children should do. And very wisely, he decided that we should not worry about the institution as our first step. It was too difficult for judges, for the public, for others to understand the running of an institution. He said what everybody knows is that children ought to go to school. Let's start with the denial of education for children with mental retardation. And so the famous Park case, the first case in this judicial revolution we have had in our country, that got started in Philadelphia in the federal court house. And, of course, it resulted, significantly, in a consent agreement. Very quickly thereafter in Washington, DC, the Mills case came to the fore. And just to give you a flavor of what happened in these cases, I was asked to make a deposition and a question which the attorney for the retarded children put to me was, "Can you state an opinion as to educational sufficiency of providing only two hours of instruction per week to institutionalized adolescents labeled as dull normal and emotionally disturbed?" And I said in answer in my deposition, "The fact that a child may have to reside in an institution does not diminish his need for schooling. To the contrary, anyone acquainted with the limitations and deprivations imposed by institutional living realizes that children in institutions need the guidance and stimulation of a full-scale education program. To provide for such children or young people two hour's instruction per week can only be compared to giving a starving child two meals a week. Two meals a week do not make a diet, and two hours of instruction per week do not make an educational program." The Mills case was the first case which was solved with a judicial decision, not just a consent decree, and, as such, as gone down in history, as a very significant federal case.

In this transcript, Tom Gilhool discusses Dr. Dybwad's contributions to the fight to win recognition for the rights of children with disabilities.

Transcript:

Allen Crocker: Our next speaker is an important one. Tom Gilhool is a civil rights lawyer of uncommon skills and devotion. He's been 30 years in the Public Interest Law Center of Philadelphia, which is a magic name

to those of you who know the field. His own career has had concerns, particularly with developmental disabilities, with poverty, with child health, and in this, he's had extensive common effort and common belief with Gunnar. Their partnership on *PARC v. Pennsylvania* was a turn point in the progress of our field. It is extremely appropriate that we share some views with Tom Gilhool.

Tom Gilhool: Gunnar would want all of you, I think, to know that his friend Allen Crocker received, just a few weeks ago, the C. Anderson Aldrich Award from the American Academy of Pediatrics for his work in child health, an award previously bestowed upon Benjamin Spock and Terry Brazelton and Anna Freud and Gunnar Dybwad. Ladies and gentlemen, friends, by 1968, in his 60th year, Gunnar enlisted as teacher and mentor of the ARC across the country. Especially as it turned out, the Pennsylvania ARC Rosemary cautioned that it was not necessarily because he loved Pennsylvanians more but because the spot on Second Street in Harrisburg was, in Gunnar's opinion, the finest greasy spoon in America. In 1968, of course, the Residential Services Committee of the Pennsylvania Association for Retarded Children conducted another of its periodic investigations of conditions at Pennhurst, Pennsylvania's flagship institution. They found that life there was nasty, brutish, and short. And they concluded that the institution was not redeemable. In December 1969, the Committee's findings and conclusions were presented at convention, the theme of which was, "Partners in Progress." Gunnar's address to the convention opened, "I hope you will let me ask you a very blunt question: What progress?" "And which partners? For 19 years," he said, "you have tried to be nice. You've kept quiet too long." He closed, "You have adopted a resolution with which you finally take the first steps to assure for Pennsylvania's retarded citizens some rights in their own country. This resolution to retain counsel to determine what legal action you as an association can take against the Pennsylvania Department of Public Welfare to either close Pennhurst or justify its continuance is what you should do." One month later, Jim Wilson, president of PARC, and later of the national ARC, and Dennis Haggerty, Chairman of the Residential Services Committee, appeared in my office. They had not known that my brother, Bob, is retarded and had lived for some time at Pennhurst. If I would undertake what they asked, they promised me a guide and a mentor. Dybwad, huh? He must be okay. He's Peter Dybwad's father. During 1970, we look at four kinds of litigation. PARC chose to sue for the right to education. What, you may wonder, did education have to do with closing the institution? PARC had noticed that nearly everybody went to the institutions when they were children of school age, most in their early teen years. They thought if we opened the schools, we will fade and end the demand for institutions, and they were significantly correct. In 1970,

12,000 children of school age were sent to institutions in these United States. By 1978, only 1,200 were, and now we are not at zero but we are tending. Moreover, to teach the courts about retardation was enough of an undertaking. Best, we thought, to do so in the context — in a context which they understood, the schools. They knew of the schools because of *Brown v. Board of Education* and all that followed, the unanimous Supreme Court decision which held segregation on grounds of race to violate the equal protection clause of the 14th Amendment of the United States Constitution. Moreover, *Brown* was the trump. Soon after the Supreme Court's decision in *Brown*, early in his tenure as NARC executive, Gunnar had called attention to the Supreme Court's decision, suggesting that what *Brown* sought to do for black children had enormous possibilities for children with disabilities, as well. *Brown* said, "... education is required in the performance of our most basic public responsibilities. It is the very foundation of good citizenship." Today, it is a principal instrument in awakening the child to cultural values, in preparing him for later training, and in helping him to adjust normally, normalization, to his environment. "In these days," the Court wrote unanimously, "it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity where the state has undertaken to provide it to any is a right which must be made available to all on equal terms." Hence, the strength of the claim. We learned later that John W. Davis, who had represented the defendant State of South Carolina in *Board — Brown v. Board of Education*, a man who was congressman from West Virginia when Gunnar was born in 1909, who was Solicitor General of the United States when Gunnar was four, who was the Democratic candidate for president when Gunnar was 24, and before Gunnar married Rosemary, had three times turned down appointments to the United States Supreme Court. Davis was a man steeped in his times. He opened his argument to the Court in *Brown* as follows: "May it please the Court, I think if the appellants' construction of the 14th Amendment should prevail here, I am unable to see why a state would have any further right to segregate its pupils on the ground of sex, on the ground of age, or on the ground of mental capacity. Davis lost the case but he won the prediction. On October 9 of 1971, the front page of *The New York Times* reported, "A special three-judge federal panel ordered Pennsylvania today to provide a free public education to all retarded children in the state. The court ruled that all are capable of benefiting from an education and have a right to one." *The New York Times*, on page one, quoted Dr. Gunnar Dybwad, Professor of Human Development at the Florence Heller Graduate School of Brandeis University, an internationally known authority on mental retardation, who said, "The decision makes Pennsylvania the first state in the union to guarantee education and training to all of its retarded children now and

in the future.” Four days later, on its editorial page, The New York Times called on the Congress to do that for all of the states of the United States. Within two months in the House of Representatives, and another month later in the United States Senate, what became section 504 was introduced, and moments later, what became the Education for All Handicapped Children’s Act of 1975. A year later came Mills, and then in Louisiana, LeBank and Spears, and then another 32 cases. At the heart of PARC was the equality principle, Gunnar’s citizenship, Gunnar’s equal citizenship, the principle that presumptively insists that the organized society treat each individual as a person, one who is worthy of respect, one who belongs. Stated negatively, the principle presumptively forbids the organized society to treat an individual either as a member of an inferior or dependent caste or as a nonparticipant. As Gunnar put it, in a word, people with retardation cannot be treated as non-people. As he put it, the long struggle of people with retardation has been to be members of the community, not just in the community. Now, understand, there was a contending legal theory. It arose from the due process clause of the 14th Amendment, not from the equal protection clause. It said that if a person’s liberty is taken, he must get something back, a right to treatment, for example. A right to habilitation, perhaps in the least restrictive environment but restrictive, nonetheless. Wyatt embodied that theory. Gunnar contributed mightily there, too. It was in Wyatt where he famously said, Partlow et Partlow, (sic) it is storage. There is no evidence of any human caring. But Wyatt resulted mostly in the fix-up of the institution. By 1974, Willowbrook had been filed but the remedy sought in the original filing was fix up the institution. In Pennsylvania, some individual families had filed Halderman. They sought to fix up Pennhurst. Gunnar took the occasion of mentally retarded citizens and the law to the 1974 PCMR Ohio state conference. The book, 1976, still the Bible to publicly reject such equivocation. He was commenting upon Yale Professor Boberg’s paper contrasting the equality principle of PARC with Wyatt’s substantive due process. Gunnar followed a commentator who had said, “We must avoid inflexible decisions that ultimately may be harmful. All or nothing, either/or must be avoided.” But of course, in Gunnar’s view, it is either/or. Gunnar said, if the Partlows and Willowbrooks are to be eliminated in favor of community alternatives, we must determine what kind of in-community resources should be mandated. So, in 1975, PARC, by then citizens, not children, intervened as plaintiff in Halderman v. Pennhurst State School and Hospital was to complete its 1969 resolution to show cause why Pennhurst should not be closed and replaced entirely with human scale community integrated living arrangements and supports. Judge Raymond J. Broderick, who died just a year before Gunnar, filed his Pennhurst opinion on the eve of the eve of Christmas of 1977. The Christmas morning banner headline in the Aus-

tin Texas Statesman American was “Public Institutions for Retarded Ruled Unconstitutional.” It was Gunnar’s testimony for PARC that Judge Broderick cited for the revolutionary proposition, which was at the heart of his Pennhurst opinion, the proposition which Gunnar had stated as the simple truth. “Given,” Gunnar and the Court said, “appropriate community facilities, all the residents at Pennhurst, even the most profoundly retarded with multiple handicaps, should be living in the community.” (Dybwad notes of testimony, volume seven, page 68). From there, there followed — and Gunnar was present at nearly all of them — Michigan, Plymouth and all; Ladd School, Rhode Island, Laconia, New Hampshire, Pineland, Maine, Mansfield in Connecticut. Southbury is now under submission. Gunnar’s beloved Massachusetts, surrounded now by states without institutions or about to be without institutions, still has six public institutions open. Surely there would be no more fitting tribute than for Gunnar’s circle of friends here to complete here the job that Gunnar so mightily advanced all around us. New Mexico became the first state west of the Mississippi without an institution on July 4th, 1996. Wyoming and Alaska have followed. Tennessee is under orders to achieve that status. Now, Tennessee is the first case — three cases, actually, run entirely by a People First organization as plaintiff, and it was Gunnar’s last courtroom testimony. Let me tell the story as my partner Judy Grande, who represents People First of Tennessee, tells it. It’s 1995. Gunnar is visiting Susan in Nashville, Ed Sewell and Judy Dee. Ed Sewell, the President of People First of Tennessee. And Judy picked him up and set out on the most wonderful trip to Memphis. Never had so much fun. They talked about everything. Stopped for fast food. Gunnar was in heaven. By then, Ed and Gunnar had become fast friends. Got to Arlington. The most they could do was drive around the institution. People First had been barred from entering the institution. That was before the court’s First Amendment order guaranteeing them access. Gunnar went to his full alert mode. His antenna for picking up things went up. He was wracked, looking as hard as he could to see if he could possibly see a person. Fascinated by every little trace, every trace. You could feel his compassion and sympathy and desire to do something. His way of connecting with people, even though at such a distance, and without the opportunity to talk with them. “Oh, thank you,” he said, “thank you, for taking me here.” The next day, Gunnar took the witness stand. He talked about his visit to Arlington, what a beautiful day it was, not a single person out of doors enjoying the day. The only people you could see were behind doors, behind windows, looking out. He conveyed to the Court this incredible sense of desolation. Now the judge began to understand what it was like to live there. The judge had been very deferential to institutional parents, skeptical of this collection of people called People First. Gunnar vouched for People First. He talked about why they were motivated

to bring this lawsuit, that they were real people with real issues who were driving and directing the lawsuit. How People First grew out of the parents' movement, that it was natural, generational, that nationally the self-advocates had grown up in an environment of education, which their parents had fought mightily, Gunnar said, rebelled in order to get. Once experiencing such a richness of life, they would not abide the institutions. Most everyone in this room has had this experience of Gunnar. The infectious insistence, the blinds lifting from the eyes, the vivid connections, the willingness to do battle, the everlasting wisdom. We loved him for all of this. Across all of the law, it is perhaps words of Justice Douglas in *Papachristou v. City of Jacksonville* which best expressed Gunnar's spirit and his service, what it is he sought and so largely succeeded in bringing to others. "The promise of a constitution of the United States," the Court said, "to each of its citizens," and Gunnar would say, as on nearly every occasion he did, "the promise of the universal declaration of human rights to each of the world's people, is independence and self-confidence, the feeling of creativity, lives of high spirits rather than hushed, suffocating silence." God bless you, Gunnar, and thank you.

Wolfensberger's Influence

American social constructs were dehumanizing for people with disabilities in the decades leading up to the Americans with Disabilities Act. No one better imparts the details, consequences, and ramifications of the origins and evolution of our history on the attitudes and perceptions of people with disabilities than Dr. Wolf Wolfensberger.

Dr. Wolf Wolfensberger was a professor and Director of the Training Institute for Human Service Planning, Leadership and Change Agency at Syracuse University. Much of Dr. Wolfensberger's work was concerned with ideologies, structures and planning patterns of human service systems, especially concerning people with developmental disabilities and their families. He was the originator of Citizen Advocacy and Social Role Valorization, and the foremost proponent of normalization in North America.

Dr. Wolfensberger chronicled the rise of social justice, compassion, dignity, transformation and empowerment from the "profound bankruptcy of vision," to the "might makes right" power politics of professionals and services in the 1950s, '60s, and '70s.

If it wasn't for the American normalization movement's positive influence on the American Civil Rights movement, the Disability Rights movement may have had a very different focus — driven by attempts to improve institutions and segregated places rather than promote inclusion and integration in the community.

Dr. Wolfensberger described how the American normalization movement's influence on education, and indirectly on the legal profession, brought the treatment of people with disabilities out of the programmatic construct and into the legal construct. Dr. Wolfensberger notes, however, that this evolution did not come without its own "mischief."

The federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) was one of the earliest pieces of legislation to have been influenced by Dr. Wolfensberger. Under former Senator Lowell Weicker's leadership, the 1984 amendments

to the DD Act preceded the Americans with Disabilities Act with legislative language that promoted independence, productivity, and integration.

Allan Bergman, a nationally recognized leader in influencing state and federal public policy relating to people with disabilities, noted the significance of these landmark declarations of valued outcomes.

Transcript:

Bergman: The 1984 Amendments were highly significant because, for the first time, and I would say this is landmark, not only in this legislation but in any federal disability legislation, we declared valued outcomes. The goals of services for individuals with developmental disabilities, and remember we're talking people with three or more substantial functional limitations in life skills — so we're talking about people with significant multiple disability/support needs. The goals, these are the goals, are increased independence, increased productivity, and increased integration. And, in the statute, not willing to leave this to the regulators, pardon me, to the bureaucrats, the words were defined. So, independence, which gets us into so much trouble because people want to take that literally and it wasn't meant that way. Independence means the ability to exert preference, choice, control, and direction. And people with the most significant disabilities can very much let us know their likes, their dislikes, their preferences, etc., and sometimes that may have to be through a surrogate, it may be through observation. It may not be verbal. What kind of music do they like or not like? What kind of food? Are there staff they like better than other? Are there people who are in their peer group that they seem to get along with better? There's a ton of data, but it takes some work to get to it. But independence is not footloose and fancy free, it's independence in the sense of the independent living movement as well, choice, control, it's my life, get out of my face. So that was the first valued goal. The second, productivity. Senator Weicker at the time, who was pivotal in this, who also happened to be the father of a son with Down Syndrome, we've had people on both sides of the aisle in our camp — didn't want to get into the work/no work. And, again, this is a long time ago in the evolution of the field. So, productivity was defined to mean "engagement in productive meaningful work for pay or volunteer work in the community." And it really translates into having a valued presence, having social value, social worth. As Wolf Wolfensberger used to teach us about social role valorization, this person has something to give back. And that's a wonderful thing to put into law, and it was clear, not everybody's going to work 40 hours a week. We got that. And these are goals. And I'll come to the third one, and then we'll come back for a second. The third goal was integration. Now remember, we had had a civil rights era. The previous decade it was still going forward along

the racial lines, and now it was sort of our turn. And integration was just what it said — being able to use, participate in all the places in the community that people without disabilities or developmental disabilities, tend to use, whether that's park and rec services, transportation services, go to the movies, go to the golf course, go wherever and be part of it and be able to access it. These are goals. And I don't climb mountains, but a few mountain climber friends of mine have advised me, "Allan, your goal as a mountain climber," their goal as mountain climbers, is always to reach the highest peak. And I said, "Tell me about that. Because if you don't go for the highest peak, you may never get to the plateau that's one before it." I believe that's the intent here. The goals were services should increase independence, productivity, and integration. Didn't say everybody's going to achieve Nirvana. I don't know what that means anyhow. But those were the benchmarks to begin to be looked at that were declared 26 years ago in this field for people with the most significant disabilities. So they were ahead of the ADA, which didn't come until 1990 with its goals of equality of opportunity, independent living, economic self-sufficiency, and full participation, which, frankly, very nicely parallel the goals from the Developmental Disabilities Assistance and Bill of Rights Act.

William Bronston, M.D., led the exposure and class action lawsuit against the State of New York's infamous Willowbrook State School on Staten Island in 1971. In 1975, he returned to California and served as a children and adult, disability services policy physician for two State of California departments. He is the founder, and chief executive officer, of the not for profit World Independence Fund Tower of Youth.

In speaking about Dr. Wolfensberger, Dr. Bronston notes that Wolf asks and gives no quarter in his telling of the history of human services, including the disability rights movement. Wolf is authoritative and judgmental. He challenges those who may feel they are playing a confident and active role in promoting social justice, compassion, dignity, transformation, and empowerment. Wolfensberger's lessons provide insight on what more needs to be done and what needs to be done differently.

Dr. Wolfensberger has also raised cautions about the perversities associated with the disability rights movement, including the Americans with Disabilities Act. Because recognizing how we have fallen short inspires us to do better.

Civil Rights: “We’re Going to Win This One”

Section 504 of the Rehabilitation Act of 1973 helped to pave the way for the 1990 Americans with Disabilities Act. Section 504 granted many rights to people with disabilities that were similar to the rights granted other minority groups in the Civil Rights Act of 1964.

Section 504 is widely recognized as the first civil-rights statute for persons with disabilities, however, its passage and implementation did not happen without a struggle. More than three years after its passage, no implementing rules had been issued, prompting a nationwide “Sign 504” campaign and sit-in demonstrations by people with disabilities. Another civil rights movement was underway.

The late United States Senator Hubert H. Humphrey worked tirelessly to secure passage of legislation that included disability anti-discrimination rights. In 1971, two years before Section 504 was enacted, he attempted to push through such language as an amendment to the 1964 Civil Rights Act but was encouraged by his colleagues to include it in the Rehabilitation Act of 1972 draft language.

Protester Judy Heumann gave tearful testimony before a congressional hearing triggered by a sit-in.

504 demonstration organizer Kitty Cone said that as one sit-in neared two weeks, pressure grew on people to give up.

Ed Roberts, Director of the Center for Independent Living, rallied demonstrators at a sit-in, telling them, “... we’re going to win this.”

Transcript:

Ed Roberts: ... [the more people], joining us for the first time in this incredible struggle, is one that leads me to believe that we’re going to win this. And we’re not going to stop until Title Four, which I believe is a basic civil rights platform, a platform that guarantees to each person with a disability in this country, that they are equal in the eyes of the law, and that they will have equal access to educational institutions, to

hospitals, to the institutions in our society which serve us all. It seems to me, that as director of the largest department of rehabilitation in this country, we are more than handicapped without these laws — we're crippled.

The Fight for 504 Regulations: “We Won’t Go Away”

Ed Roberts was a pioneering leader of the disability rights movement. His life was a life of advocacy and his dynamic spirit, a force to be reckoned with, were instrumental in bringing together so many individuals who played key roles in the struggle for civil rights for people with disabilities.

The film *We Won’t Go Away* documents a critical period in the history of disabilities: the release of Section 504 regulations. *We Won’t Go Away* is transcribed for reading in this book.

Transcript, Part 1:

Narrator Rosalie Wilkins: If you are a disabled visitor to America, and especially if you get to California, Berkeley is the place where you will feel immediately at ease. People don’t stare or deliberately not stare. You’re just taken for granted, and you soon begin to realize why Berkeley has been called the craps capitol of the world. Berkeley’s always been known as a place where movements for social change have begun, but in the more conservative and relaxed atmosphere of the 1980s, it’s hard to remember the scenes of violent confrontation, which were typical in the ‘60s when students on the Berkeley campus were rioting against the Vietnam War and campaigning for the rights of minorities.

It was in that atmosphere of protest that disabled people began to realize that they, too, were a minority, which would have to fight for its civil rights, and so a movement was born. Today, wheelchairs are a commonplace sight on the campus, but 20 years ago, it was very different. So what was it like to be a disabled student at Berkeley in the early ‘60s?

Well, to start with, you’d have been living in a hospital unit, treated as a medical problem and, apart from going to your classes, that’s where you would have stayed. There was no possibility for taking part in ordinary student life. But as the radical movement flowered, a group of

these severely disabled students decided to break out and they called themselves The Rolling Quads.

The leader of the Rolling Quads was Ed Roberts, paralyzed by polio when he was 14.

Ed Roberts: I was the only disabled student on the campus. It was very weird, I was stared at all the time. It was very clear that they didn't want me there. In the beginning, they were afraid I might die or something serious might happen to me. Once we convinced the university that I could go there, they couldn't reject me because of... I had high grades but we couldn't find a place to live, and we finally found a student health center that I could live in. And I was very much, you know, a bullet student academic and doing well until I began to realize how difficult it was for me to get around the campus and some of the awful attitudes there were on the part of professors. And I think because they started with me and I was very severely disabled and had an iron lung, they were willing to take anybody after that. All right — a breakthrough. Thank you. Bye-bye.

Narrator Rosalie Wilkins: For Ed, each bad experience was a further spur to his determination not to be restricted by his disability, and before long, he was to be joined by other disabled students with the same ambitions.

Ed Roberts: Within three or four years, there were about 12 of us. We really began to feel that we were fighting for our own independence and that there was a future for us out in the community. But we had to think really through how to do it. How were we going to make ourselves free?

Narrator Rosalie Wilkins: At about the same time, across the country in Chicago, Eunice Fiorito, blinded at 16, realized that she, too, had a fight on her hands if she wanted an equal chance in life. Eunice was to become the first president of the American Coalition of Citizens with Disabilities

Eunice Fiorito: I was a bouncy kid who liked life, and I was concerned about how I was going to live that life. But on the other hand, I was very much certain that I was, and I was going to master it

Narrator Rosalie Wilkins: Today, Eunice Fiorito is an advisor on disability in the Department of Health and Human Services in Washington.

Eunice Fiorito: I finished college in about three years. I say that to you

only because it was my vocational counselor's position that, in fact, I wasn't ever going to get through college and I was going to, if you will, be out of school and not have a degree within three years. And so I was very delighted when in three years I could walk to his office and say, "I have this degree and you were wrong." That began to make me aware of how people with disabilities were going to be treated by society. And then I tried to get a job as a teacher in the state of Illinois. And one must consider that this is now back 20 years or better ago. And the state of Illinois said, "No, you can't teach. You are blind. You can't handle children and how will they react to you anyhow?" That was the next piece, and I started to hunt for a job and I couldn't get a job. That then brought to me an awareness of the unfairness, the way people were being discriminated against.

Narrator Rosalie Wilkins: Judy Heumann was in the forefront of the rights movement in New York in the '60s. She's now Deputy Director of the Center for Independent Living (CIL) in Berkeley, begun by Ed Roberts and now a model for similar centers across America.

Judy Heumann: CIL is an organization which is run by persons with various kinds of disabilities — physical disabilities, blindness, deafness, persons with mental retardation. We have a long history of wanting to not only provide direct services for people but also to be able to begin to influence policymakers so that they could understand more clearly those policy barriers which prohibit us from being integrated within the community. For myself personally I became really actively involved in the movement after I had been through a struggle of getting education and continuing to have this image of the American Dream — if I worked hard at school and if I really studied and if I did everything that I was told to do, I would be able to go out and then get a job, and I would be able to be, you know, be Miss Middle Class America living in suburbia if I wished to do that. But in reality what happened was every step of the way was a real struggle. And even once I had gotten through university and gotten my degree to teach, I was then discriminated against specifically because of my disability. So at some point within me, I had to acknowledge the fact that no matter how hard I worked, I was still not viewed as an equal person, and if I could accept not being viewed as an equal person, then I could kind of slide away into the background, but I couldn't accept that for myself.

Rosalie Wilkins: What did you do about it?

Judy Heumann: Well I... I began working a lot with other disabled people. I had for a number of years been friends with disabled people, but we hadn't been as political as we became. And what happened over

the last 10 years in this country is that disabled people have begun to band much more closely together to form what I would define as the movement.

Narrator Rosalie Wilkins: Ralf Hotchkiss, who designs wheelchairs, and his wife Debbie Kaplan, a civil rights lawyer, became involved in the Disability Movement in Washington in the early '70s.

Ralf Hotchkiss: When I first became disabled, now 15 years ago, I got involved right away in the technology of disability. I was a bicycle maker and I...and I almost had to fix my wheelchair first weekend out, but I didn't get involved in politics for another five years afterwards. Then I was working for Ralph Nader in auto safety and all these disabled people started writing him letters, and he asked me to find out what was going on. I did. I met Judy Heumann, who you must have talked to by now, and got involved in some of the early demonstrations, setting them up in Washington, D.C.

Rosalie Wilkins: Can you tell me about those early demonstrations? What part did you both take?

Ralf Hotchkiss: Debbie wasn't disabled yet.

Debbie Kaplan: I was just becoming disabled at that point in California. I was at ... a year out of college. I had a diving accident and broke my neck, and found myself in the world of disabled people. But I remember the first thing I wanted to do when I was in the rehabilitation hospital was to find out from other disabled people what the world was really like for people with disabilities. How people functioned on the outside. What it was that made some people have independent lifestyles. And the hospital really didn't do much to provide that. And one of the groups that came to visit us was a group of the people who originated the Center for Independent Living called the Rolling Quads, and it was through people like that who were strong role models for me in my identity as a person with a disability that really got me involved.

Narrator Rosalie Wilkins: The movement had now begun to coalesce as disabled people all over America decided that they had to take action and demand access to buildings and transport and education. They wanted jobs, housing, and adequate funding and services to get them out of institutions. They wanted the equal opportunity, which they believed was their right under the American Constitution and a fighting chance to prove themselves as useful members of society.

Ed Roberts: I started in the Civil Rights Movement. I started working

with Black and Chicano civil rights, and somehow in the middle of that, when things were going very well, I stopped and said, "What am I doing here? I've learned all these great organizing skills and I should be working with my own people." And that was the transition. We realized we could do it ourselves, that we needed some support, that we needed to make the social systems like the welfare system that paid for our attendants and basic support. That had to work for us, not against us. So we had to ... that way we had to get involved with the state legislature to change the rules and regulations, and to change the laws so that it promoted independence rather than maintenance and dependence

Narrator Rosalie Wilkins: In 1975, Ed Roberts became Director of California's Department of Rehabilitation, serving over 100,000 disabled people.

Ed Roberts: One of the conditions that I took, that, you know, the Director of Rehabilitation, was that I would have the freedom to be the advocate and to be out front on issues that even the governor and the administration may not agree with me on, but that I had to have that freedom to be the out-front advocate in this movement. And that I couldn't be limited by some archaic notion of what it means to be a director of a large agency.

Narrator Rosalie Wilkins: Ed's department has a budget of 150 million dollars and a staff of over 2000. Over the years, the concept of rehabilitation has changed from finding jobs for physically handicapped people to a positive policy of nondiscrimination aimed at integration for all handicapped people. That policy was enshrined in the Rehabilitation Act introduced during the Nixon administration in 1972.

Eunice Fiorito: The Rehabilitation Act was a most progressive piece of legislation when reviewed at the time and would have opened many doors for our independence. The administration in 1972, however, I believe, and so did many other disabled people believe, that this administration felt that the piece of legislation that was then being proposed, which then included programs of independent living, what they called advocacy, client advocacy programs for people to exercise their right to get what they felt that they were justly deserving of in order to be functional citizens, were much too progressive, and President Nixon at that time vetoed the bill. We then felt, and I think we were ready to realize that we had to take command of our own lives and become political.

Judy Heumann: When the Rehab Act was vetoed by President Nixon, it was done, oh, about a week and a few days before the '72 elections with Nixon and McGovern, and a group of us from Disabled in Action

and a number of other organizations decided that we wanted to do something publicly about it. So we organized within, oh, not many days, a demonstration which started out in Manhattan at what was called the Federal Building. We had never been there before and we took like, I don't know, 60 or 80 people up to this Federal Building. And when we got up there, it was like in the middle of no place. It was on this little island, and we had this demonstration and we had these great flyers and we had this symbolic funeral of disabled people being killed by the Nixon administration. And the next thing we knew, out came these city police. They drove up in this car. They asked who the leader was and people sent them over to me. And the guy said to me, "Do you know that you're trespassing on federal property?" And I said, "Yes," and he said, "Are you going to leave?" And I said, "No," and we expected the world to end, and he said, "So stay," and he turned around and he walked away.

So we decided we weren't making the impact that we wanted to, so we were going to sit down in the street and we were going to stop traffic. So we did. We all went out into the... Most of us went out into the street. But, as I said, there were like hardly any cars coming by. So we all got into our vans and into the cars, and there we traipsed off to Madison Avenue, which in Manhattan is like ... It's a huge street. And we got out of the cars and we decided that what we were going to do is we were going to sit down in the street. So at 4:30 in the afternoon we formed this huge circle. We cut off four streets, but that was too scary because there were only 60 or 80 of us and there were huge trucks and cars. I mean, you know, Manhattan is like a crazy city in the best of times. And so we decided that we would retreat, we would only go onto one street, but still we shut the whole city down. They were announcing, "Paraplegics stop traffic in Manhattan," and the police went and got a representative from Nixon headquarters and they wanted to know what we wanted. We said we wanted a public debate with the president on national TV to debate why he had vetoed the Rehab Act. The guy thought we were totally crazy. He just walked away going, "You're crazy, you're crazy."

Ralf Hotchkiss: That was one of the biggest was when Nixon did veto the Rehab Act. On one of the snowiest days in Washington's history, many people, over a hundred, I believe, came down from New York City in buses and basically stormed the capital, visited all their congressmen and all the... all the congressmen who had voted against it, and built up enough support so that I believe that was the strongest congressional override in history, override of a presidential veto.

Narrator Rosalie Wilkins: Finally, on September the twenty-third, 1973,

Nixon signed. The Rehabilitation Act was now law, but there was yet another hurdle to be overcome.

Eunice Fiorito: In this country, when a law is passed, there must be followed, then, regulations, which really explain the law and set forth the actual policy and the practices of how that policy is going to be interpreted. Well, that did not come about, particularly within Section 504.

Narrator Rosalie Wilkins: Section 504 states, “No otherwise qualified handicapped individual in the United States shall solely by reason of his handicap be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”

Eunice Fiorito: It was 1975 and there were no regulations. And we proceeded then to come into 1976, and there were still no regulations and, therefore, the law was not being implemented.

Narrator Rosalie Wilkins: January 1977, a new president in the White House, but instead of new hope, yet more frustration as Jimmy Carter’s administration delayed the regulations yet again.

Eunice Fiorito: Within two days after the new Carter administration was put into place, about 15 of us came to see then Secretary Califano, stating the issue about the regulations not having been issued and expressing our concern and desire to work with him and his staff to get them out within a reasonable period of time, particularly since they had been circulated, people had studied them, they had commented, etc., etc.

That process then started all over again. The administration decided they wanted to review them and they wanted to study them, and we went back and forth to meeting after meeting after meeting in good faith. And we finally said to them, “Look, we have had enough. From a legal point of view, these regulations seem to have been quite good. You’ve studied them a lot and we’ve studied them. If you cannot come up with a decision, we must then take action.” And we gave them until the fourth of April. And on the fourth of April of 1977, they did not have the regulations ready for issuance. And so we had developed an alternate plan, and that plan was to bring our plight to the attention of the people of this country.

Narrator Rosalie Wilkins: The key part of the plan was to take over federal government office buildings across the USA, and in the full spotlight of press and TV attention, Judy Heumann expressed the deeply

felt frustration of the disabled minority.

Judy Heumann: The harassment, the lack of equity that has been provided for disabled individuals — that now is even being discussed by the administration — is so intolerable that I can't quite put it into words. I can tell you that every time you raise issues of separate but equal, the outrage of disabled individuals across this country is going to continue. It is going to be ignited. There will be more takeovers of buildings until finally, maybe, you begin to understand our position. We will no longer allow the government to opp ... oppress disabled individuals. We want the law enforced. We want no more segregation. We will accept no more discussion of segregation. And I would appreciate it if you would stop shaking your head in agreement when I don't think you understand what we are talking about.

Transcript, Part 2:

Jeff Moyer singing: Civil rights were knocking at our door. But Carter wouldn't stand on 504. Keep your eyes on the prize...

Narrator Rosalie Wilkins: The sit-ins to demand the signing of the regulations which would enforce the Rehabilitation Act took place in federal buildings in 10 cities across the United States. In Washington, the demonstrators moved in, determined to stay. The government officials refused to allow any food or drink into the building and, in effect, starved them out. In most cases, the sit-ins lasted only a few hours, but in San Francisco, the demonstrators stayed and stayed. They were not going to go away.

Jeff Moyer singing: Hold on, hold on.

Narrator Rosalie Wilkins: Three-and-a-half years later, we took Judy Heumann back to the Health, Education and Welfare Building where over 150 disabled people held out for 28 days. With her came three people who had shared the experience, Kitty Cohen and Ron Washington, fellow workers from CIL, and Jeff Moyer, who's blind and who became the resident musician for the demonstrators. For all of them, it was the first time they had returned since 1977 and the memories were still vivid of the day when they moved in, a strange, ill-assorted, but unique army.

Judy Heumann: In 1977, one of the beauties of the demonstration was the fact that we had persons with all kinds of disabilities and all age ranges. There were people who were blind and people who were deaf and people were in wheelchairs. They were quadriplegics and paraplegics and people who were blind and in wheelchairs, and people who

were deaf and in wheelchairs. And you just think of the kind of disability that you would want to think of, and there was someone there that was representing that constituency.

Jeff Moyer singing: Hold On. Hold on. Hold on. Keep your eyes on that prize. Keep your eyes on that prize. Keep your eyes on that prize. Hold on.

Ed Roberts: That my ability to regain a pride in myself as a person with a disability is one of the most important things that's coming out of what's happening here today. And to see hundreds of people with disabilities rolling, singing, using canes, the more severely retarded people for the first time joining us in this incredible struggle, is one that leads me to believe that we're going to win this. That we are not going to stop until 504, which I believe is a basic civil rights platform, the platform that guarantees to each person with a disability in this county, that they are equal in the eyes of the law and that they will have equal access to educational institutions, to hospitals, to the institutions in our society which serve us all.

Various people talking: And here we are. Inside. I just want to pass real fast through here. It's going to be easier this time. This was our very first headquarters. Remember how we... It looks quite the same. Gee, it looks the same. Remember that desk? Really. Do you remember how we used to use the phones at that desk? Calling all over the country... It was the first thing we did. [overspeaking] I remember crashing out on the couch. Should we answer the phone? It looks like they've got a new typewriter, must be a computerized one. Yeah, I remember people used to spend the night on that couch. They used to have a TV in here. Remember, we monitored all the media?

Demonstrator: It's the first step in a long march. We've got a long way to go, but we're on the way and we're united. There's never been a group of people so connected to each other as this group of people here, and we're ready to walk together, march together, wheel together. Find our way down the road toward real civil rights.

Demonstrator: I want California to sign 504 for many, many different reasons. One of the reasons is our deaf people want to work. We don't want to live on SSI if we can work.

Ron Washington: I was really angry when I came in because we had been meeting and there was a lot of things in the newspaper about the 504 regulations possibly being cut, some of the important things that we felt were meaningful for us as disabled people were going to be tak-

en out. And so when I got up here, I was really very angry and wanted to... I felt that we could... There were so many of us, so many disabled people, that we could probably get some changes done right then.

Judy Heumann: There was a total sense of power and control, and when the director was sitting in the chair where Jeff is now, there was like so many of us and he knew nothing and we kept... Remember we kept asking him to bring up the people from Higher Education and the people from the different parts of the Health, Education and Welfare agency who were supposed to know about the regulations. And they came up... and two guys came in and said, "What's 504?"

Kitty Cohen: It was amazing because all the demonstrators had just been preparing and organizing for weeks in advance and had just come from a really militant rally, and we all knew what we were talking about. We knew real specifically what 504 was and what was happening, and they just didn't know at all. And here they were, in charge of our civil rights. It was... They must have been astounded. I mean, they must have been just...

Ron Washington: They were shaking in their pants because...

Kitty Cohen: Oh, they were. They were scared.

Ron Washington: Yeah. As you said, we had that really powerful rally outside that just gave... I know, gave me a lot of inspiration and strength and I felt like I was Popeye and was ready to move this desk and jump on it. Poor Mr... What was his name, Maninata?

Ron Washington: He was, you know, he just really hadn't... And the people that came up also, they were just really stupid and...and.

Judy Heumann: I remember getting really furious the longer that we sat in the room. You know, there was a demonstration outside where it was like very exciting and very powerful, and then when we made it into the building. To me, it was also an incredible sense of control because we'd moved all of these people up through the elevators up onto this floor. And while there were a few of us, you know, who were planning to potentially stay overnight, the more I sat in this room and got these answers from people or these absolutely non-answers, the angrier I got. And that's when people started really feeling like we couldn't leave because no one knew what we were talking about, but we knew that they were trying to rescind the regulations.

Ron Washington: I know, Judy, you said..."You're going to sit in, aren't

you?” I said, “Well, Judy, I didn’t come prepared.” She said, “You... You gotta stay here, Ron. You gotta stay here.”

Kitty Cohen: To me, it was... There were so many things to be proud of. The fact that we managed to sustain ourselves for 28 days. We were so organized. I mean, we had our press committee, our food committee, our medical committee. Here we were, some of us severely disabled, sleeping on the floor every day, not knowing if we were going to get arrested, and going to bed at 3 o’clock in the morning and getting up at 6 o’clock, having clean-up committees so that the workers could come in and carry on their work in the building, and managing to tackle incredible political issues and refute the government when they were coming out with lies.

Demonstrator: It really wasn’t an outlaw act. We were trying to make the system work, the typical 90-day period for regulations stretching to three-and-a-half years, and after all the public input looking like they were going to pass what they wanted to anyway in terms of water-downed regulations, it made everyone feel like it was... And it was a very righteous cause.

Narrator Rosalie Wilkins: They were not to be denied their victory. At the end of April 1977, after the longest sit-in in US history, it was over. The government capitulated and signed the regulations.

Demonstrators: Power to the people! Power to the people! Power to the people! Power to the people! Power to the people!

Eunice Fiorito: 1977 was the year in which disabled people had a great deal of visibility. They come into their own as a minority group in the minds and the eyes of the people and the administration of this country. But more important, to themselves, to disabled people, they felt a strength. An inner strength, I think, developed from the success as well as from the struggle.

Woman: Can you open the elevator please?

Intercom voice: It’s right there. The doors did not open?

Woman: They just opened, thank you.

Narrator Rosalie Wilkins: In the next few years, many of the barriers to integration began to go down. Disabled people were coming off welfare and into jobs, moving around, mixing in the outside world as equals, but, of course, society was not transformed overnight. There

were continuing battles to be fought, especially over the question of mass transport where the costs of making the system accessible are so high. In some cities like Washington, Seattle, and San Francisco, it was starting to happen, but resistance by the transport companies grew. Kitty Cohen recalls the struggle to get the San Francisco Bay area bus company to conform to the law.

Kitty Cohen: It was a hard fight. We had to go into court two times suing AC Transit. We attended all their board meetings. We participated in their studies. We went to public hearings where we would bring 50 disabled people who would testify quite eloquently about their personal experiences. We, at one time, about 200 disabled people demonstrated against AC Transit and blocked their buses at commute hour. And, finally, I think they realized that they were up against a force that simply would not subside, and so they adopted a policy of full accessibility. And since that time, they have really made an effort to make the system work, and I think it's working really well. We're really proud of what's happened here.

Jeff Moyer singing: The civil rights were knocking at our door. But Carter wouldn't stand on 504. Keep your eyes on the prize, hold on. Hold on, hold on. Keep your eyes on that prize, hold on.

Rosalie Wilkins: With it all behind them, disabled people were feeling confident and hopeful as the '70s drew to a close. But in 1980, as Reagan rode to victory on a campaign promising to cut taxes, bring down inflation, and reduce government spending, the fear began to grow that rights were something the politicians would hand out in the good times and abandon when it suited them. The question disabled people were facing was: Would the struggle have to start all over again? The question that all affluent societies must face was confronting the American people: How much do you care?

Narrator Rosalie Wilkins: At his inauguration on the twentieth of January in 1981, President Reagan promised the American people a new beginning that sounded a grim note of warning on public spending.

President Ronald Reagan: For decades, we have piled deficit upon deficit, mortgaging our future and our children's future for the temporary convenience of the present. To continue this long trend is to guarantee tremendous social, cultural, political, and economic upheavals. You and I as individuals can by borrowing live beyond our means but for only a limited period of time. Why then, should we think that collectively as a nation we're not bound by that same limitation? We must act today in order to preserve tomorrow. And let there be no misunderstanding,

we're going to begin to act beginning today.

Rosalie Wilkins: On May the seventh this year, Congress was due to vote on President Reagan's budget proposals, the harsh reality of his commitment to slashing government spending on social programs while pouring money into defense. The future for disabled programs looked bleak; not only money, but the hard-won legislation was at stake. So on that day, disabled Americans from all over the states gathered on Capitol Hill to remind their Congress that the equal society for disabled Americans was in jeopardy.

Public speaker: We are here because we believe that disabilities or handicapping conditions in no way and by no means lessen, negate, or destroy our rights.

Narrator Rosalie Wilkins: The first Reagan budget proposed cut federal funding for social services by 25 percent, but the crucial issue was the decision that money for social programs would be handed over to each state on block and without strings. Effectively, this would remove the federal government's power to direct how money is spent and would thus weaken the Section 504 legislation, which relies on having the weight of a federal mandate for its enforcement.

Public speaker: Let's agree to do everything we possibly can to keep block grants from passing this Congress. At least that way, we'll have still some control over the programs that help handicapped people. I'll work with you. I'll disseminate any information you give me. I'll do everything I can, and I assure you every other liberal member of Congress will do the same, but we need more than that. We need the Republicans, we need the conservatives, and you're the folks out there that can get them. So let's all work together. Let's at least make sure that whatever money comes through is directed to specific programs and not block grants. Thank you very much.

Narrator Rosalie Wilkins: During the rally, small groups of demonstrators from each state formed delegations and moved into the Senate buildings to lobby the Senators and Congressmen who were supposed to represent their interests. Judy and her friends from CIL sought the help of Congressman George Miller of California, a Democrat.

Congressman George Miller: I don't think anybody ought to mislead you. I think that it has already been outlined and as it will be implemented, it's going to fall disproportionately on your community, on the handicapped community, on the elderly and on the poor. It's just very clear that that's where it has to fall because there's other areas of

the economy of our society have been reserved not to participate in those...in those cuts. And I think what we will find out now is that it's far more harsh than they have led people to believe. Ann and I have been going over just the cuts in our area, and you can't achieve in the Education and Labor budget, you can't achieve what the president wants to achieve without repealing the Handicapped for Education Children's Act, but he hasn't told that to the parents or to the handicapped students that that's how he has to achieve his goal. As a matter of fact, he hasn't even told that to the Congress yet. He has quietly submitted that legislation for concern. You can't achieve the kinds of cuts that he desires without outright repeal of many of these programs because certainly we're not going to participate in cutting programs to the extent where they become so inefficient they serve no one. And I think they know that. I think it's clear. I really don't know where you find \$11 billion this year in cuts in the Education and Labor budget. But very shortly, after the vote is taken here in the next 40 to 45 minutes, that's going to be our mandate on Monday to start searching for those funds. I know the announcement today that Dave Stockman is struggling to find another \$5 to \$10 billion dollars in cuts because he told us interest rates were going down, right? Well, interest rates went up over the last four or five days. And so the cuts are going to become more severe because they still believe in a Margaret Thatcher syndrome that this is how you work your way out of your problem. Well, they'll also find out that there are limits to the tolerance of people in this country. I think that people are going to have to become more militant. I think as you said, you've hit the streets before and we've had tremendous victories. And there goes the call to go vote on this matter. But I think that you're going to have to go to those legislators who have voted for these budget cuts and hold their feet to the fire. I think you're going to have to go around the country and tell people in their community what the result is because there's a great belief in politics that somehow you can escape the ramifications of your actions. And I think you've got to make it very clear that you can't do that this time, that the results are too severe and too harsh.

Rosalie Wilkins: Thank you.

Congressman George Miller: Thank you. I'm sorry you had to come all this way for this reason. You know, it wasn't too long ago you made this trek so we could implement the laws. And now you're here three years later trying to say don't repeal them. It's amazing how it works in this system. Thank you. Thank you.

Rosalie Wilkins: Thank you.

Congressman George Miller: Bye then. See you. Good-bye.

Public speaker: There are a lot of selfish people in the Congress of the United States who will do whatever they can to cut programs that are important. So it seems to me the mission that you need to perform and we need to perform is to identify those individual members who are the great budget cutters and see what we can do either to change them or cut them out of the Congress as members of the House and Senate. [Applause] So don't let your work end when you get off the plane, train, bus, or car and get back home. Continue to work to build public sentiment directing it at those individuals that you have a power and an opportunity to affect in one way or another. Above all, do not be discouraged by whatever may happen today. And I can tell you, out of my 40 years of experience in the nation's capital, much of it in that building behind us and in these buildings beside us, I can tell you that sometimes the darkest hour is the time when if the people get sufficiently aroused, they can win what seemed like a lost cause. I thank you.

Narrator Rosalie Wilkins: I asked Republican Senator Lowell Weicker, who'd voted against the block grants, if the administration was aware of the effect of its policies on disabled people.

Senator Lowell Weicker: No, I don't think the administration has assessed the effects of any of its cuts in the social programs. I think they just wanted to achieve a bottom line dollar amount. There was no evaluation of either what was good and what was bad. A good example of that would be education. Education where we know statistically for every dollar the federal government's put up, we receive some 9 dollars back in return in the sense of that person being a productive member of society earning larger wages, being taxed more, etc. We get much more back than we put out.

Rosalie Wilkins: Do you think there is a backlash amongst the America public against the demands being made by handicapped people?

Senator Lowell Weicker: I think there's a backlash in this country at anything that doesn't fit into a majority status, whether we're talking about the minority, which is racial, the minority, which is sex, the minority, which is disabled and retarded. All of this means trouble, and the majority doesn't want to be troubled right now.

Judy Heumann: What's being proposed in this country is we're going to balance the budget. But if you analyze the budget, you see that quite the contrary is true, that they're taking about 36 billion dollars out of

social services programs, but they're not putting it back into the people's hands, they're putting it into the military budget. So I think that, if anything, the Civil Rights movement have been becoming too weak and that we should be much more forthright and much more strong.

Ed Roberts: I'm convinced that we're going to go through a real traumatic time right now and, just as President Reagan is challenging these rights, I think that's going to go on for a while because there's, unfortunately, when we talk about integration with blacks and changing the schools, we didn't talk about how much it cost. It costs billions and billions of dollars. But when we talk about equal rights for the handicapped, we're talking about billions and billions of dollars and the cost issue has become the forefront issue. Not whether we should have basic rights. I think everybody agrees that that should happen, but the cost becomes the hang-up.

Rosalie Wilkins: What tactics do you think disabled people should use against Reagan's budget cuts?

Ed Roberts: Everything we can think of, especially that are theatrical and that help remind people of our basic values in this country are. That we do care about those folks that are considered the weakest and that government does have a role to play with people who aren't going to make it without some kind of government help, whether it's maintenance kinds of help or movement toward independent living. I think constantly reminding people that while we're in an age and a shortage of dollars, that we can't lose our human values and the values that we built this country on.

Debbie Kaplan: I think it will come out that the public is fairly supportive even though... I just heard a recent public opinion poll that 80 percent of the people in the country are not in favor of what Reagan is doing in social service cuts. I think people are fairly supportive once they understand what we're talking about, once they understand that we're talking about access to jobs and access to living independent lives, and we're not talking about just handouts.

Ralf Hotchkiss: All along some of our strongest support has come from the far right anyway. Self-determination, independence, those are all both left and right issues. And I don't think that we'll lose on all fronts

Rosalie Wilkins: You don't feel that civil rights is becoming a dirty word at all.

Ralf Hotchkiss: No.

Debbie Kaplan: Disabled people are not going to go away, and the increased education, the increased rights that disabled people have are going to lead to more and more disabled people who will want to partake in society and not be treated like little children all their lives. And one way or another sooner or later it's going to happen.

Senator Lowell Weicker: Now none of this comes cheap. Who's arguing that? I'm not going to sit here and say that, you know, that we can have these things and we're going to cut taxes. But what I am saying is that the purpose of government, it seems to me, is not... It's not in our officialty like a corporation. Government is there to help each individual flower to his or her greatest extent, to give expression, you know, to what they are or what's inside of them. Because government is the people. And yet in what we're doing now either cutting back on funding or once again shifting the problem back to where the problem originated, you know, I think we're washing our hands of this matter for political purposes so that the majority...so that the majority can lead their lives unencumbered by the problems of others or the cost that those problems raise.

Ed Roberts: I think that the difference between now and 20 years ago is that the movement of the disabled is concerned about all of this and has a fundamental belief that we all can take our places in the community and we don't have to be institutionalized or segregated. If you come from a basic spirit that you believe you can succeed, and that mixes in a lot of philosophies, you know, like positive mental attitude and all the different things that crop up around this country, they are definitely ingredients in what happened in Berkeley and what's happening in the whole movement in this country. It's like the people who are considered the absolute weakest in our society, we're beginning to discover that we're among the strongest in our own ways, that disability is very challenging and it can send you down in flames or it can send you up.

Jeff Moyer singing: The civil rights were knocking at our door. But Carter wouldn't stand on 504. Keep your eyes on the prize, hold on. Hold on. Hold on. Keep your eyes on the prize, hold on. Well after four years of delay, we reclaimed the ground we gained. Keep your eyes on the prize, hold on. Hold on. Hold on.

Public speaker: Some philosopher once said that if you can go to a country and just look at one or two things and make a judgment on that country, probably the thing that you'd want to do is to see how that civilization or that country takes care of its older citizens. Well, there's some partial truth in that, but I would broaden that test just a bit to say

that you ought to judge a country on how they treat their older citizens and their children and those who are disadvantaged.

Jeff Moyer singing: Hold on. Hold on. Keep your eyes on that prize. Keep your eyes on that prize. Keep your eyes on that prize, hold on.

Ethics, Medicine and Baby Doe

Prior to the Americans with Disabilities Act (ADA), in hospitals around the country doctors and parents decided against life-saving treatment, even routine medical care, for certain infants with physical or suspected intellectual disabilities. Consequently, each year hundreds, if not thousands, of newborns, who might otherwise have lived with disabilities, were allowed to die.

In 1971, the Joseph P. Kennedy, Jr. Foundation, in cooperation with Johns Hopkins Hospital, created the film “Who Should Survive” in the hope that it would stimulate thinking and discussion about this matter of life and death. However, thirteen years later, in 1984, Carlton Sherwood, CNN Reporter for CNN Special Assignment, documented in “Oklahoma Infanticide” the lack of medical treatment for babies born with spina bifida in Oklahoma. Who Should Survive and the three part series “Oklahoma Infanticide” revealed that the civil rights protections under Section 504 of the Rehabilitation Act against withholding care based on a child’s sex, race, or disability were not enough.

These videos offer a reminder still today about the importance of maintaining and advancing the ADA.

A transcript from a portion of the film “Who Should Survive” follows.

Transcript:

Dr. Bartholome: Well ... that’s it. I’ll go call the parents.

Nurse: Alright.

Dr. Bartholome: He looked very much like a child that you would’ve found abandoned somewhere and left to die in a garbage can. I can remember the parents and the decision and my agony, and I knew that I was partly responsible.

Patient: Aah.

Nurses: Good push. That's terrific. Let's have another one.

Patient: Aah, aah. Aah, aah.

Nurses: Now you relax for a minute while we listen to the baby's heart. Good push too. Good girl, keep at it.

Patient: When? Help. It hurts.

Nurse: Okay. Good girl. Here it comes.

Patient: Aah, aah.

Nurse: Okay. Now we'll get the shoulder. Good. (Baby cries) Okay, baby. Come on, let's fuss a little. (Baby cries) Look here, it's a boy. (Baby cries)

Nurse: Dr. Bartholome, is the mother awake?

Dr. Bartholome: No, she's out

Nurse: This baby looks a little mongoloid to me. (Baby cries)

Dr. Bartholome: The diagnosis of mongolism can be made with a fair degree of certainty in the nursery. In addition to the mongolism, the patient had this disorder called duodenal atresia. There was no opening between the stomach and the lower intestine.

Dr. Haller: A child with duodenal atresia doesn't look to be any other ...

Dr. Bartholome: Dr. Haller knows a good deal about mongolism and has operated on many mongols with problems.

... doing fine. He's well hydrated and we have an IV in and the NG tube is in ...

Dr. Haller: So as far as you're concerned, we're all set to go in the morning.

Dr. Bartholome: Right.

Dr. Haller: There's some possibility that they are not going to want an operative procedure on that baby. She's a nurse and apparently has taken care of some children who were mongols in the past and has some real serious reservations but ...

Dr. Bartholome: The presence of a lesion that was incompatible with

life allowed them to make the decision about whether they not only wanted their mongol child but whether they wanted their mongol child to live or die. (Babies crying) The child's life, if you look at a mongol's life, was not one of pain or suffering or misery or that he would never learn or that he would never know himself or that he would never be an individual. His life, although certainly not normal, would be a life, and he would be a living human being.

Dr. Haller: ... making an opening so that the contents can go through all right. So, as you can see, it's a relatively simple operation but it's in a fairly small baby and for that reason ...

Dr. Bartholome: Dr. Haller wanted to operate on this patient. He did tell the parents, however, that it would be their decision.

Dr. Haller: ... but the operation will have no effect whatsoever on his underlying mongolism because this is a condition which is separate from, although it may be related to the abnormality in his intestine, the mongolism condition is not going to be changed by fixing his intestinal obstruction.

Dr. Bartholome: From the parents' standpoint, they were looking forward to having this bouncing, happy, healthy baby, and then some physician tells them that their child is a mongol. Why burden ourselves, why burden society, why burden everybody with this defective child? Why not simply let God's will be done?

Dr. Bartholome: The parents don't want any operative procedures to be done on the baby. And Dr. Haller has decided to respect their opinion and their belief about what they want done for the child. So we're going to stop any artificial means of prolonging the baby's life. It was a long and agonizing wait. I actually tried very hard to avoid going in and seeing the baby. And if I did look at him, I tried excruciatingly hard not to touch him because it was very difficult for me to handle him even to examine him. I was very concerned about what this was going to do to the nurses. Their initial reaction was one of just kind of horror and disbelief that we were going to do this. We were going to take a baby, who was a completely healthy baby compared to a lot of the patients they were taking care of on the floor, who was now going to go into a bassinette in some dark corner and starve to death. This is Dr. Bartholome ... I talked to the father several times. He would call and say "How are things?" meaning is the kid still alive? ... by deteriorating I mean ... I felt uncomfortable talking to him and I felt a little funny saying, "Well, things are working out. They're just taking a little slower." It took 15 days for the baby to become severely enough dehydrated that

he finally died. That was an awful long time.

A transcript from the CNN report Oklahoma Infanticide is also included.

Transcript:

Carlton Sherwood: This is Carlton Johnson. He was born with a serious but treatable birth defect. But his mother says that a team of doctors recommended against treatment, and just four days after he was born, Carlton Johnson was transferred to an institution, without the benefit of surgery to let nature take its course.

George McCormick: They expect him to die in a very short period of time.

Carlton Sherwood: Carlton is not an isolated case. In hospitals around the country, doctors and parents are deciding against life-saving treatment, even routine medical care for certain infants with physical or suspected mental handicaps. Consequently, each year hundreds, if not thousands of newborns who might otherwise live with disabilities are allowed to die.

Carlton Sherwood: The practice is widespread, but the public rarely hears about it, mainly because of doctor-patient confidentiality laws and fear of litigation. But when the courts do become involved, what was once secret and private becomes front-page news.

Unknown: You bring people to a hospital when they're sick to get well. You don't bring them there to be starved to death. It died here.

Carlton Sherwood: At a hospital in Bloomington, Indiana, a child born with Down syndrome, a cause of mental retardation, is deliberately denied medical treatment, even food and water. The doctors and parents are taken to court but too late. Baby Doe dies after six days. That was in 1982.

Unknown: They had no business interfering with the medical decisions of parents, concerned parents, loving parents.

Unknown: Nobody has the right to deny that life.

Carlton Sherwood: Just four months ago in Stony Brook, New York, a baby girl was born with spina bifida, an exposed spine, which if left untreated usually results in infection and death. Because of the possibility of other handicaps, all treatment was suspended. A court battle over the fate of Baby Jane Doe erupts and continues today.

Nurse: Say bye-bye. Say bye-bye, bye bye.

Carlton Sherwood: Like Baby Jane Doe, Carlton Johnson was born with spina bifida, a birth defect which nearly always produces paralysis in the lower parts of the body and, in a small percentage of cases, some mental retardation. Standard treatment for spina bifida includes closure of the spine, large doses of antibiotics to ward off deadly infection, and if necessary, the implantation of a shunt or thin tube under the skin to prevent a buildup of fluids around the brain.

Carlton Sherwood: Experts in the field say with that kind of treatment, victims of spina bifida usually have a better than 80 percent chance of survival.

Dr. David Macleod: These children are born not dying. These children are likely to have a significant handicap, a handicap however, which is compatible with independent competitive existence.

Carlton Sherwood: But in Carlton Johnson's case, his mother says a team of doctors from Oklahoma Children's Hospital recommended that his birth defect not be treated, either surgically or with medication. There was no need for these treatments his mother was told, because Carlton had no chance of surviving beyond a year.

Carlton Sherwood: What did they tell you his chances were?

Mrs. Sharon Johnson: Well, not very good. They said, like six months to a year. The only thing they told me was about a shunt. And then, you know, after they told me about six months, that he would live six months without it and I just figured what's the sense? He already suffers, so why should he suffer any more?

Carlton Sherwood: That was just hours after Carlton's birth. Four days later, he was transferred to the Oklahoma Children's Shelter, a federally subsidized intermediate care facility for handicapped children. At the time CNN cameras arrived, Carlton had lived there for 17 months. Medical records obtained by CNN show he received antibiotics for an ear infection and was hospitalized for dehydration and examinations. His head, near normal size at birth, became swollen with fluids, a condition known as hydrocephalus, which can cause irreparable brain damage.

Carlton Sherwood: This is the back of a child whose spine was surgically closed. Carlton Johnson's untreated back hosted a membrane-thin sac containing about a quart of spinal fluid that was about the size of walnut when he was born.

George McCormick: The meningomyelocele is leaking, which we are afraid that it might rupture.

Carlton Sherwood: If it does rupture, what happens?

George McCormick: Infection and eventually death if they're not able to successfully treat it. Then, at that stage, it would be crisis management and not just supportive care.

Carlton Sherwood: George McCormick, Director of Nursing at the shelter, says he spent months trying to persuade physicians to operate on Carlton.

George McCormick: Sometimes I was just ignored. They moved on to other subjects. So.

Carlton Sherwood: They weren't very anxious, you're telling me, then to do anything at all.

George McCormick: No they weren't, they weren't anxious. They haven't been anxious to, uh, do or act on the behalf of any of these children. You prodded them and, essentially, you didn't let them forget.

Carlton Sherwood: McCormick secured Mrs. Johnson's consent for an operation last October. That same month, medical records show, doctors agreed to perform the surgery. But when CNN went to the shelter four months later, Carlton still had not received an operation. Can surgery be performed safely after such a delay?

Dr. David Shurtleff: Is it possible to operate on him? The answer is yes. Is it an extremely risky operation now with an extremely high morbidity and mortality? And the answer is yes.

Carlton Sherwood: Dr. Shurtleff is the Chief of Pediatrics at Seattle's Children's Hospital and a national expert in the field of spina bifida. CNN asked him to view a videotape and study the medical records that we had obtained.

Carlton Sherwood: Is that good medicine and would you have done that? Again, based on ...

Dr. David Shurtleff: My answer is no. We would have followed the child. We'd have provided it with acute illness care. We would have immunized the child, and we would have provided him with relief of pain. And by serial assessments, I'm sure that we would have ended up operating on that child to close the back and to put a spinal fluid shunt in.

Carlton Sherwood: Dr. David Macleod, Chief of Pediatrics at Chicago Children's Hospital, is also highly critical of non-treatment programs.

Dr. David Macleod: To watch the child develop a cosmetically unacceptable head and endanger the developing brain because of increased intracranial pressure is bad medicine. I just don't think that that's what is acceptable.

Carlton Sherwood: Repeated requests for interviews with the team of doctors were denied. And CNN cameras were even barred from Oklahoma Children's Hospital. Later, after additional telegram requests, the hospital relented somewhat and allowed us to talk to their Chief of Pediatrics Dr. J. Andy Sullivan. With the hospital's own cameras taping our interview, Dr. Sullivan denied any physicians there withhold live-saving treatment.

Dr. J. Andy Sullivan: We don't have any non-treatment regimen. We have some patients that receive nurturing or less aggressive surgical management, but ...

Carlton Sherwood: And despite an official hospital release form where the attending physician recommended children be transferred to the shelter, Dr. Sullivan denied any such practice exist or that he himself has treated any patients at the shelter.

Carlton Sherwood: You're trying to tell me, doctor, that the team at this hospital does not recommend sending these children to the shelter when the decision has been made not to treat?

Dr. J. Andy Sullivan: There's not a recommendation to send these children anywhere. They're discharged to the care of their parents.

Carlton Sherwood: But have you dealt with any children who have been referred, uh, or released to the children's shelter?

Dr. J. Andy Sullivan: I don't recall being involved with any children that were discharged and their families elected to place them in the shelter.

Carlton Sherwood: But according to medical records obtained by CNN, it was Dr. Sullivan who conducted an evaluation of Carlton Johnson at the shelter last September. What were his conclusions then?

Carlton Sherwood: "No further treatment or evaluation recommendations are made at this time. This child is not a candidate for an active rehabilitation program."

Dr. J. Andy Sullivan: What you have just done is read something to me that you would allude to me. I would assume if you do that, that you are violating by exposing his medical record some relationship that I have with that patient. And, uh, I do not have his record. I was not advised before this that you wished to discuss this patient, and I don't feel it would be appropriate to discuss a specific patient in front of the nation.

Carlton Sherwood: This is ... this is a statement signed by his mother releasing all of the information and allowing anyone to talk to us about him, and if you'd like to look at that.

Dr. J. Andy Sullivan: I'd prefer not to look at it. I don't discuss my patients' problems over the air.

Carlton Sherwood: Counselor, you may want to look at this. This is a statement by the child's mother we're talking about. She's given the State and the hospital and any physician permission. I'll tell you what the statement says. To discuss ...

Dr. J. Andy Sullivan: I'm really not interested in it. I have no idea if that is that lady's signature. For all I know, you could have written that.

Carlton Sherwood: Sharon Johnson did authorize CNN to look into Carlton's medical history. And she insists that it was the doctors at Children's Hospital who persuaded her that Carlton should be placed in a shelter because he was going to die.

Sharon Johnson: Everything is negative, no positive, no hopes, nothing.

Carlton Sherwood: Like what? Go ahead. Start straight through ...

Sharon Johnson: You know, just like you could say something like, "You can do this for him, you can do that for him." But it wasn't ... it wasn't like that. It was just all negative, just point blank negative.

Carlton Sherwood: No matter what you do, what's going to happen?

Sharon Johnson: He was going to die. That was ... that was the bottom line.

Carlton Sherwood: You know Carlton's mother. Did she really, truly give him up of her own ... Was that her own decision? Or was that the decision of others?

George McCormick: Mrs. Johnson was so misinformed or she was just

never given the facts on Carlton. She thought he was some sort of a monster. She thought he was blind, which he's ... he's not blind. That fact's demonstrated by him recognizing ... recognizing staff members.

Carlton Sherwood: Two weeks after CNN discussed Carlton Johnson's condition with Oklahoma officials, he was transferred to Children's Hospital where he received an operation. But he won't be returning to the shelter. It was closed recently by state officials who charged the shelter owners in a civil suit with racketeering and fraud.

Carlton Sherwood: McCormick says Carlton is not an isolated case. If anything, he says, Carlton is different only because he has somehow managed to beats the odds and has, so far, clung to life.

Carlton Sherwood: Is it normal for children to be sent over here from Children's Hospital without a shunt?

George McCormick: Some of the children do, some of the children don't.

Carlton Sherwood: What happens if they're not sent with ... What happens if they're not shunted, as a rule?

George McCormick: They die ...

Carlton Sherwood: How long?

George McCormick: here. Ah [Sighs], depending on how strong the child is and ... Anywhere from days to months and some, in a couple cases, years.

Carlton Sherwood: Carlton is one of the lucky ones, then, I take it?

George McCormick: One of the lucky ones, in that he's a survivor.

Carlton Sherwood: At least 24 other newborns with spina bifida didn't survive. They died at the shelter after a team of physicians from Oklahoma Children's Hospital recommended all medical treatment be withheld. In our next report, we'll examine how those infants were selected for non-treatment, a process which considers not only the child's medical potential but also the parents' social and economic ability to care for a handicapped child.

Carlton Sherwood: I'm Carlton Sherwood, CNN, on special assignment.

PASSAGE OF THE ADA

Towards Independence: Powerful Words

Two papers with nearly identical titles, written more than 15 years apart in different parts of the world, fueled a new era in disability politics focused not only on changing social attitudes towards people with disabilities but also on creating new rights.

In 1969, Dr. Bengt Nirje, Director of what is now the Swedish National Association for Persons with Intellectual Disability, delivered a paper entitled “Towards Independence” at the 11th World Congress of the International Society for Rehabilitation of the Disabled in Dublin, Ireland. “Towards Independence” chronicled developments in the self-advocacy movement in Sweden and spurred worldwide new social policy based on the normalization principle and “dignity of risk.”

When Dr. Nirje translated the normalization principle into English and published the concept in the 1969 President’s Report, it had a tremendous impact on American professionals. Dr. Wolf Wolfensberger at Syracuse University introduced the practice of normalization to the United States in the 1970s. Dr. Nirje developed the normalization principle in the 1960s. The principle reflects the regular rhythm of the day and the regular routine of life. It’s useful with all age groups, and adaptable to social changes and individual development. It means that the choices, wishes, and desires of the individual are considered and respected. Dr. Nirje spoke about the principle itself and its application to all aspects of life.

In 1983, Dr. Wolfensberger created social role valorization (SRV), a later generation of normalization, which promoted the importance of socially valued roles for people with disabilities. Through SRV, Dr. Wolfensberger described the role perceptions of people with disabilities and how words and images used in describing people with disabilities resulted in the suppression of legal, civil and human rights.

A subsequent series of reports in the 1970s from the Center for Human Policy at Syracuse University advanced normalization and self-advocacy. In 1976, the Center published a report on the theory and practice of “handicapism,” calling it a concept similar to racism and sexism. The report described how “handicapism” promoted myth, prejudice, and stereotyping of people with disabilities.

In 1979, under the leadership of the late Burton Blatt, the Center released a follow-up to this report entitled “The Community Imperative: A refutation of all arguments in support of institutionalizing anybody because of a developmental disability.” The “Community Imperative” declared that all people have fundamental moral and constitutional rights, and that these rights must not be abrogated merely because a person has a disability.

In “Towards Independence,” the National Council on Disability (NCD) identified for the United States Congress the discrimination in public policy that was experienced by people with disabilities. Less than two years later, in January 1987, the Minnesota Governor’s Council on Developmental Disabilities published “A New Way Of Thinking,” a monograph that articulated a new way of thinking about public policy and people with disabilities: people living in real homes, learning in regular schools and working in real jobs. This “new way of thinking” encouraged exploring new service strategies.

But, as Madeleine Will summarized— herself a parent and at that time Assistant Secretary of the Office of Special Education and Rehabilitative Services — the new policies and services had not yet tipped the balance. In 1984, in words anticipating the Americans with Disabilities Act, she said, “Citizens with developmental disabilities want the same opportunities and ought to have the same opportunities as other members of the community — not because it is cost effective, even though it is, and not because it is prudent, even though it is. They should have the same opportunities because they deserve it.”

“A New Way of Thinking” sent the message that people with disabilities “have the right to live, to work and ... to know the dignity to which every human being is entitled.”

Transcript:

Amy Powell: The time has come when we can no longer tolerate the invisibility of the handicapped in America ... These people have the right to live, to work, and to the best of their ability, to know the dignity to which every human being is entitled. This is a message that must be stressed again and again as we seek to end the segregation and isolation of individuals with disabilities. By bringing them more fully into our lives and communities, where they can receive the love, the friendship, the respect, and the dignity that comes only with living in real homes, learning in regular schools, and working at real jobs

The words of Bengt Nirje and the NCD were a powerful influence on American public policy. Nirje’s “Towards Independence” in 1969 and the NCD’s “Toward Independence” in 1985 — fostered by years of work by disability activists, supporters, and concerned citizens referred to as “a hidden army for civil rights” by Joe Shapiro — led to the writing of the Americans with Disabilities Act in 1990.

Lowell P. Weicker, Jr., Original 'Father' of the Americans with Disabilities Act

Lowell P. Weicker, Jr., United States Senator from Connecticut from 1971 to 1989, was an advocate for people with disabilities and a legislator who often worked independently to further the advancement of public policy on behalf of people with disabilities. In the halls of Congress, he often acted and spoke not only as a U.S. Senator but also as a parent of a child with a disability. He is widely regarded as the original “father” of the Americans with Disabilities Act.

In 1981, Peg Dignoti organized a hearing at the Connecticut State Capitol for Senator Weicker. Leading experts such as Tom Bellamy, Karen Green McGowan, and Bob Carl testified about possibilities. The Senator and his staff led the investigation of state institutions across the country, an investigation that culminated in strengthening the protection and advocacy legislation. The hearings were covered in a 1981 story in the Connecticut Arc and in a 1985 article in the New York Times.

During his years in the Senate, Senator Weicker introduced and co-sponsored numerous pieces of legislation that laid the foundation for the Americans with Disabilities Act. In the 1980s, the Senator became particularly interested in the institutionalization of people with disabilities, as states shielded their state institutions from allegations of abuse.

Senator Weicker and John Doyle, the Senator’s Staff Director of the Senate Subcommittee on the Handicapped, reflected on these investigations in an interview segment with self-advocate, Thomas McCann, member of the Connecticut Council on Developmental Disabilities and host of the local cable television show “MARC Matters,” sponsored by the Manchester (Connecticut) Arc. In the interview Senator Weicker recalled, “... the advantage of having the hearing was this was broadcast all over the country. The average American really never knew what went on inside these institutions, and it was high time they learned.”

Transcript:

Senator Lowell Weicker: What you probably would guess they reported back. That the institutions were terrible and the treatment of people

was terrible. And again here the advantage of having the hearing was this was broadcast all over the country. The average American really never knew what went on inside these institutions, and it was high time they learned and that was the purpose of the hearing. To go ahead and demonstrate that far from any love or any care these people were just mistreated and horribly so. So that was the hearing and that's what came out of the hearing. I know John Doyle, well we've got to let this guy speak. He can speak.

John Doyle: All right, well, the hearings as Senator Weicker said, produced results that were just astounding. They were awful. The Senator called the ... to the carpet the man in the Justice Department who was supposed to be enforcing civil rights and point out to him how he wasn't doing it. The Senator called on the carpet the Secretary of the Department of Health and Human Services who was supposed to be enforcing the inspection of these facilities and wasn't doing it. And as a result there was a whole new order of inspections, of trained personnel in the district offices and a new law for the protection of the mentally ill people which the Senator sponsored to address the conditions in the institutions. Having said that, that was sort of like putting a Band-Aid on a tumor. It wasn't going to cure it. The only cure for those large institutions was what we've seen with Mansfield: the closing and that's what the Senator did when he became Governor. But in those days just to make it better there were several initiatives that the Senator proposed that became law and that were enforced.

John Doyle: All the institutions we looked at and we had one investigator, the Senator will remember, actually that worked undercover. He got a job in one of the institutions and he was there for four or five weeks. A man named Steve Snyder, an experienced investigator. And every ... We found instances of abuse and neglect at every institution that we visited across the country.

In April 1988, in the 100th Congress, Senator Weicker introduced S.2345, the Americans with Disabilities Act of 1988. United States Representative Anthony Coelho of California introduced H.R.4498, the House version of the Americans with Disabilities Act of 1988.

Senator Weicker, Representative Coelho, and several other Senators, Representatives, and advocates testified on discrimination based on disabilities during hearings on the Americans with Disabilities Act in September 1988.

Senator Weicker's S. 2345 had much stronger language and much broader civil rights policy than the act that was eventually passed into law. However, it was S. 2345 which would become the Americans with Disabilities Act. Senator Weicker

left the Senate before the Americans with Disabilities Act was signed.

Women Leaders of the ADA

Several influential men became regarded as the “grandfathers” or “fathers” of the Americans with Disabilities Act (ADA), but in the battle to obtain support for the ADA the term “General” is only applied to a single woman, Patrisha Wright. The women presented here represent only a few of the thousands of other women who served in various leadership capacities and were instrumental in securing the passage of the ADA. They can all be considered the “mothers” of the ADA.

Marca Bristo is a pioneer of Chicago’s disability rights movement and a former patient of the Rehabilitation Institute of Chicago. Bristo helped launch Access Living, one of the country’s first ten centers for independent living.

During the 1980s, as a member of the congressionally appointed United States Task Force on the Rights and Empowerment of Americans with Disabilities, and President of the National Council on Independent Living, she helped draft and win passage of the Americans with Disabilities Act.

Elizabeth M. Boggs, Ph. D., was a parent, nuclear physicist, President of The Arc US, and member of President John F. Kennedy’s President’s Panel on Mental Retardation. She was a nationally recognized leader in influencing the development of federal and state policy relating to best practice services and supports for persons with disabilities.

Dr. Boggs was also a founding member of The Arc US in 1950. Working with the International League of Societies for the Mentally Handicapped, she was a principal author of the United Nations Declaration of General and Special Rights of the Mentally Retarded. With Justin Dart, Elizabeth Boggs co-chaired the congressionally appointed Task Force on Rights and Empowerment of People with Disabilities, an important impetus to the passage of the Americans with Disabilities Act.

Lisa Carl was the Tacoma, Washington advocate whose eloquent testimony about being denied entry to her local movie theater impressed Congress and the President. Carl attended the signing ceremony where she met President Bush, who shook her hand and said, “Lisa now will always be admitted to her hometown

theater.”

Chai R. Feldblum served on Patrisha Wright’s team as a full time negotiator and advocate. While working from 1988 to 1991 as Legislative Counsel to the AIDS Project of the American Civil Liberties Union, Feldblum was the lead attorney on the team drafting the ADA. She served as chief legal counsel to the disability community during negotiations and passage of the ADA, and was equally instrumental in drafting and negotiating the ADA Amendments Act of 2008.

In 2010, President Barack Obama nominated Feldblum to serve as Commissioner of the U.S. Equal Employment Opportunity Commission.

Nancy Fulco, U.S. Chamber of Commerce attorney, supported the concept of the ADA, but was a constant public critic of provisions that the Chamber felt would be negative for business. Fulco said, “Small businesses simply do not have the money in the bank.” She also complained that the wording of the bill was “ ... so vague it would encourage an explosion of lawsuits.”¹ Her critique and subsequent dialogue with supporters of the ADA contributed to strengthening its language and the resolve to pass the ADA. On August 15, 1989 Fulco and Justin Dart appeared in a C-SPAN discussion, and responded to people who called in to the show.

Despite concerns, the U.S. Chamber worked with the President’s Committee on Employment of People with Disabilities to achieve harmonious implementation of the ADA.

Marilyn Golden, Senior Policy Analyst at the Disability Rights Education and Defense Fund (DREDF) was closely involved with the Americans with Disabilities Act throughout all stages of its proposal, passage, and implementation. Her involvement continues to this day.

A highly lauded ADA trainer, Golden has directed and led numerous in-depth programs on the ADA. She is the principal author of the DREDF publication, “The ADA, an Implementation Guide,” also known as the “Bluebook” and a core part of DREDF’s highly respected ADA curriculum.

Pursuant to DREDF’s position opposing the legalization of assisted suicide and euthanasia, Marilyn has become nationally prominent in that struggle. She has represented the disability community in many debates and dialogs on the subject, authored articles explaining the issue, and worked to defeat assisted suicide legislation.

Judith E. Heumann got her zest for battle from her mother. As a student at Long Island University, she organized students with disabilities to fight for ramped buildings. In 1970, at the age of 22, she started her own disability rights group,

1 Newsday, 9/9/89

Disabled In Action (DIA), and engaged in political protest.

Summoned by Ed Roberts in 1973 to work at the Center for Independent Living (CIL) in Berkeley, California, Heumann served as Deputy Director of the CIL from 1975 through 1982 and blended her east coast political activism with the independent living movement. Heumann, along with Roberts, would continue to rewrite the history of people with disabilities. Their defining moment was the introduction of regulations for the implementation of Section 504 of the Rehabilitation Act of 1973.

The late United States Senator Hubert H. Humphrey worked tirelessly to secure passage of legislation that included disability anti-discrimination rights. In 1971, two years before Section 504 was enacted, he attempted to push through such language as an amendment to the 1964 Civil Rights Act but was encouraged by his colleagues to include his additions in the draft Rehabilitation Act of 1972.

Opposed to provisions regarding independent living, President Nixon twice vetoed Section 504. While Humphrey's independent living language was removed, his anti-discrimination language — with wording copied straight out of the Civil Rights Act of 1964 ruling out discrimination in federal programs — remained and was added to the Rehabilitation Act of 1973. Section 504 was then thought to be no more than a legislative afterthought. However, Nixon signed it.

Roberts and Heumann recognized the significance of the 504 language, as did the Ford administration that stalled the issuance of final regulations. The Carter administration's reluctance to implement the regulations, despite a campaign promise to do so, prompted the "Sign 504" campaign and sit-ins by people with disabilities in Washington, DC and San Francisco. The San Francisco sit-in marked the political coming of age of the disability rights movement. Another civil rights movement was underway.

Roberts and Heumann are credited for organizing the San Francisco sit-in. Roberts, then California's Director of Rehabilitation, showed up several times and gave his official blessing to the sit-in. Heumann worked with demonstrators to get messages and information to those outside the building, and gave tearful testimony before a congressional hearing triggered by the sit-in.

On April 28, 1977, the Carter administration caved in to the protest and signed the regulations without changes. Heumann and Roberts recognized Section 504 of the Rehabilitation Act of 1973 as the first civil rights statute for persons with disabilities, paving the way for the 1990 Americans with Disabilities Act.

Jennifer Keelan became the central media image for the disability movement. Eight-year-old Keelan, struggling forward on her hands and knees up the steps to the Capitol, would be the one photographic image from the ADA fight to register

in the public memory.

Numerous observers questioned organizers' tactic of crawling up the Capitol steps and particularly the inclusion of an eight year old. As one of 60 people who participated in "the Capitol Crawl," Keelan was already experienced. She was first arrested at age seven with her mom, Cynthia, at a demonstration in Montreal.

Arlene B. Mayerson has been the Directing Attorney of DREDF since 1981 and played a pivotal role in the drafting of the ADA. In a largely behind-the-scenes capacity, she led a legal team that advised Congress, drafted the legislative language, prepared congressional testimony for others, testified before Congress herself, and prepared educational materials for the national disability community. She also filed comments on the ADA regulations for more than 500 disability rights organizations.

Her intellectual prowess, vision, and tenacity strengthened the law in untold ways and shaped the debate altogether in certain key areas. She is the author of a comprehensive three-volume treatise on the ADA, "Americans with Disabilities Act Annotated-Legislative History, Regulations & Commentary,"² which sets forth the legislative history and regulations for each provision of the ADA.

Sharon Mistler, Executive Director of the ENDependence Center of Northern Virginia, helped coordinate nationwide ADA advocacy efforts and was the chief organizer of the July 26, 1990 ADA signing ceremony picnic across the street from the White house. She was a central figure in the enactment of Section 504 of the Rehabilitation Act.

In the late 1980s and early '90s, she helped shape the ADA, educating Congress and the White House about the problems that people with disabilities were experiencing while also dealing with her own battle with cancer. Though she briefed presidents and members of Congress many times, she did not seek the limelight herself, and she never became a household name. Mistler died in 2004.

Sandra Swift Parrino was the Chairperson of the National Council on Disability from 1983, when the little known council first began to seriously consider a comprehensive civil rights bill, until after the ADA's passage in 1990, She's also the mother of two sons with disabilities.

Parrino and the NCD, working through Justin Dart and its staff director, Lex Frieden, began the process of drafting the next disability rights law. In a 1986 report, "Toward Independence," which Frieden and staff member Robert L. Burgdorff, Jr. helped to write, the NCD included a recommendation that "Congress should enact a comprehensive law requiring equal opportunity for people with disabilities."

2 Clark Boardman Callaghan, 1994

The NCD suggested, “Such a statute should be packaged as a single comprehensive bill, perhaps under such a title as ‘The Americans with Disabilities Act of 1986.’” The administration official that accepted the report was Vice President George H. W. Bush.

In the days when the administration had few influential proponents, Parrino provided tenacious leadership to create the ADA as a real civil rights law and for its introduction into Congress. In the iconic photo and video of President George H.W. Bush signing the Americans with Disabilities Act, Parrino is the only female and “mother of the ADA” sharing the podium with the “fathers of the ADA,” Evan Kemp and Justin Dart.

During the late 1980s, when Liz Savage was with the Epilepsy Foundation, she coordinated the Congressional lobbying campaign, building a coalition of over 75 national disability, civil rights, religious, and civic organizations, which led to enactment of the ADA. Savage was Patrisha Wright’s strong right hand woman.

Patrisha Wright was involved when the ADA was organized and was a key contributor to its passage. She was more than a “woman of the ADA.” Her leadership during the ADA’s passage eventually earned her the nickname, “The General.” She was one of a handful of leading strategizers based in Washington, DC and worked especially closely with Ralph Neas, Executive Director of the Leadership Conference on Civil Rights.

Wright and Neas collaborated with a number of other leaders who focused on different objectives for passing the ADA, including Washington lobbyists Liz Savage and Paul Marchand; grassroots organizers Justin Dart and Marilyn Golden; and attorneys Arlene Mayerson, Chai Feldblum, and Robert Burgdorf. Wright served as chief of the negotiating team representing Americans with disabilities throughout the ADA legislative process. Justin Dart called her “one of the great Congressional negotiators of American history.”

Wright made her first major inroads into the disability rights movement at the Section 504 sit-in in San Francisco in April 1977. Although she was there largely to serve as a personal assistant to Judy Heumann, Wright began to reveal and develop her negotiating skills in dealing with authorities. This experience led her to become more involved with overall advocacy efforts.

In the late 1970s, she joined the Disability Rights Education and Defense Fund, where she worked with Robert Funk, Mary Lou Breslin, and Arlene Mayerson to advocate for disability rights on a national level. Wright was so widely respected in Congress and the White House that her highly individual apparel and colorful vocabulary were safe from reproach. The ADA’s success was due in no small part to Wright’s strategic leadership.

Task Force on the Rights and Empowerment of Americans with Disabilities

When the original version of the Americans with Disabilities Act (ADA) was introduced on April 29, 1988, most Americans were not fully aware of the need for comprehensive civil rights for people with disabilities. To gather and present on the extent and nature of such discrimination, in May 1988 United States Congressman Major Owens of New York established a Task Force on the Rights and Empowerment of Americans with Disabilities.

Thirty-seven citizen volunteers with no public funding operated the Task Force. They were:

- Justin Dart, Jr.
- Elizabeth M. Boggs, Ph.D.
- Lex Frieden
- Don Galloway
- Dale Brown
- Philip B. Calkins, Ph.D.
- Susan Daniels, Ph.D.
- Gordon Mansfield
- Michael Winter
- Paul Marchand
- Ed Roberts
- Patrisha Wright

- Frank Bowe, Ph.D.
- Elmer Bartels
- Rev. Wade Blank
- David Bodenstein
- Marca Bristo
- David Capozzi
- Julie Clay, MPH
- James DeJong
- Eliot Dober
- Charles Estes
- Keith Gann
- James Havel
- I. King Jordan, Ph.D.
- Connie Martinez
- Celane McWhorter
- Oral Miller
- Gary Olsen
- Mary Jane Owen
- Joseph Rogers
- Liz Savage
- William A. Spencer, M.D.
- Marilyn Price Spivack
- Ann Vinup
- Sylvia Walker, Ed.D.

- Tony Young

Noted disabilities rights advocate Justin Dart, Jr. chaired the Task Force. Mr. Dart was a leader of the international Disability Rights Movement and a renowned human rights activist. Mr. Dart became widely recognized as the father of the Americans with Disabilities Act. Mr. Dart gave voice and recognition to the “tens of thousands of people who fought for the first civil rights law in the history of the world for people with disabilities.”

Co-Chair of the Task Force was Elizabeth M. Boggs, Ph.D. Dr. Boggs was a parent, nuclear physicist, chair of the then National Association for Retarded Children, and member of President John F. Kennedy’s President’s Panel on Mental Retardation. She was a pioneer of the American disability rights movement, with a demonstrated depth of knowledge and experience in the field of disabilities.

Stories of Discrimination

Storytellers, not just one or a few, but thousands of them from cities and towns across the nation paved the path to the Americans with Disabilities Act (ADA).

The following is an example — one of over 5,000 stories that were submitted by citizens and organizations across the country — demonstrating the range of discrimination issues faced by people with disabilities and the many barriers that limit their ability to actively participate in their communities.

On May 28, 1988, Lisa Carl, a young woman with cerebral palsy who uses a wheelchair, wanted to see a favorite film at an accessible theater in Tacoma, Washington. The theater manager refused to accept her \$1.00 admission and the theater owner, who was called by an advocate on Lisa's behalf, said, "I don't want her in here and I don't have to let her in."

Jonathan Gottschall, author of *The Storytelling Animal*, says science backs up the long-held belief that a story is the most powerful means of communicating a message. Peter Guber, author of *Tell To Win*, says that stories can also function as Trojan Horses. The story is actually just a delivery system for the teller's agenda, a trick for sneaking a message into the fortified citadel of the human mind.

Justin Dart, widely recognized as the "father of the Americans with Disabilities Act," was aware of the power of storytelling twenty-five years ago. He knew that people with disabilities and their families had powerful stories to tell — stories about discrimination, segregation and inequality — and that these stories could impact change.

Between 1988 and 1989, Justin Dart held 62 public forums in 50 states, Washington, D.C., and Guam to collect stories of discrimination. His intent was to create a network of national support for passage of the ADA. The forums, however, served as his Trojan Horse for sneaking the message of equal rights for people with disabilities into the minds of the American public. The forums provided an opportunity for people with disabilities and other advocates to publicly disclose and express their frustrations and outrage at discriminatory practices.

The 5,000 stories collected by Justin Dart were compiled into a “diary,” the Trojan Horse to end discrimination against people with disabilities.

The stories are from a vast spectrum of Americans with disabilities, some of whom became leading advocates on disability rights, including the story of United States Representative Tony Coelho from California. In addition to Lisa Carl, Justin Dart heard these stories of discrimination from ordinary American citizens:

- The Alabama man who is deaf and was denied a modeling job because of his disability.
- The Alaskan parent revolt, referred to as the “Diaper Rebellion,” in protest of the cessation of Medicaid coverage for diapers for families caring for children with severe and multiple disabilities in their homes.
- The Massachusetts woman who uses a wheelchair but could not join her neighbors at a preliminary hearing in their lawsuit seeking to prevent the construction of a 29 house subdivision because the second story courtroom was not accessible.
- The parents of children with Down Syndrome who were successful in getting a Vice President to apologize for describing critics of an arms control agreement with the Soviet Union as “members of the extra chromosome set.”
- The Missouri man who uses a wheelchair, jailed for 95 days because of speeding tickets, but whose wheelchair was taken away because it could not fit through the cell doorway.
- The Mississippi state employee on a business trip who was charged an extra \$10 for requesting an accessible room.
- The Nebraska University associate professor of communications who was denied a place on a speakers’ bureau because he stutters.
- The Illinois school system that disciplined students with developmental disabilities or mental health issues by locking them inside wooden boxes for up to 30 minutes.

It is fitting and easy enough to celebrate the witness of leading disability advocates and their influence on what became the ADA, but it was the thousands of ordinary Americans with disabilities and their families who were prophets of the ADA. Justin Dart’s collection of stories and remind us that the prophets we most need to remember are hidden in plain sight among us.

Justin’s “diary” has become part of It’s Our Story, a mixed-media digital history archive that houses the most comprehensive collection of videos, photos and doc-

uments regarding life with disability in America. From 2005 to 2013, Scott Cooper drove over 160,000 miles, and interviewed and collected the personal testimonies of more than 1,300 people from over 250 locations for the It's Our Story archive.

Ed Roberts Day: Built Upon Alliances

The Americans with Disabilities Act (ADA) was built upon alliances. The ADA was an outcome of the self-advocacy and the independent living movements, but the ADA would not have passed in Congress without alliances.

Ed Roberts knew that. A pioneering leader of the disability rights movement, and widely acknowledged as the father of the independent living movement, Ed built alliances with civil rights and women's rights advocates, unions, politicians, and youth to bring the goals of people with disabilities into national politics.

His activism was the model used by advocates nationally to build the independent living movement into a political process linked to the wider American experience resulting in the passage of the ADA.

Transcript:

Ed Roberts: When we recognize that we're all different. And the difference is enriching. That our differences are what are attractive and what we learn from each other. And that difference itself is something that we can use to ... to get to know each other and to help us chart the future. And that's a future where anyone that wants to and anyone that needs a little help can live in the community. It's an integrated future. When we talk about integration, it's not just for people who are black or Asian; it's for all of us. It's for all of us to be a part of each other.

Voice over: Ed Roberts was the Director of the State Department of Rehabilitation for eight years. Because of polio as a teenager, he uses a wheelchair and needs a respirator to breathe. But nothing confines his beauty of spirit and commitment, a commitment to share his special insights and experiences, a commitment to help young people work past their remarkable disabilities, their doubts, fears.

Ed Roberts: There are two things that I want to let you know: One, that you can do it together, no question about it. The second thing is that you personally have to believe in yourself to make it happen. And that

takes a lot if you're disabled or not. To really love yourself and to really believe in yourself and to believe that you can do something for yourself and for others. And at the end of this week you will, you'll believe it. If we can change some attitudes and we have high expectation and we believe in all of us, if we support each other, people are going to achieve things that we never thought possible.

Read Dr. William Bronston's take on how Ed built alliances.

Transcript:

Dr. William Bronston: The key to all that was that anything, anything that's needed for a person with severe disabilities is needed by all of us. He was real clear about that because he made fundamental alliances with the elder community, because he understood that as we get older, we're going to have major disabilities and wind up in institutions, and that was absolutely unacceptable to him. He made alliances with the civil rights community, because he saw that the issues that faced African American and Latino community people around the discrimination and around impoverishment and lower incomes and lower expectations they were part of the social system absolutely had to be swept away. So that his work in building individualization with people with special needs was really the harbinger of building individualization for all of us. He made alliances with the trade union movement, with the civil rights community, with the women's rights community. And it just became part of we're Americans. We're Americans and we deserve and have to have a great society. This society was unprepared for the demands that he made on enfranchisement and democratic participation and quality of life and learning and meaningfulness and respect. There was nobody like him up to that point. There has been nobody like him since then, unfortunately. He lived an openness to people, a sense of friendship and love and community and confidence and joy and humor that absolutely transformed everything and everybody around him. It was astounding. And thank God he was political. He understood this had to be institutionalized in the society and built relationships with the most remarkable policy leaders. Jerry Brown was just one of them. George Miller, you know, who was on his board, the Congressman from the East Bay. Tom Bates, who was the head of the Social Services and Human Services Committee here in the Legislature as an Assemblyman, who essentially partnered with him in building the In-Home Support Services legislation, the Independent Living Support legislation. And then the work that Ed and I did was impacting kids. We were interested in organizing children, because that's where the future was. They did not have embedded prejudices until they were taught that people with disabilities, you know, were less.

H.R. 2273 — The ADA in the House of Representatives

On Tuesday, November 14, 1989, the Education and Labor Committee of the House of Representatives voted 35-0 in favor of a modified substitute Americans with Disabilities Act (ADA) — H.R. 2273. The modifications were negotiated by Congressman Steny Hoyer, who was overseeing the ADA in the House, and Steve Bartlett (TX), the ranking minority member of the Select Education Subcommittee.

The modifications were aimed primarily at clarifying parts of the Senate-passed bill (S. 933). The disability community agreed to the modifications. None of the modifications weakened the bill as passed by the Senate; however, the Committee defeated eight amendments aimed at weakening the coverage of the ADA. Most of these amendments were prepared in response to concerns raised by businesses and public transit operators about compliance costs.

The process was not yet over for passage of H.R. 2273. Three other House committees had jurisdiction over the bill: Judiciary; Energy and Commerce; and Public Works and Transportation.

Congressman Jim Chapman introduced one controversial amendment approved by the House at the request of the National Restaurant Association to give restaurant owners the statutory authority to shift persons with AIDS or HIV infections out of food handling positions.

Representative Tony Coelho of California had been the ADA's original House sponsor. While building support for the bill, Coelho testified about his epilepsy in a Joint House Senate Hearing. Today, he continues his advocacy work with the Epilepsy Foundation, carrying a message that emphasizes the importance of educating people about what individuals with disabilities, including individuals with epilepsy, can do in order to change the still prevalent thinking about what they can't do.

After leaving Congress, Coelho asked his closest friend, Maryland Representative Steny Hoyer, to take over. What most people did not know was that, like Coelho,

Representative Hoyer's wife had epilepsy.

Transcript:

Voiceover: For years, as a Congressman, Tony worked on a bill that would give disabled people some rights protection. It was controversial because it required extra effort on the part of businesses and cost money. Piece by piece, Tony gathered bi-partisan support for the bill. At one point, he testified in a Joint House Senate hearing about his epilepsy. It was rare at that time to have a politician be so forthcoming about a disability.

Tony Coelho: Thirty-six million Americans, deciding it's time for us to stand up for ourselves to make a difference. To say that we want our basic civil rights also. We deserve it. And give us an opportunity to do what we can do. Don't keep telling us what we can't do. I thank my colleagues.

Voiceover: From outside the House, Tony continued to fight for the bill. When it looked to be getting the runaround by Republicans in the House, he pushed every button he could reach.

Frank Luntz: There's only one time he ever called me for legislation, and he called me because he said, "Tom DeLay is thinking about undermining the ADA Act, the Disabilities Act. I want to work with Tom on it. I want to explain to him why it matters so much. Tom and I may disagree on everything. We should be allies on this. Please talk to him. I don't want to go to war. This is the only thing I'll go to war on." Because he believes it so deeply.

Voiceover: President Bush's Chief of Staff, John Sununu, was also against the bill.

Tony Coelho: They wanted it to die. And so I called him and I said, "This is going on," and I said, "Look it," and I gave him the reasons why it should move forward. And he said, "Look it, I'm opposed." And I said, "Look it, I'm going to call the President because he gave me a commitment." He said, "I know you will, and he'll tell me I have to move it, and I will move it, but you're going to have to make the call." So I said, "Okay, I will." So I called the President and I said, "You know, it's bogged down." And he said, "No problem. I'll get it done." Done.

Voiceover: It was an historic moment when President George H. Bush signed the bill into law on July 26, 1990.

President George H. Bush: And remember, this is a tremendous pool of

people who will bring the jobs diversity, loyalty, proven low turnover rate, and only one request — the chance to prove themselves.

Tony Coelho: Before 1990, people could discriminate against me openly, legally. Now they can't. But I think the ADA is about becoming an American. We're part of the dream. It's unlimited the possibilities. It's only based on what we are willing to do.

In 2007, the Epilepsy Foundation produced a tribute to Tony Coelho and his work in Congress.

Transcript:

Tony Coelho: When I came to Washington, I decided that the one thing that I wanted to do is to do something on disabilities because of what I'd experienced and what I had gone through. And I remember contacting the Epilepsy Foundation, and I worked then very closely with the Epilepsy Foundation, and was very involved with the different activities of the Foundation. And I've loved being involved with the Foundation ever since then. And there's a lot that can be done that way.

Clip of Tony Coelho speaking in Congress: Thirty-six million Americans, deciding it's time for us to stand up for ourselves to make a difference, and say that we want our basic civil rights also. We deserve it. And give us an opportunity to do what we can do. Don't keep telling us what we can't do.

Voice over: On July 26, 1990, Tony's work as the author of the Americans with Disabilities Act was fulfilled as the law was signed by President Bush.

President George H. Bush: And remember, this is a tremendous pool of people who will bring to jobs diversity, loyalty, proven low turnover rate, and only one request — the chance to prove themselves.

Tony Coelho: I think it's important that we advocate, we educate, we get out and change people's opinion about epilepsy. That those of us that are successful even though we have epilepsy need to get out there and say we can do X, Y, and Z. There are things I cannot do because of my epilepsy. That's fine. But you know what? There are a lot of things I can do. But you have to be willing to be an advocate and to speak up and to talk about the impact these things have on you. And we have to be willing to show the pain. You know, it's not easy for me to talk about some of the things that I've gone through.

Voice over: Today, Tony continues his passionate fight for enhancing

the full purpose of the Americans with Disabilities Act, as he encourages those with epilepsy to end the stigma by standing up and speaking out.

Tony Coelho: The stigma that exists today on epilepsy can be changed in our lifetime, if we're willing to advocate, if we're willing to speak up. But it's not going to if we want to sit in the closet and pretend somebody else is going to do it for us. It's not going to happen.

S.933 — Americans with Disabilities Act: 101st Congress

Late into the night on September 7, 1989, the United States Senate voted overwhelmingly (76-8) in favor of the Americans with Disabilities Act (ADA).¹ The vote took place after a lengthy Senate floor debate and after fending off many amendments that would have severely limited the scope of its coverage. The words of those who spoke in favor of S.933 are recounted below.

United States Senator Tom Harkin: “So, Mr. President, on behalf of my brother who is deaf, my nephew who is quadriplegic, and the 43 million Americans with disabilities, today we introduce this historic legislation — the Americans With Disabilities Act. Let’s celebrate the 25th anniversary of the enactment of the Civil Rights Act of 1964 by passing the ADA this year and finally recognize the civil rights of Americans with disabilities.”

United States Senator Ted Kennedy: “This really is the Emancipation Proclamation for the disabled in the country ... a proud day in the history of Civil Rights.”

United States Senator Al D’Amato: “Few are able to truly understand the struggle faced daily by millions of Americans with disabilities. The barriers the disabled must overcome in order to meet basic needs are many. Activities accomplished with ease by most — communicating, commuting, or entering the workplace—are often significant hurdles for those with disabilities. This legislation, Mr. President, will break down these barriers once and for all.”

Some of the amendments that did not pass included those regarding:

- Individuals with specific disorders such as compulsive gambling, kleptomania and pyromania;
- Coverage of the legislative branch of the United States government;
- A one year extension for compliance by private bus companies;

¹ S.933, Senate Report 101-116

- A study of wilderness accessibility issues;
- Protection of people with sexual behavior disorders, users of drugs or alcohol, and people with organic brain disorders due to drug abuse.
- A particularly vigorous exchange took place on September 7 between Senators Harkin and Helms on whether or not S.933 included or excluded “pedophiles,” “schizophrenics,” “kleptomania,” “manic depressives,” “psychotic disorders,” “homosexuals,” “transvestites,” and HIV and AIDS.

Behind the Scenes in the Reagan and Bush Administrations: Stories from No Pity

In his award-winning book on the disability rights movement, “No Pity,” Joseph Shapiro tells many background stories about overlapping events and processes through which the Americans with Disabilities Act (ADA) became law.

At the time, Shapiro was a social policies writer for “U.S. News & World Report” and received an Alicia Patterson Foundation Fellowship to study the disability rights movement. Today, he is an Investigations Correspondent for National Public Radio (NPR) News.

In “No Pity,” Shapiro documents the progress of the political awakening of people with disabilities that culminated in the enactment of the ADA. His five years of in-depth reporting uncovered many personal stories that had a direct bearing on the disability rights movement and the ADA. The following are just a few of those stories about people in the Reagan and Bush administrations.

Lowell P. Weicker, Jr., United States Senator from Connecticut from 1971 to 1989, was an advocate for people with disabilities and legislator who often worked independently to further the advancement of public policy on behalf of people with disabilities. In the halls of Congress, he often acted and spoke not only as a U.S. Senator but also as a parent of a child with a disability. He is widely regarded as the “father” of the ADA. Senator Weicker, Representative Tony Coelho, and several other Senators, Representatives, and advocates testified about disability-based discrimination during hearings on the ADA in September 1988.

Transcript:

Sen. Lowell Weicker: This is a ... I’ll correct my English. An historic occasion. The time has come to end all discrimination in whatever form.

Rep. Major Owens: For some of us, the Americans with Disabilities Act of 1988 represents the next step in the American civil right movement. This legislation grants full rights to Americans with disabilities. And moves our great nation from a respectable position of official compas-

sion for those with impairments to a more laudable position of empowering disabled Americans.

Sen. Tom Harkin: People with disabilities like racial and ethnic minorities, women are entitled to obtain a job in a restaurant or hotel, ride a bus, listen to and watch the TV, use the telephone, and use public services free from invidious discrimination. And free from policies that exclude them solely on the basis of their disability. Every American must be guaranteed genuine opportunities to live their lives to the maximum of their potential. The Americans with Disabilities Act prohibits discrimination against persons with disabilities in areas of employment, public accommodations, transportation, communications, and public services. It's my expectation that this legislation will become the law of the land during the 101st congress. However, the road to enactment will be filled with potholes and roadblocks. But if we stick together as a community and we work with groups representing employers in the hotel, restaurant, communications, and transportation industries, I believe we can succeed.

Sen. Ted Kennedy: I think as you listen to those who have spoken today, you realize there probably hasn't been a family in the country that hasn't been touched by some form of physical or mental challenge. You've heard some statements today, very moving statement of members of the family. That's been true in the Kennedy family as well. A sister who is retarded, a son, my own son, who's lost a limb to cancer. And I bet if you go across this country, there really isn't a member of a family or an extended family that hasn't been touched.

Rep. Tony Coelho: And so it is time that our government, recognize our abilities and give us the dignity to do what we can do. As a young man, I developed seizures, later diagnosed as epilepsy. For many years, for five years, as I had my seizures on a regular basis, I did not know what they were. I went to every doctor that you could think of. I also went to three witch doctors. Because I was supposedly possessed by the devil. My Republican colleagues think I am, but others believed I was. As I went to college, I was an achiever. I got outstanding grades in high school, and outstanding grades in college. Student body president in high school. Student body president in college. I was an outstanding senior in college. I was sought after by different businesses and groups to be involved with their activities and be employed by them. I had decided that I wanted to be an attorney. In my senior year, I changed my mind. I decided I wanted to become a catholic priest, and as I graduated with honors. I then had a physical exam in order to enter the seminary. The physical exam pointed out that these seizures that I'd been having for five years meant that I had epilepsy. I always remember very

well what happened, and that I walked to the doctor's office from my car, sat in the doctor's office, was told about my epilepsy, walked back to my car, got back in my car, and drove back to my fraternity house, and I was the same exact person but only in my own mind. Because the world around me changed. My doctor had to notify the legal authorities of my epilepsy. My church was notified and immediately I was not able to become a catholic priest. Because my church did not, at the time, permit epileptics to be priests. My driver's license was taken away. My insurance was taken away. Every job application has the word epilepsy on it and I marked it, because I was not going to lie. And I couldn't get a job. My parent refused to accept my epilepsy. I became suicidal and drunk by noon. And the only reason is... because I hadn't changed as a person... only reason is, is that the world around me had changed, and the light had been turned off, the light of opportunity, the light of hope. And not until a priest friend of mine turned me over to a man of hope by the name of Bob Hope did the light get lit again. And I'm here today serving in the capacity that I serve because some people believed. Not because my government protected me, not because my government protected my basic civil rights. So I'm a major advocate of this bill. Because I want to make sure that other young people, as they're looking for hope, as they believe that the system should work for them, have that hope, have that opportunity. What happened at Gallaudet University was not only an inspiration; I'm sure to the hearing-impaired. What happened at Gallaudet University was an inspiration to all of us with disabilities. In that if we ourselves believe in ourselves, and are willing to stand up, we can make a difference. That's what this bill is all about. Thirty six million Americans decided it's time for us to stand up for ourselves to make a difference, to say that we want our basic civil rights also. We deserve it. Give us an opportunity to do what we can do. Don't keep telling us what we can't do. I thank my colleagues.

After leaving Congress, Representative Coelho asked his closest friend, Maryland Representative Steny Hoyer, another member of the "hidden army," to take over. What most people did not know was that Representative Hoyer's wife also had epilepsy. Congressman Hoyer made remarks on the 20th Anniversary of the ADA.

Other notable "hidden army" politicians included Senator Edward Kennedy, whose son, Teddy, Jr., lost a leg to cancer, and the Senator's sister, Rosemary, who had a developmental disability; Senator Robert Dole, who had a paralyzed right arm as the result of a World War II injury; and Senator Orrin Hatch of Utah, whose brother-in-law had polio and slept in an iron lung.¹

Equally important as Representative Coelho's "hidden army" were the people Rud Turnbull called the "passionate insiders." Rud Turnbull, Distinguished Profes-

1 Shapiro, pg. 118

sor in Special Education and Courtesy Professor of Law at the University of Kansas, is the Co-founder and Co-director of the Beach Center on Disability. He considered himself an “accidental advocate,” triggered by the birth of his son, experience with aversive therapy, and service as an officer of a local parent’s association. As a parent advocate, Turnbull’s career included research in the late 1980s as a Kennedy Foundation Public Policy Fellow, the results of which became incorporated in the ADA. In a series of interviews, Turnbull described his influence and the influence of other “passionate insiders” on the ADA. In another interview, he spoke about “The Convergence of Disability Law and Policy: Core Concepts, Ethical Communities, and the Notion of Dignity.” Transcripts of these conversations have been included in this book.

Combined transcripts:

Rud Turnbull: Hello. My name is Rud Turnbull. I’m a Distinguished Professor at the University of Kansas and the co-founder and co-director of the Beach Center on Disabilities. The co means, of course, that I did it with my wife Ann. Let me talk a little bit about the three parts of what I’ve been doing since I really became involved, as an advocate on the field of developmental disabilities. I should say at the beginning that my son, Jay Turnbull, who died in 2009, had a developmental disability. It was an intellectual disability. He also had some autism and he had rapid cycling bipolar condition. And he was the cause of my being involved in this field. I was an accidental advocate. I didn’t really become intentionally involved with this until I had Jay and until I had an experience at the Western Carolina Center in North Carolina involving aversive therapy. I was also an officer of the Orange County North Carolina Association for Retarded Children, as it was known at that time.

So let me talk with you a little bit about the work that I have done. I’ll start first with the Americans with Disabilities Act. I was working as a Kennedy Foundation Public Policy Fellow in 1987, 1988 in Washington, D.C. My assignment was to work with the Select Subcommittee on Disability. It was the known then as the Subcommittee on the Handicapped. The chairperson was Senator Tom Harkin, a Democrat from Iowa. He had picked up an initiative started several years before ‘87 by Senator Lowell Weicker, a Republican from Connecticut, and the effort was to create a civil rights act for persons with disabilities. A comprehensive civil rights act such as protecting African American and other minority citizens and another one protecting women. It’s interesting that both Weicker and Harkin were people I called passionate insiders. Senator Weicker had a son with a disability. Senator Harkin had a brother who had a disability. So here were these two passionate insiders with a great deal of influence asking Bobby Silverstein, the chairperson of that committee, and then asking me to do some work. And the work I did was essentially around research on employment discrimination. I

can't say that it was as thorough as I wanted it to be, but it laid out the issues about pre-employment inquiries, post-employment reasonable accommodations, protection in the job, movement forward in the job, protection from discrimination in being released from a job. Those were the general areas. That was in 1987 and 1988. The President, George Herbert Walker Bush, signed ADA in 1990. It was an interesting story there. Why did he favor the bill so much? It was that he had an uncle who himself had a disability, and young George Herbert Walker Bush used to carry his uncle, George Herbert Walker, over the threshold of their home in Greenwich, Connecticut. So here you have then three. This was a lesson that I learned, a lesson I want to leave with you, three passionate insiders, Senator Weicker, Senator Harkin, and President Bush. The president signed the bill in 1990. Five years later, in 1995, I was on vacation in Mexico and I had a message at my hotel. Telephone a Casa de Blanca, Washington D.C. area code 202, whatever. I didn't know what Casa de Blanca meant. I kind of stopped and thought for a second and said, "Good Lord, it means White House!" Well, what had happened is that President Clinton decided to have a fifth anniversary celebration of the signing of ADA, and he invited my wife Ann and me to participate on a panel of about 10 representatives of the developmental disabilities and other communities. It was interesting. When I had a chance to speak with the President, with Attorney General Janet Reno, and with Treasury Secretary [Robert] Rubin, this is what I said. And this is really what motivated a lot of my work, not just around ADA but everything. I said this: "When my son Jay Turnbull was born at Johns Hopkins Hospital, he obviously had a disability — megacephaly. The doctor said institutionalize him. I did for a while, and we brought Jay back home. He was discriminated in school. He was discriminated in work. And finally we found a way to get him through school and to get him to work. Now Mr. President, Attorney General Reno, and Secretary Rubin, Jay Turnbull is paying your salary because he is working full time as a clerical aide at the University of Kansas," whereupon Bill Clinton, always one for something explosive, says, "Yes!" And it was kind of interesting why in the world would I have been involved in an ADA celebration representing the community of persons with intellectual disabilities.

It is because ADA set a framework within which I could effectively study on a broad basis what I am going to call the human condition in a policy context. And that kind of studying about the human condition, namely, disability, in the policy context is, I think, one of the reasons that ADA is so important. Yes, it's a civil rights bill. But, yes, it does more than that. It opens up for scholarship and for advocacy, opportunities to engage with difference. It opens up opportunities for people generally to engage with difference when they had not engaged with difference in the

past. The difference being, of course, developmental disability or any other kind of a disability. More than that, and this is where I've had a little bit of a theme, it creates the opportunity for what Ann Turnbull and I call the "enviable life." We've used that phrase many times in our teaching and in our writing. How do you create the "enviable life" for a person with a disability? And some people will quarrel with the idea of an enviable life. I think it's a tight way of saying quality of life. It's the kind of a life that a person without a disability would want to have for herself or himself, and if that's good enough for a person without a disability, why should it not be also the life that a person with a disability should be able to have with support? So, for me, ADA then opened up this whole issue of enviable life, quality of life, and how do we go about creating it through public policy and through informal support systems? And, finally, I look at ADA not just as a civil rights law but as a law that challenges us culturally, ethically, and technologically to respond to difference. Culturally, it's about our social norms. Ethically, it's about what's the right to do. And technologically, it is how do we go about doing what is right in order to change society and use the law for those purposes. I've had some little bit to do with ADA and more to do, however, with education.

My first work in the field of special education was to write a model statute, state statute, with colleagues at the Council for Exceptional Children. That model statute then became the basis on which I began to write the North Carolina Special Education law. I was working at a branch of the University of North Carolina at Chapel Hill, working for a Senator, Bill Creech, a graduate of Georgetown Law School and University of North Carolina. And Bill Creech came into my office one day and said, "The people at CEC say you can write a statute. Why don't you write a law for the State of North Carolina?" So I did. So here we begin with a model statute, then it becomes a state law, and then Congress begins to take the issue of education in its hands, and it passes Public Law 94-142. Now the question is, once you pass the law, how do you implement it? And this was the responsibility of what was then the Department of Health, Education and Welfare. The Department convened a group of people to advise them on the regulations to implement this statute, and my friends at the CEC, Fred Weintraub and Al Abeson, called me up and said, "We want you to serve on this regulation input team," and I said, "Well, I will, but only if you are going to be there." And they said, "Well, the three of us will be the Three Musketeers and we'll see what we can do to write some decent regulations." The regulation input team consisted maybe of 50 or so people. Abeson, Weintraub, and I were assigned to the procedural safeguard section and due process. We weren't getting very far with some of our colleagues. One night after meeting all day, though, we adjourned to, I think it was Abe-

son's home or it could have been Weintraub's home, in Reston, Virginia. And these guys, it's the middle of summer, take off their shirts, get down to their T-shirts, offer a beer. We started to have a beer. And they said all right, let's write the procedural due process regulations. And between about 10 o'clock at night and 3 or 4 o'clock in the morning, we wrote the regulations for the procedural due process provisions of Public Law 94-142. Those regulations have not been changed since we wrote them in 1976 with one exception, and that is that every time Congress changes the protections for students in discipline, we have had to rewrite those regulations. I say we, the field has had to rewrite those regulations. So, a model statute, a state law, the regulations for IDEA.

Then I wrote a book, and it was first book ever written about Public Law 94-142. It's got a very simple name, Free Appropriate Public Education, which is the theme of the statute. It was a book explaining the law. But it didn't explain just the law, it identified the six major principles of that statute, and those six principles have held true ever since 1977 or '76 when I wrote that book until today 2014. They are a conceptual framework that makes it easy to understand the law. There have been other books since then, but mine is the oldest in the marketplace. Now, at the point when President Reagan was elected to be President in his first term of office, he had campaigned on a theory of getting government, big government off people's back. And one of his primary ways of de-federalizing education, of de-federalizing human services generally, was to attack the regulations under Public Law 94-142. The theory was that if we could persuade the Department of Education Health, Education and Welfare, and Congress to loosen up some of the regulations, indeed to deregulate, then we could attack the statute itself and repeal the statute. That would clearly get the federal government out of the business of education and it would be the first step to getting the federal government out of the many other social service and human services. Well, you can imagine that strategy was provocative to say the least. Senator Weicker, again, a Republican of Connecticut, convened a hearing in Washington on deregulation. There were three panels of witnesses, and I was one of the witnesses on the second panel. The first panel consisted of one person who was the Secretary of Education, Terrel Bell. He began his testimony and Senator Weicker reached into his pocket, pulled out a document and said, "Mr. Secretary, let me interrupt you for a second. I want to read to you a letter that your deputy sent to within the Department as a statement of the Department's position. And it says, among other things, that we have to be very clever about what we're doing in deregulating because the parents are our enemies. The parents of children with disabilities are our enemies." "Mr. Secretary," said Senator Weicker, "Does that represent the posi-

tion of the Department of Education?” Well, the hearing was over, as far as I was concerned. Weicker had Terrel Bell right where he wanted him. But I talked at that hearing, as I have done at other Congressional testimony, about IDEA, about the effect, the intended effect, and the actual effect of that statute, and I could tell then the story about how the school bus came past our house on the first day of school and did not pick up Jay Turnbull to take him to school and it didn’t pick him up because he wasn’t on the school rolls. He went on the ancillary roll as a person with a disability. Now that started another issue down in North Carolina when we finally got Jay educated. But the notion of de-federalizing education became a concern of mine, namely, how do we keep the federal government properly involved in an issue — education — that traditionally has been a matter of federal excuse me, of state and local concern, particularly, local concern.

Ralph Neas, Leadership Conference on Civil Rights, developed Guillain-Barré Syndrome that left him close to death and unable to breathe without a respirator. Neas convinced reluctant civil rights leaders to put disability rights at the top of their agenda.² One of the central, most influential and pivotal members of Representative Coelho’s “hidden army” and Turnbull’s “passionate insiders” was the late disability rights activist, Evan Kemp, Jr.³ Kemp died in 1997. In 1947, at the age of 12, Kemp came down with an illness that took 16 years to properly diagnose as Kugelberg-Welander syndrome, a rare muscle weakening disease related to polio. Kemp’s parents, along with parents of children with muscular dystrophy and related conditions, founded the Muscular Dystrophy Association (MDA) and put together the first MDA telethon in 1959. In 1966, Jerry Lewis took over the national MDA telethon and, by 1981, Kemp became an opponent of the telethon. In a September 9, 1981 article on the opinion page of The New York Times, he complained that the telethon’s “pity approach” encouraged a prejudice about people with disabilities that he often experienced.

By 1964, Kemp made it through Washington & Lee University and graduated in the top 10 percent of his class at the University of Virginia Law School. He applied to work at 39 different law firms, all of whom turned him down because of his disability. Luckily, Kemp had a well-connected uncle, powerful Washington political columnist Drew Pearson, who helped him get hired at the Internal Revenue Service. Later, Kemp would move on to the Securities and Exchange Commission (SEC) where he had a successful seven-year career until a garage door accident required him to use a wheelchair. As a result, SEC removed Kemp from the management track.

In 1971, Kemp sued the SEC for discrimination and won. Incensed at the way people with disabilities were treated, he left government in 1980 to become di-

2 Shapiro, pg. 119

3 Shapiro, pgs. 12-124

rector of Ralph Nader's Disability Rights Center. It was here, as a disability rights activist, that Kemp would begin his influence on the Reagan and Bush Administrations. Kemp died in 1997.

Of all of the members of the "hidden army," the most important turned out to be President George H. W. Bush. In 1953, the Bush's three-year-old daughter, Robin, was diagnosed with leukemia and died. In addition, Bush's son, Neil, has a severe learning disability. The youngest Bush son, Marvin, had a section of his colon removed in 1985 and wears an ostomy bag. Lastly, Bush talked of the "courage" of his favorite uncle, surgeon John Walker, who was struck by polio at the height of his career.

When the Reagan-Bush administration was sworn into office in 1981, Bush was chosen to lead Reagan's Task Force for Regulatory Relief. Among the first regulations under attack were Section 504 of the Rehabilitation Act and the Education of All Handicapped Children Act. When people with disabilities and parents responded quickly and in number, Bush understood he was dealing with a hidden grassroots constituency. Bush's legal counsel, C. Boyden Gray, said the response "demonstrated to me and to [Bush] that this movement had enormous impact." Bush agreed to meet with disability groups to negotiate the administration's plan. So it was that then Vice President George H. W. Bush found himself face-to-face with Evan Kemp, Jr.

Kemp told Bush that people with disabilities wanted independence, out of the welfare system, and jobs. Gray said the "eye opener" was when Kemp said that people with disabilities were looking for self-empowerment and not "some captured bureaucracy in Washington, DC." When the administration held regulatory relief hearings on Section 504 and the Education of All Handicapped Children Act around the country, individuals with disabilities and parents were protesting and visible everywhere. By March of 1983, Bush announced that the administration had dropped its objections to Section 504 and rules related to the Education of All Handicapped Children Act.

In 1983, Wade Blank founded ADAPT (Americans Disabled for Public Transit — now known only as ADAPT) to empower people with disabilities to engage in direct action protest. At the time, the group's priority was getting all city buses equipped with lifts, and offering themselves up to mass arrest was a tactic. By 1990, Blank made ADAPT a player behind the scenes. The key link was Evan Kemp. The radical and the Republican were die-hard fans of the Cleveland Browns. They also had a common devotion to disability rights and spoke often on the telephone of their latest strategies.

The timing of ADAPT's "Wheels of Justice March" in March 1990 had been set based on Kemp's judgment of the best time to pressure Congress and send a message to the White House. Several months before, when ADAPT took over the fed-

eral building to demand that the Department of Transportation not agree to fund any purchases of city buses unless they had lifts, a call came from the White House on behalf of the President. Transportation officials were flown to Atlanta to negotiate the temporary ban on inaccessible buses.

ADAPT members returned the favor in Washington by refusing to chain themselves to the White House gate, as urged by Patrisha Wright, who argued that Bush could do more to pressure House Republicans to support the ADA. Some 475 people with disabilities, many in wheelchairs, spread across the sidewalk in front of the White House for the start of the protest. Another 250 people joined them at the Capitol. Boyden Gray appeared at the White House gate to make a brief address, assuring the crowd that President Bush was committed to signing civil rights legislation for people with disabilities.⁴

4 Shapiro, pg. 131

A Magna Carta and the Ides of March to the ADA

Protests and a Magna Carta marked the beginning and the end of the two-year run-up to the passage of the Americans with Disabilities Act (ADA). Two history-making protests, the Ides of March to the ADA, occurred in the month of March — the Gallaudet student protest in March 1988 and the “Crawl Up” the Capitol steps in March 1990.

The Gallaudet protest marked the end of the public perception of people with disabilities as objects of pity and the beginning of a new public consciousness regarding people with disabilities. The “Capitol Crawl” marked the transition from a system of paternalistic care by well-meaning but insensitive people to viewing disability as a civil rights issue.

The Gallaudet Student Protest of 1988 was a weeklong protest by deaf students at Gallaudet University, calling for the appointment of a deaf university President. It was a defining moment for the disability rights movement. This demonstration gave Americans a new rights consciousness about disability that grew out of a growing sense of oppression, gave voice to anger bottled up over years of individuals being seen as pitiful and sick, and was reflected in journalism of the time.

According to a study by Beth Haller of Temple University, post-Gallaudet journalism focused less on “supercrises” and sad cases and shifted attention to stories using the words “disability” and “rights” in the same paragraph. Lawmakers quickly made the connection. The ADA was introduced two months after the Gallaudet protest. Lex Frieden, then of the NCD said, “It would not have happened without Gallaudet raising people’s consciousness.”

It was a historical irony that deaf students, in equating disability with civil rights, gave such a boost to the ADA movement, when so many people who are deaf regard deafness as a culture, but not as a disability.

By March 1990, the ADA had already passed the Senate and had bipartisan Congressional support. More than 8,500 citizens with disabilities, their advocates and organizations, signed a petition urging prompt approval by the House of Repre-

sentatives and contributed funds for the publication of the petition on Wednesday, February 7, 1990 in *The Washington Post*.

In a sense, this petition, a creative and effective idea by the late Justin Dart, was a Magna Carta. Justin's wife, Yoshiko, recalled that it was very expensive to buy a full-page ad, but Justin convinced *The Washington Post* sales department to charge only half price.

Yoshiko solicited donations from around the country, kept up with hundreds of incoming contribution checks from \$2 to \$25, sorting and depositing them in their local bank, and entering donors' names without a modern computer system. She said Senator Tom Harkin was impressed by the ad and instructed his aide to find out who organized it. The aide called the telephone number listed in the bottom of the ad.

One week later, on February 14, 1990, Justin had an opportunity to see President Bush in the Oval Office and wanted to make sure the President would see the actual ad. So he asked one of Yoshiko's daughters to write this message: "Mr. President, Happy Valentine's! We love you!" with red marker on the full page. He presented it to the President, who then smiled.

When the ADA stalled in the House Committee on Public Works and Transportation (now the House Committee on Transportation and Infrastructure), people within the disability community became alarmed. About 475 individuals, many in wheelchairs, gathered on the sidewalk in front of the White House to launch the "Wheels of Justice Campaign." Sixty protesters with disabilities "cast aside their wheelchairs, crutches, and walkers to crawl or drag themselves, step by step, up the 78 marble stairs of the Capitol's West Front.

This protest, which came to be known as the "Capitol Crawl," was intended to openly illustrate the struggles that people in the disabilities communities faced, and spur Congress to pass the ADA. About 1,000 other protesters watched as members of ADAPT (Americans Disabled for Accessible Public Transit, now known only as ADAPT) threw themselves out of their chairs and began their crawl. Together, the march and the crawl comprised one of the largest disability direct actions to date.

The late Michael Winter, former Executive Director of the Berkeley Center for Independent Living, contributed his reflections on the "Capitol Crawl" to ADAPT's Twenty-fifth Anniversary "I Was There Series" of firsthand accounts:

"Some people may have thought it was undignified for people in wheelchairs to crawl in that manner, but I felt that it was necessary to show the country what kinds of things people with disabilities have to face on a day-to-day basis. We had to be willing to fight for what we believed in."

ADA: The Final Push

At the beginning of the George H. W. Bush administration, the Americans with Disabilities Act (ADA) became the property of disability lobbyists, including Patrisha Wright of the Disability Rights Education and Defense Fund (DREDF), and liberal Democratic lawmakers. Democratic Senators Tom Harkin of Iowa and Edward Kennedy of Massachusetts, working with Wright, rewrote a more conservative version of the ADA of 1988 than the version written by Republicans on the National Council on the Handicapped. They narrowed the scope of the accommodations to be made so that the bill was more palatable to business and therefore more likely to become law.

On May 9, 1989, Senators Tom Harkin, Ted Kennedy, and David Durenberger introduced the ADA in the Senate as S. 933. Former Senator Lowell P. Weicker provided testimony as a parent of a child with a disability.

On the same day, Congressman Tony Coelho introduced H.R. 2273 in the House. Congressman Major Owens and Silvio Conte were also original sponsors of H.R. 2273. When Coelho left Congress, Congressman Steny Hoyer provided Democratic leadership as chief sponsor of the ADA. Hoyer was chair of the Democratic Caucus in the House.

The Senate Labor and Human Resources Committee held four hearings on S. 933; the first three hearings focused on different titles in the bill. On June 21, 1989, Attorney General Dick Thornburgh, who has a son with developmental disabilities, outlined the Bush administration's position on the ADA. Bush, as Vice President, endorsed the original version of the ADA and expressed support for the rights of people with disabilities throughout his presidential campaign. However, it wasn't until that point that his administration had showed support for the ADA. Thornburgh articulated the administration's commitment to sign the bill into law, but also outlined concerns that the administration had. These concerns included the scope of the remedies allowed, the reach of the public accommodations provision, and the potential financial impact on small business.

The Senate Labor and Human Resources Committee expected to hold mark-up

on S. 933 in mid-July. During the summer, Senate leadership and bill sponsors reached an agreement with Bush administration officials on major provisions. The President supported the legislation only after sponsors agreed to limit remedies for findings of discrimination largely to those available under the 1964 Civil Rights Act.

In the House, four committees held jurisdiction over the ADA: Education and Labor, Judiciary, Energy and Commerce, and Public Works and Transportation. Each of these Committees expected to hold hearings during the summer, but they were extended throughout September and October. It was hoped that Committee hearings would be completed before the end of October so that the bill could be voted on before the Thanksgiving recess.

In support of the ADA, James S. Brady, former assistant and White House Press Secretary under President Reagan, wrote an editorial that appeared in *The New York Times* on August 29, 1989.

On September 7, 1989, the Senate voted overwhelmingly (76-8) in favor of S. 933.¹ The vote took place after lengthy Senate floor debate that lasted late into the night with more than a dozen amendments added to the bill and several adopted before the Senate took floor action.

The amendments included the following:

- The ADA was made applicable to the activities of Congress (Senator Charles Grassley, IA);
- In deciding whether to apply penalties in suits brought by the Attorney General, judges would be required to consider whether a defendant accused of discrimination had acted in good faith (Senator Rudy Boschwitz, MN);
- The compliance period for buses to be fully accessible would be extended for one year and the President would be authorized to extend the deadline one additional year, if needed (Senator Ernest Hollings, SC);
- If any provision of the act was found unconstitutional by a court of law, that provision would be severed from the Act, without affecting the enforceability of the rest of the Act (Senator Tom Harkin, IA);
- Current users of illegal drugs would be excluded from the definition of “disabled” for the purposes of ADA (Harkin);
- The term “disabled” would not apply to an individual solely on the basis of “transvestitism” (Senator Jesse Helms, NC);

- The term disability would be “more clearly defined” to exclude people with a variety of social behaviors and/or conditions including homosexuality, pedophilia, compulsive gambling, gender identity disorders, kleptomania, pyromania, and “current psychoactive substance induced organic mental disorders, as defined by DSM-III-R, which are not the result of medical treatment (Senator William Armstrong, CO).
- An amendment offered by Senator Orrin Hatch (UT) that would have provided up to a \$5,000 credit for businesses with 15 or fewer employees and gross receipts of less than \$1 million annually was rejected.

C-SPAN captured the September 7, 1989 Senate floor debate on S.933 (and Fiscal Year 1990 Appropriations) and the comments of many Senators on video. This includes Senator Ted Kennedy, who spoke in support of the ADA on the Senate floor, as well as Senator Harkin.

On Tuesday, November 14, 1989, the House Education and Labor Committee voted 35 to 0 in favor of a modified substitute ADA. Congressman Hoyer and Steve Bartlett (TX) — the ranking minority member of the Select Education Subcommittee — negotiated the modifications, which were primarily aimed at clarifying parts of the Senate-passed bill. None of the modifications weakened the bill. Eight amendments aimed at weakening the coverage of the ADA were defeated. Further committee action did not take place until January 23, 1990 — after the holiday recess.

On May 17, 1990, the House began consideration of the ADA. Earlier that day, Representative Steve Bartlett (TX) held a viewer call-in. Portions of the House debate on the ADA (House Resolution 394) and procedural controversy were also captured by C-SPAN.

One controversial amendment, permitting employers to transfer workers with contagious diseases to non-food-handling jobs, was introduced by Representative Jim Chapman (TX) and approved by the House on May 17, 1990. On May 21, 1990, ramifications on the House bill were discussed in a C-SPAN viewer call-in with Judy Heumann of the National Council on Independent Living and Mary Reed of the National Federation of Independent Business.

On May 22, 1990, the House of Representatives overwhelmingly approved H.R. 2273. A number of amendments to weaken various provisions of the bill were introduced during floor debate and defeated by wide margins. The vote on final passage of the bill was 403-20. On July 11, 1990, the Senate debated a conference report on S. 933 (that included an Omnibus Crime bill). Two controversies arose — how Senate employees should be covered by provisions of the ADA and whether employers should be permitted to transfer persons with AIDS out of food handling jobs. That lively debate with Senator George Mitchell and a resolution was cap-

tured by C-SPAN.

On July 12, 1990, Representative Steny Hoyer (MD) spoke forcefully on the House floor against a motion to recommit the ADA.

Upon passage of the ADA in the Senate on July 13, 1990, Senator Tom Harkin delivered a speech on the Senate floor in American Sign Language (ASL). Similarly, in a fitting memento to his leadership on the ADA and upon his retirement, Senator Tom Harkin closed his farewell address in ASL.

Signing the ADA

With the support of a powerful coalition of the “hidden army” of people with disabilities and their families, politicians, disability professionals, and “passionate insiders,” the ADA moved swiftly through Congress. On July 26, 1990, President George H.W. Bush signed the ADA into law with 3,000 of the “hidden army” on the South Lawn of the White House. Bush declared, “Let the shameful wall of exclusion finally come tumbling down.” At the end of the signing ceremony, President Bush plants a kiss on Kemp’s head.

Transcript:

Woman: Ladies and gentlemen, the President of the United States and Mrs. Bush.

Evan Kemp: I would like to introduce the Reverend Harold Wilke, of the healing community, to offer a message. Please remain seated.

Reverend Harold Wilke: “Let my people go,” you did decree, O God, demanding that all your children be freed from the bonds of slavery. Today we celebrate the breaking of the chains, which have held back millions of Americans with disabilities. Today we celebrate the granting to them of full citizenship and access to the promised land of work, service, and community. Bless this gathering, this joyous celebration. Bless our president as he signs the Americans with Disabilities Act, and strengthen our resolve as we take up the task, knowing that our work has just begun. Bless the American people and move them to discard those old beliefs and attitudes that limit and diminish those among us with disabilities. Our prayer is in your name, O God, whom we call by many names: God and father of our Lord Jesus Christ, Allah the compassionate and merciful one, the God of Abraham, Isaac, and Jacob and of Rebekah and Sarah and Ruth, the ground of all being, the infinite source of love and light. Amen.

Evan Kemp: I am delighted to be here today with so many old friends to celebrate with all of you this great victory for the disability rights com-

munity. So many people worked tirelessly to develop this civil rights bill in the administration, in Congress, and in the disability community: Justin Dart, Sandy Parrino, Pat Wright, and Arlene Mayerson. But all of you from the grass roots and many who could not be here today are responsible for all the success of this effort. Without the steadfast support of one man, this bill would not have become law. I have been witness to his commitment to disability rights for over nine years. Like Abraham Lincoln, he had the political courage to support an unpopular idea. He had the wisdom to insist that we move into the 21st century and welcome all Americans into the mainstream. Today he will sign the most important civil rights legislation in the last quarter of a century. I have the great honor of introducing to you the foremost member of the disability rights community, our good friend, the President of the United States, George Bush.

President George Bush: Thanks, Evan. Thank you so much. [Applause] thank you so much. Thank you all. Thank you all.

Sandy, Jus, great day. Evan, thank you so much. And welcome to every one of you out there in this splendid scene of hope spread across the south lawn of the White House. I want to salute the members of the United States Congress, the House, and the Senate who are with us today — active participants in making this day come true. And this is, indeed, an incredible day — especially for the thousands of people across the nation who have given so much of their time, their vision, and their courage to see this act become a reality. You know, I started trying to put together a list of all the people who should be mentioned today, but when the list started looking a little longer than the senate testimony for the bill, I decided I better give up, or that we'd never get out of here before sunset. So, even though so many deserve credit, I will single out but a tiny handful. And I take those who have guided me personally over the years: of course, my friends Evan Kemp and Justin Dart up here on the platform with me. And of course — I hope you'll forgive me for also saying a special word of thanks to two who, from the White House, but again, this is personal, so I don't want to offend those omitted — two from the White House, Boyden Gray and Bill Roper, who labored long and hard. And I want to thank Sandy Parrino, of course, for her leadership. And I again ... [Applause] it's very risky with all these members of Congress here who worked so hard, but I can say on a very personal basis, Bob Dole has inspired me. [Applause] This is an immensely important day, a day that belongs to all of you. And everywhere I look, I see people who have dedicated themselves to making sure that this day would come to pass: my friends from Congress, as I say, who worked so diligently with the best interests of all at heart, Democrats and Republicans; members of this administration— and I'm

pleased to see so many top officials and members of my cabinet here today who brought their caring and expertise to this fight; and then the organizations — so many dedicated organizations for people with disabilities, who gave their time and their strength. And perhaps most of all, everyone out there and others— across the breadth of this nation are 43 million Americans with disabilities. You have made this happen. All of you have made this happen. [Applause] And to all of you, I just want to say, your triumph is that your bill will now be law, and that this day belongs to you. And on behalf of our nation, thank you very, very much. [Applause] Three weeks ago, we celebrated our nation's independence day, and today we're here to rejoice in and celebrate another independence day, one that is long overdue. And with today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom. And as I look around at all these joyous faces, I remember clearly how many years of dedicated commitment have gone into making this historic new civil rights act a reality. It's been the work of a true coalition, a strong and inspiring coalition of people who have shared both a dream and a passionate determination to make that dream come true. And it's been a coalition in the finest spirit — a joining of Democrats and Republicans, of the legislative and the executive branches, of federal and state agencies, of public officials and private citizens, of people with disabilities and without. This historic act is the world's first comprehensive declaration of equality for people with disabilities — the first. And its passage has made the United States the international leader on this human rights issue. And already, leaders of several other countries, including Sweden, Japan, the Soviet Union, and all 12 members of the EEC, have announced that they hope to enact now similar legislation. Our success with this act proves that we are keeping faith with the spirit of our courageous forefathers who wrote in the Declaration of Independence, "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their creator with certain unalienable rights." These words have been our guide for more than two centuries as we've labored to form our more perfect union. But tragically, for too many Americans, the blessings of liberty have been limited or even denied. And the civil rights act of '64 took a bold step towards righting that wrong, but the stark fact remained that people with disabilities were still victims of segregation and discrimination, and this was intolerable. And today's legislation brings us closer to that day when no Americans will ever again be deprived of their basic guarantee of life, liberty, and the pursuit of happiness. This act is powerful in its simplicity. It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, the opportunity to

blend fully and equally into the rich mosaic of the American mainstream. And legally, it will provide our disabled community with a powerful expansion of protections and then basic civil rights. It will guarantee fair and just access to the fruits of American life, which we all must be able to enjoy. And then, specifically, first the ADA ensures that employers covered by the act cannot discriminate against qualified individuals with disabilities. Second, the ADA ensures access to public accommodations such as restaurants, hotels, shopping centers, and offices. And third, the ADA ensures expanded access to transportation services. And fourth, the ADA ensures equivalent telephone services for people with speech or hearing impediments. And these provisions mean so much to so many. To one brave girl in particular, they will mean the world. Lisa Carl, a young Washington state woman with cerebral palsy, who I'm told is with us today, and now will always be admitted to her hometown theater. Lisa, you might not have been welcome at your theater, but I'll tell you — welcome to the White House. We're glad you're here. The ADA is a dramatic renewal not only for those with disabilities but for all of us, because along with the precious privilege of being an American comes a sacred duty to ensure that every other American's rights are also guaranteed. And together, we must remove the physical barriers we have created and the social barriers that we've accepted, for ours will never be a truly prosperous nation until all within it prosper. And for inspiration, we need look no further than our own neighbors. With us in that wonderful crowd out there are people representing 18 of the daily points of light that I've named for their extraordinary involvement with the disabled community. We applaud you and your shining example and thank you for your leadership for all that are here today. Now, let me just tell you a wonderful story, a story about children already working in the spirit of the ADA — a story that really touched me. Across the nation, some 10,000 youngsters with disabilities are part of little league's challenger division. And their teams play just like others, but — and this is the most remarkable part — as they play, at their sides are volunteer buddies from conventional little league teams. And all of these players work together. They team up to wheel around the bases and to field grounders together and, most of all, just to play and become friends. We must let these children be our guides and inspiration. I also want to say a special word to our friends in the business community. You have in your hands the key to the success of this act, for you can unlock a splendid resource of untapped human potential that, when freed, will enrich us all. I know there have been concerns that the ADA may be vague or costly or may lead endlessly to litigation, but I want to reassure you right now that my administration and the United States Congress have carefully crafted this act. We've all been determined to ensure that it gives flexibility, particularly in terms of the timetable of implementation, and we've been commit-

ted to containing the costs that may be incurred. This act does something important for American business, though — and remember this: you've called for new sources of workers. Well, many of our fellow citizens with disabilities are unemployed. They want to work, and they can work, and this is a tremendous pool of people. And remember, this is a tremendous pool of people who will bring to jobs diversity, loyalty, proven low turnover rate, and only one request: the chance to prove themselves. And when you add together federal, state, local, and private funds, it costs almost \$200 billion annually to support Americans with disabilities — in effect, to keep them dependent. Well, when given the opportunity to be independent, they will move proudly into the economic mainstream of American life, and that's what this legislation is all about. Our problems are large, but our unified heart is larger. Our challenges are great, but our will is greater. And in our America, the most generous, optimistic nation on the face of the earth, we must not and will not rest until every man and woman with a dream has the means to achieve it. And today, America welcomes into the mainstream of life all of our fellow citizens with disabilities. We embrace you for your abilities and for your disabilities, for our similarities and indeed for our differences, for your past courage and your future dreams. And last year, we celebrated a victory of international freedom. Even the strongest person couldn't scale the Berlin Wall to gain the elusive promise of independence that lay just beyond, and so together we rejoiced when that barrier fell. And now I sign legislation, which takes a sledgehammer to another wall, one which has ... [Applause] one which has for too many generations separated Americans with disabilities from the freedom they could glimpse but not grasp. Once again, we rejoice as this barrier falls for claiming together we will not accept, we will not excuse, we will not tolerate discrimination in America. And with, again, great thanks to the members of the United States Senate, the leaders of whom are here today, and those who worked so tirelessly for this legislation on both sides of the aisle. And to those members of the House of Representatives with us here today, Democrats and Republicans as well, I salute you. And on your behalf, as well as the behalf of this entire country, I now lift my pen to sign this Americans with Disabilities Act and say: let the shameful wall of exclusion finally come tumbling down. God bless you all. Come on over, Evan. May I ask the members of the House and Senate with us to stand up, please? All of you, so all can salute you and thank you. Thank you all. Well done.

Also during the signing ceremony, T.J. Monroe, President of People First of Connecticut, self-assuredly walked up and presented Bush with a carefully printed letter. The President thanked Monroe, put the letter in his inside jacket pocket, and promised to read it later. Bush's administration would promptly issue regulations

for the ADA.¹ The law took effect in 1992.²

1 Shapiro, pg. 209.

2 Shapiro, pg. 140.

AFTER THE ADA

The Olmstead Decision

The Olmstead decision was the most important Americans with Disabilities Act (ADA) victory for people with disabilities. On June 22, 1999, the United States Supreme Court ruled, in the case of *Olmstead v L.C. & E.W.*, that states violate the ADA when they “unnecessarily” institutionalize people with mental disabilities. Lois Curtis and Elaine Wilson had been confined to a Georgia institution even though state workers said they could be served well in the community. Tommy Olmstead was the Commissioner of the Georgia Department of Human Services. In its 6-3 decision, Justice Ruth Bader Ginsburg wrote:

“States are required to place persons with mental disabilities in community settings rather than in institutions when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”

The implementation of Olmstead is an ongoing struggle over rights and resources.

In the wake of the Olmstead decision, the federal government issued a series of directives to states and suggestions for how to comply with the ADA that included affording people with disabilities the opportunity to make informed choices. The evolution of community services contributed to the adoption of the concept of “dignity of risk” and the establishment of principles in the ADA —and reinforced in the Olmstead decision.

Initially, President Clinton followed the Olmstead decision with a directive to all state Medicaid programs to draw up plans to comply with the Olmstead ruling and the “integration mandate” of the ADA.

On the twelfth Anniversary of the Olmstead decision, June 22, 2011, President Barack Obama reaffirmed the thrust of this landmark ruling and recommitted his administration to end all forms of discrimination. On the fifteenth anniversary of

the Olmstead decision, June 22, 2014, we were reminded again about the impact of this decision on the lives of individuals with disabilities.

In celebration of the fifteenth anniversary, a companion video was released featuring the “voices” of individuals with disabilities, family members, advocates, and stakeholders from across the nation whose lives have been positively impacted by Olmstead’s promise of community integration. Videos capturing more of the many stories that have been collected continue to be shared. The Fifteenth Anniversary of Olmstead video compilation is a Department of Justice and Department of Health and Human Services tribute to the actors involved in the Olmstead decision. The videos begin with a dedication by Secretary of Labor Tom Perez and conclude with a statement by Associate Attorney General Tony West, highlighting the enforcement actions that the Civil Rights Division is taking to make The Promise of Olmstead a reality.

The evolution of disability rights litigation that led up to the ADA, and the subsequent Olmstead decision, was captured in a video interview with David Ferleger, J.D. Ferleger argued five cases before the United States Supreme Court; assisted the courts; represented individuals and government agencies; taught law school; and has written, lectured and consulted nationally.

In the interview, Ferleger reflected on how disability rights have developed over time with social workers such as Dorothea Dix, movements spawned by the civil rights movement, and community organizing by parents and self-advocates. Ferleger also traced institution litigation in the 1950s, 1960s, and 1970s — which questioned both the purpose of institutions and the confinement of people in institutions — to the use of the ADA language in the Olmstead decision. Dr. Ferleger discussed the right to treatment as well as the Constitutional right to community services.

Transcript:

Ferleger: There is an arc, which we only see in retrospect, how disability rights we look at today have developed over time and I think it’s worth looking at. The last century, just to start, the last couple hundred years was really the world in the beginning of the social reformers, Dorothea Dix and other social workers, who saw the plight of people with disabilities was part of the overall effort to try to help society move toward a level of humane treatment of people with disabilities. In the ‘50s and ‘60s, the civil rights movement in the United States began to spawn other movements, prisoners’ rights, women’s rights; and a number of communities and activists, former mental patient groups began to organize, to get legislation enacted and to bring public attention to what happens to people in institutions as they leave institutions, and to try to get more of a... an appreciation of the dignity of people with disabilities. In the mental health area, it was people doing things for them-

selves, mostly. In the developmental disabilities or intellectual disabilities area, it was the parents who began to organize the Association for Retarded Citizens and other groups began to push for protection of people with intellectual disabilities. That kind of community organizing phase, I'll call it, began to lead — and it was an eventual incremental development — to interest in the way, I put it is first, how people get into institutions, what happens when they're in institutions and then whether they should be in institutions at all. So, the early legislation and litigation was about commitment procedures. Do you have a right to an attorney? Do you have a right to a hearing before being involuntarily committed? Do you have a right to put on your own evidence? Can one or two doctors sign people into an institution? So, there was a lot of litigation around those kinds of questions. Among the questions that came up, were questions about children. When can parents sign a child into an institution? And, I brought one of the early cases of that to the Supreme Court a couple times. *Bartley vs. Cremens* was one incarnation. The other one was *Institutionalized Juveniles vs. Secretary of Public Welfare*. And there the question was, what kind of hearing, if any, does a child have before being committed? The Supreme Court there decided that a child does not have a right to a full hearing but a right to some independent review of a need for commitment. So, that phase of institutional commitment procedures bled into concerns of what happens when people are in the institution.

In the below transcript, Ferleger talks about victories in front of the Supreme Court.

Transcript:

Ferleger: Let's talk about civil commitment, institutions, and the development of the least restrictive alternative, the least restrictive environment right. The Supreme Court eventually came to these kind of issues, but did so only in recent decades. But, still based on individual cases, not large, rich, giant cases, but small cases over time in lower courts and in other courts. In the *Josiah Oakes* case, the Supreme Judicial Court of Massachusetts in the mid-1800s dealt with a man who had been put into an institution on the petition of his children, because after his wife died he began to act strangely, got involved with a much younger woman, and they thought that was peculiar. He was committed and the court rejected that kind of treatment because it wasn't fair, it wasn't just. And, there was no reason to think he needed to be in a hospital. Judge David Bazelon, a federal district judge in Washington D.C. dealt with a couple of cases in the '50s and '60s involving individual commitments. One, *Lake vs. Cameron* involved a woman who was found wandering the streets with all of her possessions in a bag, wandering the streets in Washington, was committed to an institution

and he held on a very important decision that she can't be kept in an institution if there's some less restrictive way to keep her safe, and not have to suffer the effects of being in an institution. So the Supreme Court first looked at what happens when people are institutionalized in the *Robinson v. California* case in 1962. In that case, there was a law that allowed somebody who was a narcotics addict to be treated as a criminal, and therefore to be kept, essentially indefinitely, as an addict for that crime in an institution. The U.S. Supreme Court said we can't punish people for an illness or a mental health condition and said that there might be some cases where involuntary commitment would be allowed but not just because of a mental illness. So the Supreme Court didn't define what that meant, didn't say what involuntary treatment would look like, what the procedures would be, but set the stage for later looking at it so that, in 1972, in *Jackson vs. Indiana*, the court declared a basic principle that I think is the foundation for what we think of today when we think of commitment under the law. In that case, Theon Jackson was a deaf mute; he couldn't read, he couldn't write, he had very much difficulty communicating anything at all, and he was charged with petty larceny, locked up having been found not guilty by reason of insanity. The law was, having been found incompetent to stand trial... the law was that if you're incompetent to stand trial, you wait and wait in jail or in a hospital until you become competent. Well, Theon Jackson would never become competent. He was intellectually disabled and went to court and said, I will be here essentially for life because of my disability. And the Supreme Court rejected that order that no one can be held indefinitely until they become competent. And, Justice Blackmun wrote what I consider to be some of the most important words in the history of this legal principle. And he wrote: "At the least, due process requires that the nature and duration of commitment bears some reasonable relation to the purpose for which the individual is committed." So that notion that the nature and purpose of being in the institution has to have a relationship, a reasonable one, to the purpose for the commitment really is what speaks to all the law I think that's developed since then. So, the Jackson case didn't say what happens when you're committed, it just referred to the nature of the commitment and the duration. So, in 1956, Ken Donaldson, not knowing he would become a big Supreme Court name, he traveled to Florida to visit his elderly parents. He came from up in Philadelphia; he thought people were trying to poison him, acted strangely. He was believed to be acting. He was committed to an institution, stayed there for 15 years in a hospital with only one doctor, an obstetrician, only one nurse, and she worked only in the infirmary, a thousand patients, no treatment and he stayed and stayed. Imagine, year after year, being in an institution, no danger to anybody, and receiving no treatment at all. He went to court; a jury awarded him thousands of dollars in damages. The case

went to the Supreme Court and the U.S. Supreme Court, now building on the earlier Robinson case, said that nobody can be confined in an institution without more than just custodial care if you're not a dangerous person. If you can do well, do fine out of the institution with help of family or friends, you cannot be confined in an institution. So, that decision was really a reminder almost that we had the local case, I'll call it, of Lake vs. Cameron in 1966 that Judge Bazelon had made. So the court begins with the general principle coming out of the criminal law area and it begins to be extended to Ken Donaldson's case. You can't be kept in a hospital for your own good if you can live outside the institution. Meanwhile, in the U.S. in 1990, the first President Bush signed what he called the Declaration of Independence for people with disabilities, the Americans with Disabilities Act — bipartisan, great support in the country. And eventually, although that law mentions institutionalization just in passing almost in the beginning sections, the Supreme Court in Olmstead vs. L.C. in 1999 declares that it is illegal discrimination under the ADA to confine a person needlessly in an institution, because that confinement, that segregation itself, is discrimination forbidden by the ADA. So we get back to the duration, and nature of the commitment bearing some relationship to the purpose and the Supreme Court now says that the segregation, which is part of, virtually the purpose of institutionalization, cannot stand under the ADA. So we now have a least restrictive idea coming back from Lake v. Cameron, through those early Supreme Court cases and now under the Olmstead decision.

In the below transcript, Ferleger talks about winning the right to treatment in the Supreme Court.

Transcript:

Ferleger: When I first looked at this, which was 1971, '72 — when I was in law school, and wrote my first lawyer review article — I wrote one article about seven or eight topics that had been hardly looked at before at all, some of them not at all. And, then was one article, it was 10 or 20 pages, now there are books about individual topics, like restraints, like the right to refuse treatment, like the right to treatment. So, there were many people who began, in that period around the 1970s, to say, when people are in the institution, do they have a right to say no drugs? Do they have a right to not be put in seclusion or restraints? With what kind of procedures? Do people have a right to visitors, to access for advocates? And, then as folks began to think about those questions, the question arose: What happens when people don't need to be in an institution? People like me and other advocates — including Bill Johnson, here in Minnesota — people began to say, "Maybe we don't need either as many institutions, or any at all for some folks." So, there began to develop out of the litigation around conditions in institutions, litiga-

tion like the Halderman v. Pennhurst State School and Hospital case in Pennsylvania. Wyatt v. Stickney in Alabama, the Willowbrook case, NY Association of Retarded Citizens vs. various state officials. They began to develop litigation that said, number one, we don't need bad institutions, and number two, for some people, there's no need to be institutionalized at all. So, that kind of litigation began to move through the courts, and eventually, in 1990, the Americans with Disabilities Act was passed, which referred in its preamble, I'll call it, to needless segregation of people with disabilities, but didn't directly address what the rights are of people in institutions. The U.S. Supreme Court in 1999 decided the landmark case of Olmstead v. L.C., and in that case, for the first time, the Supreme Court declared that needless institutionalization in itself is discrimination because institutions segregate people with disabilities from people without disabilities and therefore, it is illegal. So we have, without right now going into all the history, we have, really, a shape, I think, of the social and legal developments around people with handicaps and disabilities, where we begin with social moral considerations, move into a rights orientation. Rather than it being a good thing to do, it's the right thing to do, it's a legal right. And then, where the focus is begins to develop and shift from how we get into institutions, what happens when we're there, and then whether or not we need to be there at all. Some reflections on some of the work I've done and some of the cases that I've done — because it's been an interesting journey for me — in 1971, '72, I was finishing law school, and created the first mental health advocacy project in an institution in the United States — two foundation grants, an office with a desk made out of a table propped up on two sawhorses, a typewriter borrowed from a former mental patient — and then began doing this work at an institution called Haverford State Hospital in Pennsylvania and brought some of the early lawsuits that nobody had ever done before. I brought one case involving the right not to be forced to do labor. Downs vs. Department of Public Welfare, the first case that ever declared that forced institutional work, which used to be the norm, violates the 11th Amendment ban on slavery, on involuntary servitude. I also brought there a case that I never thought would take as long as it did, and that was a case involving the rights of children not to be committed to institutions simply on the say so of their parents. I represented a few individual children in a class action, and in one of the hearings in front of a three-judge court, the court said, Well these are kids, don't they need a guardian ad litem for the lawsuit to represent them? I deferred to the judge and said, Maybe they do. And the judge right then and there appointed me the guardian ad litem of all 6,000 children in all Pennsylvania mental institutions. And I had that responsibility through a couple of arguments in the Supreme Court. When I began the Halderman vs. Pennhurst State School and Hospital case, it was one of the first

suits I filed. I had been a lawyer just a couple of years and never thought it would have such an impact as it did. And the way that case began is worth recording because it really exemplifies how many other cases have preceded Terry Lee Halderman, who had been injured at the institution 30 some times, I think. Her mom was upset. Her mom asked the assistant superintendent what should she do. The assistant superintendent told her, call David Ferleger and sue me. So that case began, not because I was there for some other reason. I had done mostly mental health, not intellectual disability type cases, but because the institution itself, an official said we need to be sued about what we are doing. The case was in front of Judge Raymond J. Broderick, an incredible federal judge, a Republican conservative who, through the course of a 32-day trial eventually ruled that no one with retardation, now called intellectual disabilities, needs to be in any institution at all and that people have a right to live in the community. So, I've counted it up once, I think I've been in 30 or more states, looking at institutions or litigating in institutions and the images unfortunately stay with you for a while. In a Wyoming institution, I remember a very dark room with volunteer grandparent types holding very little children, trying to rock them to sleep or comfort them. Children who need never have been in an institution at all. In Florida, as a court appointed monitor, I had heard that they were using a new kind of restraint and went down on behalf of the court to see what it was. This was called the mat wrap in which the client with the behavioral outburst, let's say, was rolled up on a mat and I'm thinking that I was protected by the court order, protected by the other two court monitors there, the head of the institution. I ingeniously, I guess could say, volunteered and said let me try it. Let me have myself wrapped up in the mat. They hesitated, I laid down, stuck my head out, tried to use my elbows to give myself some room. They rolled me up in this mat and it was the most terrifying experience I've had in my life. I felt that I would never get out, even though I knew intellectually that they wouldn't wrap up a court monitor for hours, but it was so terrifying for me who could intellectually understand what was happening. And it made me really think about what the experience was like for someone without that much intellectual capacity who doesn't know why, doesn't know what's happening, doesn't know how it will end, what to do to make it end, and how incredibly traumatizing that would be to someone without the kind of capacity I thank God that I have. So, among the things that have happened, that people in my generation of advocacy have seen is the closing of institutions in the last 10, 20 years — dozens of state institutions for people with intellectual disabilities have closed. People have moved to the community. Governments have seen, the community has seen that people don't need an institution, to have a quality of life — their right to education laws have helped. Children are no longer being admitted to institutions, and so we've seen

some really wonderful changes. It's been quite an experience for me, an amazing experience to be able to argue some of these cases at the U.S. Supreme Court. The court gives... everyone who argues finds on their table a little quill pen that's hand carved from some geese feather, whoever it is that contributed the feather and that's one of the things that's left. Another thing that's left is one of the stories that I like to remember, and that was in the case involving children, and children's rights to a hearing or some process before a commitment. The state's lawyer argued that children could file a petition for Habeas Corpus. A child unnecessarily locked up could go to the court and say, "I shouldn't be here." And that was an alternative to my proposal for some kind of hearing. And Justice Thurgood Marshall said, "What are you saying, how can a child file a petition of Habeas Corpus" and the state's lawyer said, "well if the child couldn't do it, then a friend could do it" and Thurgood Marshall, famous for his humor, he said, "Well aren't most friends of 12-year-olds also 12 years old?" Everybody laughed and we went on. So, what will the future hold? The future will hold fewer and fewer institutions, more scrutiny of quality community care, and some developments that I think will occur in the law regarding community life that deserve some attention elsewhere.

In the below transcript, Ferleger talks about the constitutional right to community services.

Transcript:

Ferleger: Let's talk about what I call the Constitutional right to community services. Now I call it that, Judge Raymond Broderick in the 1970s called it that. The Supreme Court hasn't said that is a right. No courts have really said that there is such a constitutional right. I advocate that there is such a right, and it's important because the *Olmstead vs. L.C.* decision of the Supreme Court is based just on the ADA, the Americans with Disabilities Act. So a right that is based on a statute has certain limitations. The *Olmstead* decision itself has limitations. The *Olmstead* decision said that your right to be in the community is limited, perhaps by budgetary or institutional, state institutional considerations. Your right to be in the community is limited by whatever you can glean from the ADA, and of course a statutory right can be taken away anytime. So, it's important to begin to think about whether and how the Constitution protects one's right to be in the community. And, without making this a legal treatise, let's talk about a couple of the rights that might give rise to that constitutional level of protection for people with disabilities. One is that the due process clause of the Fourteenth Amendment to the Constitution has an element, called substantive due process, not just the procedures that you get when you're affected by state action, but the core — some basics of how one is treated — which

require a fair treatment. So those Supreme Court decisions like Jackson vs. Indiana, which discuss the institutionalization, are an example of the application of substantive due process. So, under that kind of test, I think it is legitimate to argue that in this day and age, it is no longer fair or reasonable to confine someone with disabilities, intellectual disabilities, let's talk about that, to an institution, because it's not being done any longer for somebody's protection. We're not protecting society and it really no longer makes sense. So, similarly, the equal protection clause of that same Fourteenth Amendment, forbids the irrational treatment of people in our society by the government. So, similarly it is no longer a rational thing to do to say that you or me, or someone with intellectual disabilities needs an institution, as opposed to being able to live in the community. So, although the Supreme Court has held that the class of people with retardation or intellectual disabilities in the current terminology, that those folks are not a group that has special treatment under the protection clause, if we confine the class under examination to people needlessly institutionalized, I think when that case gets to the Supreme Court, the court will hold that group is specially protected, and does have a right to live in the community. Many decades ago, in the 1960s, a professor Jacobus tenBroek wrote an article about the right to be abroad in the land. That was his phrase. And he talked about the rights of people to be in the community. This was long before any Supreme Court decision on the topic, long before the ADA. And, he happens to be, at the time, probably the foremost scholar on the Fourteenth Amendment. And, he was blind. He was a blind professor who was able almost to see into the future and say that the rights we talk about, the right to be abroad in the land, the right was so essential that he wrote that's what it means to live. So, I think we can go back to the inspiration of Professor tenBroek, and realize that the rights we're advocating for today, the Constitutional right to community services — now existing mainly in my mind, and in a laureate article — is a right that will be, and deservedly be recognized by the courts. So, we went from ancient history to the future.

From the Least Restrictive Environment to the Most Integrated Setting

Litigation in the 1950s, 1960s, and 1970s questioned both the purpose of institutions and the confinement of people in institutions, and progressively led to the Americans with Disabilities Act (ADA), and language that the United States Supreme Court would later use in the Olmstead decision — declaring that to needlessly confine a person in an institution is segregation, that segregation is discrimination, and the ADA forbids such discrimination.

It began in 1954 with *Brown vs. the Board of Education*, the civil rights case that established the principle that school segregation denied students an equal educational opportunity. The United States Supreme Court held that separate was not equal, and although the *Brown* decision referred to racial segregation, it began to influence thinking about people with disabilities. In the aftermath of *Brown*, a number of subsequent court challenges held that people cannot be confined to institutions if less restrictive measures could be taken to keep them safe in the community. The concept of “least restrictive environment (LRE)” then began to find its way into court decisions in the late 1960s and early 1970s. From there, the concept continued to evolve.

During the 1980s, advances in assistive technology and services, coupled with a values base, advanced the notion that people with disabilities be included in society. The concept of inclusion was based on the premise that all individuals with disabilities had a right to participate and not just be present in the community, and in activities with their neighborhood peers, siblings, and friends. Least restrictive was not enough; more was required.

Following the passage of the ADA in 1990 and as directed by Congress, the United States Attorney General issued regulations implementing Title II that are based on the regulations issued under section 504 of the Rehabilitation Act. The Title II regulations require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” The preamble discussion of the “integration regulation” explains that “the most integrated setting” is one that “enables individuals with disabilities

to interact with nondisabled persons to the fullest extent possible...”

The language of full integration, the integration mandate, was then incorporated into the ADA by virtue of these regulations and reflected in the Olmstead decision.

Dr. Patrick Schwarz is a professor at National-Louis University, Chicago, as well as an author, motivational speaker, and leader in inclusive education. In a recorded conversation, Dr. Patrick Schwarz described the movement of a student from a least restrictive environment to an inclusive education classroom. His remarks are included within the pages of this book.

Transcript:

Patrick Schwarz: When a student has extreme behavior support needs, you couldn't include him, correct? And I want to talk about Matt here. So Matt was a student that I worked with, and I worked with him in a public school. And during his first, second, and third grade years, Matt was in a self-contained classroom that had students with learning and behavioral challenges. So, he was in a special education environment. In grades four and five, Matt started to become included, so where he was included he had a general education teacher and he received special education supports in the general education classroom. He also received some individual supports in general areas of the school. He had a little study time in the library where he got to work on homework and things such as that. And things were going well for Matt with the support system from special educators and related service providers in the general education classroom. So thinking about that, what happened one day is Matt threw a desk at a teacher. And that's a big concern because one of the things that every school district or school has on their policy is safety. So that's a safety concern. However, I went back to that thing that I talked about with Frankie is what we wanted to do is find out what Matt was communicating. So teachers were talking about doing all these different things and therapeutic supports, and I said, Why don't we investigate Matt's current situation a little bit more closely? And we found some things out. So first of all, what we found out is Matt's father had left his mother and Matt. And Matt and dad had been close, and he had moved into another state, and Matt and dad weren't communicating as much anymore. That's a hard thing for a fifth grader. The second thing is the dominoes started to fall after that, and Matt's mom had a tough time finding work locally, so she had joined her sister in a neighboring community. And Matt, before the incident, had been living with grandma and grandpa, and guess what? Matt and grandpa didn't get along. So think about Matt's life as a fifth grader. Dad moved away, mom had to move away, and he was having to live with somebody he didn't get along with. It's a hard knock life for us. And so I asked the team, I said, "Is there a way we can creatively prob-

lem solve this?” Because Matt is a student. Clearly, when you look at what his communication is, he is grieving. He is in a very, very tough situation. And I said, “If he was to go into something that was therapeutic, what would be your criteria for reintegrating him?” Because we have something in our law that’s called the least restrictive environment. So here are the models we have for special education placement. First off, we have the general education classroom. Then we would have after that which would be something more like a resource type of model. After that, we would have a mainstreaming situation. Now, I’ve talked about inclusion. Mainstreaming and inclusion are different. So the homeroom in a mainstream situation would be a special education environment or self-contained environment, and then the student would go out for certain subjects. The first tier of subjects would be what people call the specials. So it would be art, music, physical education, recess, and lunch. The second tier might be science and social studies, but usually in a mainstreaming model, students are not included for mathematics and reading and literacy. Then we would have after that, we would have self-contained classroom and then we would have alternative school. So Matt started out his educational career in grades one through three in a self-contained type of environment, then went to the inclusive situation, threw the desk at the teacher because he was in a grieving situation, and then they’re saying he should go to the alternative school. It’s kind of like the continuum of services dance. And something that happens is sometimes people say, “Well, you know what? He threw a desk at a teacher. He should just stay in that alternative environment or school.” Whereas in our law, we have something called the least restrictive environment. And the least restrictive environment to me is the general education classroom. So anybody who is not there, I think, should have an integration plan for getting there or a reintegration plan if they’ve been there already; and so this is what the team came up with. They said they thought Matt should have therapeutic supports for a quarter. They also said, “If he was to come back, he should be receiving outside therapeutic support and shown acceptance of his current living situation.” Matt did get back. And isn’t it a better scenario that Matt went through a process where the least restrictive environment was honored and that there was a reintegration plan in place and that he didn’t stay in an alternative school? I want teams to creatively problem solve and to work out things that promote full academic access and inclusion of students who have disabilities.

ADA's International Impact

On December 3, the United Nations celebrates the annual International Day of Persons with Disabilities. The Americans with Disabilities Act (ADA) is significant in the history of the United Nations with regard to people with disabilities. The ADA was the first major piece of national legislation in the world to address systematically the discrimination, barriers, and challenges faced by people with disabilities. Other countries followed suit by adopting similar ADA principles.

Between 1991 and 1999, the ADA inspired disability rights laws in Luxembourg, Italy, Japan, the United Kingdom, and Sweden. A website titled “The Emancipation Proclamation for the Disabled” was created as a National History Day (NHD) Project by students Srijia Reddy, Niti Malwade, Hamsini Nathan, Devika Patel and Khira Patel. NHD is a highly regarded academic program for elementary and secondary school students. The website won Second Place in the Kenneth E. Behring National History Day Contest, in the Junior Group Website category. The web site is an excellent summary of the pre-, peri- and post-ADA movement.

Rodrigo Jimenez Sandoval, a Costa Rican lawyer and consultant specializing in the rights of people with disabilities and women, described the ADA's influence on Latin American countries in comments made at the University of Alabama School of Law.¹ The first Latin American disability legislation approved was a 1992 Brazilian law. The Chilean “Social Integration of Disabled Persons Law” followed in 1994, and in May 1996, the Costa Rican “Law on Equal Opportunities for Disabled Persons” was approved. Similar laws followed in Guatemala, Nicaragua, Peru, and Venezuela.

In the years following enactment of the ADA in the United States and similar laws internationally, people with disabilities and governments around the world began meeting and discussing an international treaty that would require other countries to protect the rights of people with disabilities.

In 2006, these discussions culminated in the Disability Treaty — also known as the Convention on the Rights of Persons with Disabilities (CRPD) — which is based

1 Alabama Law Review, Vol. 52:1:419-423, 2000

on the principles of non-discrimination and inclusiveness that underlie the ADA. The convention was also inspired in part by the ADA, and the United States provided important technical assistance during the convention's negotiation and drafting process.

The United Nation's International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities entered into force in 2008 and the United States signed the convention's principles in 2009. When the Disability Treaty was opened for signature in 2007, it was signed by 82 countries and ratified by one. Currently, 151 countries have ratified the convention, but not the United States.

The United States missed an opportunity to further display global leadership on disability rights on December 4, 2012, when the Senate failed to ratify the CRPD. Opposition claimed erosion of U.S. sovereignty and reluctance to take up a treaty during a lame duck Congress. The Senate vote took place during the post-election ("lame duck") session of Congress and included debate and votes by senators who were not returning to the next Congress in January 2013.

On July 23, 2014, former Senate Majority Leader Bob Dole returned to the U.S. Capitol to urge ratification of a global Disability Rights Treaty. Other former supporters of the ADA who have expressed support for U.S. accession to the Disability Treaty include former President George H.W. Bush; C. Boyden Gray, former White House Counsel to President George H.W. Bush; and former U.S. Congressman Tony Coelho.

In addition, ADA activist and life-long disabilities and civil rights advocate Judith E. Heumann was appointed Special Advisor for International Disability Rights at the U.S. Department of State.

The role of the United Nations with regard to people with disabilities is still discussed today.

Judge Donovan W. Frank

Donovan W. Frank took the oath of office on November 2, 1998 to become a United States District Court judge. His career was profoundly influenced when he was as an Assistant St. Louis County Attorney for the St. Louis County Attorney's Office in Virginia, Minnesota, where he was involved with people being committed into the mental health system. Judge Frank served as the Chief Judge of the sixteen-judge Sixth Judicial District from 1991 to 1996, prior to his appointment to the federal bench.

In a discussing developmental disabilities issues, U.S. District Judge Donovan W. Frank never directly mentions the Americans with Disabilities Act (ADA), but his comments on bigotry, employment, abuse, and especially on the influence of self-advocates, reflects on how far our society has come since the passage of ADA, the importance of maintaining the ADA, and the need to advance the ADA, particularly through the influence of self-advocates on the disability justice community.

Transcript:

Interviewer: Can you describe how you became involved with developmental disability issues?

Judge Frank: The quickest way for me, the most important way to do that, is to roll ahead to my first couple years out of law school, where I met many individuals with, primarily developmental disabilities, many parents, and I want to say that because they ... in addition to meeting people and the stereotypes falling away, that we have more in common together than we have differences. I also was taught so much by these individuals, and I'm sure that had some role then — when I started prosecuting out of law school sex crimes, domestic abuse crimes — competency was never an issue of either children with me, or individuals with a variety of developmental disabilities. And so, because I had seen that all too often, that was used as an excuse not to file a lawsuit and not to prosecute a crime. I didn't have one case — and I actually did have the first case to go to the Minnesota Supreme Court thanks to a very courageous state trial judge on ... on how to explain

competency to juries with an expert witness, and children who had been victims of sex crimes, because the people want to dismiss people as, “well they don’t think,” “they don’t remember,” “they don’t recall,” “they can’t express themselves” — ALL untrue. It’s more the inability of people like me to communicate. That’s the first place that I saw it and how I got educated — just by luck of the draw, I would say, rather than misfortune, I said “fortune.” My first job out of law school was doing mental health commitments and placements as a lawyer for St. Louis County, and in that role I end up being placed on developmental achievement board in Eveleth, Minnesota, and then the Range Mental Health Center, and I got all sorts of education about “this is how you treat people who have disabilities.” And so... because I used to see it in the courtrooms day in and day out — and that was my first exposure, other than growing up as a child and hearing the ridicules of people before mainstreaming, and making fun of children that were in special Ed classes. And I’m just very thankful I was raised, “that is not tolerated so ...” But my first exposure before I became a judge was prosecuting a lot of those cases, and again I credit advocates for children and adults with disabilities. They ... I think they watch for young lawyers coming out of law school, they say “I think he’s trainable, I think we can train this guy and teach him something and perhaps we can.” They’re the ones that really taught me, because I don’t consider myself an expert and I also got taught by many of the people with disabilities that I worked with, who taught me and showed me who they were. So that, but... it’s that inability to believe... and then of course I came out of law school at a time when with these major local and U.S. Supreme Court decisions the phrase, “You have a right to live in the least restrictive alternative.” You just don’t take individuals regardless of their disability and lock them in a state hospital, drug them up or restrain them down. And that’s not living, that’s not humanity, and so all of these things were happening in the ‘70s when I came out of law school.

Interviewer: What can we do about open bigotry against people with disabilities?

Judge Frank: You know, I think I’ve referred to individuals with disabilities as the forgotten minority. You know, people... and what I think it is, it’s as they finally get the promise that the Constitution makes for all citizens in this country — of equal opportunities, equal justice, equal access, living in the community, working, like in this building, and I work with individuals who maintain the building — you don’t live and work with people with disabilities without those stereotypes falling away. And so, I think getting challenged... one of the first things we did — and I give at least two people, Colleen Wieck and Shamus O’Meara, credit — we did a presentation to the Federal Bar Association saying

“As we talk about unrepresented minorities, the largest group, in our opinion, are people with disabilities.” It’s time to educate the local bar, which is in... we’ve done actually two seminars, and there’ll be more, to train people, to say, “Well, we’ve forgotten about these individuals, and the... and the representation isn’t as difficult as you might think, if you educate yourself.” And so, I think, challenging the system, those traditional stereotypes that are so contrary to reality and so damaging to individuals, especially with disabilities — much like stereotyping people of color and most especially African Americans were during the civil rights movement — those are the changes being made. But who are we being challenged by? It’s the individual with disabilities, and their parents and friends and loved ones, it’s the advocates, lawyers, non-lawyers — because make no mistake about it, it isn’t the intellectuals, it’s not the judges. I take an oath; I’m just trying to keep my promise and follow my oath. But it’s these individuals who are saying, “We’re not going to tolerate this anymore,” and they’re educating us. There are... so I think that... I don’t want to be over-simplistic about it, and we’ve got a ways to go, but that’s what’s changed I think.

Interviewer: What are the challenges and successes with employment issues?

Judge Frank: Well a couple of... In my own opinion, again it’s the... and again, I don’t speak as an expert. I’ll talk mostly about the people that I know, and in the employment area, for example, let me just take a couple of employers in downtown St. Paul. Let’s take our courthouse. We have 22 individuals that work in this building. Virtually all of them, with maybe the exception of one or two, have some type of developmental disability. Well, how many people think, even when we’ll talk about their opportunity to be hired here... how many people think of, well if you cut back money for transportation, public transportation... to cut back on public transportation is to destroy someone’s livelihood or work, because everybody can’t afford to own a car, everybody can’t drive a car. And if you take away, whether it’s a transportation program or public transportation generally, those are things that now the disability community is putting on our radar to say, “You know, we have to look at isn’t it our responsibility to give everybody equal opportunities and equal access, and how do you do that if there is no public transportation and all these government programs are cut? Giving people a chance to work and properly train them.” When I first started working here in this building in 1998, I kind of, out of ignorance would... if I had a complaint about something happening in the building — I should... this is not unique to the disability community — it seems like people to get the blame for things, it’s not the hierarchy. It travels down the ladder, and so I finally had to start going to supervisors saying, “We love

working with the individuals here, and we think all of our individuals that are hired should be... they should be individuals with disabilities, because they're fully capable of doing the work, but they're like everybody else if you don't train them and tell them what their responsibilities are," and that really was the problem. Well, there are a lot of progressive employers who understand that maybe our courthouse, or private or public employer, should look like they represent the people that live in the community. That means not just race issues but people with disabilities. It isn't that they can't do the work, if they are not given the opportunity to do the work, and it's the full package. It's accommodating the hours with making sure there is public transportation, there is proper training. I won't name the company, because somebody would think it would be an endorsement, but there's a private corporation here in downtown St. Paul — and I think there's a disability group, LifeWorks, and there's others — well, this company hired three severely autistic young men and women and the first thing they did in the first two weeks is brought in trainers to say, "Let's educate you, since your employer is willing to hire and do the right thing here, let's educate you on this condition so you don't do something out of ignorance or unintentionally." Well, I know a couple of people who work at this organization; they're saying, "There's NEVER been more work done in this area," and instead of not getting the work done, these three individuals at different times are coming to their desks and saying, "We're done. You must have more work for us to do." Well, that took just education; they do the work just fine — there's no impairment there. They're educated and they're doing the work just fine, but it's the opportunity, and it's the stereotypes fall away, and we have a long ways to go but we're much further today. I maintain that much of it's happening because state hospitals have been closed, because many of the laws that were passed did not mandate that regardless of the nature or degree of one's disability, they're entitled to any job they want; it's you pursue... they have the same opportunities based upon their skills, and they just ask to be given a fair chance like each of us do and drop off those stereotypes and they will be hired. I mean, I see it every day. But I think those are the inroads; it's mostly education and getting to know individuals and the stereotypes fall away. For most, not all.

[Interviewer asks about origin and growth of self-advocacy].

Judge Frank: Well, I've been introduced to many self-advocates, and I think I can say this without... you'll probably detect a little emotion in my voice... one of things that I do is... because this is the most kind of a profound example I can give... First, I want to say on the self-advocacy, I don't know. I suspect its origins are from the individuals with disabilities themselves and their friends — loved ones and family. But it's again...

it's to know and walk with our fellow human beings and citizens, and then to have them advocating on their own behalf. It really demands — no matter what somebody's predisposition is — all the stereotypes, the preconceived notions, the bias, the prejudice, it all falls away. The most... The best example I can give is, I have had the privilege of having... not just speaking at a couple of self-advocates' get-togethers, but they've visited here in the courthouse, and I have met with a number of them at a number of the facilities where they work and live. And I would say that... I'll just take the most recent visit a few months ago here at the building... One of the questions I'd ask college students, I ask high school students, and this day I asked the self-advocates, "What are the most important rights to you? What's most important out of the Constitution?" I think that's almost word for word what I asked. Now, I am quite certain that before they came here, they hadn't read the Universal Declaration of Humanity, Human Rights — that's in effect worldwide — but what they each said, each hand went up without any reservations; it's as if they knew more than all the rest of us because of what's here. [Points to his heart]. The first hand went up, "I want to be treated with respect." The next hand went up, "I want to be believed as a sexual assault victim, the victim of a crime." The next hand went up, "I want to live on my own." The next hand went up, "I wanted to be treated with kindness and without bias." I mean, over and over they gave more intelligent answers, as if they were familiar with the Constitution, and some of these International Declarations of Human Rights. They gave more intelligent answers than, than no offense, than 90 percent of the student groups we bring in here — whether they're college students, high school students — because they walk the walk. I haven't walked the walk. And so, I still ... and if you would have seen some of my staff, there was a tear or two coming down because they said, "You know, we think get it, but we really don't." I mean, where these are these teaching moments, and actually I am so glad in this profile we're going to be doing of me, nationally, they choose to leave that experience I had in, because it really has affected me. Just when I think I kind of understood and (had) been taught — and I'd been taught plenty by all of these individuals — the self-advocacy as they went around the room, I'm saying, "who could ask for a better advocate than that?" Because ... and I can't capture it, because if you capture it, it isn't just the words; it's the commitment, it's the passion. But whoever, however this came up with this self-advocacy, they are making the rest of us pay attention. They're educating us.

[Interviewer asks about self-advocacy tours].

Judge Frank: It's just like the day that I invited a group, and I have a picture in my chambers here; we'd been inviting all these student groups.

I've told the story a number of times. I called my friend who is no longer living now — this was years ago — the Director of Special Education for the northern St. Louis County. I said, "Why is it all these groups of citizens come in to visit the courthouse — we give tours, we talk about rights and justice — never see people with disabilities or special education students?" I should have known him well enough to have known that's all it would take. For the next few months, I had every special education group of students in my courtroom. I don't think we missed one school district in all of northern St. Louis County. Then one day I get a call from a group of social workers and parents saying, "We know we've heard about what's going on at the courthouse, but there's a whole group that's been forgotten here through nobody's fault perhaps: adults with developmental disabilities. They've never been invited to your courthouse." So in we came one day —and I have a picture of them because it was such a special day for me — and well, the first thing that happens is, again these assumptions, these stereotypes, just because we communicate differently, that people don't understand, and they track the information the same as everyone else — and in almost all cases they do. So a young woman, probably I call it young now, because I'll be 60 next year, but a young woman raises her hand in her 30s and said, "Well, you've talked about equal justice, I'm someone that has ... I have a disability. Does that mean I get the same rights as the wife of the President of the United States in the White House?" And I turned to her and said, "That's exactly what it means." Then on kind of a sad but very moving moment then — this is something that gets a lot of ... I think is getting more publicity thankfully today — at the end of our tour and interview the social worker comes up to me privately and said, "We have three women all with disabilities here in your group and they've been sexually harassed, sexually abused — one has been raped. They're getting no help from law enforcement or anyone else. Would you talk to them?" And, truthfully, until that moment, even though I'd dealt with competency issues I'd never really thought about the fact that, as it turns out, nearly 85 percent of all women with developmental disabilities will be sexually harassed or abused during their lifetime.

Interviewer: What is being done to reduce the abuse?

Judge Frank: Well, there's some projects underway. In fact, again, thanks to ... I would have to say — because I don't want to leave the impression that suddenly people like me and other lawyers in the state and federal system have somehow suddenly got enlightened — we've been trained by the disability justice community, the self-advocates, the people who are in these ... and I keep ... she'll chastise me when we're done; Colleen Wieck takes no credit for anything, but people like

her, and the unsung heroes and heroines, I would say, they have not let us get off the hook. They respectfully... they get these things in front of us and they don't go away. And they say, "What are you doing about this," you know, "Does your walk follow the talk?" And they always do it in an appropriate way. Well, because of them, not because of any enlightenment that I came up with on my own one morning. They've gone to county attorneys. Well, there's a small group of us that are going to make a presentation later this year, and a statewide seminar to all prosecutors, on competency issues as it relates to the not stereotyping, and they're going to prosecute and investigate. Because it's just not prosecutors; it's police, it's other people like that, law enforcement with no ill intentions, but the effect on the victim of the crime is the same. We're going to be doing some training and a CLE (Continuing Legal Education) on competency issues as it affects the inability to prosecute, or refusal to investigate and prosecute, and one person who is making sure it's happening — because he's an influence in this disability justice — is Jim Backstrom, who has been the contact with me and others. So he... a group of us are going to go. Lots of things like that are happening that weren't on anyone's radar less than just, I think, a few years ago.

Interviewer: How have self-advocates helped you?

Judge Frank: "You remind me and you teach me what my oath of office means about equal justice, and you make me a better person." Because you know, we need reminders like that. Well look at, let's just tell you the journey we've been on, let's tell you about what we believe and what's important to us. And you're not with people and individuals like this without walking away... I get re-energized every time, and I wish I could say that about everybody else I know (laughs). No offense, but if you haven't met these individuals you are going to be... it'll be a good time.

Interviewer: What does the future look like for people with disabilities?

Judge Frank: Well, I'm optimistic both with the... because for a couple of reasons. One, I have seen the EEOC take a much more aggressive — in a positive way — role. And I've seen, for example, civil divisions of our local U.S. Attorney's Office. That's why they're all involved when we talk about going out and speaking to the community. They've been going with me. So the head of that... I don't know if it happened in other parts of the country, but it didn't happen a few years ago. More importantly, I think that even at that, with the changes, as the stereotypes fall — and they fall when people are working in the community, they're working in a building like this, they are living in the community, you

don't work and live and participate in serious things, fun things, with individuals with disabilities without learning something — and when that happens and the stereotypes fall away, equal opportunity increases. And maybe finally we're closer — we're not there yet — to that promise that the Constitution gives everybody of equal justice, equal opportunity. And there's still a lot of discrimination and bias, and I think people have to understand, I'm not talking about pointing a finger at someone and saying, "You intentionally discriminated" — that goes on, but much, much less. It's acting on stereotypes and assumptions about individuals with disabilities, and to meet individuals and to have them working and living with us as all citizens have a right to do — and they have been, for too many years, the forgotten minority — they are the best advocates for themselves. And so, I'm optimistic as I sit here today. I can look you straight in the face and say, "I think we've come a long way." We've got a ways to go, but I'd say, it's mostly because of the disability justice community and those individuals with disabilities, they do not let us live each day in ignorance, and they're their own best advocates. And when that happens — and it's been happening — changes are made. I would just tell you that is the reason why we're soon to have what's called a Minority Bar Summit. I happen to be President of the Federal Bar Association this year and one of my best friends — maybe he is my best friend, Chief Judge Michael Davis of the Federal Court — we're having what's called a Pro Se Bar Summit. And, as we speak, there is a one hour seminar being put together to train all these lawyers on disability discrimination. And we're saying, "You've all heard about race discrimination, other types of discrimination: We're here to educate you and train you and please don't use the word diverse anymore." I am repeating what I have been told without using the words disability discrimination, and that is going to be a central piece of this summit. We're bringing all state, pro bono areas, referral services, federal, we're all coming together and that's going to be a centerpiece of that. Because for example: Who do you call if you're an individual that's poor and if you have a disability, or you're in another minority group; who do you call if you're being discriminated against?

[Interviewer asks about the future of home services, employment, and security]

Judge Frank: Well let's... since you raised the issue of the future, let's talk about... if I may say something, you know, and I'm saying this irrespective of political parties and so forth — because, as a sitting judge, I can't talk politics, and I don't think this is... if it's politics, it's not party politics; it's the parties will have to come to terms with it as government agencies will. But unfortunately the disability community is — I'll use that phrase in a very respectful way — they're vulnerable to the

same thing and difficult economic times in non-mandated services as other minority groups, is sometimes those non-mandated services are the first ones to get cut. Health care, you know, dental care, there's a long waiting list of people; individuals with disabilities — who the law gives them the privilege and the right to live on their own in independent living or a much less restrictive form of supervised living — people are on waiting lists because of processing. So I still will remain optimistic, but I do worry about some of the budget cuts. Public transportation, as I mentioned earlier, that disproportionately affects individuals with disabilities and that has to be on people's radar screen, because it just isn't depriving someone of a ride, it's depriving someone of a job, which is depriving someone of being a productive member of the community when they have all the skills to be. And so, I do worry about that piece, because I've watched, and it just isn't... it's services for... there's a lot of different people that get affected, just not those with disabilities. Chemical dependency services, people for those... there's a number of areas where those non-mandated services get cut, so why do I remain optimistic? Because of self-advocates. Because of training and education, of reaching people like me and others who have a responsibility, as well as to lend a caring and responsible hand. Well, the first webcast was done a few months ago on disability discrimination, and more are going to follow. Two law schools now — there was one, now there's two — they have disability law societies. That wasn't even being discussed two years ago.

Solidarity Forever

Justin Dart, Jr., a leader of the international Disability Rights Movement and a renowned human rights activist, is widely recognized as the advocate father of the Americans with Disabilities Act (ADA). He gave recognition to the “tens of thousands of people who fought for the first civil rights law in the history of the world for people with disabilities.”

The CD *Solidarity Forever!*, created by Jeff Moyer, includes a background narrative that provides a context for the origins of the music. The narrative accompanies Justin Dart’s oratory and explains how the music came to be recorded. Each song relates in some way to disability history, and the role that each plays in that history is explained.

A video titled, “Storyville” featured Mr. Dart and a few of the people who were a part of the great fight for civil rights: Patty McGill Smith, Jane Smith, Brad Johnson, Jim Dickson, Becky Ogle, Claudia Gordon, Pat Wright, Kyle Glozier, and Sarah Reinersten.

Justin Dart died on June 22, 2002.

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