

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Project

Thomas K. Gilhool

LEGAL ADVOCATE FOR DEINSTITUTIONALIZATION AND THE RIGHT TO
EDUCATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Interviews conducted by
Fred Pelka
2004-2008

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It is recommended that this oral history be cited as follows:

Thomas K. Gilhool, "Legal Advocate for Deinstitutionalization and the Right to Education for People with Developmental Disabilities" conducted by Fred Pelka between 2004 and 2008, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2010.



Thomas K. Gilhool

Fortieth Anniversary Symposium of the Public Interest Law Center of Philadelphia,
October 1, 2009. Photo by Lauren R. Mirowitz

ACKNOWLEDGMENTS

The Bancroft Library's Disability Rights and Independent Living Movement project was launched with field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education.

Funding from DBTAC-Pacific ADA, as part of a study of "Antecedents, Implementation, and Impact of the Americans with Disabilities Act," supported the continuation of the disability history program and the completion of the Thomas K. Gilhool oral history.

Thanks are also due to other donors to this program over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Raymond Lifchez, Raelynn Rein, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation.

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Table of Contents—Thomas K. Gilhool

Series History	xi
Interview History by Fred Pelka	xvii

Interview 1: September 23, 2004

Audiofile 1	1
-------------	---

Birth in Ardmore, Pennsylvania in 1938, grandparents' and parents' background—Grandfather and uncle killed in a mining accident, father also in the coal industry, working in a wholesaling office—Bus trip south in 1953, first exposure to discrimination when the bus driver enforces racial segregation as the bus crosses into the South—First experiences with black people, a black housekeeper who worked for his mother, the small black neighborhood in Ardmore, playing with housekeeper's son—Birth of his younger brother—Discovery that his brother had a disability, brother is labeled mentally retarded—Encountering the attitude that his brother's disability was his parents' fault—Father has a “nervous breakdown” in 1947, in part as a result of harassment at work due to being the father of a disabled child—Brother is sent to “special class” in public school—Family moves to Sauquoit, New York—More on father's breakdown, hospitalization and electric shock treatments—No discrimination against Bob among his classmates or peers—Two children on his block contract polio in 1950—Visits the Bryn Mawr polio wing—Memories of childhood friends and family occasions when Bob was included—Influence of Catholicism and the preaching of Bishop Sheen and Norman Vincent Peale—Never personally experienced guilt or shame about his brothers' disability, never blamed his family—Medical explanation for Bob's disability—Discussion of the eugenics movement—Bob institutionalized at Pennhurst State School in 1954, following father's death—Getting Bob admitted to Pennhurst—Discussion of the backgrounds of some of the judges in what would become the Pennhurst case—Ray Broderick, Milt Shapp, Arlen Adams—His role in having Bob institutionalized—Visiting Pennhurst “campus” with his mother—Family not allowed to visit when Bob first institutionalized, but then visited him quite often—Learning more about Bob's life later, during the Pennhurst trials—Bob's friends at Pennhurst, and the symbolism of “Jailhouse Rock”—“They talked a lot about restraints...and how lazy the attendants were...”

Audiofile 2	24
-------------	----

Bob transferred to White Haven, a former tuberculosis sanitarium—Bob's current medical problems—White Haven a better place than Pennhurst, Bob able to come home for visits much more frequently—Discussion of staff at White Haven, Bob's relationships there—More details about Pennhurst: number of residents, description of the physical plant—History of Pennhurst, how it was founded after lobbying by the eugenics movement—Quotes from *The Menace of the Feebleminded* (eugenics pamphlet published in early 1900s)—Reads from the

appendix to the Olmstead case on history of Pennhurst—Gilhool’s first involvement with poverty rights/minority rights law—Goes to his first law firm and then to Community Legal Services—Reasons for going to law school—Time at Yale Law School—Involvement with the National Student Association, gathering support for southern civil rights student activism in early 1960s—Growth of northern student movement—Helping to pull together the Law Students Civil Rights Research Council—Doing legal advocacy on poverty issues as part of the Yale Law School Tutorial Project—Writing about the similarities between poverty law and the framing of the protection and advocacy systems—Graduating law school, going to England as a Fulbright scholar—Working in Philadelphia finding plaintiffs for the Girard College civil rights case—Other civil rights work in Philadelphia—Helping to found the Community Law Service (CLS)—Work trying to save poor peoples’ homes from being destroyed by “urban renewal” and beating back plans for an eight lane expressway through Philadelphia—Fighting residency requirements for public assistance and fighting for legal services for poor people—Organizing the Philadelphia Welfare Rights Organization—Getting the first call from PARC about taking their case (*PARC v. Pennsylvania*)—Meeting Jim Wilson and Dennis Haggerty from PARC—Gunnar Dybwad, and his son Peter Dybwad—Learning about the ARCs, and the parents movement—The objective of the suit was to close down Pennhurst.

Audiofile 3

45

Framing *PARC v. Pennsylvania*—Unease and controversy within PARC and ARC about the wisdom of bringing a lawsuit, of trying to shut down the institution—Role of Gunnar Dybwad in that decision—Gilhool “disappears” for nine months to research the law and develop a strategy—Meetings with Dybwad, Jim Gallagher and Donald Steadman—Gunnar and Gilhool become “intellectual companions”—Dybwad’s immediate recognition of the importance of *Brown v. Board of Education* to disability rights—Dybwad’s special relationship with PARC—“Right to treatment” and PARC—Mental health law as cutting-edge civil rights law—Decision to frame *PARC v. Penn.* as a right to education lawsuit—Secret tape recordings of arguments before the Supreme Court—Discussion of a 2004 conference in New York City of Pacific Rim legislators, rehabilitation professionals and disability rights activists from Japan and South Korea.

Interview 2: April 11, 2005

Audiofile 4

59

Decision by Eleanor Kephart to resign from ARC because of the PARC decision to litigate—Others in the ARC reluctant to sue the state—Tension in ARC between providing services and doing advocacy, similar tensions evident in Japanese movement today—The development of the legal strategy for *PARC v. Pennsylvania*, five possible strategies were considered: the right to education, the right to treatment, due process, et cetera—Some strategies rejected for fear a victory would strengthen institutions, rather than close them—Development of

treatment in the community as a right—Development of community services in Pennsylvania—The “Matched Twins Study” and its use in the Pennhurst case (1977)—The open purpose of the PARC case was to close down Pennhurst, controversy around this idea within PARC—Explanation of the “double barreled” legal approach in *PARC*: equal protection (under *Brown v. Board*) and due process—Lack of access to education meant that disabled children were at risk for being institutionalized—Description of the state laws excluding children with disabilities from public schools.

Audiofile 5

85

Learning from the mental health deinstitutionalization movement—Safeguards against homelessness of deinstitutionalized people during the Pennhurst case—Who was sued during *PARC*: decision not to sue the governor as an individual, to allow him leeway to intervene politically—Decision to file in the interregnum between administrations—Getting coverage in the *New York Times*—*PARC* connections to the *Times*—Media strategy, who was in charge, who it was designed to influence—Op ed piece in the *Times*—Impact of *PARC* case on the drafting of Section 504 of Rehabilitation Act of 1973.

Interview 3: April 18, 2005

Audiofile 6

96

Gilhoole developing the legal strategy to *PARC*—Role of Gunnar Dybwad, Fred Weintraub, Alan Abeson, Paul Dimond, David Kirp—Relationship of Gilhoole to *PARC*, Jim Wilson, L. Stuart Brown—The trial itself, *PARC* witnesses testify: Ignacy Goldberg, Jim Gallagher, Don Steadman, Burton Blatt—Commonwealth of Pennsylvania concedes the case—Reasons why the state conceded—Negotiating the consent decree—*PARC* in the context of Pennsylvania gubernatorial politics—“Zero redact education”—Negotiating with the attorney general—Local school districts oppose the draft of the consent decree—Arguing for the decree before the panel of three federal judges—Impact of judges Arlen Adams and Ray Broderick—Negotiations on regulations enforcing the decree—Conducting a census to find children with disabilities—Ed Martin, Ed Sontag, and training teachers pursuant to *PARC*—Norris Haring, Lou Brown, and the founding of the American Association for the Severely and Profoundly Handicapped (AAESPH) (predecessor of TASH)—Provision for “compensatory education”—*Burlington v. Dept. of Education of Massachusetts*—Formulating the integration provision—Children labeled mentally retarded still largely segregated in public education, despite *PARC* and IDEA—Never any discussion of including children with other disabilities besides mental retardation in the provisions of *PARC*—The *Mills* case in Washington, DC—Other cases following on *PARC*—Precedent used for children with all disabilities—“Tracking” in schools as a civil rights issue—Discussion of *Mills*, connection to *PARC*—*PARC* decree and due process hearings—“Legalization” of the hearings—IEP [Individualized Education Program] not a part of the *PARC* decree. Interview 4: May 2, 2007

Interview 4: May 2, 2007

Audiofile 7

124

Background to *Halderman v. Pennhurst*—Pennhurst established in the early twentieth century as an institution to segregate people with developmental disabilities—Role of the eugenics movement in the building of large state institutions—*PARC v. Pennsylvania* as first step in a strategy designed to close the state institutions in favor of community living arrangements—*Halderman* filed while Gilhool was teaching in California—Gilhool returns to Pennsylvania—PARC intervenes in the case—Mental health law and its role in providing cutting edge individual rights litigation—Legal underpinnings of *Halderman*—Halderman family, and the Parents and Family Association of Pennhurst—Preparing for trial, documenting conditions at Pennhurst—Shifting the legal strategy from “right to treatment” to “equal protection”—Intervention by the US Department of Justice—Importance of the intervention, role played by the Department of Justice—Role of Gunnar Dybwad—PARC and the National ARC—Resistance by some parents to the idea of closing the institutions—Differences in the way various Pennsylvania administrations responded to the *Pennhurst* litigation—Judge Raymond J. Broderick, and how he conducted the trial—Role of expert testimony, “It’s interesting to note that retarded people didn’t testify”—The twin study, and research on the feasibility and benefits of community residential programs.

Audiofile 8

145

Judge Broderick’s decision in favor of closing Pennhurst—The tipping point in winning Broderick over—Reaction to the decision—Building community programs, role of Title XIX of the Social Security Act—Importance of the Pennhurst case in paving the way for other deinstitutionalization efforts—Commonwealth of Pennsylvania appeals the decision—Decision upheld by the Appeals Court—Appointment of master by the court, implementation underway while the case is appealed—Missed opportunity for the labor movement—Thornburgh administration appeals the decision to the US Supreme Court.

Interview 5: December 14, 2007

Audiofile 9

156

Discussion of the role of a parents’ group [The Pennhurst Parent and Staff Organization] opposed to deinstitutionalization and demanding a “parental veto” of any movement of institutionalized individuals into community settings—Ambivalence of the National ARC to the idea of total deinstitutionalization—The ruling of Judge Broderick that “parents are welcome to participate” in the deinstitutionalization process, but not to veto it—Broderick’s ruling is affirmed by the Third Circuit Court of Appeals—Appointment of a hearing master by Judge Broderick—The case goes to the US Supreme Court—The role of the

Pennhurst staff union in the case, supporting the PPSO, and retaining attorney Joel Klein to file an amicus brief with the US Supreme Court—Klein’s role in crafting a legal strategy in an attempt to derail deinstitutionalization, leading to the Supreme Court striking down the Developmental Disability Services and Bill of Rights Act as “unenforceable”—The role of this precedent on subsequent Supreme Court decisions overturning the Violence Against Women Act, the Drug Free Schools Act, the AIDS Discrimination and Employment Act, and other statutes—The role of the Federalist Society in framing the case for these decisions, and Klein’s relationship to the Federalist Society—How the original *Pennhurst* Supreme Court decision might have been affected had the case come before the Court a year later—Congressional intent and authority as they relate to disability and general civil rights law, and how the Court’s perception of these issues has changed over time, and the role of *Pennhurst* as the forerunner of that change, as the Court has become more conservative—The use of the ADA [Americans with Disabilities Act] and the Home and Community Based Services Amendment in arguing the *Olmstead* case—The role of C. Boyden Gray at the Bush White House, his membership in the Federalist Society, his relationship to Evan Kemp and President George H. W. Bush—“Relationship trumps ideology” as an explanation for conservative support of the ADA—The two great strengths of the disability rights movement: its grounding in the quest for equality before the law, and the prevalence of disability and people with disabilities in almost every American family—The role of AFSCME [American Federation of State, County and Municipal Employees] in supporting the PPSO, and the work of Joel Klein, and the irony of a union framing a legal argument that will eventually be used by those opposed to organized labor—Gilhool approaching the leadership at the time of the Pennhurst litigation in a failed attempt to get AFSCME to support deinstitutionalization, in return for a commitment on the part of PARC to support the organizing of direct-care workers in community settings.

Interview 6: January 4, 2008

Audiofile 10

175

The *Pennhurst* case at the US Supreme Court for the second time—The possibility that conservatives on the Supreme Court “set a trap” for civil rights advocates—The role of disability in the family life of Chief Justice Burger and the impact this may or may not have had on his rulings—The *Pennhurst* case is sent back to the Appellate Court—The role of Arlen Adams and Max Rosenn—Litigation to recover legal fees for PILCOP—“Mental health” deinstitutionalization litigation as opposed to “mental retardation” deinstitutionalization litigation, and why Gilhool and PILCOP were opposed to mixing the two—How the *Pennhurst* case drove the creation of community services all across the country.

Interview 7: March 31, 2008

Audiofile 11

190

Conceptual evolution of the 504 training workshops of the late 1970s, coming out of the Legal Services trainings of the 1960s—PILCOP’s role in the 504 trainings—The role of Ron Mace, Sharon Mistler, Frank Laski, Ned Stutman, Jim Raggio, Deborah Yager, Nancy Zollers in the first 504 trainings—Designing the workshops—The first trainings done at Wilkes-Barre and Boston—“Logistics were a nightmare”—Description of the workshops—People with disabilities in general had little experience exercising citizenship rights—Developing ways during the workshops to overcome internalized oppression—The three rules of successful political advocacy—Who came to the workshops—Nurturing differing styles of advocacy—The “culture” of legal advocacy—Welfare rights advocacy as a forerunner to the 504 trainings—Marc Galanter, and “Why the Haves Always Come Out Ahead”—Follow up to the trainings, assessment and providing ongoing technical assistance to various advocates and groups—The impact of the trainings—Providing organizational infrastructure for the coming effort to pass the Americans with Disabilities Act.

Audiofile 12

212

Advocacy tactics, learning from Cesar Chavez—The movement’s need today for a contemporary equivalent of the 504 trainings—Effective CILs vs. ineffective CILs—The Parents Training and Information Centers [PTIs]—Role of PTIs in saving the Individuals with Disabilities Education Act—The evolution from advocate to service provider, especially in the parents’ movement.

Interview 8: April 16, 2008

Audiofile 13

219

Discussion of *City of Cleburne, Tex. v. Cleburne Living Center*—Attempt by local authorities to exclude community residences through the use of zoning ordinances—Decision by Fifth Circuit Court of Appeals to strike down the ordinance as unconstitutional—“The three-tiered system of equal protection” as “bad law, bad history, bad analysis”—“Functional families” and “unrelated persons”—The history of segregation of people with disabilities, as collected for the briefs by Tim Cook and Judith Gran—The Supreme Court’s rejection of “heightened scrutiny” of disability based laws—Gilhool’s justification of disability-based laws as needed to address the history of segregation and oppression—*Cleburne* briefs not a part of the ADA legislative history—The generational shift in how the courts have viewed the interaction between people’s lives and the law—Discussion of *Cleburne*, ADA, and *Olmstead*—Section 504 upheld—Reauthorization of IDEA in 1997, the struggle that “saved the ALL in the Education for All Handicapped Children Act”—Elizabeth Boggs, and the role of parent advocates—The roots of Normalization.

[End of Interview]

SERIES HISTORY by Ann Lage
Disability Rights and Independent Living Movement Oral History Project

Historical Framework

The latter half of the twentieth century witnessed a revolutionary shift in the worldview and legal status of people with disabilities. In major cities across the United States, people with disabilities began in the 1960s and 1970s to assert their rights to autonomy and self-determination and to reject the prejudices and practices that kept them stigmatized, isolated, and often confined to institutions or inaccessible homes under the care of family members.

Within a few years of each other, groups of people—usually young, often with a university connection, and frequently wheelchair users with significant physical disabilities—formed organizations in Berkeley, New York, Boston, Denver, St. Louis, Houston and elsewhere to foster independent living in the community and to advocate for laws and policies to remove barriers to autonomy. Characterizing these groups, which formed relatively independently of each other, was the evolution of a new core set of beliefs that gave a distinctive character to this emerging disability rights and independent living movement. Their members came to insist on self-determination and control over their organizations. They resolved to make changes in their own lives and in society. And as they engaged in political actions, they began to recognize the shared experience of discrimination and oppression among groups with diverse disabilities.

Very quickly, informal regional and national networks of activists developed, often including people with a range of disabilities, who shared information about the nuts and bolts of funding, peer counseling, and service delivery. They joined together to advocate for essential personal assistance services and for the removal of architectural and transportation barriers. These networks were formalized in national organizations, such as the American Coalition of Citizens with Disabilities (founded in 1975), and national gatherings, such as the 1977 White House Conference on Handicapped Individuals, which served in turn as catalysts for national and grassroots organizing on a cross-disability basis.

From the beginning, the movement was a part of the activist and countercultural climate of the times, evolving within the context of civil rights demonstrations, antiwar protests, and the emerging women's and gay rights movements. Early leaders such as Judith Heumann, Fred Fay, Ed Roberts, Lex Frieden, and a host of others conceptualized their issues as a political movement, a struggle for the civil rights of people with disabilities. A wide-ranging group of activists absorbed this civil rights consciousness and cross-disability awareness during a series of defining political actions, such as the nationwide sit-ins and demonstrations in 1977, organized to demand the issuance of regulations for section 504 of the Rehabilitation Act, and during the subsequent peer trainings on the rights of people with disabilities, which were carried out nationwide.

As the political movement grew, the new cadre of activists made connections with the emerging parents' movement and its efforts to free people with developmental disabilities from the massive and dehumanizing state institutions of the time. A series of landmark federal lawsuits, most notably *PARC v. Pennsylvania* (1972) and *Mills v. Board of Education* (1972), established

for the first time a right to a public school education for children with disabilities. Alliances and coalitions also developed with a number of traditional, disability-specific organizations, which were themselves undergoing changes during this period.

New organizations devoted to pursuing legal and legislative reforms, such as the Disability Rights Education and Defense Fund (1979), ADAPT, a grassroots direct-action organization (1983), and a growing number of other local, state, and national disability organizations and alliances profoundly influenced national policy in education, transportation, employment, and social services. Their best known legislative victory was the passage of the Americans with Disabilities Act in 1990, which, although compromised by subsequent court decisions, offered broad civil rights protection for disabled Americans and has served as a beacon for the creation of disability rights legislation in fifty other countries.

Less concrete than the legislative accomplishments and legal cases, and still evolving, is the shift in attitudes and consciousness that was driven by, and has transformed the lives of, people with a wide variety of physical and mental disabilities, challenging the notion of disability as stigma and instead embracing disability as a normal facet of human diversity. Theoreticians and artists with disabilities play a prominent role in defining and communicating concepts of disability community and disability culture, and academicians are promoting disability as a category of cultural and historical analysis.

These achievements, as significant as they are, have not ended the discrimination or the prejudice. Indeed, the first years of the twenty-first century have seen several Supreme Court decisions which have limited the expected scope and effectiveness of disability rights law, and many disabled Americans remain economically and socially marginalized. While the need for change continues, the tremendous accomplishments of the disability rights and independent living movement cannot be denied. American society has been profoundly transformed, and any accurate account of the social and political landscape of the late twentieth century will acknowledge the contributions of disability rights and independent living activists.

Project Design, Interviewees

The Disability Rights and Independent Living Movement Project at the Regional Oral History Office, the Bancroft Library, UC Berkeley, preserves, through oral history interviews, the firsthand accounts of the activists who have made significant contributions to the origins and achievements of this movement. The Bancroft Library also collects, preserves, and provides access to the papers of organizations and individuals who have been a part of the struggles for disability rights and independent living. All of the oral history texts, finding aids to the archival records, and selections from the archival papers and images are available on the Internet, as part of the Online Archive of California, California Digital Library.

The first phase of the project, completed in 2000, documented the movement during its formative years in Berkeley, California. Berkeley was the site where the concept of independent living was most clearly articulated and institutional models developed, originally by and for students on the Berkeley campus and soon after in the community, with the founding of the nation's first independent living center in 1972. These organizations and their dynamic leaders, together with the activist tradition in the Bay Area and a disability-friendly climate, made Berkeley an

important center of the disability movement and a natural focus for Phase I of the project.

During Phase I, Regional Oral History Office interviewers recorded forty-six oral histories with Berkeley leaders, many of whom have also been figures on the national scene. The Bancroft Library collected personal papers of interviewees and others in the disability community and archival records of key disability organizations, such as the Center for Independent Living, the World Institute on Disability, the Disability Rights Education and Defense Fund, and the Center for Accessible Technology.

Phase II of the Disability Rights and Independent Living Movement Project (2000-2004) expanded the oral history research and the collection of archival material to document the growth of the movement nationwide. The project again focused on those leaders whose activism began in the 1960s and 1970s. The forty-seven Phase II interviewees include founders and organizers of disability rights groups and early independent living centers in New York, Boston, Chicago, Texas, and California. Of these, many have also been national leaders in the movement and founders of national organizations who helped to conceptualize disability rights as a political movement and shaped the programs and philosophy of independent living. Others have been key figures in the development of disability rights law and policy, as organizers, strategists, and lobbyists behind the scenes. The project's ongoing Phase III has continued interviews with the founding generation, but incorporated leaders whose involvement began in the 1980s and 1990s.

A number of interviewees have held positions in state and federal government agencies and commissions, helping formulate government law and policy on transportation access, social security and health benefits, and personal assistance, education, and rehabilitation services. Several have worked to free disabled people from institutions, and others reflect on their own experiences living in institutions. Some interviewees were deeply involved with the parents' movement.

The international disability movement is represented by Yoshihiko Kawauchi, a leading proponent of universal design and disability rights in Japan; many American activists interviewed for the project also have connections to the international movement. Two interviewees are pioneering artists with disabilities, who discuss their careers as artists and the relationship of art and advocacy. Several have taught disability studies at colleges and universities, contributing to the concept of disability as a category of analysis analogous in many ways to class, race, gender, and sexual orientation.

Interview Themes and Topics

An overarching research goal for phases I and II of the Disability Rights and Independent Living Movement Project was to explore and document how a broad group of people with disabilities, in key cities across the country, initiated and built this social movement, and how it evolved nationally, within the context of the social and political fabric of the times. Lines of inquiry include social/economic/political backgrounds of interviewees and family attitudes toward disability; experiences with medical and rehabilitation professionals and with educational systems; identity issues and personal life experiences; involvement in civil rights or other social movements of the era; and developing consciousness of disability as a civil rights issue.

Interviews record how people with disabilities built effective organizations, with information about leadership, organizational structure and style, organizational turning points, stumbling blocks, achievements, and failures. Challenges particular to the disability community are addressed; for example, leaders of independent living centers point out the difficulties of providing much-needed services to clients and answering to government funding agencies for their service mandate, while still maintaining the essential advocacy roots of the independent living movement.

Interviews explore the building of national alliances and coalitions, investigating networking among groups from different locales and among groups accustomed to aligning on the basis of a single disability. Indeed, the issue of inclusiveness within the movement—the nature and meaning, and sometimes tenuousness, of cross-disability alliances and the inclusion of newly recognized disabilities—is a complex and significant theme in many project interviews, and offers an area for future oral history research.

Interviews document the range of efforts—from protest demonstrations, to legislative lobbying, to litigation in state and federal courts—to influence disability law and policy, to embed disability rights into the canon of civil rights, and to alter and expand the very definition of disability. Several interviews also reflect on a recent philosophical shift of some movement thinkers, who draw on a human rights framework and acknowledge the disability community's need for social supports along with equality of opportunity and civil rights.

Also examined by many narrators are race, gender, and sexual identity issues: the role of women (large) and minorities (limited) in the movement; the development of programs for women and girls with disabilities; questions of sexuality and disability; and the disability movement's relationship over the years with the women's, gay and lesbian, and African American civil rights movements. The involvement of able-bodied advocates, including parents of children with disabilities, is examined by many interviewees, both disabled and able-bodied, with telling accounts of often awkward and sometimes painful struggle over their place in the movement. (For instance, one organization toyed with the idea of granting able-bodied members only three-fifths of a vote.)

Another important theme running through these interviews is the question of equal access. This includes the impact of technological advances—from motorized wheelchairs in the early days of the movement to adaptive computer technologies more recently, all of which have profoundly extended opportunities for people with disabilities. And it includes the campaigns, legislation, and lobbying—on campuses, in communities, and in Congress—for removal of architectural barriers to people with disabilities, for access to public transportation, and for access to personal assistance services, all essential requirements for independent living.

Many interviewees reflect on the process of developing a disability identity and a sense of belonging to a disability community. Several explore the concept of disability culture and its expression in the arts and in media, and theoretical explorations of disability by scholars and educators. Interviewees who have pioneered the fields of disability scholarship, arts, and ethics point out the contributions of disability studies to the broader society in fostering new and more complex ways of thinking about the body, about normality, about crucial ethical issues relating to abortion, euthanasia, and physician-assisted suicide; and in contributing a unique disability

perspective to scholarship in history, literature, and cultural studies.

Project Staff and Advisors

Since its inception the project has been collaborative, with staff members and advisors drawn from the disability community, from academia, and from the Bancroft Library and its Regional Oral History Office. The national advisory board for Phase II includes disability rights leaders Fred Fay, from Boston, and Lex Frieden, from Houston; scholars Frederick Collignon and Sue Schweik from UC Berkeley, Paul Longmore, historian from San Francisco State University, and Karen Hirsch, disability scholar from St. Louis.

Ann Lage directed the project for the Regional Oral History Office, providing years of experience in oral history and leadership for the interviewing team. Interviewers for the project had a unique set of qualifications, combining historical perspective, training and experience in oral history methods, personal experience with disability, and, frequently, activism and participation in disability organizations. Oral history interviews were conducted by Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, cofounder and former president of the Disability Rights Education and Defense Fund, policy consultant and lecturer on disability civil rights topics, and Henry Betts Award winner; Kathy Cowan, librarian for a public interest law firm; Esther Ehrlich, oral history interviewer and editor in the areas of disability arts and community history; Denise Sherer Jacobson, writer and educator on disability issues; and David Landes, former coordinator of student affairs for the Computer Technologies Program. Susan O'Hara, former director of the Disabled Students' Program at UC Berkeley and the initiator of the original idea for this project, served as consulting historian, occasional interviewer, and convenor of monthly project meetings.

Fred Pelka joined the interview team in 2000 and conducted major interviews primarily in the East. Pelka is a writer specializing in disability rights politics and history, author of *The ABC-CLIO Companion to the Disability Rights Movement*, and a recipient of a 2004 Guggenheim Fellowship for his proposed book, "An Oral History of the Disability Rights Movement." Harilyn Rousso, educator and consultant on issues of women and girls with disabilities, and Laura Hershey, writer and disability activist, also contributed interviews to the project.

Oral History and the Oral History Process

Oral history provides unique and irreplaceable sources for historical study. It preserves the reflections and perspectives of those who have participated in historical events, documenting with firsthand accounts how events happened, how decisions were made, and the behind-the-scenes interplay that underlies the public face of an organization or social movement. Beyond documenting what happened and how, the words of participants reveal the personal and social contexts and the institutional and political constraints which profoundly shape events but may not be apparent in the written record. Most significantly for this project, oral histories offer an opportunity to elicit reflections on often elusive matters of identity, changes in perception and consciousness, and the personal experience of living with a disability. Finally, they provide a record of how people remember and understand their past, often an indication of personal values and cultural meanings.

The DRILM project team all contributed to the design of the project and assisted in developing interview protocols. Once narrators were selected and arrangements made, they prepared a preliminary outline before each interview session, based on interview protocols, background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. The length of each oral history varied according to the length and complexity of the narrator's involvement in the movement, but also was dictated by scheduling and availability limitations.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and to give additional information when needed, but to preserve the transcript as much as possible as a faithful record of the interview session. Interviewees were offered the opportunity to seal sensitive portions of their transcripts, or omit them from the Internet versions. Many of the oral histories are supplemented by a videotaped interview session. Video and audiotapes are available at the Bancroft Library. The project Web site (<http://bancroft.berkeley.edu/collections/drilm/>) links to the full-text of most of the completed oral histories, with video and audio clips, and to related projects on Artists with Disabilities and the self-advocacy movement.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Richard Cándida Smith and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. Regional Oral History Office interviews can be accessed at <http://bancroft.berkeley.edu/ROHO/>. Print volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections.

The Bancroft Library's Disability Rights and Independent Living Movement Project was funded by field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education. Additional interviews, focusing on antecedents, implementation, and impact of the Americans with Disabilities Act, were completed for the project under a 2006 contract funded by DBTAC-Pacific ADA. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agencies.

Thanks are due to other donors to this effort over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Raymond Lifchez, Judith Stronach, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation. Special thanks go to Professor Raymond Lifchez for his generous donation in 2006 in honor of Susan O'Hara.

Ann Lage, Project Director
Regional Oral History Office

Interview History—Thomas K. Gilhool

Thomas K. Gilhool was invited to be interviewed as part of the project on the Disability Rights and Independent Living Movements because of his work as the lead attorney in *Pennsylvania Association for Retarded Children v. Pennsylvania*, his other significant disability rights litigation, his role in the 504 trainings of the late 1970s, and his general contributions to disability rights legal theory and practice.

Often characterized as the *Brown v. Board of Education* of the disability rights movement, *PARC v. Pennsylvania* in 1972 established the right of children with disabilities to a public school education. It was Gilhool who crafted the argument that the blanket exclusion of children with disabilities from the public schools was a violation of their constitutional rights to due process and equal protection under the law, resulting in a consent decree that became a precedent for much disability rights litigation to follow.

Like *Brown v. Board*, *PARC* had political as well as legal repercussions. Its success inspired the nascent disability rights movement all across the country, leading not only to a slew of similarly crafted right-to-education cases, but also lending credence to the idea that the treatment of people with disabilities was an issue of civil rights that were enforceable through litigation in the federal courts, thus moving beyond the medical, charitable and rehabilitation models of disability that had previously held sway. One direct outcome of *PARC* and the cases that followed was the passage, in 1975, of the Education for All Handicapped Children Act, since amended and renamed the Individuals with Disabilities Education Act, or IDEA. *PARC* was also an impetus to the drafting of Section 504 of the Rehabilitation Act of 1973.

For all its impact, the *PARC* litigation was only the first step in a legal strategy crafted by Gilhool and the leadership of the Pennsylvania ARC to close down the massive state-run residential institutions for people with developmental disabilities and replace these with community-based services. In 1974, Gilhool, representing the parents of institution residents, filed suit in *Halderman v. Pennhurst State School & Hospital*. The case was eventually argued by Gilhool before the US Supreme Court. Like *PARC*, *Halderman* would become a model for similar deinstitutionalization litigation nationwide.

Thomas K. Gilhool was born on September 10, 1938, in Ardmore, Pennsylvania. He earned his B.A. in international relations from LeHigh University in 1960 and both a master's degree in political science and a J.D. from Yale University in 1964. Gilhool first made his reputation as a legal advocate in several groundbreaking poverty law cases he litigated while an attorney with Community Legal Services, Inc., in Philadelphia, from 1966 to 1969.

I interviewed Gilhool by phone on eight occasions beginning in September 2004, with our final interview conducted in April, 2008. Although offered an opportunity to review the transcripts of these interviews, Gilhool declined, stating, "I hate reading my own transcripts." However, every effort has been made to make these transcripts as accurate as possible, and Gilhool made himself available for follow-up questions and clarification.

The oral history with Thomas K. Gilhool was initiated as part of the Disability Rights and Independent Living Movement project funded by a field-initiated research grant from the

National Institute on Disability and Rehabilitation Research, a division of the U.S. Department of Education. Funding from DBTAC-Pacific ADA Center for interviews on the antecedents, implementation, and impact of the Americans with Disabilities Act supported completion of the interviewing and processing the oral history. Interview transcripts are available for research in the Bancroft Library and in the UCLA Department of Special Collections. Audiotapes of the interview sessions are available for listening in the Bancroft Library. Transcripts of this oral history and others in the Disability Rights and Independent Living Movement series are on line at <http://bancroft.berkeley.edu/collections/drilm/>.

Fred Pelka, Interviewer

February, 2010

Interview #1: September 23, 2004
Begin Audiofile 1

01-00:00:00

Pelka: You understand that I have turned on the tape recorder, and you are being tape recorded, and—

01-00:00:05

Gilhool: Yes, indeed.

Pelka: —and that's ok with you.

01-00:00:07

Gilhool: Yes.

Pelka: This is an interview with Thomas K. Gilhool, on September 23rd, 2004. This is interview number one; this is tape number one, side A. Now, did you receive the questions I sent—

01-00:00:22

Gilhool: I did.

Pelka: —through the email? OK. So I'm going to go through— this is a shortened version of the interview format that I sent a while back, but—

01-00:00:31

Gilhool: I look forward to getting to that longer one at some point.

Pelka: OK, great. OK, well, first of all, just basic biographical information. Where and when were you born?

01-00:00:41

Gilhool: September 10, 1938, in Ardmore, Pennsylvania. We were living in Ardmore, Pennsylvania. I was born at Fitzgerald Mercy Hospital in Upper Darby, Pennsylvania.

Pelka: OK.

01-00:00:55

Gilhool: I was born in a house on Rising Sun Road, in Ardmore.

Pelka: Wow. OK.

01-00:01:02

Gilhool: You may remember that Ben Franklin closed, I believe, the Constitutional Convention by saying, "I have often sat here pondering the sun, which is on the back of the chair."

Pelka: Mm-hm.

01-00:01:21

Gilhool:

It was Washington's chair. I guess he was— And he said, "And wondering whether it was a rising sun or a setting sun. And I am now, after all of our work and deliberations, quite confident that it is a rising sun."

Pelka:

Mm. Mm.

01-00:01:46

Gilhool:

And that chair is owned by the Pennsylvania State Library, which, when I was Secretary of Education, was within my realm. And we used to have wonderful jokes about sending the State Police, in the dead of night some time, to take it back to Independence Hall—

Pelka:

[laughs] Ah.

01-00:02:10

Gilhool:

—[laughs] where it still sits, in the Declaration and Constitution room.

Pelka:

Oh. What was your family background? What did your parents do?

01-00:02:23

Gilhool:

My father, Thomas Martin Gilhool, was born in 1907. He was third generation. His grandparents had come, one in 1848, and his grandmother in 1851. And he— [pause] He had gone to the University of Scranton, which was then called St. Thomas College, a Jesuit university in Scranton. He was first in his family to college, and he, after three years at the University of Scranton, he went to the University of Pennsylvania to do, in the same year, the last year of college and the first year of medical school. And in June of 1925, his father and his brother Paul were killed in a mine accident in Archibald, Pennsylvania. His father and brother had been miners. His oldest brother Frank was a miner for all of his years, lived into his nineties. And he left medical school. And initially, he taught chemistry at St. Thomas College, and was delighted, I remember from my childhood, frequently to tell the story about when he—and understand, he died in '53, so my memories are from the late forties—he was always delighted to tell the story, post-Hiroshima and Nagasaki, that when he taught chemistry, the atom was the smallest indivisible unit of matter. [laughs] And then he went, like everyone, went into a different segment of the coal industry. Like everyone in Scranton. And it was a— What would you say? I guess it was sort of a broker. It was sort of a wholesale coal company, called Pennsylvania Hudson Company.

Pelka:

A what coal company?

01-00:05:08

Gilhool:

Wholesale.

Pelka:

Wholesale, ok.

01-00:05:10

Gilhool: They collected the coal from the mines, and then distributed it around the state, and probably around the region—called Pennsylvania Hudson Company. And then, in 1937, when he and my mother married, he came to Philadelphia, where he was with the Delaware and Hudson Coal Company, whose offices were here in downtown Philadelphia. Ardmore is a suburb.

Pelka: Mm-hm.

01-00:05:50

Gilhool: And he was an enormously bright, well educated, curious, too handsome for words— He used to travel the train a lot, especially during the war, and post-war as well, when exporting coal to Europe was such a big thing, and earlier, during the war effort. And people would mistake him, on the train, either for Stuart Symington or Cary Grant.

Pelka: Wow.

01-00:06:24

Gilhool: And my mother was the seventh daughter—{Francis?} Mary Kane was the seventh daughter of a seventh daughter. Her mother was of German lineage, and her father of Irish. Her father was also a miner, but had come to have a job above ground, essentially superintending running the coal breaker, about, oh, three-hundred yards down the road from their house, in Dixon City, Pennsylvania. And my mother was actually second in her family to college. An older, very much older sister had gone to Bloomsburg Normal School, way back in the 1910s. My mother went to Marywood College, which had only recently been founded, in Scranton, and graduated from there in 1929. And like my father, took all the prizes. And both of them were very much interested in theater. And our son [laughs] got those genes. And we lived in Ardmore until about 1951 or so, when I was in eighth grade, when we moved to Sauquoit,, New York, farming country in the middle of New York State, just south of Utica. And he ran the New York office of Utica Coal Sales Company.

Pelka: Wait, let me interrupt you for two seconds. Could you spell Kane for me? Francis?—

01-00:08:38

Gilhool: [Over Pelka] Yes. K-A-N-E.

Pelka: OK. And you just mentioned a town in New York, south of Utica.

01-00:08:45

Gilhool: Yeah, Sauquoit. Sauquoit. S-A-U-Q-U-O-I-T, an Indian word.

Pelka: OK.

01-00:08:53

Gilhool: I went to Sauquoit Valley Central School, after parochial school here in Ardmore.

Pelka: OK.

01-00:09:02

Gilhool: And then I was dispatched for a wonderful month, in the summer of '53, to next door neighbors from Ardmore, who now lived in Miami, and took a bus ride both ways, through the South, across the Mason-Dixon Line. It seemed to me, in memory, many times [laughs] crossing the Mason-Dixon Line, because it was shuffling seats on the bus. And that's when I first became aware of—well, in some sense—the race question.

Pelka: Hm.

01-00:09:47

Gilhool: In any event, I came back to learn that my father was dying. And he died of pancreatic cancer, on October 12th of 1953. And then we returned to Scranton, Pennsylvania, near where my mother and father had both been raised.

Pelka: Mm-hm.

01-00:10:11

Gilhool: My mother had been a teacher of Latin, between her graduation from college and their wedding, in public schools in Dixon City, Pennsylvania; and did not work during all of the time my father was alive; and then returned to working afterward. Socioeconomic status was probably pretty good. That is to say, I don't even know how to do the quintiles at that time.

Pelka: Mm-hm.

01-00:11:00

Gilhool: We weren't rich, by a long shot, but we were certainly middleclass, and maybe upper-middleclass.

Pelka: OK. Let me... OK, the tape is on again.

01-00:11:09

Gilhool: My sister Beth is three years younger than I. She was born November 11 of 1941; and Bob is three years younger than she, born February 25th, 1944.

Pelka: OK. I want to just back up two seconds. You talked about shuffling seats once you got to the Mason-Dixon Line. Maybe you'd elaborate on that just a little bit. What do you mean by that?

01-00:11:38

Gilhool: Well, I mean it literally. I remember crossing one state line. And I may misremember that it was crossing into Florida.

Pelka: Mm-hm.

01-00:11:48

Gilhool: And I had been, for some time on this trip, seated in the next to the back seat, with a black man, who maybe still was, but had recently been in the army, and stationed in Germany. And we had a wonderful long conversation about the difference in how he was treated and felt, when he was in Germany, as against here. He joined the passengers sometime after my first experience of a rest stop, probably in Virginia, maybe in Maryland, where the bathrooms were segregated and had the usual signs. And I can vividly remember the water fountain. And we were having this wonderful conversation, in which he found post-war Germany's appreciation of a black man and treatment of him much better than what he had experienced in the United States.

Pelka: Mm-hm.

01-00:13:03

Gilhool: And then at some point, as I remember, as we reached a state line, the bus driver stopped the bus and asked me to come up front. And he said, "There are seats up front now, and you have to move up front." [laughs]

Pelka: Mm.

01-00:13:24

Gilhool: Because blacks and whites can't sit together.

Pelka: Hm.

01-00:13:29

Gilhool: And I was then a sophomore, I guess, in high school.

Pelka: Mm-hm.

01-00:13:39

Gilhool: And I remember writing an essay for the [laughs] opening of the school year, in the English class, about all of that. And I no longer remember whether I moved or whether I didn't move.

Pelka: Mm.

01-00:13:56

Gilhool: I have no memory of that, of which I can be certain.

Pelka: Hm.

01-00:14:02

Gilhool: And it's kind of fun sometimes to tell the tale, and some people will say, "I'll bet you moved." [laughs] And some people won't say. [laughs]

Pelka: Hm.

01-00:14:19

Gilhool: Anyway.

Pelka:

OK.

01-00:14:22

Gilhool: That was an impressive experience. But it was not my first experience of race. Just to jump into the middle a little bit, of your questions about my brother, we— My mother and father had a woman who lived in South Ardmore, which was the small black neighborhood of Ardmore, in the late forties, who cleaned, once, maybe twice a week, for them. And very frequently, she would bring her son with her. This now probably is preschool, late forties, middle-late forties. And I remember remembering that when other people in the neighborhood were not so enthusiastic about playing with Bob, Scooter was always engaging with him. They were contemporaries, the same age. And I remember in 1961, on the first evening of the gathering of people from many college campuses to start, here in Philadelphia, the Philadelphia Tutorial Project, college students tutoring black high school kids and junior high school kids. And we all sat around the kitchen at [pause] Berean Institute, in North Philadelphia, telling about what brought us there. I remember saying that Scooter was my first experience of race, and it really meant a great deal to me about the dignity of black people and so on, that he struck this continuing relationship with Bob.

Pelka:

Mm.

01-00:16:44

Gilhool: And that I was sure that a great deal of my interest in the civil rights matters had arisen from that.

Pelka:

Mm-hm. You said the Berean Institute?

01-00:17:00

Gilhool: Yeah, B-E-R-E-A-N.

Pelka:

OK.

01-00:17:03

Gilhool: It was actually run by Bill Gray's father. Do you remember Bill Gray, who resigned from the Congress about twenty years ago? [William H. Gray III, Congressman from Pennsylvania 1978-1991]. He was number three in the House hierarchy. He had been on the Budget Committee, which was then new; was about to become chair of the Budget Committee. And in the years since, would've been, [laughs] as it turns out, Minority Leader of the House. That was Senior Bill Gray's son.

Pelka:

Hm.

01-00:17:34

Gilhool: And Berean Institute was his place. And two people, who then became very dear friends, kinda cooked dinner for us [laughs] that night, as we all explained where we were coming from.

Pelka: Mm-hm.

01-00:17:47

Gilhool: And one of them was Bill Gray's older sister, {Marion?}, and the other was Chris [Christine] Philpot, who later turns up a year behind us at law school, and did some very significant things over the last couple of decades. Christine Philpot, and {Marion?} Gray, she's a teacher of ethics at Howard Divinity School, for many, many years.

Pelka: Now, is that Howard Divinity?

01-00:19:06

Gilhool: Howard, yeah.

Pelka: Yeah, ok. As opposed to Harvard.

01-00:19:09

Gilhool: Washington.

Pelka: OK.

01-00:19:10

Gilhool: And during that summer, she and Paul {Dandridge?} and a woman whose first name was Carol and whose [laughs] last name is out of my head, and I used to double date. And young Bill Gray, who was then a late teenager, we would often sit in front of her house in Paul's car, and Bill would come loping by. Anyway. So that was '61, probably.

Pelka: [Over Gilhool] Yeah. OK. I want to get back to your brother.

01-00:19:51

Gilhool: Yes.

Pelka: You know, your brother was six years younger than you—

01-00:19:55

Gilhool: Right.

Pelka: —is that right? Born in 1944. And he had a disability, is that right? Has a disability.

01-00:20:02

Gilhool: Yes.

Pelka: OK.

01-00:20:03

Gilhool: Yeah.

Pelka: OK. Could you talk a little bit about that? Was he born with a disability? Or was this was acquired disability?

01-00:20:10

Gilhool: He was born with it. And there were the debates usual for the time: Was that because oxygen was cut off at birth? Or why was it?

Pelka: Uh-huh.

01-00:20:21

Gilhool: And I don't— There aren't any answers to that question that are reliable. But he was retarded from birth. That was not noticed initially. He was active and rambunctious and very curious, as an infant and a toddler; was slow to talk and slow to toilet train. And whether before or after my mother and father got a diagnosis, I remember conversations about, "Well, Einstein was slow to talk."

Pelka: Mm-hm.

01-00:21:11

Gilhool: That kind of conversation was also kind of common among families with retarded members then. The Einstein stories were famous. And I think probably in many developmental disability families who had spent some time in colleges and such like—that was a frequent reference.

Pelka: Mm.

01-00:21:33

Gilhool: I also remember that the diagnosis was very wrenching to my mother and father. And I came to understand that that was, in significant part, because of the learned and then, certainly, and in many places for a long time after, and still now, the learned understanding that it was, of course, the parents' fault; that these things were genetic, not to say eugenic; and that they should be embarrassed and ashamed, and feel guilty. And in my father's instance, he had, probably in 1947, what was then called a nervous breakdown. And this matter and his work situation were very much intertwined in that breakdown. He had been the heir apparent of this small in size, small in office staff— I mean, there couldn't have been more than twelve people running this company, but in the coal industry, an important company. And he had been the heir apparent. And the fellow who was president of the company— I couldn't trace it all, by any means, but I remember the sense that Darlington had begun to use Bobby against my father.

Pelka: Hm.

01-00:23:42

Gilhool: And the two questions got all intertwined. And after his breakdown, he left there, after recovering from it. And that's when we moved to Utica, New York.

Pelka: Hm. How old were you, and how old was Bob, when you received this diagnosis?

01-00:24:05

Gilhool: I think it was probably, though I don't have any way to know, it was probably around '47.

Pelka: OK.

01-00:24:14

Gilhool: Maybe late '46, '47. It was certainly post-war.

Pelka: OK.

01-00:24:20

Gilhool: And it was— [pause] Well, now, let me see. We moved from Ardmore in 1951. I think my father's breakdown was somewhere in the period '47 to '49.

Pelka: Hm. OK. So certainly, the attitudes then were, it sounds, fairly repressive.

01-00:24:51

Gilhool: Yes.

Pelka: Can you talk a little bit more about that? I mean, how— It sounds like your parents adopted, internalized a lot of those attitudes.

01-00:25:03

Gilhool: Yes, I think so.

Pelka: Yeah.

01-00:25:05

Gilhool: Absolutely. And I think that was entirely common. One of the questions you asked was, was there any relationship to the movement, or the ARCs [Association of Retarded Children, now known as The Arc] or what have you?

Pelka: Mm-hm.

01-00:25:21

Gilhool: I don't remember any such relationships, either from the late forties or from our time in Utica. Though I wouldn't be surprised that there were some inchoate relationships, as the ARC was being founded.

Pelka: Mm-hm.

01-00:25:39

Gilhool:

My brother went— We were going to a parochial school in Ardmore, called St. Dennis. And I remember he went in our last year, probably '50, to a public school, in a bit of a different direction in Ardmore, to a special class. And I also remember that it was— Sometimes it was hell on wheels. [laughs] And I think he sometimes went and sometimes didn't go, and so on. And I do not know what kinds of parental support groups, if any, there were around that fairly early education program. But— Then when we went to Sauquoit, we lived in a village just outside of Utica, and my father's office was in Utica. And he had a similar kind of relationship. I can remember the name of the teacher, Mrs. {Updegraff?}.

Pelka:

Mm-hm.

01-00:27:03

Gilhool:

Or {Upgraff?}, I guess, without the D-E, who was the teacher. And he went to this kind of freestanding class for retarded kids, in the city of Utica itself.

Pelka:

Mm-hm.

01-00:27:22

Gilhool:

Again, not with any steadiness or any particular payoff. So that was pretty much his experience of education.

Pelka:

Mm. I want to back up a little bit. You said that the president of the company used Bob against your father.

01-00:27:46

Gilhool:

Yeah.

Pelka:

Can you talk a little bit more about that?

01-00:27:49

Gilhool:

Well, I don't have a terribly clear picture. But I just remember in the moments of being distraught, including occasions at the start of my father's breakdown, that one of the things that had my mother and father very much upset was that; that somehow, there was something wrong with my father, Darlington was saying, because they had this youngster Bob, who was disabled. And I just figured it was just the whole kind of— This fellow, as he comes through to me, was a very mean guy, who, for a set of reasons I do not know now, suddenly wanted to reverse—it certainly came through to the family as suddenly—the relationship with my father. And he used that in surrounding my father with what we would now call a hostile environment, I suppose.

Pelka:

Mm. Mm. You said your father had a breakdown. Was he hospitalized?

01-00:29:21

Gilhool:

Yeah.

Pelka: OK.

01-00:29:22

Gilhool: I can remember going to the hospital. It was not an institution, it was a hospital. And I think he was probably there for a couple of weeks, and had, then common, shock treatments.

Pelka: So you had some fairly significant experiences with disability—

01-00:29:50

Gilhool: Yes, yeah.

Pelka: —as a child. Yeah.

01-00:29:52

Gilhool: And which I understood later, recapitulated very nicely the [laughs] social history of all of this—

Pelka: Yeah.

01-00:30:02

Gilhool: —driven by the eugenics stuff.

Pelka: Yeah. How about your relationships with your peers at school? Did the fact that you were first—

01-00:30:18

Gilhool: Never entered in. We were on a street with lots of kids, and I probably overdo the Scooter story, because each one of us—Beth and Bob and I—had peers in at least three, sometimes four or five families on the block. And everybody went to St. Dennis, and we all played touch football in the street. And Bob participated in that. Not a whole lot, but was not excluded. And there was none of that, that I recall, from—and I'm quite confident there wasn't any—from our peers. Two of the children on our block—one my sister's contemporary, and the other, Bobby's contemporary—had polio. Probably in— We left in the summer of '51, so it was probably as early as 1950 and 51. It's possible it was just after that. And I have a close friendship now, since we returned to Philadelphia, with Joe Bodell, who was one of them. And he will remember. But I can remember peering into the Bryn Mawr Hospital polio wing, where everybody seemed to be, you know, in an iron lung when they were there. And I don't remember any particular relationship made by anybody that there was this genus called disability; any relationship between Bob's situation and Joe and Sister's—she was called Sister Hudson—situation. But it was present, and— One of them was actually the national March of Dimes poster child [laughs] in the early fifties.

Pelka: Hm.

01-00:32:44

Gilhool: And I think it was Joe, but I'm not positive.

Pelka:

And then how do you spell his last name, Bodell?

01-00:32:52

Gilhool: Yeah, B-O-D-E-L-L.

Pelka:

OK.

01-00:32:53

Gilhool: And her name was Jeanette Hudson.

Pelka:

OK.

01-00:32:56

Gilhool: But she was called Sister. And I'm making notes on your questions, and I will ask Joe if I'm recollecting that correctly, and which of them it was who was the poster child.

Pelka:

Mm-hm. Yeah, and I'd actually like contact information for him at some point.

01-00:33:14

Gilhool: Sure. He's right here in Philadelphia. Unfortunately, Jeanette is taking care of an accident in a car this morning, or I would have at my fingertips the directory.

Pelka:

Mm-hm. Hold—

01-00:33:31

Gilhool: [Over Pelka] She's at a law firm called Bodell, Bove and some others. [Bodell, Bove, Grace and Van Horn].

Pelka:

OK. Hold on just a second here. [audio file stops, re-starts] OK, this is an interview with Thomas K. Gilhool on September 23rd, 2004. This is interview number one; this is tape number one, side B. OK, you were talking about Joe Bodell and—

01-00:34:26

Gilhool: He's Joseph T. Bodell, Jr.

Pelka:

OK.

01-00:34:30

Gilhool: His father worked for the Pennsylvania Railroad, whose headquarters were then at 30th Street Station. And not only did the children have strong relationships, but the family there had enormously strong relationships. And my father was, in many ways, the ringleader, and a great teaser. And I vividly remember gathering in our living room and in other living rooms of that

generation, in which all of us children, including Bob, were more or less included. I mean, it's the classic stories, sometimes of sitting at the top of the steps eavesdropping and so on.

Pelka: Mm-hm.

01-00:35:18

Gilhooll: But I remember thinking, at whatever stage of life it is when you wonder about these things, that I had always enjoyed conversations with adults more than [laughs] I did with kids.

Pelka: Mm.

01-00:35:32

Gilhooll: And that was a function of this remarkable neighborhood.

Pelka: Mm. Was there any— You talked about Bob's disability didn't seem to affect your relationship with your peers in the neighborhood. How about your father's disability? Do you recall any impact?

01-00:35:53

Gilhooll: No. And I think the response was very supportive.

Pelka: Mm-hm.

01-00:36:04

Gilhooll: And while I don't recall any particulars, I think it was not unfamiliar at that time, the late forties. Maybe because of the post-war. Maybe because of the war, maybe for other reasons. But the neighbors were enormously supportive, and he seemed to have lost none of the respect or affection or standing of— And I remember particularly— My father was not a notably religious person, but during that period of time, struck close relationships with two priests—I was, as you can imagine, an altar boy—with two priests at St. Dennis. That was quite meaningful to him. I also remember— You're just too young, probably, to remember Bishop Sheen.

Pelka: I know the name.

01-00:37:10

Gilhooll: Yeah. A television program in the early fifties.

Pelka: Yeah.

01-00:37:13

Gilhooll: Each week, I think on Thursday nights. And it was very much— I don't want to overdo the social action part of it, but it included that dimension. It was kind of that view. And also, very humanist. And Father Shine, particularly, and Father Riley, to another extent, were quite present to my father, and in a counseling and supportive relationship. And I remember that Shine

recommended that he should read Norman Vincent Peale. *The Power of Positive Thinking*. Which was also very big at that time, and in some ways, a 1950s defining element of our culture, I think. And there came a time later, when for me—and probably for many, and to an extent, almost culture-wide—when Norman Vincent Peale and *The Power of Positive Thinking* got to be scorned.

Pelka: Mm-hm.

01-00:38:37

Gilhool: Lots of jokes and stuff. Probably in part, [laughs] distributed by late-night television. But again, later—in, like, eighties, nineties—I reflected that what Norman Vincent Peale was about really was what we now call cognitive therapy.

Pelka: Mm-hm.

01-00:39:03

Gilhool: An uncanny—and it came not from any professional reach. The fellow who invented cognitive therapy, or at least developed it highly, is a Philadelphian, and an acquaintance, if not a friend of ours. And it's very impressive to me how much the Norman Vincent Peale—who I think of as having been a minister in one of those great New York churches—

Pelka: Mm-hm.

01-00:39:37

Gilhool: —either the one, I think not likely, that Bill [William Sloane] Coffin recently led.

Pelka: Riverside, or—?

01-00:39:47

Gilhool: Yeah, Riverside or one of those other upper Manhattan churches.

Pelka: [Over Gilhool] Yeah. Do you recall having an attitude towards disability, or thoughts about disability in general at the time? OK.

01-00:49:06

Gilhool: [Over Pelka] No. No, I don't think so. Nor, of course, did I know the word.

Pelka: Mm-hm.

01-00:40:20

Gilhool: I think, no, it was just a part of life.

Pelka: Mm-hm.

01-00:40:24

Gilhool: You know, it was just a part of the experience of life. And it was not very much a separate category.

Pelka: But you hadn't seemed to have incorporated the kind of eugenic viewpoint that your parents did, to a certain extent. I mean, you weren't wondering, "What's wrong with my family?"

01-00:40:50

Gilhool: That's very interesting. No. Never, to my conscious recollection. Absolutely never. And while I remember— [pause] Well, I guess I remember sharing what came to be my family's anger at Darlington's *use* of retardation.

Pelka: Mm-hm.

01-00:41:20

Gilhool: But there was never any pause, nor, I think intellectually, was there among my mother and father— Though a little bit, maybe. A little bit. And indeed, it became prominent in— at the time this was all going on. Bob had been delivered by a good friend of my mother and father's, who may have been in medical school with him. And the explanation, that it was a deprivation of oxygen at birth that caused Bobby's retardation, was clear.

Pelka: Mm-hm.

01-00:42:06

Gilhool: You know. And now that you ask the question, may have played an important part; it may have been sought in order to explore and negate the eugenic explanation.

Pelka: Mm-hm, mm-hm. Right.

01-00:42:23

Gilhool: And you raise a larger point, too. I remember when I told you about [laughs] the oxygen cut-off a few moments ago, I said that that etiology, that causal relation, whatever, was fairly common, I think, at that time. And it may have functioned to negative the eugenics stuff.

And remember, it was just postwar. And while I have no particular or general recollections of it, my guess is that the rejection of all of that— And of course, it was a rejection framed in terms of the Axis, but it was very widespread. And of course, the ARC was built, as it got organized by veterans and the rest, very much around that experience.

Pelka: Mm-hm.

01-00:43:39

Gilhool: And I must say, I guess it's a connection I have lightly made, but it may actually be the aggressive intellectual and social and political rejection of that

view of the world, which had been so dominant. And I now learn, dominant everywhere.

Pelka: Mm-hm.

01-00:44:04

Gilhool: The Japanese laws, Fred, as you saw, are just amazingly parallel to ours in their language and in the whole eugenic source. Starting with and dating before 1897, Japan eugenic law. But I think that may have been a coincidence in the history of ideas that significantly freed people not to retreat to the attic, but eventually, to become very much assertive. Self-assertive and assertive of personhood.

Pelka: Mm-hm. Now, eventually, Bob was sent to Pennhurst, is that right?

01-00:44:54

Gilhool: Yeah.

Pelka: OK. What—

01-00:44:57

Gilhool: [Over Pelka] That comes right after my father died.

Pelka: OK.

01-00:45:00

Gilhool: My father died on Columbus Day in 1953. [clears throat] We moved back to Scranton promptly thereafter. And Bob went to Pennhurst in '54.

Pelka: Mm-hm.

01-00:45:19

Gilhool: And it's plain that would not have happened if my father had lived. As he was dying, he was very clear. And I remember not lengthy, but brief conversation, just with me, and between him and my mother, that probably, you'd have to look around and find a place for Bobby, because surely, you shouldn't— you will not be able to keep him at home.

Pelka: Hm.

01-00:46:00

Gilhool: There was a period, by the way, probably late forties, when I remember my mother and father looking at Vineland. And I remember the brochures being around. You know Vineland?

Pelka: I know the name.

01-00:46:17

Gilhool: Well, it's an historically very important—state or private, I'm not sure; I always had the feel of private—here in South New Jersey.

Pelka: Uh-huh.

01-00:46:29

Gilhool: And it was a study group. It was a resource, a residence of the eugenic analysis.

Pelka: OK, yeah.

01-00:46:43

Gilhool: As Cold Harbor, in New York—

Pelka: Right.

01-00:46:45

Gilhool: —where many of the studies were done—so-called—were done out of Vineland.

Pelka: Mm.

01-00:46:51

Gilhool: And I remember my mother and father, you know, thinking about it and reading about it. I don't remember if they ever went to visit. I have no recollection of doing that. But my mother and father's rejection of that, if not explicit, was certainly implicit in our life in the late forties and early fifties. But his death changed that. And at that time, as for quite a long time, it was not automatic that you could get access to an institution like Pennhurst or any kind of other arrangement.

Pelka: Hm.

01-00:47:50

Gilhool: And a dear friend of my mother's and father's was the Orphans Court judge in Scranton, {Jimmy Brady?}. And he, in the course of those four or six or eight months, was instrumental in getting the authorities to have, to admit Bobby. And that, too, is a story that comes back again and again and again in all of this history. Two welfare secretaries in the mid-sixties, Arlin Adams for Governor Bill Scranton, and Max Rosen for Governor Ray Shafer [Raymond P. Shafer] and Lieutenant Governor Ray Broderick, both went promptly from their secretaryships—Adams ran the Nixon campaign in Pennsylvania in '60—and they both went promptly to the Court of Appeals. And Adams was *the*— In those days, when there three-judge courts, one of them was always a member of the Court of Appeals. And Adams was the Court of Appeals member of the PARC [Pennsylvania Association for Retarded Children] three-judge court [on the *PARC v. Pennsylvania* case].

Pelka: Oh, OK.

01-00:49:23

Gilhool:

And he disqualified himself from all the Court of Appeals in Bank considerations of the Pennhurst case, because he was a private advisor to Frank Rizzo, who was Mayor of Philadelphia; and Philadelphia was a defendant. The second, Max Rosen, sat on all of those panels, and was, I think, a very important person in the formulation of those several opinions. And ultimately, after the second decision of the Supreme Court, rejecting the second of the [chuckles] twenty-five or so grounds in the case—we'll come to some fun stories about that—I filed a petition with the Court of Appeals, asking them to appoint a judge of the Court of Appeals to preside over an effort to settle the case. And when I filed the [laughs] petition, I more or less explicitly said, "And, you know, make it a judge who hasn't participated so far," thinking it would be Arlin Adams. But instead, they appointed Max Rosen. And Max did that. And we'll come to it a bit later. But both of them, in both of the cases, I think, drew extensively upon the experiences that they had. Max was from Wilkes-Barre, and a very important civic figure. And Arlin Adams was the same here. Chancellor of the bar, and at the center of a wide community. And then again, as Secretary of Welfare, they would frequently be called upon, just as my family called upon {Jim Brady?}, to help people go into institutions, and would regard it as a good service for families and friends and so on, you know, to help that happen.

Pelka:

Mm.

01-00:51:31

Gilhool:

And then, while— [pause] Max and I particularly used to talk a bit about Pennhurst, and probably could now. He's still living, by the way. And so is Arlin Adams. Arlin is very active. My sense was that their experience of Pennhurst— Max was Secretary— probably he was secretary in '68, when PARC did its investigative report, it's most recent and last investigative report of Pennhurst. And they came to know the conditions there quite well.

Pelka:

Hm. Now—

01-00:52:23

Gilhool:

[Over Pelka] Indeed, Ray Broderick, who had in '71 been the Republican candidate for governor, during that campaign, twice—and my mind's eye picture is—flew—probably by helicopter—into Pennhurst.

Pelka:

Hm.

01-00:52:41

Gilhool:

Milt Shapp [Milton J. Shapp], who beat him, had issued superb [laughs] position papers, and had some ARC people, Philadelphia ARC people, advising him, and had all of the correct positions. But Ray Broderick actually flew in there. And Broderick and Adams and Rosen were kind of all of the same cut of human interest, human-responsive Republican.

Pelka: Mm-hm.

01-00:53:12

Gilhool: And so I always figured that they— Anyway, you've heard those stories, I'm sure. I remember Floyd McDowell, who is great on many fronts, both on education and de-institutionalization, spent an early career in Texas, and actually was head of an institution there when Governor Connally used to help his friends put their kids there.

And even as recently as a year or two ago, Bill Copeland was telling me the stories about the last round in Minnesota. You may notice that Minnesota shows up on all of Braddock's data as having a small but fairly constant number of people in the state institutions, retardation. And Bill said to me that that was actually the final compromise, that they neutralized the political hesitation by actually identifying the families who wanted their kids there. And [laughs] our side said— you know, allowed that, as a kind of compromise, to end it for everybody else.

Pelka: So the sense, then, is that institutionalization, at that time, was seen as a fairly good thing.

01-00:54:48

Gilhool: Yeah.

Pelka: A viable option for families that had—

01-00:54:50

Gilhool: [Over Pelka] Yeah. And I don't think— I don't recall anybody regarding it as a good thing for the person who was being institutionalized. The consideration was in family terms.

Pelka: Uh-huh.

01-00:55:02

Gilhool: My role was, as Bobby was going there, my role was to make it— turn it into a good thing for my mother.

Pelka: Mm-hm.

01-00:55:12

Gilhool: Right? And I [laughs] remember, and reflected on it often, through the decades of this work, I remember seeking to persuade my mother. And, well, I would say, "Gee, just look around. This looks like a college campus."

Pelka: And you were sixteen at that time?

01-00:55:37

Gilhool: Well, let's figure it out. '54. Yeah, I was probably fifteen, going on sixteen, that September.

Pelka: OK.

01-00:55:45

Gilhool: Yep.

Pelka: OK.

01-00:55:46

Gilhool: Embarrassing as hell.

Pelka: Yeah. So you—

01-00:55:50

Gilhool: And of course, it *did* look like a college campus, outside.

Pelka: Uh-huh.

01-00:55:53

Gilhool: I don't remember *ever* getting inside any of the buildings, except the visitors center and the superintendent's office, until much later.

Pelka: When did you first go there?

01-00:56:05

Gilhool: When— [pause] My guess is, we went down to look around. And then I delivered Bobby. My mother and I, and probably Beth, and probably one of our aunts or one of my mother's close friends, drove him down.

Pelka: You went down to look around. Now, was this an arranged visit? Were you given a tour guide? Or could you just drop in unannounced and walk—

01-00:56:40

Gilhool: [Over Pelka] I don't remember.

Pelka: OK.

01-00:56:44

Gilhool: But— I don't remember any tours. I do remember sitting in the superintendent's office, a fella named 120Podkansky?}, who was, you know, one of those very warm institutional superintendents, who had enormous human talents.

Pelka: Hm.

01-00:57:10

Gilhool: And I don't remember anything except seeing the externals of it. The range of the campus, and the buildings outside, and the outside, but kind of internal connecting walkways, and that kind of thing.

Pelka: Mm-hm, mm-hm.

01-00:57:30
Gilhool: And it *did* look like a college campus. It looked like Penn State.

Pelka: Uh-huh.

01-00:57:33
Gilhool: Same brick, et cetera.

Pelka: Uh-huh.

01-00:57:36
Gilhool: What a wonderful Potemkin thing.

Pelka: [chuckles] OK.

01-00:57:42
Gilhool: Wonderful horrible.

Pelka: Yeah. Did institutions like that have a reputation at that time? I mean, were people— You know, you said it looked like a college campus, but—

01-00:57:58
Gilhool: No.

Pelka: There was— people—

01-00:57:59
Gilhool: I think it was just a given.

Pelka: Yeah.

01-00:58:03
Gilhool: That's what there was.

Pelka: Yeah. But people didn't— I mean, just as a contrast, when I was growing up on Long Island, there was an institution called Central Islip. Actually, what was it called? It was Pilgrim State or something like that, but it was in Central Islip. And as a young person, on the playground, people would, you know, kind of joke and threaten, "Oh, you're going to go to C.I." You know, Central Islip. "They're going to send you away."

01-00:58:33
Gilhool: Yeah.

Pelka: And it was like, "The boogeyman's going to get you."

01-00:58:37
Gilhool: Yeah.

Pelka: And the idea was that this was a very scary—

01-00:58:40

Gilhool: Yeah.

Pelka: —not great place to be.

01-00:58:43

Gilhool: Yeah. That was not the feel in any of the quarters where I was attentive. Though I would be sure it happened around Spring City, in Phoenixville.

Pelka: Mm-hm. OK.

01-00:58:55

Gilhool: Yeah.

Pelka: OK. So what was Bob's reaction?

01-00:59:01

Gilhool: O-h-h-h. [sighs] You know, he was— Gee. He was nine or ten. I don't recollect any resistance or crying or what have you.

Pelka: Mm-hm.

01-00:59:28

Gilhool: But that doesn't— I don't know if that's a meaningful recollection or not. This was still a period when, after admission, families could not visit.

Pelka: Hm.

01-00:59:45

Gilhool: For a significant period. And I don't have any sense of how long that was. But I remember being pissed about that. You know, I had the usual older brother protective instincts, though they were much subservient, I think, to my concern about my mother, and playing that role, after my father's death.

Pelka: Hm.

01-00:60:24

Gilhool: And— [pause] He was— Bob was entirely verbal and expressive, long since, by now. And we visited him quite a lot during his first years there. And we came to know Valley Forge very well, nearby, and it's where you went for a picnic or stuff like that.

Pelka: Mm-hm. How far away from your home was Pennhurst?

01-00:61:08

Gilhool: Probably two-and-a-half hours, then.

Pelka: OK. So you could drive, you could do a day visit; you didn't have to stay overnight. OK.

01-00:61:16

Gilhool: That's exactly right.

Pelka:

OK.

01-00:61:21

Gilhool: And I have no recollection of his complaining. I have no recollection of scars or marks or what have you. And that may simply have been my own obtuseness. And then he left Pennhurst and was transferred to White Haven in the early sixties. And that was kind of at my initiative. Could even have been late fifties. And I had command of that date once. And I could probably find it again.

And while that was chiefly to have him closer to home in Scranton—that was forty-five minutes away instead—there was also—I have the sense that it [Pennhurst or White Haven?] wasn't a very good place. I learned more about his life at Pennhurst very much later.

Pelka:

Hm.

01-00:62:30

Gilhool: During the eleven-week Pennhurst trial, very early—perhaps from the very first week—{Mary Jane Leonis?}— There was a transit strike on in SEPTA, and she lived up at Ridge and Lehigh, which is a good three or five inner city miles from the courthouse. And she walked everyday, to be at the trial. And she had lived at Pennhurst. And she had come out of Pennhurst some significant period of time before. Actually, before the initiation of community living arrangements and so on. And she lived with a black family, and at various times, so did other young women who had come out of Pennhurst. And my brother came down to be in the courtroom during the trial. And he walked into the courtroom and spied— it was more or less a big square. And Mary Jane always sat on the front bench on the state side [laughs] so that in front of her were the state lawyers, and behind her were the Pennhurst staff— [laughs] and officials. And she had great fun engaging with them, all of whom she knew. And my brother was not more than a step in the courtroom, when he spotted her across the courtroom and shouted out, “Mary Jane!” And Mary Jane said, “Bob!” And there ensued—let's see, that was '78—there ensued twenty years of renewed friendship. And they saw each other a lot, subsequently. She died in '98. But they used to talk a lot about Pennhurst with each other.

Pelka:

Mm-hm.

01-00:64:36

Gilhool: And they called it the jailhouse rock. That, you will remember, was, in the late fifties, early sixties— I think it was a Chubby Checker song. No, it may've been—

Pelka: No, it was Elvis.

01-00:64:48

Gilhool: [Over Pelka] —an Elvis Presley song—

Pelka: Yeah.

01-00:64:51

Gilhool: —is what it was. And [laughs] they knew the song from the time they were there together at Pennhurst. And I assume they called it the jailhouse rock from the beginning.

Pelka: Hm.

01-00:65:07

Gilhool: And [laughs] recognized the place from the song. And so— [pause] Hm. What is the wonderful word about something that symbolizes and expresses something else?

Pelka: Emblematic?

01-00:65:26

Gilhool: Yeah, so emblematic was it, that when, later, even after Mary Jane died, when we would go shopping for clothes at— it was the Gap, I think. And they actually had— they were selling rock-and-roll posters. Bob turned directly for the Jailhouse Rock poster [laughs] and insisted that we buy it. And it still sits on his door—on his wall, at his house. But they talked a lot about restraints and acted them out. They talked about doing all the work, and how lazy the [laughs] attendants were. And they talked about bad people and good people. And they talked a lot about friends, and so on. But that all came later.

Pelka: Mm-hm. OK, I'm going to pause this for a moment here.

Begin Audiofile 2

02-00:00:01

Pelka: This is an interview with Thomas K. Gilhool, on September 23rd, 2004. This is interview number one, tape number two, side A. You were talking about your brother Bob recollecting his experiences at Pennhurst during the eleven weeks of the trial.

02-00:00:23

Gilhool: Yeah, well, during the friendship that was renewed—

Pelka: Yeah.

02-00:00:26

Gilhool: —at the trial.

Pelka: OK.

02-00:00:28

Gilhool: Those conversations were all subsequently—

Pelka:

OK.

02-00:00:32

Gilhool: —over the course of a couple decades.

Pelka:

Yeah. You said that he was transferred. Well, how long was he at Pennhurst?

02-00:00:40

Gilhool: I don't know. I need to get the precise thing. My sense is that he went to White Haven just as I was starting law school. That would've been '61. But it may be that he went to White Haven shortly after— later, in the fifties.

Pelka:

Mm-hm.

02-00:01:08

Gilhool: White Haven had been a tuberculosis sanitarium, and it was converted, at a date certain. And a significant number of people from Pennhurst were moved there, people whose roots were in the northeast of the state.

Pelka:

How is Bob doing, by the way?

02-00:01:26

Gilhool: [Laughs] We still don't know what the dickens was going on with him.

Pelka:

Yeah.

02-00:01:34

Gilhool: And this community agency, like I suspect most around the state, has a penchant for third-class medicine, instead of first-class medicine.

Pelka:

Yeah.

02-00:01:50

Gilhool: And so he ended up first on the presenting asthma, difficulty in breathing stuff. And then, two hours after release, on a dizziness-couldn't-stand thing, back in the hospital. So he was there, essential, from Sunday to Saturday.

Pelka:

Hm.

02-00:02:09

Gilhool: And it's the usual story, though better than most third-class medicine, probably. I mean, the nursing staff and the emergency room staff and all those folks were just terrific. And the docs are— hardly exist.

Pelka:

Yeah.

02-00:02:25

Gilhool:

So he had a CAT scan and an MRI and the physical therapy workup, but nothing that qualifies for a neurological workup. My hunch is it could be Parkinson's, because it was stark when we came back. He was into the shuffling gait and shaking hand and so on. And we thought, gee, that— You know, it's the usual over-medication syndrome. And God knows he had enough medication over the time he was in the institutions. But we don't have a clue, still, as to what's going on.

Pelka:

Do you think he'd be amenable to being interviewed?

02-00:03:06

Gilhool:

Oh, I think he'd *love* it.

Pelka:

Oh, ok.

02-00:03:09

Gilhool:

Absolutely love it.

Pelka:

OK.

02-00:03:12

Gilhool:

Yeah.

Pelka:

Well, that— I'd actually be interested in doing that.

02-00:03:17

Gilhool:

That's a great idea.

Pelka:

If you could—you know, next time you talk to him—

02-00:03:21

Gilhool:

Yes.

Pelka:

—if you could run this by him.

02-00:03:23

Gilhool:

Absolutely.

Pelka:

And then if he seems agreeable, you know, I'd get the contact information and I can get in touch with him.

02-00:03:31

Gilhool:

Absolutely.

Pelka:

That'd be great. You said he was transferred to White Haven. And then I believe you said something to the effect of the conditions at White Haven were not— you had the suspicion they weren't as good as—

02-00:03:48

Gilhool: No, the reverse.

Pelka: OK, the reverse.

02-00:03:50

Gilhool: The reverse.

Pelka: OK.

02-00:03:51

Gilhool: Yeah. My recollection, just to start with one of the questions you asked, was that he came home with small frequency, from Pennhurst. Probably for Christmas, maybe for Easter, maybe for Thanksgiving. But once he was at White Haven, then he came home regularly at those times, and occasionally some other times.

Pelka: Mm.

02-00:04:26

Gilhool: White Haven— [pause] Well, right now— The way I was trying to describe {Podkansky?}, back at the point of when Bob first went to Pennhurst. My predominant impression from those conversations was that this was a very loving guy, who was at pains to try to assure my mother, and to some extent me, and maybe a little bit Bobby, that this was a good place, where he would be well cared for. In White Haven, it was, as it had been as a TB sanitarium, the major employer there, apart from the schools. It's kind of a village in the middle of— not the middle, maybe the northwest part of the Poconos, with a lot of summer tourists around, too. But the staff was superb. In the last period there, the superintendent was a fella named Wesley White, MD, who in the history of institutions, was a kind of significant figure. He had been in Colorado and so on. And he was a driving force, like Jim Clements and so on for, you know, some attention to non-injury, which, of course, didn't succeed, but— and in quality of relationship and so on.

Pelka: Hm.

02-00:06:20

Gilhool: And Wes, who had been in many institutions over his career, thought he had at White Haven, the best staff he'd ever had. And Bob formed many friends there, including mostly staff, as usual, but including some residents. He was sort of the guardian angel for a fellow who was blind and physically disabled, and he did a lot of attendant care for him. And Bob was modestly in love with one of the women there, who subsequently, with Steve Gold's help, married another man, [laughs] who was there, after they moved out. And it's— You know, and he went to school forever, and the teachers were just really cool. And, though I suspect he would've picked it up from the family anyway, he's very interested in news and political events and so on. And then in his last couple of years there, he actually had the first good job, and last good job,

he's ever had. He commuted ten, fifteen miles to— [pause] Oh, I guess it was a recycling facility for the Poconos, where he and inmates from the state prison [laughs] nearby, and ordinary people all worked together in this thing. And he actually got paid a decent wage and so on.

So he was there for quite a long time. And I need to track down the date when he moved to Philadelphia to a CLA. That was well after Pennhurst. It was after my time in Harrisburg, so it was early nineties, probably.

Pelka: OK. How—

02-00:08:50

Gilhool: [Over Pelka] After my mother had died.

Pelka: Uh-huh. When Bob was admitted, how large a facility was Pennhurst? How many people were living there?

02-00:09:01

Gilhool: Do you know, I don't know. At the point that we closed it, it was about— well, the class of Pennhurst residents was about eleven-hundred people. And that, I think, included all the people who were there at the point of the filing of suit initially, in eighty— [pause] '74, my God. '74 or '5. But it had been much larger, two-thousand, maybe as high as twenty-eight-hundred. And it was probably somewhere around two-thousand or between the two bracketing numbers, when Bob left.

And indeed, it was probably many score people who went to White Haven. And at the time they were opening other institutions and putting people, quote, "closer to home." And so that was probably a very significant population reduction off the twenty-eight-hundred or the two-thousand.

Pelka: Now, I've never been to Pennhurst, so I really don't have much familiarity with how it looks and the kind of setting. Was it a rural area?

02-00:10:32

Gilhool: Yes. Yes.

Pelka: OK.

02-00:10:33

Gilhool: A rural area. A river ran by. It was in Spring City, adjoining Phoenixville.

Pelka: OK.

02-00:10:44

Gilhool: About twenty-five miles from the center of Philadelphia.

Pelka: OK.

02-00:10:48

Gilhool: A very large campus. It had had a farm. I think the farm was modest and then desuetude. And it had a tight, but probably a quarter-mile on edge of a square, set of buildings.

Pelka: And do you know when it was founded?

02-00:11:13

Gilhool: Oh, I certainly do. 1913.

Pelka: OK.

02-00:11:18

Gilhool: This was Pennsylvania's flagship institution. Governor Pennypacker of Montgomery County had been the only governor in the country to veto a sterilization law. He did that in 1905, is my recollection. And in 1913, preceded by the pamphlet from the Pennsylvania Association of Charities and Corrections, the Pennsylvania chapter of the National Conference or Council on Charities and Corrections, they did *The Menace of the Feeble-Minded* in Pennsylvania. That was the pamphlet, in '12, '13, '11, signed by all of the leading families of Pennsylvania. It was the instrument that is very common around the state. And much later, when, for the Cleburne case, we went to work collecting this history—and in most states, got fairly full histories—surely, you've seen the appendixes to the Cleburne brief.

Pelka: Yes.

02-00:12:39

Gilhool: And then we put it in front of the court at least three or four times since, again, in *Olmstead [versus L.C.]*, and in Garret, maybe on one other occasion. But it was the model of the Pennhurst history, which we knew from the Pennhurst case itself, and had used. And this was— Hold on, I'll get you the words. [After long pause] From *Olmstead*, Appendix A. And if you read those brilliant three pages that Marshall wrote in his concurring and dissenting in Cleburne, and the much more abstract, but no less moving recitation that Stevens wrote for himself and Burger, believe it or not, you can see this collection of materials reflected. Hold on. M-N-O-P. [pause; reads] *In 1893, the Pennsylvania General Assembly authorized construction of a large institution in western Pennsylvania, with a capacity of at least eight-hundred inmates, to include a custodial or asylum department for the reception and detention of idiotic and feeble-minded children. In 1903, another— a second institution was authorized to be built in the eastern part of the state. By 1911, the Pennsylvania Conference of Charities and Corrections argued to the legislature that it had a large problem on its hands. The legislature decided that a comprehensive study was necessary, and so adopted a joint resolution to establish a special commission, the duty of which commission shall be to take into consideration the number and status of feeble-minded and epileptic persons in the commonwealth, and the increase of such persons, and to report*

to the General Assembly, at its next session, a plan or plans for the segregation, care and treatment of such defectives. That was the first appearance of the segregation word. *The resolution said a proper regard for the public welfare requires that some action be taken, looking to the segregation of such feeble-minded and epileptic persons—and the commission report—unfit for citizenship,* a phrase that Marshall made famous, attributing it to Mississippi, quite correctly; but it had appeared here, as it did in many places.

Pelka: Hm.

02-00:16:00

Gilhool: *The condition of mind in amentia is irremediable. The segregation, as a rule, should therefore be permanent.* And so on. And then six weeks later, the legislation creating Pennhurst and declaring its purpose to be the segregation of idiotic, imbecile or feeble-minded persons. And that was 1913. So yes, that's when Pennhurst was constructed.

Pelka: OK.

02-00:16:41

Gilhool: And opened.

Pelka: OK. I guess I want to move on to the beginning of— Well, to kind of jump ahead, actually, I guess it would be some of the work you did at Community Legal Services in Philadelphia. But before we do that, I'm just wondering if there's anything else you wanted to say about this particular facet or period in your life, and in Bob's life.

02-00:17:19

Gilhool: I think you've got it.

Pelka: OK. I'm jumping ahead in the longer format. What I wanted to do was to talk some about your work with Community Legal Services in Philadelphia. And that was 1966 to '69? Have I got that right?

02-00:17:47

Gilhool: That's right.

Pelka: OK. What got you interested in welfare rights and issues of poverty?

02-00:17:56

Gilhool: Well, that's going to put us back into law school.

Pelka: All right, well, we'll do that then.

02-00:18:01

Gilhool: From law school, I came to Dilworth Paxson. Had more names then— Dilworth, Paxson, Kalish, Kohn and Levy— a Philadelphia law firm. I chose,

essentially, between Dilworth Paxson here and Paul Weiss, Wharton, Rifkind and Garrison, in New York. And I was choosing law firms whose leadership was very much publicly involved. And as it happened, both publicly involved in education. Lloyd Garrison was chairman of the New York School Board at the time. I had worked there for a summer. [pause] A very significant summer, the summer of the March on Washington. Anyway, I came to Dilworth, and Dick Dilworth— Philadelphia had just created a new school board, and he was its first chairman. And he was appointed chairman by Jim Tate, the mayor, to be sure he wouldn't run for mayor again. [laughs]

Pelka: Mm-hm.

02-00:19:13

Gilhool: Wouldn't or couldn't. And he had been mayor of Philadelphia in the early fifties. And in fact, Sorenson, early in his book on Kennedy, says in '58, they thought Dick Dilworth was probably their chief opponent for the Democratic nomination in 1960.

Pelka: Mm.

02-00:19:45

Gilhool: So I was there from— Let me try to get this right. I was there '65 and '66. And then went to Community Legal Services, which had just been founded, opened its doors. And then in '69, I went back to the Dilworth office, where I stayed until '71. I was at the Dilworth office when the ARC came to me with their Pennhurst investigation.

Pelka: Mm-hm. [after a pause] Well, just getting back to the question of how it was you were interested in doing this sort of law.

02-00:20:43

Gilhool: Yeah. I had gone to college expecting and intending to be a lawyer.

Pelka: Uh-huh.

02-00:20:50

Gilhool: During college, I changed that. By the last year, law school seemed to be so dull and dry, I thought from afar, that I didn't really want to spend three years there. My interest and commitment had, from as long as I can remember, after thinking about [laughs] the priesthood—which all Catholic schoolboys do—had been public life. And I considered Yale philosophy, Harvard social relations—Reachmen[?], then—and Chicago's committee on social thought, and chose Yale's philosophy department. And my model was a philosopher who was at Syracuse, who had spent a decade or two in the United States Congress. And my other model was a former dean of the graduate school at Yale, who had been Governor of Connecticut. And so I thought, "What a wonderful way [laughs] to construct life." University and political and public matters. And I went to Yale in philosophy. And saw the law school up close,

and found the stretch between the *Second Critique* and the *New York Times* larger than I wanted habitually to make. And so I moved, after a year, across the street to the law school.

Pelka: Mm-hm.

02-00:22:40

Gilhool: And this was an extraordinary time, of course, in the history of— at the Yale Law School, and generally, for our generation. I am resolved sometime I'm going to write a biography of my generation, to be entitled *The Lucky Generation*. By which I mean two things. One, we were lucky to come to majority at a time when circumstances made it possible to act with many others, and make things change in the United States. Rare, even across our history. And second, we were the smallest generation of all of the twentieth century.

And only much later, did I reflect that a part of the success of the civil rights movement and then the women's movement was that there weren't enough white men to man the stations.

Pelka: Mm-hm.

02-00:23:46

Gilhool: And so, while all of us [?] noticed, of course, that people got tenure at universities, and full professorships, and were vice presidents of banks, and all that kind of thing, and we ascribed it to our special singular [laughs] cleverness and wisdom, it was because there weren't many of us. And everybody got moved into things much more quickly than in other generations.

I'm rambling a little bit. I'm trying to figure out a way to shorten the law school stuff and get to the place where you want to focus, which is the legal services program.

Pelka: Mm-hm.

02-00:24:30

Gilhool: What had taken me to the basement kitchen at the Berean Institute was the Northern Student Movement. When I was at Lehigh, in that February—do I remember correctly?—the sit-ins happened in North Carolina. And the National Student Association, in which I had been very active, put out a news bulletin. And we called, at Lehigh, in front of the library, a demonstration, and raised some money to send south for the students to use. It turned out to be the first Northern demonstration in support of the Southern Student Movement.

02-00:25:18

And when I went to Yale, my year in graduate school was the Kennedy campaign. And with almost of the [laughs] people at the graduate school,

many of us were very active in that. But by the time I moved over to the law school, and I spent that summer— Let me make sure I'm right about this. Yes. I spent that summer on Operation Crossroads Africa, which you may be familiar with. Jim Robinson, a minister in East Harlem, had organized—I think we were the second group, and there were at least another five or ten more—college students going to newly independent African nations to work with students there, over a summer.

02-00:26:13

And the student civil rights movement was very much advanced. And Peter Countryman had started, with some inspiration from Marian Wright, who was then a first year student at the law school, the Northern Student Movement, whose initial avowed purpose was to support the movement in the South. And by early the next year, my first year in law school, I got very much involved in the Northern Student Movement, and was first its treasurer, and then for the rest of my years at law school, its chair. And Peter was its executive director, and we operated out of Dwight Hall on the Yale Campus. And at some point, Chuck McDew—who was then the president or chair of SNCC, the Southern Nonviolent Coordinating Committee—in one of his visits, said, “We’re going to deliver Mississippi before you guys even start in Harlem.”

02-00:27:35

And so we turned our attention to trying to do something in the North. And the first thought in that regard was the tutoring stuff that I mentioned earlier. And PTP was the first institutional emanation of that. And it happened all over the Northeast, and in California, and as far Midwest as Chicago and Wisconsin and Minnesota.

02-00:28:08

And many of those projects turned, in the course of the sixties, into community organizing. Philadelphia Tutorial project did a lot of movement organizing that— Peter’s son has written his PhD, and the University of Pennsylvania is about to publish it, on black Philadelphia, forties, fifties, sixties, seventies. And out of those things, grew the black political movement in Philadelphia. But that’s a whole ’nother set of stories. But in any event, I was very much involved in that. And at the law school, we used to say we knew what was happening in the South before the *New York Times* reported it. And then, of course, the *New York Times* reported it very well. And very [laughs] considerably. And that’s because Marian was there a class ahead of us, Eleanor Holmes Norton—Holmes, then—was there a class ahead of us. Timothy Jenkins—who had been national affairs vice president of the National Students Association, and who, at one of the early house[?] conferences, had first directed Bobby Kennedy’s attention to voting as the crucial matter to be moved upon, as it became—was in our class. Several of the faculty were very much involved. Lou Pollack had, as a very young man, been on the brief in Brown [versus Board of Education]. And many faculty people took substantial roles with the Legal Defense Fund and otherwise.

02-00:29:50

So there was very much attention to all of that. I was among the three or four people who, in '62, '63, put together what became the Law Students Civil Rights Research Council, which institution may still be going. At least it was going a couple of years ago. And just as its name suggests, its point was to support the movement with [pause; laugh] law student skills.

02-00:30:22

And it was during that time, while we were at law school, that the Ford Foundation funded the gray areas projects in Lower East Side of New York, and New Haven, and Philadelphia. And in New Haven and in the Lower East Side of New York, that included a lawyering arm for the address of poverty. And two wonderful people, one of whom had graduated and was *the* lawyer for the New Haven Legal Services program, Jean Cahn and her husband Edgar Cahn, who was just graduating, I guess, when we started, wrote the article which framed for Shriver the legal services program nationally. It was called the *War on Poverty-colon-A Civilian Perspective*. It's still *very* much worth looking at.

02-00:31:34

I wrote a piece that, in some ways, is an adumbration, an echo of that piece, which is in the second edition of PCMR's *Changing Patterns in Residential Services for the Mentally Retarded*, called "The Uses of Courts and Lawyers," in which I described a style of lawyering from the six, eight years experience of the poverty program, and the style of lawyering from which *PARC* had come, and which we hoped would frame the protection and advocacy systems which the Congress was then in the process of— They're fun to look at.

Pelka:

OK.

02-00:32:43

Gilhool:

Edgar and Jean subsequently were co-deans of the Antioch Law School, founded in Washington, with malice aforethought, and running there still. And Jean died too long ago. Edgar has continued at many things. He was the son of the great NYU philosopher, Edmund Cahn, whose father divorced him when he married Jean, who was black.

Pelka:

Hm. Let me— We need to pause for two seconds here.

02-00:33:26

Gilhool:

Sure. [audio file stops, re-starts]

02-00:34:13

Pelka:

This is an interview with Thomas K. Gilhool on September 23rd, 2004. This is interview number one. This is tape two, side B. OK. You were saying?

02-00:34:27

Gilhool:

Drew Days, who was two years behind Gillian and me at law school, and who subsequently was Carter's Solicitor General— Not Carter, Clinton's Solicitor

General. He was Carter's Assistant Attorney General in charge of Civil Rights, and has been teaching at Yale in between and since. And now he's also practicing law. A couple years ago, we were both decorated because of our work together for the academy and its chapters on children's healthcare. And I presented him and he [laughs] presented me. And I wish I could remember—Gillian will remember—the Biblical phrase he used. But from that period in law school that was so extraordinarily fertile and productive on so many counts, he chose to describe me as the person, among all the people he knows, who started more institutions—small “I”—than anyone else he knew of. And he had a *wonderful* Old Testament [laughs] phrase for it that I am going to try to recover. That, you know, for me, with the kind of resonance that continues from these earlier events that we've talked about, this is what kind of exploded it for me. You know, as I've said, I somehow knew—and I think it came directly from my mother and father, who were just extraordinarily interested in the world and its shape and— [pause] And to some degree, from my grandmothers, who had lived through the Depression, and who, for our generation, their stories were—at least what we received was—there is no greater happiness than participating in struggles to rearrange things. And of course, Scranton had been the site of much union organizing in the twenties, among the miners, and then surviving the Depression. I'm quite convinced, by the way, that the same grandmothers told the same stories to what I call the greed generation. Bill and Hillary Clinton's generation.

Pelka: Mm-hm.

02-00:37:00

Gilhool: But that that generation took an entirely different lesson from their grandmother's stories. The lesson they took was, “Always be very sure that you have a very good job.”

Pelka: Yeah. You call it the greed generation?

02-00:37:18

Gilhool: Yes.

Pelka: OK. As opposed to the green generation.

02-00:37:22

Gilhool: No.

Pelka: All right.

02-00:37:23

Gilhool: [laughs] Indeed. No. The greed generation. Well, that's a longer story than—

Pelka: Yeah.

02-00:37:30

Gilhool:

Deep analysis, that we can come back to at some point, but— I was formed by the time law school ended. It was also, our class at law school, like almost every class that goes to the Yale Law School, of course, entered resolved that they would, of course, never practice law, but would do other things. But that [pause] being lawyers and thinking like lawyers was— And of course, our class, like every other class, went 95% to big law firms, as did I. The other theme of the time was returning home. And there was a lotta conversation about going back to Buffalo, going back to Denver, going back to Philadelphia, which I think had a lot to do, as well as the Tutorial Project stuff, with my choice of Dilworth and Philadelphia, rather than Paul Weiss, Wharton, Rifkind and Garrison in New York.

Pelka:

Mm-hm.

02-00:38:46

Gilhool:

And indeed— And we were all eager to do things. And I had won a Fulbright to London School of Economics. And I had actually wanted to go to Greece, to do city planning with {Doxiotis?}. But they wrote me a letter and said, “We reserve Greece for classicists. [laughs] How 'bout England?” So I switched my thoughts, and got it. And I remember sitting down with Lou Pollack, for whom I had been a teaching assistant at the law school, in legal research, attached to his constitutional law class. And he was a very close friend of Bill Coleman's, William T. Coleman, Jr., a black lawyer who couldn't get a job in Philadelphia, despite having graduated from Harvard, and *Law Review*, and clerked for Frankfurter and so on. And he commuted for lots of years to New York, where he and Lou Pollack shared an office at Paul Weiss, Wharton, Rifkind and Garrison. Anyway, I remember talking [laughs] seriously with Lou, saying, “I'm really inclined to turn this Fulbright down, because Philadelphia has decided it's going to do a new board of education, and I would like to get on that board of education.” Our generation had chutzpah, if nothing else. “And I really want to go back and get started.” And Lou said, “Be assured, nothing happens in life that is of any significant, permanent, changing thing in a year's time, except having a kid.”

02-00:40:39

And so we went. But when I came back to Philadelphia to the Dilworth office, it was in this context. And that year-and-a-half, I was fortunate enough to do, with Bill Coleman, the Girard College case, the last round of the Girard College case.

02-00:41:08

Stephen Girard had left a handsome fortune in the 1840s for an institution for poor white male orphans, and there had been efforts in the fifties to break the will. And it came back in the sixties, because of civil rights demonstrations around the gates and so on. And Governor Scranton had actually appointed Bill Coleman and Charlie Biddle at another firm, Drinker Biddle and Reath, as special deputies attorney general, to open the gates in court. And so I became

the guy who worked with Cecil Moore, the NAACP guy, who had done the demonstrations, in finding plaintiffs. And I did the complaint and things like that.

And I also worked with Bill on a case that created the Southeastern Pennsylvania Transportation Authority, and a third that had public dimensions, that is the point. And then, during that year-and-a-half, the Philadelphia Bar Association was creating the Poverty Lawyering Institution here. And I became sort of the special assistant to Bill Klaus, the chair of the committee who did it, around all of this. And we had several important court battles, because in Philadelphia, as in many places, parts of the bar—especially neighborhood lawyers—objected in court to the launching of these things. And I did the briefings and some other things like that.

Pelka: I'm sorry, I just wanted to— It was Bill Klaus?

02-00:43:24

Gilhool:

William R. Klaus. He was— Arlin Adams, the selfsame Secretary of Welfare, was the chancellor of the bar association, when they decided to launch Community Legal Services, and Bill was chair of the public service committee. And Raymond Pace Alexander wrote two opinions, which rejected the challenges, and while they continued around the country, essentially, authoritatively dispelled them. He had been the first African-American city council member in Philadelphia, and the first African-American on the state bench. And he was a graduate of the Harvard Law School in the 1970s. And his wife, Sadie Tanner Alexander, also a lawyer, had been the first black PhD at Penn. Though DuBois had written his dissertation at Penn, and came from Harvard.

Pelka: Mm-hm.

02-00:44:32

Gilhool:

So I moved over to CLS. Well, actually, something happened before that. I designed and ran, sort of, a part of the CLS for two purposes. One, to train staff that was full-time staff; and two, to train volunteers. Part of the whole thing was to put volunteer lawyers to work for people who were poor. And I designed what must have been a three- or four-month, night-a-week, occasional Saturday training sessions in poverty law. All of which was inventing. And of course, there was a lot of inventing going on around the country. Ed Sparer in Mobilization for Youth, the Lower East Side, Ford Program and Jean Cahn in New Haven, and so on. And then I decided I would go to CLS in a position that was described as consumer advocate. And the theory was that most of CLS would be service, but this would be, quote, “law reforms.” This would be rolling back the stuff, from the time of Elizabeth, in the law that plagued poor people, changing the rules, in some set of ways. And it was actually initially focused on consumer, meaning consumer.

Pelka: Mm-hm.

02-00:46:19

Gilhool: I did no [laughs] consumer work when I went there. And I was there from—gee, you know, it may be '67 to '69. I'll have to get those dates for you. They're on my resume.

02-00:46:38

And my first piece of work was in an urban renewal area. A building occupied by about a-hundred-and-twenty people of low income; five, six story, handsome and architecturally very important building—I forget its architect now—from the 1890s. And I worked very closely with a legendary—then, and for forty, fifty years afterward—neighbor activist, Alice Lipscomb, a black woman, who was maid to the state senator's family when the [laughs] state senator was growing up, and who was a street activist of *enormous* imagination and powers. With some others, we beat the cross-town expressway, eight lanes, underground—or at least in a ditch—from river to river here. One of only three highways to be beaten in the country, one of which didn't stay beaten, the Central Expressway in Los Angeles. But she's done very many things, many of them focused on landlord/tenant. And we organized the tenants, and crafted, out of some traditional law, a receivership to run the place, instead of the failed landlord. At his expense, [laughs] however.

Pelka: Mm-hm.

02-00:48:19

Gilhool: And to wage, in city council and publicly, a battle to recast the urban renewal plans for Washington Square West to include significant housing for people of low income.

Pelka: OK.

02-00:48:43

Gilhool: And that was a two- or three-year battle that was a signal, in Philadelphia and for the new legal services program all over the country. And then— [pause] the residents-requirement case arose, actually, from one of the neighborhood offices. Ed Sparer who had been Mobilization for Youth in New York, had invented welfare law, and had articulated by now an agenda, who Beth described shortly thereafter as, How do we turn public assistance into a guaranteed annual income?

Pelka: Hm.

02-00:49:46

Gilhool: And a part of it was to shave away the limitations, the disqualifications—like man in the house rule, and residence requirements, and so on, and a part of it was to so raise the grants that they could support a family decently.

Pelka: Mm-hm.

02-00:50:14

Gilhool: And someone got Juanita Smith to me, who had moved back to Philadelphia from Delaware, who had a handsome number of children—five, six, something like that—and who couldn't get public assistance 'cause she hadn't lived here a year. That was a keystone of the English Poor Law, to keep people out in the county, so they would be available to do the harvest at the proper seasons.

Pelka: Hm.

02-00:50:44

Gilhool: And had continued here, and had actually been enshrined in the Social Security Act public assistance titles, in '36. And I filed here the first case. And then, when you were challenging constitutionality of federal statutes, you had to have three judges. And that's—I'm sorry. The constitutionality of state statutes. When you were challenging them, you had to have three federal judges. And that's how both this case, *Smith vs. Reynolds*, and *PARC* came to have three judges. And Arlin Adams was on that panel. Tom Masterson was the originating District Court judge and—No, I'm dead wrong about that. I take that back entirely. Arlin Adams was not, not at all. Harry [Ellis] Kalodner was, and he actually dissented.

But anyway, I pleaded that case, and there was a national association of—Oh, boy, what did we call it? National Legal Aid Association. NLADA, National Legal Aid and Defender Association, dating from 1917, when William Howard Taft and Charles Evans Hughes and so on had kinda started this essentially charitable, essentially *not* law change, though, predecessors of the legal services program. And I remember conducting sessions with those pleadings for lawyers all around the country to bring similar suit. And we won here. Connecticut won, D.C. won, and then there were another twenty-five, twenty-six cases all around the country, all of which won in Federal District Court—with the exception of a decision [laughs] in Pittsburgh, where Harry Kalodner, who had dissented in our case, wrote the majority opinion—but which, of course, had no effect, because [laughs] the Philadelphia injunction required Philadelphia to suspend it.

And during the time we were putting that case together and doing it, the state welfare department—[sighs] Arlin and Max Rosen were successively secretaries then. And when the poverty law program was starting, Arlin had me come up to address his senior staff about poverty lawyering and so on. And I discovered that these guys who were working in state bureaucracies were real pros. They were, in many ways, cut from the same cloth as this generation of lawyers; but they had all chosen, in the thirties or forties, to be social workers, because that's where you change the world. And they had enormous allegiances to their clients, and to their professional mission, and to

the *good* words declared in national statutes about what all of these programs were supposed to be about.

02-00:54:24

Anyway, that resulted in, Shapiro and Thompson became the first legal services case argued in the United States Supreme Court. And it, like Pennhurst, was argued— *Pennhurst* [*Halderman v. Pennhurst State School & Hospital*] was argued three times, but *it* was reargued. And we won six to three. And— [pause] why am I doing that? I got waylaid from—the welfare right organization.

Pelka: Right, right, right.

02-00:54:58

Gilhool: Philadelphia had had its riots earlier than most other cities. And as the welfare department's ranking leaders, one of whom later went to law school and practiced here with us at the Law Center, Eli [Elias S.] Cohen, who was a great gerontologist. Each day, they looked at the arrest lists from Philadelphia. And they were delighted to find that nobody receiving public assistance was on the arrest list. And then they reflected a little bit, and they concluded it was a *terrible* thing that nobody [laughs] on public assistance was among those arrested in the riots, because what it told them was that they were so depressed, oppressed and down that they didn't even participate in *that*.

Pelka: Hm.

02-00:55:53

Gilhool: And so they actually set out to give some money, and did, to the Health and Welfare Council of Philadelphia—you know, kind of a United Way attached study group, about such issues—to organize the Philadelphia Welfare Rights organization.

Pelka: OK.

02-00:56:10

Gilhool: And the organizer was a guy who came, Terry Dellmuth, who had been a banker, who went to Bryn Mawr School of Social Work and came out. And one of his acts, and mine, at CLS was to go see each other. And—

Pelka: [Over Pelka] And who is—

02-00:56:27

Gilhool: And what came out of that, an extraordinary welfare right organization, happening all around the country, too. But this one actually went through four or five distinct generations of leadership. That is to say, it persevered with vitality across; in most places, after the first generation of leadership, they were gone.

Pelka: OK. I think, again, I want to look at the time. I want to get into *PARC*—

02-00:57:20

Gilhool: Yes.

Pelka: —in Pennsylvania.

02-00:57:21

Gilhool: And all of that says why I think it is that Jim Wilson, you now know—

Pelka: Mm-hm.

02-00:57:28

Gilhool: —and Dennis Haggerty called one day to say, “We’ve just done an investigation of Pennhurst and we’ve got this report. And we have had a vote of the association that we want to go to court. Can we come see you and talk about working on it, and what we might do?” I was back at the Dilworth office then.

This was ’69. And Jim Wilson and Dennis Haggerty, who was the chair of the residential committee of ARC, came in. And it has always been my judgment that they came because they understood that they needed [chuckles] boldness and imagination and a thick skin in their lawyer. And the stuff I’ve just mentioned had conveyed my identity to them, with some notoriety. And that’s why they came.

Pelka: Mm-hm.

02-00:58:32

Gilhool: And so why don’t we just go from there—

Pelka: OK.

02-00:58:38

Gilhool: —to *PARC*, shall we?

Pelka: Sure. That sounds good. So these folks from ARC approached you. What do you remember of that first meeting?

02-00:58:49

Gilhool: Oh, I can still see them sitting. I had a long rectangular office, and my desk faced the wall, with a window to my right, and my chair was there, and that exhausted the width of the place. They sat on the inner side of the room, the two of them. And we talked. Oh, geez! You know, for a considerable period of time, maybe an hour-and-a-half, two hours. They had not known about Bob. And I told them about him. And that was edifying both to them and to me. I am quite sure that it was in the course of that conversation that they told me about Gunnar. Because I’ll replicate, I’ll describe to you in a moment, his role, which you know much about. And Peter had been two years or one year behind Gillian and me at law school.

Pelka: Mm-hm.

02-00:59:55

Gilhool: And his closest friend, actually, had lived in the room next to mine, in the dormitories. Dominic Squatrito, who is now a federal district judge in Connecticut. And a good one. And— [pause] And I had known enough about Peter to know something about his father.

Pelka: OK.

02-00:60:28

Gilhool: Though if you had asked me prior to this time, I wouldn't be able to identify the human service endeavors in which he was engaged.

Pelka: This is Peter— last name?

02-00:60:40

Gilhool: Dybwad.

Pelka: Oh. OK.

02-00:60:43

Gilhool: And I remember thinking, as I think I said at Gunnar's memorial service, I remember thinking, when they said, "And Gunnar Dybwad has worked with us on all of this, and he's a great man, and he knows everything, and he would be delighted to teach and tutor you," I remember thinking, "Well, he's Peter's father, so he must be a good guy."

Pelka: Mm-hm.

02-00:61:19

Gilhool: Not a position that Peter was in, [laughs] for much of his life, I think.

Pelka: Hm. Hm.

02-00:61:25

Gilhool: That is to say, usually. Peter was a good guy 'cause his father was a good guy.

Pelka: Hm.

02-00:61:32

Gilhool: And so they either gave to me then or left with me their study. [pause]

Pelka: Did it feel right to you from the beginning? Did you think, I am definitely taking this case?

02-00:61:53

Gilhool: [Over Pelka] Yeah. Yeah. Yeah.

Pelka: There was no hesitation?

02-00:61:56

Gilhool: Yeah.

Pelka:

OK.

02-00:61:58

Gilhool: On the contrary. It just seemed, [chuckles] providential.

Pelka:

Yeah. And had you known about what they were going to talk about before they came to your office? I mean, had you an awareness that this was coming to your office? Or did they just show up? Make an appointment, show up and—

02-00:62:14

Gilhool: They called and made an appointment, and I'm sure they told me something of what it was about.

Pelka:

Uh-huh.

02-00:62:21

Gilhool: But I had no idea of what an ARC was.

Pelka:

OK.

02-00:62:26

Gilhool: Or of its context or what have you. No. It was just the world opening up, for both of us. And you know, it was *so* right [laughs] that we just enthusiastically committed to each other right there.

Pelka:

Uh-huh. So you really didn't know much about the parents' movement at all, at that point.

02-00:62:56

Gilhool: Oh, no.

Pelka:

OK.

02-00:62:57

Gilhool: No. I don't even know if I would've recognized Pennsylvania Association for Retarded Children.

Pelka:

Hm.

02-00:63:05

Gilhool: I think I *must* have. Right?

Pelka:

Yeah.

02-00:63:08

Gilhool: But I had had no personal, and my family had had no identifiable to me relationships with its predecessors, their predecessors.

Pelka: Mm-hm.

02-00:63:28

Gilhool: I was probably tangentially aware of the CBS Philadelphia channel series on Pennhurst, which they had arranged—and I'm quite sure it had happened before this time—which they had arranged, coming out of their investigations at Pennhurst. And I think I'm right that they were earlier.

Pelka: Mm-hm.

02-00:64:07

Gilhool: Jim Conroy will know. He even has the tapes. A fella named Bill Baldini did them. [pause]

02-00:64:21

Pelka: So what was the next step, then? They left you this study.

02-00:64:30

Gilhool: Yeah.

Pelka: And they said, "Here. We want to do this case." Did they have a sense as to what it was they wanted to accomplish with the case and how they wanted to do it? Or how specific were they?

02-00:64:44

Gilhool: [Over Pelka] No.

Pelka: OK.

02-00:64:45

Gilhool: They did not know what kind of a case they wanted to bring. They had, as I remember it, they had already voted that they wanted to litigate. And they had some ideas that I don't remember, but I suspect were probably articulated in right to treatments terms.

Pelka: Mm-hm.

02-00:65:13

Gilhool: Right to treatment had been in the air. Judge Bazelon had gotten it started, actually, with some of my classmates as his clerks, on the mental health side, in the late sixties. They had been very taken— They were self-consciously imitating the civil rights movements—

Pelka: Mm-hm.

02-00:65:44

Gilhool: —in thinking about using the courts.

Pelka:

Mm-hm.

02-00:65:48

Gilhool: And the very mission of presenting a tack was to figure out what kind of suit or suits might be brought. [pause] They came to me— Here's what had happened, all of which, I think they told me about in that first meeting. But I don't think, in retrospect, all of it they could have told me about. So some of the emanations of this are probably not correct. They came to me after the board had voted to litigate. And that was a highly controversial, painful process.

Pelka:

Mm-hm.

02-00:66:48

Gilhool: They came to me after they had articulated as their objective, closing Pennhurst.

Pelka:

OK. So, that was—

02-00:67:00

Gilhool: Yeah.

Pelka:

—right there from the start. Let me just stop you for two seconds here, because I have to change the tape.

Begin Audiofile 3

03-00:00:05

Pelka: OK, this is interview with Thomas Gilhool on September 23rd, 2004. This is interview number one; this is tape three, side A. OK, I'm sorry, I interrupted you.

03-00:00:16

Gilhool: Not at all. Both of those decisions had been arduous. And I don't know if they were made separately, or even stated separately, or done together. I remember that their resolution had been framed in terms of, "Consult a lawyer to discover whether a case can be brought." And then that was characterized as to show cause why Pennhurst should not be closed, or be closed. Now, that document actually exists somewhere.

Pelka:

That resolution.

03-00:01:12

Gilhool: Yeah. In any event, the point I was trying to make is, I think that what I separated out analytically, the decision to sue and the decision that their objective was to get rid of Pennhurst, were intertwined closely. And it had

been a very, very difficult process. On the one hand, obviously, whatever they had for their kids, adults and not, existed by grace of the state. And they were DBW programs, and they were early— not called early childhood then, but you know, schools which were being run by UCPs [chapters of United Cerebral Palsy] or churches or Easter Seals or what have you.

Pelka: Hm.

03-00:02:13

Gilhool: And I remember their describing it as— many of the objectors said, “How can we sue the people in the state, upon whom we depend?” And it was around that issue, not the other one—analytically, the other issue—that Eleanor—oh, damn it! I just had her name—who had been, quite recently, president of the National Association for Retarded Children, resigned, because she thought it was an error of the gravest sort to go after the state in a courtroom.

Pelka: Hm.

03-00:03:01

Gilhool: And the decision about the purpose of closing of the institution, in any event, merged with that. And the picture that is vivid in my mind’s eye today, a picture which I had initially from Dennis, and then everybody who was in the room one time or another told me about it, and Gunnar told me about it, as well. The ultimate decision came when Gunnar and Dennis—Dennis was probably presiding at the meeting—when Gunnar showed the pictures from Pennhurst, and made people face them, and reminded them of how long they had been trying to so change things at Pennhurst that this kinda stuff would not continue to happen. And when he said, “What choice do you have? These guys give you an arm around the shoulder and encouraging words, but they can’t or won’t, and they don’t, do anything,” these guys in the state.

Pelka: Yeah.

03-00:04:25

Gilhool: And so on. And— [pause] I am thinking or seeing— [pause] I think it was probably Dennis Haggerty, whom I heard on many occasions subsequently, at conferences brought by the PTMR or what have you, delivering, you know, full scale descriptions of what happened that day, and Gunnar’s challenge that just pierced to the hearts of everybody. And they came up right. And some people fell away.

Pelka: Mm-hm.

03-00:05:21

Gilhool: Dennis is living, though has not been in good health. Jim Wilson, as you know, is hale and hearty. And both of them, I think, either of them, may actually have, you know, some written descriptions of that time.

Pelka: Mm-hm.

03-00:05:39

Gilhool: I had, for the longest time, the report on their investigation. I don't think I have it anymore. And then I also had for the longest time, and even longer, every other page of the report on possibilities of litigation that I wrote for them.

Pelka: Mm.

03-00:06:05

Gilhool: Yeah. And then I did disappear for about nine months. 'Cause I think it was that long before I gave them a report with the alternatives for litigation.

Pelka: Well, let me back you up just a second. Is there an archive anywhere of the kind of papers you're talking about—

03-00:06:24

Gilhool: No.

Pelka: —for the *PARC* case? There's no— no one has collected this stuff?

03-00:06:27

Gilhool: No.

Pelka: Well, that's a shame.

03-00:06:29

Gilhool: Yes. I'll bet in Gunnar's papers there is a subset. Do you think so?

Pelka: That could very well be. The only chance I've had, really, to look through Gunnar's papers came when I interviewed him a couple of years back, and I actually stayed with him for a couple of days, and we rummaged around— [laughs]

03-00:06:59

Gilhool: Yes, yes.

Pelka: —the house. I don't recall, you know, asking specifically about that then. And if they weren't there, then they'd be at what was the Fernald School, and what is it now? The Irv Zola collection. What's the name of the library that they've established there? [The Samuel Gridley Howe Collection at the former Fernald State School in Waltham, Massachusetts]

03-00:07:19

Gilhool: Oh, oh. I thought you were going to say Emile Zola. {inaudible}

Pelka: [Over Gilhool] No, no, Irv, Irv Zola. But I don't know now if that's really the name of it. Anyway, I just wanted— that was just an aside.

03-00:07:34

Gilhool: Yeah, and I may be dead wrong, of course. I mean, Jim Wilson or Dennis Haggerty may be aware of some archives. And the other person who was present at the time—she may have been out of the state at this *very* time—she had been a former president of the ARC—is Eleanor Elkin, who is living right here in Philly.

Pelka: Mm-hm. Can you get—

03-00:08:02

Gilhool: Eleanor Kephart is the former national president, who resigned.

Pelka: OK.

03-00:08:06

Gilhool: K-E-P-H-A-R-T.

Pelka: OK. What I might ask is for contact information for Dennis Haggerty and Jim Wilson.

03-00:08:19

Gilhool: Yes. Jim Wilson lives on South Smedley Street, here in Philadelphia.

Pelka: Mm-hm.

03-00:08:26

Gilhool: I think the address is 335 or something like that.

Pelka: [Over Gilhool] South Smedley Street.

03-00:08:30

Gilhool: And I can get the number, too. And [laughs] whenever we put out the sheet of everybody who was in New York, he'll be on it, of course.

Pelka: Oh, ok.

03-00:08:38

Gilhool: And Dennis lives in Delaware County, and his office has been both in Philadelphia and in Media. Haggerty. H-A-G-G-E-R-T-Y. I will get both.

Pelka: OK. Great. OK. So yeah, so getting back to you disappearing [laughs] for whatever—

03-00:09:01

Gilhool: Two other— one other person who's living— I'm sorry, two other people who are living, who were most surely present here, and were very much present subsequently, two later presidents, after Jim Wilson, of the Pennsylvania ARC, Pat Clapp, C-L-A-P-P, who now lives in North Carolina; and Stuart Brown, L. Stuart Brown, S-T-U-A-R-T, who is from Philadelphia suburbs; and {Elsie Schmidt?}, who died a bit ago, and who was very

important, because she was from a different class than the other ARC presidents. She was kind of from the working class, and these guys were all kind of middleclass.

Pelka: Mm.

03-00:10:12

Gilhool: Now, I do remember how very long it took for me to produce this report. I'll be damned if I can remember what I was doing in between. When I saw the question, Fred, I thought, Well, what was I doing in between was— [pause] You know, Gunnar became my teacher. And he sent me to Ignacy Goldberg, at Columbia Teachers College.

Pelka: Who's this now?

03-00:10:45

Gilhool: Ignacy Goldberg.

Pelka: OK.

03-00:10:47

Gilhool: Ignacy Goldberg, a contemporary of Gunnar's, a great man in all of education, an early figure and president of CEC. And Gunnar sent me also to Jim Gallagher and Don [Donald J.] Steadman. "The young men," he called them. Jim had been Assistant Commissioner of Education for the education of handicapped children, in the— probably Johnson and Nixon administrations. That position was created, I think, in '66 or that kind of era legislation.

Pelka: Mm-hm.

03-00:11:38

Gilhool: The exhortation, the giving states money to think about education of kids with disabilities, in whose framework the '75 act then turned it all mandatory, with all of its specifications. Anyway— [pause] And I remember a long Sunday, probably, at Jim Gallagher's house, in the woods of North Carolina, with Jim and Don. But I now think that most of that probably was after my report and PARC's decision to go with the education suit.

Pelka: Mm-hm.

03-00:12:36

Gilhool: On the other hand, Gunnar and I pretty promptly became constant intellectual companions, if not being physically together. And he, you know, shortly after that conversation, gave me a whole lot of stuff to read and understand. And I began— [pause] As you know, he had been counseling with many ARCs across the country, through most of the sixties.

Pelka: Mm-hm.

03-00:13:24

Gilhool: And as you know, he had written early on, within moments of Brown—and I actually, I think, succeeded in getting a copy of this when he died—he had written a piece in the ARC Newsletter, I think just before he was executive director, but it may have been in the early months when he was, in which he said, “Look at Brown. That applies to us, too.”

Pelka: Wow, OK. That’s very interesting.

03-00:13:57

Gilhool: Yeah, well indeed, yeah.

Pelka: I mean, having talked to Gunnar, I know that he made that connection—

03-00:14:04

Gilhool: Yes indeed.

Pelka: [Over Gilhool] —at that time, immediately.

03-00:14:06

Gilhool: He wrote it.

Pelka: I wasn’t aware that he’d written about it.

03-00:14:09

Gilhool: Yes.

Pelka: OK.

03-00:14:10

Gilhool: And his work with ARCs around the country, you know, was much about getting that to be understood. And for [laughs] reasons that I’ve never been entirely sure of, he spent an *especial* lot of time with the Pennsylvania ARC, throughout the sixties. And certainly, in the three or four years leading up to ’68 and ’69. And my guess is, you know, that he was there when they decided they would go look at Pennhurst again, et cetera.

Pelka: Mm-hm.

03-00:15:03

Gilhool: And made it happen. There was just an extraordinarily warm relationship. And I used to kid Rosemary [Dybwad] that the reason why Pennsylvania was so lucky as to have him in this way was that we had the best greasy spoon on the East Coast.

Pelka: Uh-huh.

03-00:15:27

Gilhool: And I can almost call its name. On the main street of Harrisburg. It’s actually still there. Now, I— to figure out how the hell it came to take me nine months,

except that I've always been very slow, particularly at this end of things. You know, kind of trying to formulate things strategically and sort of whole hog. This was '69. I ran for city council in 1969 in Philadelphia. And I would bet that my conversation with Jim and Dennis was before that, and the report was after that.

Pelka: Mm-hm.

03-00:16:25

Gilhool: And that that was a goodly part of the nine months. I had been prepared to say to you that it was all of those rich conversations with Ignacy and et cetera, but I think that came later.

Pelka: When you went into this, did you have— I'm trying to think how do I— Did you have a sense as to what this was going to look like at the end of the process? Or were you completely fresh, open about this?

03-00:17:08

Gilhool: Well— [pause] The right-to-treatment stuff was in the air. At some point during these years, Wyatt and Stickney [*Wyatt v. Stickney*, (1974)] was actually filed. And the first opinion in *Wyatt v. Stickney* is in the same book as the first opinion in *PARC*, of the federal reports, FSupp [Federal Supplement]. [pause]

Pelka: So you had Wyatt as a kind of—

03-00:17:45

Gilhool: No, because it was developing at the same time.

Pelka: OK.

03-00:17:49

Gilhool: And Gunnar introduced me to Dean, lawyer Dean. What was his first name? [George W. Dean] A brilliant, very—by style of both thought and personal style—country lawyer, who I think actually lived in the panhandle in Florida, who had gotten hooked up with employees at— What was that institution in Alabama? [Partlow State School and Hospital].

Had gotten hooked up with the employees. And that's what it was initially about, you know. Wyatt and Stickney grew out of the employees trying to improve their condition. But, you know, it hit the books at about the same time. But Gunnar was involved in all, you know, conversations in everything that was going on then. And so I was, perforce, involved with him. The rights treatment stuff was in the air, chiefly as an intellectual matter. And the real experience had been St. Elizabeth's in Washington, the two great opinions of David Bazelon, which I think were probably '67 or '68. I had had a seminar, last year in law school. Gillian and I took it together, and so did Monroe Price, who's just been visiting me. And Charlie Halpern and Bo Burt and a whole

lotta people whom you know. Last year. Law, Psychiatry and Psychoanalysis, taught by Joe Goldstein, Jay Katz, the latter, a psychiatrist, the first a brilliant lawyer who had dedicated his first book to the trash men of London. And Anna Freud.

Pelka: Hm.

03-00:20:03

Gilhool: And do you know, we had talked about things like right to treatment and the whole schmear. It would really be fun, in fact, to find—Joe died just a year ago, Jay is still living—to look at the syllabus from that time. But it was a formative seminar for all of us. And indeed, the clerks to Bazelon at the time when he did the right to treatment stuff on the mental health side— And it was chiefly about mental health. I don't think other disabilities were ever mentioned there.

Pelka: Mm-hm.

03-00:20:45

Gilhool: For a long time, as you know, in U.S. law school, the mental health context has been the place to refine and consider questions of liberty.

Pelka: Mm-hm.

03-00:21:00

Gilhool: Always regarded as where those questions were hardest, and so a good place to look at them. Though there's a piece of paternalism in the regard of it as "the hardest," right?

Pelka: Mm-hm. Do you recall whether— You talked about conversations with Gunnar. Did he have a sense as to— I mean, I see him as having this kind of overarching strategy of using the federal courts to gain rights for people with, certainly, cognitive disabilities.

03-00:21:40

Gilhool: Absolutely right.

Pelka: But was he also involved in developing the kind of tactics that you—

03-00:21:47

Gilhool: Oh, very much.

Pelka: OK.

03-00:21:50

Gilhool: And very much involved in— I mean, we were in constant conversation about, What about this alternative? What about that alternative?

Pelka: OK.

03-00:22:05

Gilhool:

Very much. And so was— [pause] See now, I don't know where quite to put it. Stuart Brown became my closest client guide and intellectual companion. But what I can't quite place is whether that arose at the time after we had decided that we were going to do education first, or whether it was true during the time we put together the five possible lawsuits. And I do not remember where the thoughts about education came from. They could well have been Gunnar's steering of thought in that direction.

Pelka:

Mm-hm.

03-00:23:05

Gilhool:

The power of education here was, of course, unavoidable, because of Brown. [*Brown v. Board of Education*, (1954)] And Gunnar certainly would've called attention to it. I mean, all of us at law school, but then after law school, in anything we were doing—for me, the Girard College case was the example—just were constantly tapped in, tuned into the several layers of desegregation, school desegregation lawsuits that were going on around the country and in the Supreme Court.

Pelka:

Mm-hm.

03-00:23:57

Gilhool:

I must tell you that I have remained uncertain when it was that we discovered that opening line in argument in Brown, where John Davis said, "May it please the court, I think if you should rule for the Negro children here, it would catch within its sweep not only the Negro, but the—" I think he said feeble-minded— "and women."

Pelka:

Mm-hm.

03-00:24:35

Gilhool:

And— [pause] for the life of me, I cannot remember— I remember vividly the delight between Gunnar and me, when we discovered this. But my predominant memories are that we actually discovered this piece, not his initial full appreciation of the relevance of Brown to us, which was very early, after the *PARC* decision.

Pelka:

Mm-hm. OK.

03-00:25:12

Gilhool:

And one test of that would be whether we used it in the briefs.

Pelka:

Yeah.

03-00:25:20

Gilhool:

And I have not ever gone back to get 'em. I'm going to ask. I need to do this anyway. And I'll do it for Pennhurst, as well. Though it's much easier for

PARC, because the District Court file is so much smaller. And in *Pennhurst*, I will get the arguments.

Pelka: OK.

03-00:25:40

Gilhool: They were secretly transcribed, when *Pennhurst [Halderman v. Pennhurst State School & Hospital (1978)]* was three times argued, as you put it. And it was reading your questions that reminded me it's worth getting.

Pelka: OK. Secretly transcribed.

03-00:25:54

Gilhool: Nobody was ever told. [laughs] Isn't that remarkable? It was only after Nixon that they [the Supreme Court justices] waited a suitable period of time, and made a public disclosure, and made them available at the library of the Supreme Court.

Pelka: Ah. [laughs] That is interesting. I remember going into—I forget what case it was, but Denise Karuth and I went to a Supreme Court sitting, you know, a question period, of attorneys. It may've been *Olmstead. [Olmstead v. L.C. and E.W. (1999)]*.

03-00:26:28

Gilhool: Right.

Pelka: And, you know, no paper or pen, no notes, [laughs] no recording equipment.

03-00:26:36

Gilhool: [laughs] Right, right, right.

Pelka: [laughs] They were very particular about that.

03-00:26:39

Gilhool: [Over Pelka] Only the justices were allowed recording... [they laugh]

Pelka: Anyway.

03-00:26:45

Gilhool: It's very interesting. Before the first argument of *Pennhurst*, it was known that there were transcripts. And I went in and I read the transcripts of several arguments that seemed to have some relevance. And I actually opened my argument, in the first arguments of *Pennhurst*, with a reference—and it turned out to have been [laughs] a very bad move—to a conversation between a justice and counsel that was *very* germane. And I looked across the nine faces, and there wasn't a spark in recognition [laughs] in any of them. I had, in effect, wasted a minute-and-a-half of the conversation.

Pelka: Mm.

03-00:27:36

Gilhool: I thought I was going to draw somebody whose analysis would've helped us a lot. Didn't. Damn. Look, I'm sorry to say, unless you want to do something in five minutes, we probably ought to reschedule.

Pelka: Yeah, yeah.

03-00:27:55

Gilhool: [Over Pelka] For sometime next week.

Pelka: Yeah. Yeah. Well, what would be a good time for you?

03-00:28:01

Gilhool: I'm into this Thursday morning thing. Why don't we make Thursday morning our hour?

Pelka: OK.

03-00:28:10

Gilhool: Ten thirty?

Pelka: Ten thirty.

03-00:28:11

Gilhool: And as of now, at least—and it depends on whether my hopes are realized. As I mentioned to you, I had hoped [laughs] to have a Florida complaint in children's health care{?} drafted before today. I don't.

Pelka: Ah.

03-00:22:28

Gilhool: But it's now actually flowing in such a way that I might have it fully drafted by next Thursday. If I do, we could go as long that day as we need to.

Pelka: OK.

03-00:28:40

Gilhool: And if I don't, probably it's another two hours.

Pelka: OK. OK. Yeah, I have no problem with dividing this into two-hour segments, because it takes a certain amount of stamina to kinda stay with it, you know, certainly, on your end, and also on my end.

03-00:29:01

Gilhool: Yep.

Pelka: Just to be able to pick out points that I need to be elucidated further, so—

03-00:29:12

Gilhool: Yep.

Pelka: OK, well, this has been great.

03-00:29:15
Gilhool: Yep.

Pelka: And the other thing is, if you could possibly get the contact information.

03-00:29:20
Gilhool: Contact information for Wilson, Haggerty, Clapp, Brown.

Pelka: Yeah.

03-00:29:23
Gilhool: I'm going to find out, and I'll get you a copy. Have you ever seen a copy of the Pennhurst tapes?

Pelka: The Pennhurst tapes?

03-00:29:30
Gilhool: Yeah. From Channel 10.

Pelka: No.

03-00:29:33
Gilhool: OK. I will get you a copy, and I'll also find out what the timing relationship is—

Pelka: [Over Gilhool] All right. And if—

03-00:29:40
Gilhool: —with PARC's decision.

Pelka: And if you get to talk to Bob, run this idea by him.

03-00:29:45
Gilhool: Oh, count on it. Yeah, and he will be very enthusiastic.

Pelka: OK.

03-00:29:49
Gilhool: And I always stumble on the middle three numbers. So you can just call him and— I think it'd be really good for you to come down for that.

Pelka: OK. Alright.

03-00:30:01
Gilhool: So think about doing it at a time when that kind of travel makes sense to you.

Pelka: OK. OK.

03-00:30:05
Gilhool: He would be *just* delighted!

Pelka: OK.

03-00:30:08
Gilhool: And he'd love to welcome you to his house. [chuckles]

Pelka: OK. Alright. Great.

03-00:30:15
Gilhool: That's really great. And Joe Bodell, as well. He has, you know, renewed his friendship with Bob, and I think may have even more reflections on those early years than I have probed.

Pelka: Mm-hm. OK.

03-00:30:39
Gilhool: All right?

Pelka: Great.

03-00:30:40
Gilhool: And his own polio experience.

Pelka: Great. Great.

03-00:30:44
Gilhool: OK, kiddo.

Pelka: OK, well, thanks a lot, and I'll talk to you next week.

03-00:30:47
Gilhool: And for Denise, tell her whenever, in whatever form.

Pelka: OK. I'll let her know that handwriting is an option. Because I think she does, in fact, have lots— pages and pages of handwritten notes that she's trying to, you know, put into some kind of form.

03-00:30:00
Gilhool: [Over Pelka] Yeah. Into a pristine black and white script.

Pelka: Yeah. So—

03-00:31:06
Gilhool: Yeah. And just remind her that the first use of these minutes will be by {Yazu?}, with what he called the social concern groups that have formed some time ago. Within the last year, they went sort of coherent. And they are workers in institutions, and social workers, and teachers, and lawyers, and

some disabled people, as well. But his concern that they are not adequately attentive to empowerment and choice.

Pelka: OK.

03-00:31:43

Gilhool: You know. The role of people with disabilities themselves.

Pelka: OK.

03-00:31:46

Gilhool: And Kazuo [Seike] was the sparkplug organizer of People First, in Tokyo and across Japan. And I think he wants very much to use these conversations to underscore those things, in order to get all these good guy professionals not pursuing paternal things, but pursuing things *with* People First and the rest of the disability movement.

Pelka: [Over Gilhool] OK. OK.

03-00:32:18

Gilhool: So tell her not to hesitate to editorialize from the conversations.

Pelka: OK, great.

03-00:32:25

Gilhool: Great.

Pelka: All right. Very well, talk to you next week then.

03-00:32:28

Gilhool: Bye for now.

Pelka: Bye-bye.

Interview #2: April 11, 2005
Begin Audiofile 4

04-00:00:00

Pelka: This is an interview with Thomas K. Gilhool on April 11, 2005. This is interview number two. This is tape four, side A. How are you doing?

04-00:00:13

Gilhool: [laughs] OK, how are you?

Pelka: All right. We meet at last. I have a couple of follow-up questions, listening to the tapes of the last interview.

04-00:00:23

Gilhool: Good.

Pelka: So I wanted to kinda take care of those, and then get back into the format.

04-00:00:29

Gilhool: Sure.

Pelka: Last time, you talked about Eleanor Kephart, I think it was, resigning over the decision to litigate.

04-00:00:38

Gilhool: Right.

Pelka: And I was wondering, was that over specifically the decision by PARC to litigate or—

04-00:00:45

Gilhool: Yes.

Pelka: OK. It wasn't a more general—

04-00:00:49

Gilhool: Nope.

Pelka: OK.

04-00:00:50

Gilhool: Nope. She was a Pennsylvanian. She had been a president of Pennsylvania ARC, and she had been, as of this time—which would've been the period immediately after they did the investigation of Pennhurst, and were deliberating what they wanted to do with it.

Pelka: Mm-hm.

04-00:01:10

Gilhool: That would've been '67, maybe '68. And she—and others—resigned.

Pelka: Oh.

04-00:01:20

Gilhool: They were really torn up by suing the hand which fed them. Or to put it more pleasantly, suing the people upon whom they depended for what little they had, mostly institutions, for their kids.

Pelka: Mm-hm.

04-00:01:43

Gilhool: They were, after all, as Eleanor would've said, good people who were doing their best, and suing was tantamount to a declaration of war.

Pelka: Now, she was the president of PARC, or the national ARC?

04-00:01:57

Gilhool: Both. She had been both.

Pelka: Oh, ok.

04-00:02:00

Gilhool: She was neither at the time.

Pelka: OK.

04-00:02:02

Gilhool: But it was just a few years earlier. Eleanor Elkin would remember this very well. She was also, at that time, a past president of national and a past president of PARC. And she lives here in Philadelphia, at Logan Center. Jim Wilson, who was president during that time, and who chaired all of those sessions, and was president into the filing of the case, and was present at the [laughs] trial and so on, has resurfaced. He is living in the three-hundred block of South Smedley Street here. He is retired. But [chuckles] not really.

Pelka: Mm-hm.

04-00:03:00

Gilhool: He's the guy who had been in the business department of the *New York Times* in '71, to happy effect here, and who subsequently worked on the business side of *U.S. News and World Report*, and on the business side of *Forbes*. And last four for five years, he was publisher of a joint venture, Hearst and *Isvestia*, [chuckles] in Moscow.

Pelka: Oh, wow. OK.

04-00:03:30

Gilhool: Anyway. He's around, if you should want anything from those dates. And to the current point, he is agreed to chair an effort that we'll launch sometime in the next couple of months to raise some serious money nationally, for the Law Center's disability work.

Pelka: OK.

04-00:03:52

Gilhool: Anyway.

Pelka: I'm sorry, go ahead. You were going to say?

04-00:03:56

Gilhool: Anyway, that's the story about Eleanor.

Pelka: OK.

04-00:04:00

Gilhool: And Jim remembers it well, and I'm sure Eleanor does, and it was true of many others. It was— you know, they were self-consciously borrowing a leaf from the civil rights movement. And despite de Tocqueville's acknowledgement way back in 1831 that sooner or later, all important public questions end up in the courts in the United States, there's— The ambivalence that we see now [laughs] about suing was very much alive then. And it was coupled with, you know, with kind of part deference, right?

Pelka: Mm-hm.

04-00:04:45

Gilhool: To state officials, who were doing their best, and who were good people, and upon whom we had come to rely. And while this was not true of PARC, I think even those days, you'll remember that during the sixties and seventies, there was a major theme in the ARCs nationally about, Get, don't provide. And the Pennsylvania association had actually religiously determined, right about the same time, that it would stop providing services, and it would be in the business only of getting, of advocacy.

Pelka: Mm-hm.

04-00:05:28

Gilhool: So there was some of that real life conflict, underlay that sentiment.

Pelka: And that, of course, is a conflict in the larger disability right movement, in terms of the independent living movement.

04-00:05:43

Gilhool: Yes.

Pelka: You know, all down the line. I mean, that's a real—

04-00:05:47

Gilhool: Yes, Fred. And it's on my mind in part, because I just got a two-page summary of his dissertation from a fellow doing his at the University of Michigan, a fellow named Leon Brown, who was in Japan while we were there, as a Fulbright, and who has stayed, doing some [chuckles] consulting

for drug companies. But his dissertation is about that conflict in the Japan disability movement.

Pelka: Wow. OK.

04-00:06:13

Gilhool: It's a switch of his topic. His original topic was, How come, in 1994, at the next revision of the Japanese Fundamental Law, the Diet and the movement were unable to get—the Diet champions—were unable to get an ADA, or *any* anti-discrimination provisions.

Pelka: Mm.

04-00:06:38

Gilhool: I don't know why he abandoned that, but he picked up this other interesting thing. And you're right, of course. It's very interesting, isn't it?

Pelka: Yes.

04-00:06:50

Gilhool: And his particular focus is on government funded services, of course, government paid for services.

Pelka: Mm-hm.

04-00:06:57

Gilhool: And that, of course, is one of the reasons why the protection and advocacy agencies were created, right?

Pelka: Yeah. Yeah.

04-00:07:04

Gilhool: In an effort to approximate the independence, which OEO [US Office of Economic Opportunity] legal services had, and by the time of the early seventies, had really memorialized, by changing their form to become a public corporation, funded by the Congress, no longer run through an agency. Anyway, there are a lot of things there, aren't there? I just wrote Leon a long letter that I'm not sure [laughs] he has any interest in having it or not, about these themes of the American experience. I'll send you a copy of it.

Pelka: Sure. That'd be great. And while we're talking about loose ends and contact information, you were going to try to—we just talked about Jim Wilson—you were going to try to get contact information for Dennis Haggerty?

04-00:07:56

Gilhool: Yes, and I almost mentioned his name a moment ago, 'cause he, of course, had chaired the investigation. And of course, he and Jim, and Gunnar at their elbow, who talked all of this through the PARC deliberative processes. I will.

Pelka: OK.

04-00:08:15
Gilhool: Let me check something.

Pelka: Mm-hm.

04-00:08:17
Gilhool: [off mic] Hold on a minute. I have to run to get a directory.

Pelka: OK.

04-00:08:21
Gilhool: Legal directory of greater Philadelphia. Because I'm a little worried that—
Dennis was not well when I saw him last, and that's been true for a while.

Pelka: Mm.

04-00:08:34
Gilhool: And I worry from time to time— Let me see if he's still listed. Yeah. [pause]
You go ahead while I—

Pelka: Oh, OK. Dennis was an attorney at that time?

04-00:08:53
Gilhool: Yes, uh-huh. And he practiced out in Delaware County, and he was a leader of
that chapter. Never came to be president of PARC. Was very active with the
president's committee in the sixties and seventies.

Pelka: President's committee on?

04-00:09:20
Gilhool: Mental retardation.

Pelka: OK. [pause] OK. Well, while you're looking through that, there's another
follow-up question. At one point, you mentioned that there were five possible
lawsuits—

04-00:09:38
Gilhool: Right.

Pelka: —that you were considering. And I was wondering if you could fill that out a
little bit.

04-00:09:42
Gilhool: Yep. I'll turn to that immediately. First, I'll give you Dennis' contact
information. [contact information omitted.]

Pelka: OK.

04-00:10:23

Gilhool: This lists him as a GP. He had a son who was young then, and actually—dear me—may have died a few years ago. And he did a lot of wills and estates work typical for that era, both generally in his practice, and for families and people with disabilities.

Pelka: OK.

04-00:10:52

Gilhool: But that's his number, and I hope you find him well.

Pelka: OK. Now, getting back to the five possible lawsuits.

04-00:11:00

Gilhool: Yeah. I don't know if I ever supplied you with every other page of the memorandum, which I wrote for *PARC* in '69, I guess, which laid out the five possibilities. And then they wrestled with 'em, as I did at their elbow. And we came up with the right education. So one was to open the schools.

Pelka: Mm-hm.

04-00:11:36

Gilhool: The second was a right to treatment. One would say a right to treatment in institutions, because— You'll remember there had been a couple of decisions by David Bazelon for the District of Columbia Court of Appeals declaring a right to treatment in mental health context. And the way that got sliced, it was— And the risk, from *PARC*'s point of view as well as mine, was that it would just perfect the institutions.

Pelka: Mm-hm.

04-00:12:17

Gilhool: That would've been a kind of due process clause theory. The school case was built on the equal protection clause. And there's a very fine article by Bo Burt, Robert A. Burt, a classmate of mine and a good friend, who did a paper on Partlow, right? Partlow, the Alabama case.

Pelka: Right. The Wyatt case. We were trying to think of the—

04-00:12:48

Gilhool: [Over Pelka] And— Right. Wyatt, exactly. Wyatt versus Stickney. Which Dennis, by the way, was kind of on the edges of, because it was he who first knew the lawyer down there who brought that case on behalf of workers at Partlow, initially about [laughs] wages and working conditions. And then it turned into what it turned into. But in any event, that was the second possibility. And in the end, it was rejected because *PARC* was not eager to run the risk of improving the institutions.

Pelka: Mm-hm.

04-00:13:34

Gilhool:

Well, let me say why things were rejected later, at the end, 'cause there's a set of reasons. A third was— [pause] to end involuntary servitude in the institutions, to require that people be paid, and thereby, to increase the cost of institutions, and hence, diminish their life chances. [laughs]

Pelka:

Mm-hm. OK.

04-00:13:57

Gilhool:

To help 'em fade away.

Pelka:

Mm-hm.

04-00:14:10

Gilhool:

That was three. Boy. I'm going to have to have trouble with the fifth. This next one was actually the fifth. It was a state law action. The legislature of Pennsylvania—this would've been 1969—had, partly in response to PARC's investigation and the attendant publicity—particularly on Channel 10, the CBS television channel here, over a long period of time—the legislature had appropriated, I want to say twenty-five-million; it could've been twenty-one-million dollars—to fix up Pennhurst. And the action which we contemplated was an action under state law, state administrative law, that said you shouldn't do irrational things, like invest more money in an institution that was fated not to be improved.

And that action was actually of great interest for a good long— for a while. But PARC very promptly went to work on the administration. This was the Shafer/Broderick administration. Broderick was Lieutenant Governor in that Republican administration. And his leadership brought the administration and the legislature to un-appropriate it for the improvement of Pennhurst, and to appropriate it instead, first, for the creation of a typology of community living arrangements, and then to begin to pay for and open them. That study was done by a man who became a dear friend. It's terrible. Retired not long ago in Delaware. Floyd McDowell, who had actually been an institution superintendent, fired by John Connally in Texas, when he refused to admit [chuckles] any more people to the institution.

Pelka:

Oh.

04-00:17:08

Gilhool:

And subsequently, a *very considerable* educator, a leader of Council for Exceptional Children, a graduate student in a seminar in the early sixties, by the person—I believe at Minnesota, and I should be able to call his name; Gunnar would call it immediately—who ran a seminar of graduate students, and then subsequently, as an almost or an immediate past chair of Council for Exceptional Children, wrote a strong piece, around 1966 or '7, calling for integration in the schools. Let alone admission of folks, but integration in the schools. What we would now call inclusion. A very great man, and I'm

suppressing his name for a minute. And Floyd was one of three or four subsequently well known people in that seminar who, in fact, had begun to raise in his typical teaching, Well, you know, why the heck aren't these kids integrated?

And it stimulated him to write this wonderful piece. Anyway, Floyd did design what I remember as seven or eight kinds of community living arrangements, all of which were quite small, except for one that may have approached the ICF/MR [Intermediate Care Facility for persons with Mental Retardation] limit of fifteen that was for multiply-complicated people. None of those was ever built in Pennsylvania. But anyway, it was a wonderful report. And perhaps as early as the Shafer administration, they served into 1971, January of 19— Wrong. Jesus. Hold on now. [pause] Anyway, they started very promptly to open community living arrangements. You'll remember Pennsylvania already had a sixty-seven county MH/MR system, joined together at that time, all— Pennsylvania was, as I recall it, the very first state to adopt an MH/MR act, after the Kennedy initiatives in '63. And a very good one it was. And it's always amusing [laughs] to hear the people in California, who adopted theirs somewhat later, insist that they're the only state in the country that makes community services an entitlement.

Pelka: Mm-hm.

04-00:20:29

Gilhool: Which, of course, is dead wrong. And most statutes were cut from the same cloth in those days. And the Pennsylvania courts, like the courts of many other states, had said if you needed something, community services were an entitlement, under the state law.

In any event, that network existed; and it was, of course, much stronger on the mental health side than it was on the retardation side, in the late sixties. And that's part of the reason why the retardation movement, as it gathered strength, drove the separation of those two services. But in any event, that network existed. And it was, of course, much stronger on the mental health side than it was on the retardation side, in the late sixties. And that's part of the reason why the retardation movement, as it gathered strength, drove the separation of those two services.

Pelka: Mm-hm.

04-00:21:08

Gilhool: But in any event, that county network, and its network within counties of base service units, kind of case management outfit, opened a significant number of community living arrangements, taking people from institutions as well as from home. And it was that undertaking which provided us, by the time we got to trial in the Pennhurst case, in the eleven weeks in the summer of 1977, with the comparison to institutions. And those community living arrangements

were the source for what we called the Matched Twins study. They weren't twins at all, but rather, they were people with similar configurations of disability at Pennsylvania; and we matched all of them to at least one, and usually a couple, of people in the community, to make the point from the proof, that everybody at Pennhurst could make it in the community if they were provided with sufficient stuff.

Now, all of that comes from that analysis of that suit that we considered, but did not have to bring because PARC, at about the same time it had decided to do education as the suit of choice, undertook to lobby the legislature and the lieutenant governor for—and the governor—for the design and creation of a community living arrangement system.

Pelka: Mm-hm. So I just want to, just to be sure, the Floyd McDowell study that you're talking about, that original study of hypothesizing varieties of different community arrangements, that was in '68, '69? What year would that have been?

04-00:23:22

Gilhool: My guess it was it was '70 or so.

Pelka: OK.

04-00:23:29

Gilhool: I used to have it. Floyd, so far as I know, is living. I haven't talked to him since we've been back from Japan. My colleague Mike Churchill talks with him with some frequency. He's in Newark Delaware. But I used to have that piece, and I'll betcha it's in Gunnar's collection at Fernald.

Pelka: OK.

04-00:23:57

Gilhool: The other thing that might be in Gunnar's collection are the missing pages of the report on the five pieces of litigation.

Pelka: Oh, this is the report that you have every other page of.

04-00:24:08

Gilhool: Yes, exactly right.

Pelka: OK.

04-00:24:10

Gilhool: And at that, I *have* had every other page. I don't have a current understanding of where it is. I never produced that for you, did I?

Pelka: No. No.

04-00:24:25

Gilhool: I think Bo Burt uses it in his article, which is in *President's Committee on Mental Retardation*, Mike Kindred, editor. Couple of other editors, but Mike was the real editor. *Mentally Retarded Citizen and the Law*, published by Glen Cove Free Press in 1973 or '4 or '5, I guess.

Pelka: OK. Yeah, I've seen that.

04-00:24:55

Gilhool: And I have a long piece in there, as well, which is called something like "The Right To Community Services." That might also use the memorandum.

Pelka: Mm-hm.

04-00:25:07

Gilhool: And the book, of course, which tells all of this— much of this story, and all of it with considerable accuracy, is Leo Lippman and Ignacy Goldberg, I. Ignacy Goldberg—they were both at Columbia Teachers College—called *The Right to Education: an Anatomy of the Pennsylvania case*.

Which book, I think it's not unfair to say, though I wouldn't use the phrase more publicly, I essentially dictated. I mean, [laughs] they both came down, and we sat for long hours. And I wouldn't even be surprised if that memorandum is an appendix there.

Pelka: Hm.

04-00:26:02

Gilhool: It's possible. That book, for a long time, was very widely used across the country in Special Education One.

Pelka: OK. One thing I want to also get back to, just— I just want to make sure of something that you mentioned. You just mentioned it now, and you mentioned it in the last interview. And that is that, really, from the inception of the *PARC* case, this was seen as a way to close down—

04-00:26:32

Gilhool: Yep.

Pelka: —Pennhurst. I don't know if that's commonly— if that's the common perception. I mean, it's seen as a right to education case.

04-00:26:41

Gilhool: Yes.

Pelka: And generally, described in those terms. But you're clear that from the very beginning, what they wanted to do was close down Pennhurst—

04-00:26:50

Gilhool: Yes.

Pelka: —and right to education was the lever—

04-00:26:54

Gilhool: The vehicle of choice, yes, exactly.

Pelka: [Over Gilhool] OK. OK.

04-00:26:58

Gilhool: PARC had resolved to abandon their twenty year efforts to improve Pennhurst and the other institutions. But Pennhurst was the flagship institution, and not much worse [laughs] than some of the others. But from the get-go, after their report—maybe even before they retained me, though I'm frankly uncertain about that—they had resolved that their ultimate objective was to close the institutions and bring people into the community.

They were very clear-headed about that. And that Jim and Dennis and Eleanor would all be able to tell you those stories, as would Gunnar.

Pelka: Mm-hm.

04-00:27:57

Gilhool: And Gunnar was— Have we talked about this? We're talking '68 and '69, I think. And he had been, of course, the national ARC executive, and was at Brandeis by now, and made himself available to associations for retarded children all around the country. And he made himself very much available to Pennsylvania, and was a close participant with them throughout, I would say, throughout the latter half of the 1960s.

Pelka: Mm-hm.

04-00:28:50

Gilhool: As you may remember, I said to Rosemary [Dybwad], at the celebration, "We always thought that he came to Pennsylvania because we were so wonderful. But he actually may have come to Pennsylvania because we had, as he put it, the best greasy spoon on the East Coast."

Pelka: Right. Right. You talked a little bit about—

04-00:29:19

Gilhool: And that, too, you know, acting so strongly as to be acting against the institutions may have put an edge on Eleanor Kephart's wish to leave.

Pelka: Right, that's exactly what I was going to ask you about.

04-00:29:35

Gilhool: She left before the discussion of litigation alternatives, and at the point where there was a resolution to sue, in whatever form, and to retain counsel to look at it, and a resolution to their ultimate objective.

Pelka: Was there *serious* opposition within— let’s say, taking it first within PARC, was there serious opposition to the idea of going after closing the institutions entirely?

04-00:30:12

Gilhool: Oh, yes. Yes. Yes.

Pelka: [Over Gilhool] OK. Was it—

04-00:30:14

Gilhool: I was not— understand, I wasn’t present during any of this time.

Pelka: Uh-huh, ok.

04-00:30:18

Gilhool: They came to me only with those two resolutions in hand, to engage counsel.

Pelka: Oh.

04-00:30:26

Gilhool: But as I came to understand the story from all of the people that we have mentioned, yes, it was *very* hard. Gunnar and Dennis, at the ultimate meeting, managed to show the pictures—slides, I guess—from the investigation, and in effect, to say to those who were reluctant or recalcitrant, “Look, you owe it to these people.”

Pelka: Right.

04-00:31:08

Gilhool: And it was very much a prime set of emotional experiences for everybody who was working it through in that period. And it didn’t happen, you know, quickly. It wasn’t a matter of one meeting, it was a matter of a series of meetings.

Pelka: Once you came onboard and you had this resolution decision to go forward with litigation, was there opposition, or feedback from—

04-00:31:44

Gilhool: [Over Pelka] No. I was not aware of any.

Pelka: OK, from outside, from let’s say, the national ARC toward PARC, or other state ARCs toward PARC, was—

04-00:31:55

Gilhool: No.

Pelka: Nothing like that?

04-00:31:56

Gilhool: No sign of it. Though I early became conscious, as everybody was, that the National Association for Retarded Children was not the barricades. Or put it another way, not on the frontier.

Pelka: Mm-hm.

04-00:32:19

Gilhool: Some of it was. Some of its thought was. Some of the things they wrote and said were. But you will know that the national has always been torn, pillar to post, for a very long time. I mark the final end of that, Fred—and this may be preciously optimistic—with Steve Eidelman’s intervention in California, in the first year or so, when he became the national executive director of the ARC. And he said to California—CAR, it was called; California Association of the Retarded—“You’re out.”

Pelka: Hm.

04-00:33:17

Gilhool: “Because you are committed to protecting these institutions, and you can’t do that and be in the ARC.” And he actually expelled them.

Pelka: What year was this, do you—

04-00:33:30

Gilhool: Very recently.

Pelka: OK.

04-00:33:36

Gilhool: I may be wrong, but I want to say ’99.

Pelka: OK.

04-00:33:41

Gilhool: I mean, he hasn’t president—

Pelka: Yeah.

04-00:33:43

Gilhool: —I mean, executive director, for all that long.

Pelka: Right. Hang on a second, I’ve gotta flip the tape over. [audio file stops, re-starts]

04-00:33:20

Pelka: This in an interview with Thomas K. Gilhool, April 11th, 2005. This is interview number two, tape four, side B. Getting back to the reaction of, let’s say, the national movement, were you all open within the movement, about the goal of closing the institutions? I mean, as I say, the perception—

04-00:34:52

Gilhool: Yes.

Pelka: —of *PARC* is right to education.

04-00:34:54

Gilhool: Mm-hm.

Pelka: But you were out front in talking to other advocates around the country and saying, “What we’re really trying to do here is simply close down these institutions.”

04-00:35:07

Gilhool: I think the answer to that question is yes.

Pelka: OK.

04-00:35:09

Gilhool: I think all of the people who led and spoke for *PARC* were very clear about that. I don’t know that they would’ve rubbed it in everybody’s faces.

Pelka: Mm-hm.

04-00:35:19

Gilhool: But the clarity of their judgment surely would’ve shown through. I was not— And it may even be that there was some protest from other chapters, or from the national, of a formal variety. What I said earlier was that I was not aware of such. And there’s no reason why I *would’ve* been aware of such. I mean, I didn’t really— As I was preparing the case, and then having pled the case, preparing proof, I wandered around the movement a lot—chiefly with Gunnar as my tutor—to various people. But I did not begin to spend much time with the organized ARCs until after the preliminary injunction in the *PARC* case in the November of 1971, I think. Yeah, ’71.

Pelka: OK.

04-00:36:31

Gilhool: Yeah. But Jim or Dennis may have had—you know, and Eleanor—more of a sense of that. But in any event, for me, it was very clear where they were coming from and what they wanted to achieve. And I believe we will find that the memorandum—which much have been eighteen, twenty pages, I think, exploring the possibilities for advancing the agenda—was very clear about what the agenda was; analyzed the lawsuits from the point of view of their potential contribution to that objective, as well as their basis in law, and in persuasion.

I’m really sorry I cannot remember the fourth of the options. I think it partook of some kind— If there was education, right to treatment, involuntary servitude, and kind of administrative good sense—anyway, spending the

money in productive ways—my guess is that the fifth option was another institutional option. I'm sorry it's out of my head.

Pelka: Mm-hm.

04-00:38:07

Gilhool: But all of those options would've been evaluated against those three heads.

Pelka: Mm-hm.

04-00:38:18

Gilhool: And I can pick through, if this is a good time, why it is that I recommended. And remember, these recommendations were hardly written in isolation, but very much played off conversations, and so it isn't a question of my writing and their disposing, but that everything all sorta happened at once.

Pelka: Right. Before you do that, who was the memorandum distributed to?

04-00:38:47

Gilhool: It was distributed to the board of directors of the Pennsylvania Association for Retarded Children.

Pelka: OK. And anyone else? Or that was pretty much it?

04-00:39:01

Gilhool: I'm not aware of its being distributed to anybody else, but—

Pelka: OK.

04-00:39:05

Gilhool: —Dennis, or Jim Wilson, or Gunnar, or anybody else may have distributed it.

Pelka: OK.

04-00:39:11

Gilhool: But I wrote it for the board.

Pelka: OK. And then did the board take a decision to accept it, and then take it to the membership? Or were they—

04-00:39:24

Gilhool: No, I don't think it went to the membership, as such.

Pelka: The board was—

04-00:39:31

Gilhool: Sure. The board has always been plenary body in the ARC.

Pelka: OK.

04-00:39:38

Gilhool: Mm-hm. Which is not to say that they didn't invite everybody to participate, both before and after.

Pelka: Did you speak to the board when you presented the memorandum?

04-00:39:49

Gilhool: [Over Pelka] yes, yes.

Pelka: OK.

04-00:39:49

Gilhool: After I had presented it, I'm sure.

Pelka: OK.

04-00:39:53

Gilhool: At whatever the next meeting was.

Pelka: And do you recall how long it took them to come up with a decision?

04-00:40:01

Gilhool: No, I don't. I don't think it was a terribly long time.

Pelka: OK.

04-00:40:10

Gilhool: My guess is that the decision evolved in the course of that very meeting.

Pelka: OK.

04-00:40:16

Gilhool: You know, they had had the paper some time before, and they'd been discussing it for a year or so, better. Yeah.

Pelka: OK. OK, now, you wanted to explain why it was you came down on— Now, we're talking now this— I think it was Bob Burgdorf who called it the double-barreled approach; equal access, due process—

04-00:40:38

Gilhool: Equal protection, right to education.

Pelka: [Over Gilhool] Equal— right, right to education. So—

04-00:40:42

Gilhool: Yes, in those lovely pages. Which, by the way, may have been written by— Darn. He's at Hahnemann [hospital in Philadelphia]. He's a lawyer/psychiatrist. Lovely guy. And you'll see his name, because he did about a quarter of the book—

Pelka: OK.

04-00:41:02

Gilhool: —that Bob signed. Damn it, I can't remember his name. Sorry, I thought I could.

Pelka: And you said he was where, now? He was at—?

04-00:41:11

Gilhool: He was— Bob's book, if I understand—which, by the way, remains the best, I think, though there's a new one out I have not seen, just learned about— Geez, you're going to have to help me. Was it edited by Bob and his wife?

Pelka: You know, I can't recall.

04-00:41:35

Gilhool: Me, either.

Pelka: Yeah.

04-00:41:37

Gilhool: And in addition, there were a couple of other sub-editors.

Pelka: Right.

04-00:41:42

Gilhool: And I think Bob was deeply involved in all of it. But much later, I became aware of this lovely guy who had actually taught at the University of Southern California just after I was there, and subsequently came here to Hahnemann and Villanova.

Pelka: Oh, OK.

04-00:42:03

Gilhool: Ah. Still can't remember his name. And he may've been responsible for those parts of the book, I don't know. Anyway, yes, you're right, he did that double-barreled thing. And yes, it was double-barreled. And, well, the easiest place to start is with the strength of the legal theory, which of course—well, in its equal protection dimensions—rested on Brown.

And you'll remember that famous paragraph in the Brown opinion, which ends, "The right to an education, where a state has undertaken to—" Ah. "An education, where the state has undertaken to provide it to any, is a right which must be made available to all, on equal terms."

Which is to say that there was a great resonant strength, as a matter of the law and legal doctrine, right under the lawsuit, in Brown.

Pelka: Mm-hm.

04-00:43:38

Gilhool: The due process cases were relatively new. The due process right to treatment cases were relatively new. Involuntary servitude from time to time had reared its head, but had not become a matter of moment in any of the courts.

Pelka: Now, just an aside. Involuntary servitude, in this context, you're talking about things that residents—or however you want to term them—

04-00:44:11

Gilhool: Yes.

Pelka: —inmates of these institutions—being forced to work on the—

04-00:44:15

Gilhool: Exactly.

Pelka: —farm or in the shops, or do piecework, or whatever.

04-00:44:21

Gilhool: Yep.

Pelka: And this, under the guise of— well, sometimes not even under the guise, but often under the guise of therapy or—

04-00:44:25

Gilhool: [Over Pelka] Keeping the place going.

Pelka: Yeah. Yeah.

04-00:44:29

Gilhool: And Pennhurst had had a farm, still had a small one at this time. And you know, the people did the food service and all that kind of thing.

Pelka: Right. Without compensation.

04-00:44:44

Gilhool: Yes.

Pelka: OK. I just wanted to throw that into—

04-00:44:48

Gilhool: Yep. And the theory of that case, of course, was that if we won the case, people could buy their own way out of the institution.

Pelka: Right.

04-00:44:55

Gilhool: And then on the other hand, it would so impose additional costs on an institution that it would not any longer make economic sense for states to stay invested in them.

Pelka: Mm-hm.

04-00:45:07

Gilhool: But this one had the benefit, one, of that underpinning of the law, in such a remarkable way.

Pelka: Mm-hm.

04-00:45:20

Gilhool: And you will remember that Gunnar had written early, while he was still exec at the ARC—in '54 or '56, I'm a little uncertain when—he had written in the national newspaper, a piece saying, "Hey, look at Brown. This ought to apply to us, as well."

And while Gunnar was quite convinced, I think, that we had come up with what I will tell you about now, and used it during the *PARC* case, in fact—and I've gone back to double check it a couple of times—I think we never came up with what I will [chuckles] tell you now, until after the *PARC* case. And that was the opening lines of the lawyer for South Carolina, one of the greatest appellate, probably the greatest twentieth century Supreme Court advocate, who had refused appointment two or three times, to the Supreme Court, once at Wilson's hand; he had been congressman from West Virginia, and then Wilson's Solicitor General, and president of the ABA. And his name is out of my head. But it may come back, and it's familiar, we'll get it. He opened argument in Brown saying, "May it please the court, I think—" [pause]

Pelka: This was the quote where if you rule in favor of—

04-00:47:12

Gilhool: That's right.

Pelka: —children of color, or—

04-00:47:15

Gilhool: Yes.

Pelka: —Negroes or whatever, this will eventually encompass—

04-00:47:21

Gilhool: That's— yeah.

Pelka: —the feeble-minded, or whatever the phrase was.

04-00:47:24

Gilhool: Yeah. And the phrase, I think, was the mentally deficient.

Pelka: OK.

04-00:47:31

Gilhool: And he also included women. [laughs]

Pelka: Right.

04-00:47:38

Gilhool: And age. He said he thinks if the Negro children should fall within the equal protection clause in this way, there would no longer be any reason within the schools to segregate on the basis of gender, or sex. I think it was— I'm not sure.

Pelka: Mm-hm.

04-00:48:02

Gilhool: On the basis of age, or on the basis of mental deficiency.

Pelka: OK.

04-00:48:08

Gilhool: But we didn't have that going for us [laughs] until afterward. In any event, that was the legal strength of the case. Second, whenever you go to court, you— Well, let's go back a jump. People with retardation were new to the courts, so we had to teach them about people with retardation, and retardation. Right?

Pelka: Right.

04-00:48:36

Gilhool: Having also to teach them about institutions. And the rather new legal doctrines concerning with the right to treatment would've meant we'd have to teach them *two* big new things. But with education, the courts—either actually, or because of courts' knowledge and awareness, all around the country, of the Southern school desegregation stuff—*knew* schools, of course.

Pelka: Mm-hm.

04-00:49:13

Gilhool: Or felt that they knew schools, and were comfortable with them. So our theory was that we could teach them about retardation. But they already knew about schools, and that was a real gain for launching, starting with this case. That make sense?

Pelka: Yeah. Oh, yeah.

04-00:49:35

Gilhool: And third, it— [pause] It had become very clear— [pause] And sometimes I assign the wrong things to {inaudible} first edition of *Changing Patterns in Residential Services for the Mentally Retarded*, published by the President's Committee on Mental Retardation. The first edition was published in 1968, and the second and third editions published subsequently, one in around '74. [pause] But in any event, it was there, I think, that the point was made. And in any event, the ARC people knew it, and Gunnar certainly knew it, that the

very greatest number of people sent to institutions were sent to institutions in their early teen years.

Pelka: Hm.

04-00:50:56

Gilhool: Between twelve and fourteen. Usually, to stay there for life. Well, why were [laughs] they sent then? Well, because their families were alone. There was nothing else.

Pelka: Yeah.

04-00:51:16

Gilhool: Except an occasional ARC or UCP run program, et cetera, et cetera. And so, when their children with retardation started acting like teenagers—[laughs] namely, getting considerably rambunctious and reaching out to take control of their world—the families were all alone in dealing with it. They didn't even have the relief in time, of sending the youngsters off to school. And so their vulnerability to sending the youngster off to an institution was, of course, at its height.

Pelka: Mm-hm.

04-00:52:06

Gilhool: Probably strongest at birth, and a lot went there, et cetera. It's very interesting. In that 1968 thing, there is a map of the origin of the people then living in institutions [chuckles] in California. And there are no dots in Watts, or even [laughs] Los Angeles. And that initially struck us as a little curious. But of course, when you think about it, it wasn't strange at all. Because by and large, it was high {SES?} conflicts which peopled the institutions. Right?

Pelka: Uh-huh.

04-00:52:56

Gilhool: Poor people, and people with a vibrant or an alive, functioning, more or less functioning in traditional society tended to keep them at home. In any event, that's a bit of a detour, but the main fact is, that's when people went to institutions.

So the analysis was, and I— Geez. It'd be interesting to see if it's in the memorandum. The analysis was that if we can open the schools, then the demand for institutions will fade away.

And indeed, that is kind of what happened. I used to have these figures at my fingertips. But in 1970, something like fifteen-thousand children of school age were sent to live in institutions. By 1978, the first year of the full effectiveness of 94-142, something under five-hundred were. And then at various times, it

has faded away toward nothing, though some state always pops up still doing it, as California has been again, until recently.

Pelka: Hm. Let me ask you. Now, it seems as though in order to sell this to the court, what you would've had to do is you'd have to argue that there was, in fact, a right to education, which you were able to do; that the needs for education were not being met in the institutions, and *couldn't* be met in the institutions; and—

04-00:54:49

Gilhool: {inaudible}

Pelka: OK, so you were confident before—or the board, at any rate, was confident, before they took the decision, that they would be able to do that.

04-00:55:01

Gilhool: Well, that's really interesting. I don't think— The second one is the interesting one. I don't think that's— That's *very* interesting, Fred. I don't think we thought we had to prove that it couldn't happen in the institutions.

Pelka: OK.

04-00:55:26

Gilhool: And that's partly because nobody in this environment, anyway, was making an argument that it *did* happen in the institution, or *could*.

Pelka: OK.

04-00:55:42

Gilhool: Rather, the foul here, the unlawful violations, were the school exclusionary laws of Pennsylvania, which it turned out every state had adopted in the first couple decades at the turn of the century. And there were four or five particular mechanisms in that law whose function and purpose was to exclude people with retardation, and palsy, and epilepsy, and a couple of other things, from the schools.

Pelka: Mm-hm.

04-00:56:30

Gilhool: One of them was, you can't start school unless you reach a mental age of five. Well, as mental ages were calculated, there would be a whole lot of people who would be five, six, seven, eight, nine, and ten, and not reach mental ages of five. There was a second provision, very common among the states, that said— [pause] which gave school boards authority to exclude from their schools children whom they found to be uneducable and untrainable.

Pelka: OK. And of course, that could be arbitrary.

04-00:57:23

Gilhool: Yes, indeed.

Pelka:

I mean, that was left to the local educators, or the people in charge of local education, to determine.

04-00:57:33

Gilhool: Yes. And you know, there's now a considerable history in all of this. CEC [The Council for Exceptional Children], Fred Weintraub and Alan Abeson, and as an intern with them, [chuckles] David Braddock—can you believe it?—

Pelka:

OK.

04-00:57:55

Gilhool: —during these years—'69, '70, '71—collected and published—I'm not sure what dates—but collected the education statutes of all of the states.

Pelka:

Mm-hm.

04-00:58:13

Gilhool: Right? And one of the first things Gunnar did was to say, “There're two sets of young men that you must go meet with.” And one set was Fred and Alan, and the other were Jim Gallagher and Don Steadman, who were both then at the University of North Carolina. Jim had been the Assistant Commissioner of Education for the United States, in charge of special education. He was a predecessor to that lovely guy who was there for a long time, who ended up on Long Island. Anyway. I think Jim was the first, and I think that happened about 1967. In any event. [pause] Where was I?

Pelka:

You were talking about these folks collecting all of the statutes, education—exclusionary education statutes.

04-00:59:19

Gilhool: [Over Pelka] Yes, yes, yes. And so we saw these patterns. What was in Pennsylvania law was pretty much in every state's law.

Pelka:

Mm-hm.

04-00:59:27

Gilhool: And those were the mechanisms that we alleged were unconstitutional. One, because they denied to children who could profit from an education, the opportunity to be in school; and two, because they did so in ways which denied due process.

Pelka:

OK. And all of these statutes pretty much originated during the eugenics—

04-00:60:03

Gilhool: Yep.

Pelka: OK. Early twentieth century.

04-00:60:04

Gilhool: Exactly right.

Pelka: OK.

04-00:60:06

Gilhool: Have you ever read the collection of state statutes that we did, at first, to the Supreme Court in *City of Cleburne, Texas versus Cleburne Living Center* [1985]?

Pelka: I don't think so.

04-00:60:19

Gilhool: I—

Pelka: I may have, actually.

04-00:60:21

Gilhool: Yeah, yeah.

Pelka: Because I've got that.

04-00:60:23

Gilhool: But I must send you one— [laughs]

Pelka: Yeah.

04-00:60:24

Gilhool: —before we run out of 'em.

Pelka: OK.

04-00:60:26

Gilhool: We've put 'em back in front of the Supreme Court in *Olmstead* and in *Garrett* [*University of Alabama Board of Trustees versus Garrett*].

Pelka: Right.

04-00:60:32

Gilhool: And in one other case, too. And they contributed mightily to Thurgood Marshall's spectacular concurring and dissenting opinion in *City of Cleburne, Texas*. But yes, they are all of a cut. I mean, the focal point of the statutes in all of the states were segregation and sterilization.

And then sometimes in the same statutes, but more often four or five years later, the school codes were amended—sometimes to charge superintendents with seeking out these people, and taking them to the institutions, whether or not the parents objected.

Pelka: Mm-hm.

04-00:61:29

Gilhool: And that was a kind of enforcer for the segregation and the sterilization; but it was also the tippy edge of the school exclusion provisions.

Pennsylvania was the only state whose governor vetoed sterilization. That was in 1905. Governor Pennypacker. And then in 1913, was the statute that happened to be Pennhurst, which created the Eastern State School for the Feeble-minded and Epileptic, in order to segregate the feeble-minded, epileptic, et cetera.

Pelka: Mm-hm.

04-00:62:14

Gilhool: For life, et cetera.

Pelka: Mm-hm.

04-00:62:16

Gilhool: So we didn't have sterilization. That was '13. We had segregation and the creation of the institutions. And then it was around 1917, '18, that these exclusionary provisions for the schools arose.

Pelka: Mm-hm.

04-00:62:33

Gilhool: And— Yeah.

Pelka: And the due process part comes I because there was no appeal mechanism, there were no hearings. There's nothing formalized like that. It was simply the decision of the educator, We will not accept your child, period.

04-00:62:53

Gilhool: Yes. At core, you are right. But it had a particular, very resonant, almost sexy cast to it. The Supreme Court, by— Let's see, we filed in early '71. It took us about a year after the decision to put it together to file it. So in 1970, or a few years before, the Supreme Court had decided a case called Wisconsin versus Constantineau [1971]. And it will take me a bit to get back precisely the factual framework of that case. And that case says you can't impose *stigma*, without due process. Isn't that remarkable?

Pelka: Yeah.

04-00:64:08

Gilhool: Isn't it remarkable? And that was the basis for the court's finding that the lawsuits sounded in due process, as well as equal protection.

Pelka: When was this decision?

04-00:64:26

Gilhool: Oh, [laughs] shortly before 1970. It was—

Pelka: [Over Gilhool] OK.

04-00:64:30

Gilhool: —sometime in the sixties.

Pelka: OK.

04-00:64:37

Gilhool: And it has been subsequently disfavored by the Rehnquist Supreme Court. But it lasted full-blown for a good twenty or thirty years. And I will, at some point, recall—or you will—see the case, its— Exactly the structure, the framework, and what the issue was in that case that led to that decision expressly about stigma, is out of my head at the moment. But wasn't that uncanny?

Pelka: Yeah.

04-00:65:25

Gilhool: So we had *Brown and Wisconsin versus Constantineau*.

Pelka: OK. I want to do a quick aside here.

04-00:65:38

Gilhool: Mm-hm.

Pelka: Sorry to interrupt the flow, but I just wanted to— I'm not sure where to insert this question. The last time we talked, you said that, Wyatt hadn't been decided yet, *Wyatt v. Stickney*. But that was— the right to treatment was pretty much in the air. There were some— I guess it was the Bazelon decisions, but—

04-00:65:58

Gilhool: Yeah.

Pelka: —right to treatment. And it—

04-00:66:01

Gilhool: The clerks at whose time had been law school classmates of Gillian's and mine.

Pelka: OK.

04-00:66:09

Gilhool: Yeah.

Pelka: OK. And I know one of the things that happened in the mental health side of the de-institutionalization movement—

04-00:66:20

Gilhool: Yes.

Pelka: —was that, in fact, right to treatment did lead to closing down a lot of these massive institutions, because it was, in fact, too expensive to provide quality treatment in the context—

04-00:66:37

Gilhool: Yeah.

Pelka: But it was also very expensive to try to reform these institutions to provide that kind of treatment. I was wondering if, as you all were moving toward the goal of shutting down Pennhurst, if you had that in mind.

04-00:66:55

Gilhool: That's very interesting. And you are right in identifying that as a phenomenon. I think maybe starting around '69, '70, and becoming increasingly evident thereafter, you will remember that the mental health de-institutionalization movement was really driven by medical assistance.

Pelka: Mm-hm.

04-00:67:25

Gilhool: Which had, of course, been invented by the Congress, at Johnson's request, in 1965. And it had provided for Title 19 and Social Security Act medical assistance to fund nursing homes; and driven by the community mental health centers, what in Pennsylvania, we called base service units, which here, like everywhere, tended to get up and running originally, chiefly on the mental health side; and the community mental health movement, which was honored in statute as early as sixty— certainly, by '65, maybe in '64. The Midtown Manhattan studies on community mental health, they were famous when I was in law school. So there was already a considerable head of steam for community mental health. And it was—

Begin Audiofile 5

05-00:00:00

Gilhool: —ill moved to nursing homes.

Pelka: OK.

05-00:00:31

Gilhool: You with me?

Pelka: Right.

05-00:00:06

Gilhool: And then— [pause] And then two things happened, one of which is the thing you put your finger on, maybe. The other is the growth of homelessness. You

know? Which I don't think we quite saw yet. But the community systems were incomplete, et cetera. And by the time we got to Pennhurst, it's at that time that we were learning strongly from the mental health movement's experience, such that we were extra careful in framing the orders under which implementation would proceed in the court; and some eyes, additional eyes and ears for the courts, the masters, would see to it that nobody got lost.

Pelka: But this is already— we're talking now mid-seventies to late seventies.

05-00:01:10

Gilhool: Yes.

Pelka: OK.

05-00:01:12

Gilhool: Pennhurst was decided on the eve of the eve of Christmas in '78; it was tried in '77.

Pelka: OK.

05-00:01:19

Gilhool: Yes. And it was formulated, essentially, from '75 on.

Pelka: OK.

05-00:01:26

Gilhool: Just as Willowbrook [*New York ARC v. Rockefeller* (1973)] was formulated— It's substantially the same time. In fact, the trial team for Willowbrook, for the Department of Justice, was the trial team for the Department of Justice in the Pennhurst case.

Pelka: Oh.

05-00:01:42

Gilhool: And Mike Thrasher's, and the very young Art Peabody's, becoming convinced that community was where it should be, is what led to the Department of Justice changing its position out of the Wyatt bag and into what would be the Willowbrook and Pennhurst bags. Namely, everybody out into community.

Pelka: OK.

05-00:02:11

Gilhool: Yeah.

Pelka: OK. I just— like I say, it was an aside. When you said that before, about—

05-00:02:19

Gilhool: Yes.

Pelka: —using right to education as a kind of lever—

05-00:02:24

Gilhool: Or right to treatment, yeah. I think you're entirely correct about that. And we would've had some sense of that at the time, though not a terribly imposing one. And the important thing in the analysis, of course, was that it was just another way of saying that, Look, our objectives are two steps removed from a right to treatment. [chuckles]

Pelka: Mm-hm.

05-00:02:55

Gilhool: And we might as well try to do things that are a little more direct.

Pelka: Right.

05-00:03:00

Gilhool: Yeah.

Pelka: Right. Another just kind of picky question. Who precisely did you sue in *PARC v. Pennsylvania*? I read somewhere that each of the individual school districts in the Commonwealth of Pennsylvania was named as defendants. Is that right?

05-00:03:19

Gilhool: Yes, that is right.

Pelka: OK. And—

05-00:03:22

Gilhool: We sued— I'll do it upside-down. We sued the class of school districts.

Pelka: OK.

05-00:03:30

Gilhool: A defendant class. You can have class actions for plaintiffs, and you can have class actions for defendants. And they are fairly unusual, except sometimes in the antitrust world, where of course, class actions by plaintiffs are familiar. But frequently—for example, in the electrical antitrust cases—the defendants were classes, too. The class of all of the companies that made electrical wire.

Pelka: OK.

05-00:04:03

Gilhool: And I chanced [laughs] to know about that, because I had learned how to practice law at a famous plaintiff's antitrust law firm here, Dilworth. But— so we sued fourteen individual named school districts, that's approximately right. There were fourteen plaintiffs.

Pelka: OK.

05-00:04:25

Gilhool: One or two of whom may have been in the same school district.

Pelka: OK.

05-00:04:30

Gilhool: So we sued all of their school districts, and then we sued them as representatives of the entire class of, then, probably five-hundred-and-one Pennsylvania school districts. The lead plaintiff was the Commonwealth of Pennsylvania. And we, by and large, always named the Commonwealth of Pennsylvania as the lead defendant, 'cause it was impersonal.

Pelka: Right.

05-00:04:58

Gilhool: Right? That wasn't the governor, it wasn't the secretary. You weren't picking on someone. We did not sue the governor, as in those days, it had been my habit—and I think the habit of very many good social change lawyers—not to sue governors, the theory being that we wanted to leave the governor free to come to terms with the case without forcing him to be prematurely defensive, and to hold open the possibility that he governor would want to become the hero and compose it all.

Pelka: Ah-ha.

05-00:05:40

Gilhool: And so we sued the secretary of education of the commonwealth. I think probably—though I'm not positive—the state board of education. I know we sued the Department of Public Welfare, because such formal programs as existed for children in those days were funded by the Department of Public Welfare, and significantly run by the UCPs and the Easter Seals, and occasionally, by public bodies.

Pelka: OK.

05-00:06:16

Gilhool: Right? And then we probably went down the cranking order to the director of special education, Bill Orhrtman, who played a very important role in turning things around. So it was a set of state officers, departmental officers, and then the school districts.

Pelka: OK. And did any of these entities have any idea that this was coming down the pike? Had there been any communication with them at all before the suit was actually filed?

05-00:06:58

Gilhool: Well, we filed the suit in the interregnum between governors.

Pelka: OK.

05-00:07:06

Gilhool: [laughs] And that, too, was intentional. Because the outgoing Shafer administration, of which Raymond J. Broderick was Lieutenant Governor, had done those superb things, with creating community living arrangements.

Pelka: OK.

05-00:07:21

Gilhool: Right? And in the gubernatorial election campaign of the fall 1970, Milton Shapp, significantly, advised by the then executive director of the Philadelphia Association for Retarded Citizens, but like Ray Broderick, who was the Republican candidate, all drawing upon ARC people, they had all promised to do good things.

Pelka: Mm-hm.

05-00:07:56

Gilhool: And Milt Shapp, in fact, who was a very wealthy man early in the television cable industry, had contributed significantly to the ARC of Philadelphia, particularly. Not statewide, but otherwise. And so we didn't want to pick on anybody or blame anybody. And Fred Speaker was the appointed—as they were in those days—attorney general for the outgoing Republican administration. And he graciously sent the state police to pick up the complaint at my office, so that we could serve it immediately, and it wouldn't, you know, hit anybody wrong. If we put it [laughs] in the mail or did it by the sheriff, who knows where it might've ended up, when? You know what I mean?

Pelka: Uh-huh. Oh, sure.

05-00:08:50

Gilhool: Fred, a year later, became the director of the national Legal Services Program, the first director in the Nixon administration, who literally saved Legal Services from the rotten forces in the Nixon administration.

Pelka: OK.

05-00:09:11

Gilhool: Anyway, that was to emphasize how much it was cast at the interregnum. But I've now lost your question, the threshold of which got me into that.

Pelka: Oh, just basically if there'd been any contact, or if—

05-00:09:30

Gilhool: Ah.

Pelka: —anyone on the receiving end of the lawsuit was aware of what was coming.

05-00:09:38

Gilhool: I think everybody was.

Pelka: OK.

05-00:09:42

Gilhool: ARC, you know, it's a part of the Gephardt phenomenon. But it wasn't Gephardt. But ARC was very close to the bureaucracies in both Education and Welfare. And I know the Shapp administration had not yet appointed a Secretary of Education. I think they probably had appointed a Secretary of Welfare. But the people down the line in the departments, the civil service people, knew in some sense that it was coming.

Pelka: OK.

05-00:10:32

Gilhool: And then when it came, of course, *PARC* put it way up front, on the front pages of everywhere, including, I think, the day it was filed, on the front page of the *New York Times*.

Pelka: Hm.

05-00:10:47

Gilhool: I need to double check that, don't I? I haven't had that thought in a long time.

Pelka: I was going to ask you, I mean, at some point, we're going to talk about the media campaign around *PARC*.

05-00:11:01

Gilhool: Yes.

Pelka: But you were talking earlier about one of the members working at the business side—

05-00:11:10

Gilhool: Yes.

Pelka: —of the *New York Times*. That was during the—

05-00:11:14

Gilhool: Yes.

Pelka: That was during this period. I guess I'm throwing this question out of order, but did that have any influence?

05-00:11:20

Gilhool: [Over Pelka] Yes.

Pelka: [laughs] OK. [Gilhool laughs] Rather naïve question, but I had to ask.

05-00:11:25

Gilhool: It did, it did, it did. It absolutely did. Look, Jim and Dennis had come to see me at my office at the Dilworth firm, where I had started to practice, and then gone to Community Legal Services and then come back to the Dilworth office.

Pelka: Uh-huh.

05-00:11:42

Gilhool: And they came to me, it has always been my sense, because of the notoriety I had gotten at Community Legal Services—

Pelka: OK.

05-00:11:55

Gilhool: —doing some of the early Welfare rights and public housing and et cetera litigation, and other actions. And so early on, we talked about the courts as not a rarified institution, but as an institution of a small P political variety that was a part of our polity, and you used the opportunity, you used litigation to advance things in all the other forums, right?

Pelka: Mm-hm.

05-00:12:27

Gilhool: And they struggled and I struggled around—and Gunnar made an amazing contribution to this, that I must keep in focus—struggled around the very writing of the complaint, so that it would be salient. Right?

Pelka: Mm-hm.

05-00:12:47

Gilhool: Understood by the media, and used by them.

Pelka: OK.

05-00:12:51

Gilhool: And remember, their investigation of Pennhurst had resulted in probably a ten part series on Channel 10 television here.

Pelka: OK.

05-00:13:05

Gilhool: So they were very used to using the media in every way. And—

Pelka: So—

05-00:13:14

Gilhool: Go ahead.

Pelka: Oh, no, I'm just— So you're saying that there was a media strategy built in, really, from the very beginning.

05-00:13:21

Gilhool: Sure.

Pelka: OK. And now, who was the media strategy designed to influence? The courts?

05-00:13:28

Gilhool: [Over Pelka] Everybody.

Pelka: Everybody. OK.

05-00:13:30

Gilhool: [Over Pelka] It was designed to influence public understanding, the stigma, the appreciation of the facts the people could learn. It was designed, in some low key way, to affect schools people, so that they would begin to know that this would be [laughs] fun and exciting, or at least hopeful. Right?

Pelka: Mm-hm.

05-00:13:55

Gilhool: And it was certainly designed to affect legislative and executive decision makers. Gosh, the guy who was majority leader of the state senate during these times, Tom Lamb, said, was quoted as saying—I didn't know him at the time—quoted as saying, the day the decrees were announced, snapping his fingers, "Damn! I wish *we'd* done that." [Pelka laughs] Right? So it was designed for everyone. And of course, it was also designed for the constituency. That is to say, families of people with retardation, people who are retarded, their relatives, et cetera.

Pelka: Uh-huh.

05-00:14:46

Gilhool: You know, for all the sensible reasons that it could affect their senses of themselves.

Pelka: OK.

05-00:14:56

Gilhool: Yeah.

Pelka: OK. Was there a media committee, or people in charge of the media campaign, specifically assigned to that?

05-00:15:05

Gilhool: Well, that's a nice question. There almost has to have been, doesn't there?

Pelka: Yeah.

05-00:15:13

Gilhool: That'd be fun to ask Jim and Eleanor and Dennis.

Pelka:

Yeah.

05-00:15:22

Gilhool: After the decree, the media committee, the *publications* committee, was led by Marlene Burda, a phenomenal woman in Allegheny County. She's *wonderful*. And she produced a *host* of material, including what became a very famous yellow book. It was a booklet that told the story of what the schools had to do, and how we expected them to go about doing it. Jim and I were just chuckling about it the other day, Wilson. And all of these things, in the course of these conversations, Fred, we've gotta somehow, among us, collect for you.

Pelka:

Yeah. Well, we were talking last time that, to your knowledge—and maybe you've found out differently since then—but to your knowledge, there is no archives, no central repository for all of the documents having to do with the *PARC* case.

05-00:16:30

Gilhool: Quite right.

Pelka:

Is that right? OK.

05-00:16:32

Gilhool: Quite right. I asked one of the secretaries here. We have— Whether they're complete or not, I don't know. We have the files in storage here.

Pelka:

OK.

05-00:16:44

Gilhool: And I sent her looking for a couple of particular things. But I really just have to get them back, and see what's in it. Yeah. But I do think that Jim was successful in getting the very filing of the lawsuit on the front page of the *New York Times*. We'll double check that.

Pelka:

OK.

05-00:17:09

Gilhool: But he certainly was crucial to getting—October whatever it was—did you get away with a copy of it, from New York?—the front page story on the decrees that had been preliminarily approved by the courts, on the front page. And then Jim was directly responsible for—he'll remember his last name—the long time editorial director of the *New York Times* editorial page, was a wonderful guy whose first name was John, and whose last name I'm now blocking on. And I remember Jim picking up, not in my presence, by a long shot, or necessarily, but just picking up the phone to call him and saying, "Hey, this thing's going to be in the paper tomorrow. Take a look at it, will ya? And maybe you want to write an editorial next week." And so he did.

Pelka: Ah-hah.

05-00:18:14

Gilhool: And then that editorial and front page stuff, I have always been quite convinced, was responsible for [John] Bradimus and the great guy from Tennessee in the house, and [Senator Hubert] Humphrey, and {VanEck?}—not {VanEck?}, it was VanEck in the House. Humphrey and [Senator Charles] Percy and some others, who introduced what became 504 within a couple of months, those preliminary decrees, in 1970.

Pelka: OK, this is 504 of the Rehab Act—

05-00:18:55

Gilhool: Yeah.

Pelka: —of 1973.

05-00:18:57

Gilhool: Yeah.

Pelka: OK, but I guess it was— first it was '72, and then it was vetoed by Nixon, and it took until '73 to get passed.

05-00:19:06

Gilhool: [Over Pelka] Right, exactly.

Pelka: Right.

05-00:19:08

Gilhool: And this would've been— they were introduced in late '71 or early '72.

Pelka: OK.

05-00:19:16

Gilhool: Yeah. OK.

Pelka: OK, well, we're— Yeah, I was going to ask you how you're doing on time. We're—

05-00:19:23

Gilhool: Well—

Pelka: We're approaching quarter-after-three here. We're now on tape five, by the way, for the transcriber, tape five of the interview with Thomas K. Gilhool, on April 11th, 2005.

05-00:19:36

Gilhool: Why don't we call it a day here.

Pelka: OK.

05-00:19:40

Gilhool: It certainly went like a whiz.

Pelka: OK.

05-00:19:41

Gilhool: Thank you for thinking to arrange things this way.

Pelka: OK. And what's up for— What's your next available— What we were going to do was try to do every Monday.

05-00:19:51

Gilhool: I've put you on the calendar for the next five Mondays.

Pelka: Oh, wow! OK, fantastic! So we're talking Monday, April 18th, at two o'clock. Great. And you'll get that release form off the fax number at ROHO.

05-00:20:07

Gilhool: [Over Pelka] Right. And were you pretty confident that Jeanette knows where to send it and how to fill in that line?

Pelka: Yeah. If there are any questions, she can always call me.

05-00:20:16

Gilhool: OK.

Pelka: Great.

05-00:20:16

Gilhool: Good.

Pelka: OK. Well, thank you. Thank you so much.

05-00:20:19

Gilhool: Excellent. Love to your ever loving.

Pelka: OK, you, too.

05-00:20:22

Gilhool: Bye for now.

Pelka: Bye-bye.

Interview #3: April, 18, 2005
Begin Audiofile 6

06-00:00:00

Pelka: OK, I've turned the tape on. This is an interview with Thomas K. Gilhool. This is interview number three, April 18th, 2005. This is tape six, side A. First of all, I hope you don't mind answering a lot of questions about *PARC v. Pennsylvania*. You may have gone through all this material for people before. I don't know if you have or not. But I definitely wanted to ask a number of specific questions, if that's ok.

06-00:00:41

Gilhool: [Over Pelka] Go ahead.

Pelka: OK. Getting back to *PARC*, then.

06-00:00:45

Gilhool: Yeah.

Pelka: You're listed as the attorney for the plaintiffs. Was there anyone else involved in the nuts and bolts preparation of the materials?

06-00:00:57

Gilhool: Nope.

Pelka: OK.

06-00:00:59

Gilhool: I was a social— [chuckles] I was a single practitioner at that time.

Pelka: Oh, OK.

06-00:01:06

Gilhool: Wilson and Haggerty came to see me after I had left Community Legal Services and rejoined Dilworth Paxson, et cetera.

Pelka: Mm-hm.

06-00:01:16

Gilhool: And I left Dilworth Paxson—hm, I don't know—subsequently, by months or years. And then I was hanging my hat with Ned Wolf, who was then called the Lawyers Committee for Civil Rights Under Law, Philadelphia Chapter—I always say Philadelphia committee—on the top two floors of 1 North Thirteenth Street. Yeah. And I had very close counsel from Gunnar, whom Jim and Dennis had both mentioned when we first met. And I knew Gunnar by reputation, because his son Peter had been two years behind us at law school.

Pelka: Oh. OK.

06-00:02:09

Gilhool:

And a close acquaintance, even a friend, I would say. And through Gunnar's introduction, Fred Weintraub and Alan Abeson were both then at CEC, in—came to be Reston; it may have been Arlington, initially, just outside of D.C. And they were, at this time, collecting all of the current—and published, eventually, and analyzed—all of the education statutes of the state.

Pelka:

So you— I'm sorry. You said CDC?

06-00:02:49

Gilhool:

CEC. Council for Exceptional Children.

Pelka:

Oh, ok.

06-00:02:53

Gilhool:

Which was the professional organization of teachers and administrators in education for kids with disability, that had a prehistory as a unit of the National Education Association.

Pelka:

Right.

06-00:03:09

Gilhool:

Frankly, I don't know when they went off and became independent.

Pelka:

OK.

06-00:03:12

Gilhool:

But it was the major professional organization. And during that time, I had a close relationship with the Center on Law and Education, then in Cambridge. It was the OEO funded back up center for education work. And in fact, for a period, I thought I was probably going to go up there and run it. That was just subsequent to the August trial. Or maybe just prior thereto. Two people from the Law Center sat in on the one day [laughs] of trial.

Pelka:

OK.

06-00:03:57

Gilhool:

Paul Dimond, who shows up on the domestic policy staff in the White House in the Clinton years; and David Kirp, who has been, for a very long time now, at the Public Policy School at Berkeley.

Pelka:

OK.

06-00:04:18

Gilhool:

David wrote, David Kirp, and William Buss, who was at Iowa Law School, and Peter Kuriloff, who was here at the University of Pennsylvania's Education School. They did, sometime subsequent to the two decrees, they did a three jurisdiction study of due process hearings that appeared probably in—gee—probably in the Harvard education journal, that was very influential.

Their primary finding was that families won if they had lawyers. And then within a few years, it came to be that families won if they had experts.
[laughs]

Pelka: Uh-huh.

06-00:05:10

Gilhool: But I was sole counsel.

Pelka: OK. OK. Do you recall— I imagine you were also meeting with the board at PARC from time to time—

06-00:05:22

Gilhool: Oh, yes.

Pelka: —to explain your progress. Did you—

06-00:05:27

Gilhool: [Over Pelka] Two people in particular, Jim Wilson and L.. Stuart Brown— Stuart was chair of the litigation committee just about immediately.

Pelka: OK.

06-00:05:34

Gilhool: And our habit always was to ask for a litigation committee and a liaison to the lawsuit. And they, too, sat in on the trial. And we went for a drink at the Ben Franklin Hotel. It still stands, right next door to where we are now. And I remember, while they went to the men's room, David Kirp or Paul Dimond said, "Who are those two young lawyers?" [laughs] Meaning Wilson and Brown.

Pelka: Uh-huh.

06-00:06:09

Gilhool: They weren't lawyers, but they were.

Pelka: Do you remember the final meeting with the PARC committee before going into trial?

06-00:06:18

Gilhool: Not particularly.

Pelka: So there weren't any, as *you* recall, there weren't any final jitters or nerves or particular anticipation that you remember? Nothing like that.

06-00:06:31

Gilhool: No, no.

Pelka: OK.

06-00:06:32

Gilhool:

I do remember we had—I had prepared four witnesses. We had a list of seven or eight witnesses. The opening witness was Ignacy Goldberg, who did the brilliant historical stuff, which is reflected in the opinion. And Jim Gallagher and Don Steadman, both of whom were then at the University of North Carolina, one of whom was subsequently a provost at Duke, Steadman. Jim had been the Assistant or Associate Commissioner of Education for the U.S. in charge of disability education, and had just returned to North Carolina. And they both testified to the underlying educability facts. And the fourth witness was Burton Blatt, from Syracuse, whose [laughs] dissertation was about the changeability of intelligence.

Pelka:

Huh.

06-00:07:42

Gilhool:

And he testified about something quite different [laughs] than was involved in the trial. He testified about the changeability of intelligence. And I didn't care whether intelligence was changeable or not. What I cared about was whether people could learn.

Pelka:

Had you met with the witnesses before— OK, and—

06-00:07:58

Gilhool:

[Over Pelka] Yes, yes. I went to North Carolina and spent a day with the two North Carolinians; and went to Syracuse and spent some time with Burt; and went to New York a couple of times with Ignacy. But their final preparation was the afternoon and right through the night of the day of the trial.

Pelka:

So did you have a chance to lay out to them what it was exactly you wanted them to—

06-00:08:27

Gilhool:

Sure. Sure.

Pelka:

Sure, yeah. But, well, the best laid plans, I guess. OK. Had you—

06-00:08:36

Gilhool:

They had testified at the close of the day.

Pelka:

Mm-hm.

06-00:08:40

Gilhool:

Weintraub stood up and said, "Your honor, we surrender." [they laugh] So we never called—there was a woman from Columbia, who was then current president of CEC. There was a woman from Maryland. And there was Gunnar, who was going to be the last witness.

Pelka:

Oh.

06-00:08:59

Gilhool: Because we were saving the best for last.

Pelka:

Yeah. You mentioned Weintraub. He was the counsel for—

06-00:09:06

Gilhool: No, he wasn't counsel.

Pelka:

Oh, ok.

06-00:09:07

Gilhool: He was at the council, C-O-U-N-C-I-L—

Pelka:

OK.

06-00:09:11

Gilhool: —for Exceptional Children. He was an educator. In fact, he had come out of Columbia Teachers College. I think I'm right about that.

Pelka:

Oh, I'm talking about *Ed* Weintraub.

06-00:09:22

Gilhool: No, I'm sorry. Yes.

Pelka:

OK. He was the deputy attorney—

06-00:09:24

Gilhool: [Over Pelka] Yes, yes, two different things.

Pelka:

Yeah.

06-00:09:26

Gilhool: [Over Pelka] And you know, I don't think I've ever put that together before. But yes, Ed Weintraub was the third or fourth Deputy Attorney General assigned to this case.

Pelka:

OK. And was he the major person who was handling it, or—

06-00:09:47

Gilhool: Yes, mm-hm.

Pelka:

[Over Gilhool] OK. OK. Had you met with him before, to discuss the case, before the day of the trial?

06-00:09:57

Gilhool: No, not particularly. It had been a very hard case for the defendants. Stuart Bowie had handled the motion to dismiss, and maybe the class determinations. And he just hated the case. He didn't want to be doing it. And he didn't understand why the hell the state was defending it. [they laugh] He was embarrassed to be handling it. He's a very good guy. Weintraub was a

very thoughtful, good guy. And as I may have mentioned, after the August day of trial and his announcement to the court, we essentially lived together for the next three months, working on the decree—

Pelka: OK.

06-00:10:58

Gilhool: —which, see, in the— I think you put it in October.

Pelka: Mm-hm.

06-00:11:06

Gilhool: We did some of that at my office, we did some of it in his backyard in central Pennsylvania.

Pelka: OK.

06-00:11:13

Gilhool: And he consulted extensively with the Director of Special Education, Bill Ohrtman, and with the secretary, and with representatives of the governor's office—

Pelka: OK.

06-00:11:31

Gilhool: —and we put it together.

Pelka: Did you have an inkling when you went into trial, that the whole thing was going to be over in a day, and the state would essentially surrender?

06-00:11:43

Gilhool: I'm not aware of having that inkling.

Pelka: OK.

06-00:11:50

Gilhool: I'm sure we had the hope that, as in those days, we did with just about everything. [laughs]

Pelka: So you were prepared to argue the entire—

06-00:12:02

Gilhool: Sure.

Pelka: —the entire case.

06-00:12:03

Gilhool: Sure.

Pelka: Did the defense have witnesses that they were going to call, do you recall?

06-00:12:10

Gilhool:

That's a *very* good question, Fred. And I think we can tie that down. I need to get the District Court clerk's office to bring out of storage the file from the case, and we'll see if they had filed. It has since become standard, and it was pretty much standard, though not absolutely always, that both parties would file their list of witnesses and so on well in advance.

Pelka:

Mm-hm.

06-00:12:48

Gilhool:

But I have no current recollection of it.

Pelka:

OK. At some point, I want to talk to you about the papers relating to PARC. But we can do that later.

06-00:13:01

Gilhool:

I did make one footnote when we talked before, but I didn't complete it. When you get the complaint, as it stands out in my mind, the day— You know, we circulated the draft of the complaint to all of PARC and to Gunnar. And probably, to the experts, and Fred and Alan. And Gunnar said, "You say, of each of the individuals, 'ineducable and untrainable.' And even though you have it in quotes, you really ought to say, '*said to be* [laughs] ineducable and untrainable.'" And so we did.

Pelka:

Mm-hm.

06-00:13:51

Gilhool:

And you'll see, the headline litany through the complaint became "the non-education of, Nancy Beth Bowman" or whoever the individual person was, which was the obvious play on *The Education of Henry Adams*, which was very big in my generation. You know.

Pelka:

Yeah, yeah. OK. There were three witnesses. Four witnesses, I'm sorry. And then at that point, the defense attorney stood up and said to the judge— Interrupted the proceedings, or—?

06-00:14:33

Gilhool:

We deposed for the day.

Pelka:

OK.

06-00:14:36

Gilhool:

And it was the time to talk about when we would continue. And I do not remember whether we had planned to continue with evidence the very next day or whether it had been scheduled for the next week. I simply don't remember. But the scheduling orders from the docket oughtta tell us. And he stood up and said either, "I've consulted with my clients," or "I wish to consult with my clients, to see if we can't compose this matter."

Pelka: OK. I was going to ask if he had the authority to— You know, obviously, he did. But he may well have checked with folks before announcing that decision.

06-00:15:26

Gilhool: I expect he did. And if he did, I expect he said it.

Pelka: OK.

06-00:15:32

Gilhool: And he had been very close by jowl with the governor's office, as well as the Secretary of Education, in all of the run-up to it, so— Yes, I'm sure he consulted.

Pelka: OK. Now, was it your impression that what had happened was, is that the strength of the case and the testimony had entirely won the day? Or do you think there was political pressure being exerted? You talked last time about, you know, media campaign, things like that. Was it some combination of that, too, or—?

06-00:16:12

Gilhool: All of the above.

Pelka: OK.

06-00:16:16

Gilhool: It was a very visible case. PARC itself made it visible. And they were an extensive organization, and they published their own internal stuff. It had had significant media coverage. And as I mentioned to you, both— Well, I didn't quite complete that thought, either. Both of the candidates for governor, who— And Governor Shapp took office in January of '71. He beat Raymond J. Broderick in November of '70. And both of them had made important parts of their campaign, their commitments to people with disabilities, particularly people with retardation. Ray Broderick had actually helicoptered into Pennhurst twice— [laughs] during the campaign. Milt Shapp, who was a bit more abstracted, has issued position papers. But those position papers were pretty much written by a guy at the Philadelphia Association for Retarded Citizens. And so yes, those commitments for, and the working of the public processes bore— there was no particular lobbying by PARC or otherwise, of the administration; but everybody knew what everybody was looking for. And I think I mentioned to you that Tom Lamb, who was then the Democratic Majority Leader of the State Senate— The decree was announced at a governor's joint press conference with PARC. [pause] Isn't that interesting? Either the day it was filed with the court, or the day or day after the court issued that preliminary opinion, and gave notice. I'm now unclear about which it was. But Tommy Lamb was famously quoted as having said, on the floor of the State Senate, "Look what this court has done. Damn! I wish *we'd* done that."

Pelka: [laughs] Well, they *could've*.

06-00:18:53
Gilhool: [laughs] Yes, exactly.

Pelka: There was nothing stopping 'em. So you then went off—and that would've been with Weintraub—

06-00:19:05
Gilhool: Mm-hm. [Yes.]

Pelka: —to write what would become the consent decree.

06-00:19:09
Gilhool: Mm-hm. [Yes].

Pelka: OK, and you said you did that over the summer.

06-00:19:11
Gilhool: Mm-hm. Actually, it would've been early fall.

Pelka: Early fall, ok.

06-00:19:16
Gilhool: The day's hearing was sometime in August.

Pelka: OKay.

Gilhool: And we met a couple of times with Bill Ohrtman, and some of his other people, at the department in Harrisburg. And it was Bill, in those formulations, who said, "You know what this is, this is zero redact education."

Pelka: Mm-hm.

06-00:19:42
Gilhool: And he was the phrasemaker for that phrase, that then became quite widespread in describing the admission of kids with disability to schools.

Pelka: As you worked out the terms of the consent decree, was there a lot of resistance? Was it a question of simply— Well, was there resistance to some of the things you wanted?

06-00:20:08
Gilhool: No, I don't think so. Some of them were fairly complicated. As you read the October or the November thing, whichever it is—the October 7, did you call it?

Pelka: October eight, I think. But anyway.

06-00:20:23

Gilhool: You will see that the state statutes are construed by the Attorney General to mean new things.

Pelka: Mm-hm.

06-00:20:34

Gilhool: And that allowed us to say to the court, “You don’t have to declare these statutes unconstitutional.” The Attorney General of Pennsylvania—in those days, the Attorney General was not elected, but was appointed by the governor—but as always, had the power to construe state statutes, to interpret them.

Pelka: Mm-hm.

06-00:20:58

Gilhool: And I was just trying to remember how it was we came to that device. But we did. And that’s what pulled the cutting edge and the stings on the statutes, and made the injunctive part of the orders relatively easy to formulate. And it required, ultimately, that the court not declare any of the statutes unconstitutional, but simply find that the court had subject matter jurisdiction, and that this agreement made it possible for the court to issue injunctive orders.

Pelka: OK. OK.

06-00:21:44

Gilhool: Now, the— [pause] After the first orders were published {in Issues?}, there was then necessary a class hearing; in fact, two hearings, for the two classes, the plaintiff class of children who had been excluded from the schools, and the defendants class of school districts, who had done the excluding. And as you know, under the class action rules of the federal courts, there has to be a fairness hearing, to see to it that the interests and rights of all of the members of the class are adequately protected.

Pelka: Mm-hm.

06-00:22:36

Gilhool: And after that notice was given, several school districts—the number twelve sticks in my head—retained counsel and came in to oppose it.

Pelka: Mm-hm.

06-00:22:50

Gilhool: One of those was the Montgomery County Intermediary unit in suburban county, Pennsylvania’s wealthiest county. And there were an array of individual school districts and their counsel, who came in to oppose it. On the family side, only one family showed up. And I just preached the eulogy at Marge {Kalich’s?} funeral. She and her husband have both now died. And

they came in. And there's a long footnote and a couple of shorter footnotes about their contributions to the final consent decree. And it's enormously interesting. And I'm probably not going to be able to pin down how I know this. Arlin Adams subsequently— who was one of the three judges. There were three-judge courts in those days, whenever the constitutionality, under the U.S. Constitution, of state statutes may have been at issue.

Pelka: Mm-hm.

06-00:24:03

Gilhool: And so the court was Arlin Adams, Tom Masterson, who was the originating court when we filed it, it was assigned to him in the District Court. Arlin Adams was on the Court of Appeals. And Ray Broderick, who had, subsequent to the election, been appointed to the court—and he was very fresh on the court, indeed—filled out the court. And Arlin subsequently said—my recollection is that he said this either to Steve Gold, who's now a colleague of mine here, does a great deal of disability work, particularly transportation, physical disability, all the community based services stuff—that this was the most important case he had ever sat on. This is one of the most distinguished judges of courts of appeals in the land, who had an appointment to the Supreme Court, until the afternoon of the day when Nixon appointed Rehnquist.

Pelka: Hm.

06-00:25:09

Gilhool: He had managed Nixon's Pennsylvania campaign—twice, actually; in '60 and in '68—and had been Secretary of Welfare of the Commonwealth of Pennsylvania in the Scranton administration. And a very good one. And he's still living; the other two have died. Anyway, he said that. And the other thing that I remember is that going into the final argument, after the hearing on the classes, that—I wish I could remember how I knew this—that Arlin Adams used to say to his clerks that there's only one case in which he had had his mind changed by the argument.

Pelka: Hm.

06-00:26:10

Gilhool: That he had gone into the argument in this case quite convinced that they were going to have to disapprove the settlement, that they would have to say that they didn't have jurisdiction. And the argument that Ed and I jointly made persuaded him to the contrary. And I also— [pause] My view has been that Ray Broderick's presence had a great deal to do with the court staying with it.

Pelka: Mm-hm.

06-00:26:52

Gilhool: Right?

Pelka: Mm-hm.

06-00:26:54

Gilhool: I've described him to you before, and you know him from his subsequent work. But he was a person who had a great sense of the real world, and had been a very good lieutenant governor, albeit an accidental one. The actual lieutenant governor candidate, Walter Alessandroni, had been killed in a light plane accident in the Alleghenies, early in the 1966 campaign, and he was chosen to be his successor. OK. So those are two dimensions of the rest of it.

Pelka: OK. Well, some more questions about the consent decree. There was one provision I found very— Well, yeah. Was there any disagreement about the date that all this would happen? I mean, essentially, you were calling for education to become open. The doors would open for children with mental retardation on, I think it was September 1st, 1972—which was not a whole lot of time, as these things go, to leave the state, the district, some way of dealing with all this. Was there disagreement about that date? Negotiation?

06-00:28:20

Gilhool: I don't know. Probably. There may have been some jockeying. In a way, structurally and logically, subsequent to the court's decrees, there ensued a lengthy series of negotiations between the ARC and the department, formulating regulations; and more to the point, formulating what that first order referred to as— Actually, there were two plans. One is the plan, the identification, location and evaluation of people.

Pelka: Mm-hm, mm-hm.

06-00:29:09

Gilhool: Right? That was COMPILE, Commonwealth Plan for Identification, Location and Evaluation. And the second was a commonwealth plan for their education and training. And while I can't parse it exactly, I think those— Well, I'm not sure. But I think those negotiations took place— They started soon after the October filing of those preliminary decrees, and continued through the winter and spring. And again, I'm not sure, but I think those plans were completed, maybe by the time of the class hearing; certainly, shortly thereafter. And— Though maybe not, because the court appoints, in June—was it June or May?—appoints Dennis Haggerty and—oh, isn't it terrible?; wonderful educator at Yeshiva—as masters of the court, to oversee these negotiations and those plans. Right?

Pelka: Mm-hm.

06-00:30:38

Gilhool: So I may be out of time on that. In any event, they were very extensive negotiations. And they were all about implementation. And for example, the defendants agreed; and we chose three or four districts where the districts would actually go door to door to find people. So that beyond beating the

bushes, and advertisements, and putting things out on the networks and things of that kind, we had three or four school districts where they were going door to door. A kind of enumeration of school children that it was then common, in Pennsylvania and most states, that got done annually or periodically. I think annually.

Pelka: Mm-hm.

06-00:31:30

Gilhool: And one of those districts that actually [chuckles] did that was Pittsburgh School District. And we could find who the others were.

Pelka: Mm-hm. These were employees of the school district—

06-00:31:48

Gilhool: Yes.

Pelka: —who would go to homes of people who were listed as having children? Or just go door to door?

06-00:31:53

Gilhool: [Over Pelka] Door to door.

Pelka: Door to door at rand— through the neighborhood?

06-00:31:58

Gilhool: [Over Pelka] Door to door, complete census-like.

Pelka: OK. And in an effort to identify—

06-00:32:05

Gilhool: Uh-huh.

Pelka: —children with disabilities.

06-00:32:06

Gilhool: Yep. And we wanted to— PARC insisted on that, so we would have a double check on the other, more approximate ways of locating everybody.

Pelka: Uh-huh.

06-00:32:17

Gilhool: And Ruth Scott. Hah! You've done a great service. For the last two weeks, for a different purpose, I've been trying to come up with Ruth Scott's last name. She was then the Director of Special Education for the Pittsburgh School District. And she was a tough, wonderful old curmudgeon type. And she said, "We're not going to find anybody I don't know." And we said, "Do it." [laughs] And she did. And they didn't find anybody they didn't know already, in Pittsburg. In the other districts, in fact, they uncovered some others. And there are actually numbers somewhere on the numbers of kids who were

identified and brought in. And— [pause] There was a whole superstructure for training teachers.

Pelka: Uh-huh.

06-00:33:15

Gilhool: And round about the same time, Ed Martin, who was Jim Gallagher's successor at the Assistant or Associate Commissioner of Education of the U.S., in charge of disability education, and his chief assistant, Ed Sontag, who was one of Tommy Thompson's chiefs of staff—the one in charge of inside HHS the last four or eight years—they began to do things, too. One, they put significant training resources into Pennsylvania.

Pelka: OK, hold on just a moment. [audio file stops, re-starts]

06-00:34:31

Pelka: This is an interview with Thomas K. Gilhool. This is interview number three. This is tape six, side B, April 18th, 2005. I'm sorry, go on.

06-00:34:40

Gilhool: Not at all. And second, they said to themselves, "Geez, you know, this is going to move right across the country. And how are we going to help the schools be prepared to attend effectively to the children who are so new to them?"

Pelka: Mm-hm.

06-00:34:58

Gilhool: And they placed telephone calls to people like Norris Haring, who was then at the University of Washington, and Lou Brown, who was already at the University of Wisconsin at Madison, and asked for their help. And they convened. And that was the foundation of AAESPH, the American Association for the Education of the Severely and Profoundly Handicapped.

Pelka: Mm-hm.

06-00:35:30

Gilhool: Do you know that name?

Pelka: No, I don't.

06-00:35:32

Gilhool: It is the predecessor organization of TASH.

Pelka: TASH, ok.

06-00:35:39

Gilhool: Ed Sontag tells this story in his history of TASH, written in *JASH*, the *Journal of the Association for the Severely Handicapped*. AAESPH—I always regretted that they gave up that wonderful Old Testament kind of acronym.

Pelka: Mm-hm. [laughs]

06-00:35:59

Gilhool: But they did. They became then The Association for the Severely Handicapped, and then became just TASH—

Pelka: [Over Gilhool] TASH.

06-00:36:09

Gilhool: —very much later. But he tells this story in one of the early issues of the journal.

Pelka: OK. And what was the— it was the American Association—

06-00:36:22

Gilhool: For the Education of the Severely and Profoundly Handicapped.

Pelka: OK.

06-00:36:26

Gilhool: AAESPH. A-A-E-S-E[sic]-P-H. AAESPH.

Pelka: OK. Was there any— Oh, going back to the consent decree for a little bit longer, there was one part of it that I thought was really interesting, which was the idea of having hearings, to hear arguments on the question of the obligation of defendants to a quote “compensatory educational opportunity for members of the plaintiff class of whatever age, who are denied access to a free public education, of education and training, without notice and without a due process hearing, while they were ages six years to twenty-one, for a period *equal* of the period of such wrongful denial.”

06-00:37:19

Gilhool: Is this in October?

Pelka: Yes, this is in October. And I was— I looked at that, and I was kind of *stunned*.

06-00:37:28

Gilhool: Yeah.

Pelka: That’s *huge*.

06-00:37:30

Gilhool: Yeah.

Pelka: Did that actually happen, that you know of?

06-00:37:34

Gilhool: I don’t know. I do not know. We’ll have to thrash around a little bit and see what recollections may be. You know that it was a Massachusetts case in the

Supreme Court, *Town of Burlington School District versus Department of Education of Massachusetts* [1985], in which Rehnquist, in probably the early eighties— The question in the case was tuition reimbursement. Put it another way, families couldn't get decisions reversed quickly enough in the due process hearing to be of much meaning. And as Rehnquist points out, families who could afford it wanted to and did—and if they hadn't, then they would've been without remedy—send their kids to a school that worked. And in that opinion—very short opinion, very much worth reading; Burlington is how it's known—he said 94-142 contemplates such a remedy.

Pelka: Mm-hm.

06-00:39:10

Gilhool: That decision caused the 8th Circuit Court of Appeals, which had, while that case was pending in the Supreme Court, faced the question of whether, under IDEA, or Education of All Handicapped Children's Act, as it was then called, a court could order compensatory education or not. And the 8th Circuit had held no. And when the Supreme Court decided the Burlington case, the 8th Circuit revisited the question, and changed their minds, and decided there would be such a thing as compensatory education. And that was probably mid-eighties, and the name of the case will occur to me. And in the Bradley case in the 8th Circuit, it's a case that I argued there in the middle, late nineties, when Arkansas said there's an Eleventh Amendment problem with IDEA; you can't really sue the states. And we got a judgment saying that you could. That's all by way of saying that in that brief, which is accessible to me, I kind of do the history that I've just abbreviated for you, of the compensatory remedy. But what that demonstrates is that the compensatory remedy was not widely—was not *anywhere* applied, or widely applied, until the middle, late eighties.

Pelka: Mm-hm.

06-00:41:18

Gilhool: So—

Pelka: I was very interesting in how that ended up in there—

06-00:41:26

Gilhool: Yeah.

Pelka: —and how the state was convinced to agree to that. Because potentially, that is quite far reaching.

06-00:41:38

Gilhool: Yep. Pennsylvania had—and this may actually be recited there—a system of adult education which allowed— It was some number, like seventeen or nineteen or twenty-three. Any twenty-three adults could petition any school district for any course. And that was fairly common among the states. The

education statutes of almost all of the states were pretty thoroughly rewritten in American history, in the 1910s. And at the same time that the exclusionary provisions were going in, such adult education, immigrant directed— They were both, in some ways, immigrant directed, right?

Pelka: Yeah.

06-00:42:30

Gilhool: Because it was “the feeble-minded progeny of the foreign hoards that were crowding our shores” that needed to be excluded from the schools. On the other hand, to engage the immigrants in American life, there were these further education provisions. My guess is, that’s where it was framed. My recollection is that the children, the fourteen or so who were the individual plaintiffs, were a full range of ages. And a goodly number of them, even when we started, were teenagers.

Pelka: Mm-hm.

06-00:43:15

Gilhool: And you know, I used to talk with—including quite late—with Nancy Beth Bowman’s parents, and some other families. And they all had an after-history of due process and further orders and further education. And I simply have no recollection of what happened with that provision.

Pelka: OK.

06-00:43:57

Gilhool: I think we will be informed by what {COMPET?} says, or COMPILE. There may be a reference to it. It was— Well, yeah.

Pelka: OK. Were there any provisions that you wanted to get into the decree, that you weren’t able to?

06-00:44:21

Gilhool: None that I can recall. The formulation of the integration provision. Did you notice that?

Pelka: Uh—

06-00:44:34

Gilhool: “Placement will be in the context of a presumption that children shall be educated in regular classes.”

Pelka: Mm-hm.

06-00:44:42

Gilhool: And then there’s a kind of hierarchy.

Pelka: Oh, yeah. OK, I know what you’re talking about. I can’t put my finger on it—

06-00:44:49

Gilhool: Yeah. Yeah, yeah. Yeah.

Pelka:

—at this exact moment, but I know what you mean.

06-00:44:52

Gilhool: Yeah. I have a sort of memory that I would've liked that to have been sharper, and that we started with something else, and that it got recast, in terms of a presumption.

Pelka:

“Training appropriate to the child’s capacity, within the context of a presumption that among the alternative programs of education and training required by statute to be available, placement in a regular public school class is preferable to placement in a special public school class; and placement in a special public school class is preferable to placement in any other type of program of education and training.”

06-00:45:36

Gilhool: Yep.

Pelka:

OK.

06-00:45:37

Gilhool: Which is pretty good, and has some pretty good bite. But you can see in that, the formulation of 94-142.

06-00:45:52

Gilhool: Which is to the maximum extent—what does it say?—appropriate.

Pelka:

Mm-hm.

06-00:45:57

Gilhool: That it’s a— Anyway. Which—[pause]—you know, could’ve been sharper.

Pelka:

Mm-hm.

06-00:46:15

Gilhool: And [laughs] in some ways, the language that you just read, it’s actually, I think, the equivalent of the 94-142 language, but it sounds a little surer, doesn’t it?

Pelka:

Mm-hm.

06-00:46:35

Gilhool: “The maximum extent appropriate.” I remember there was a wonderful opinion out of a Federal District Court in the 6th Circuit, that really read, To the maximum extent appropriate means to the maximum extent, God damn it!

Pelka:

Mm-hm. [laughs]

06-00:46:51

Gilhool: But most people, of course, read that phrase as a terrible *reductio*.

Pelka:

Mm-hm.

06-00:46:48

Gilhool: Which fairly, it's not. Do you know how bad the integration—yes, you do—figures are nationally on retardation, autism and so on? I mean, nationally, it's 24%—

Pelka:

Oh.

06-00:47:12

Gilhool: —are 80% or more integrated.

Pelka:

Mm-hm.

06-00:47:15

Gilhool: It's just— it's embarrassing. And astonishingly bad. Anyway. Go ahead.

Pelka:

Couple of things, just real quickly. You quoted, just a while back, “feeble-minded progeny of foreign hordes.”

06-00:47:35

Gilhool: Yes.

Pelka:

And that comes from— I just want on the record, where exactly that comes from.

06-00:47:40

Gilhool: Let me think now. Which was the good guy, and which was the bad guy? Fernald was the bad guy. And Howe was the good guy, right?

Pelka:

Yeah.

06-00:47:50

Gilhool: And this is quoting Fernald—

Pelka:

OK.

06-00:47:53

Gilhool: —saying, “That good doctor,” meaning Howe, “Wrote before the feeble-minded progeny of the foreign hordes crowded to our shores.”

Pelka:

Mm.

06-00:48:07

Gilhool: And that is— I don't remember whether Marshall does it, but that is a central passage in the twenty pages—not the appendix, but the text—of our brief to

the Supreme Court in City of Cleburne, Texas, where we do the history of where segregation and sterilization and school exclusion came from.

Pelka: Mm-hm.

06-00:48:39

Gilhool: And that was Fernald saying, Geez, you know, Howe lived in an earlier day; he was really naïve. [laughs]

Pelka: Uh-huh. This is Samuel Gridley Howe.

06-00:48:52

Gilhool: Yep.

Pelka: And what was Fernald's—

06-00:48:55

Gilhool: Fernald. What's his first name? [Walter E.]

Pelka: Oh, I should know this, 'cause there's the Fernald School here, and he's a huge—

06-00:49:02

Gilhool: Yes.

Pelka: —huge figure. But at any rate, I just wanted to—

06-00:49:06

Gilhool: He's saying this as late as the first or second decade of the twentieth century.

Pelka: Yeah. Oh, yeah. Well, a contemporary of *Buck v. Bell* [1927]—

06-00:49:16

Gilhool: Yeah.

Pelka: —and the whole eugenics.

06-00:49:17

Gilhool: Yes, absolutely.

Pelka: OK. One other quick question about the consent decree. Do you recall, at any time, whether or not there was discussion about including children with disabilities other than mental retardation?

06-00:49:33

Gilhool: No. There was not.

Pelka: OK.

06-00:49:36

Gilhool:

There was not. We— [pause] I think it was an unspoken agreement that— certainly, it was for Pennsylvania; and it would be fun to double check this— but the regulations which— Well, in fact, the very— I'm not sure—the very terms of the statutory reinterpretations that take place—that's interesting—in the October document, it might be fun to see if they seem a little bit more open-ended than retardation. On the other hand, we were only dealing with those exclusions. On the third hand, it was understood that, of course, everybody else would follow. And in Pennsylvania, that did happen.

Pelka:

Mm-hm.

06-00:50:42

Gilhool:

Help me. But I think *Mills* was actually the second case, in D.C.

Pelka:

I was just about to ask you about that. Yeah, *Mills*, right.

06-00:50:52

Gilhool:

Mills was framed in terms of all disability.

Pelka:

OK.

06-00:50:57

Gilhool:

The third case, in New Orleans, which John Reed handled—a poverty lawyer there, or then a recent poverty lawyer—was just retardation. And then there are another three dozen or so cases, some of which at least are recited in the 94-142 legislative history. And all of them—except, I think, one in Ohio Federal District Court—prevailed. And at some point, I'm sure we did a count of how they were framed.

Pelka:

Mm-hm.

06-00:51:44

Gilhool:

But it played out across those cases in such a way that it included everybody. And by the time the hearings were held, and the amendments, and then the ultimate amendments in '75, it was wide open.

Pelka:

Mm-hm. OK.

06-00:52:03

Gilhool:

The other— [pause] Come back to that.

Pelka:

Mm-hm.

06-00:52:07

Gilhool:

But it just occurred to me—and I can hold this for a minute, if you like. Damn, it's outta my head again.

Pelka:

[laughs] That's all right. I was going to say, did you— *Mills* was more or less contemporaneous with *PARC*. I mean, it came fairly soon after—

06-00:52:26
Gilhool: Oh, they're *very*, very closely related.

Pelka: Yeah.

06-00:52:29
Gilhool: I mentioned Paul Dimond and David Kirp?

Pelka: Uh-huh.

06-00:52:36
Gilhool: It'd be fun to parse this exactly. John Reed became quite a famous lawyer in New Orleans, on the criminal side, around famous people.

Pelka: Mm-hm.

06-00:53:01
Gilhool: *Very*, very good guy. [pause] *Mills* has a prehistory. A great school case in D.C. is called— Boy oh boy. [pause] Hm, hm. Hold on a minute.

Pelka: Mm-hm.

06-00:53:37
Gilhool: v. Hanson.

Pelka: *Hobson v. Hanson?*

06-00:53:41
Gilhool: Yep. There is an opinion that dates from about 1968, in *Hobson v. Hanson* [1967], in which Skelly Wright, a Court of Appeals judge on the D.C. Federal Circuit— The case was not in front of a District Court, because a panel of District Court judges in D.C. appointed the school board, and so they couldn't sit on any cases against the D.C. school system.

Pelka: Mm-hm.

06-00:54:23
Gilhool: You with me?

Pelka: Yeah.

06-00:54:23
Gilhool: And Skelly Wright wrote a brilliant opinion, that you probably know, which held tracking unconstitutional.

Pelka: Ah.

06-00:54:31
Gilhool: And there's a very lovely footnote by Brennan for a unanimous court, in a case called *Townsend versus Swank* [1971], in which he says, citing *Hobson*

and Hanson, that if it were to be shown that different tracks lead people to different status, economic and otherwise, in life, then surely, it could not pass equal protection muster.

Pelka: Mm-hm.

06-00:54:58

Gilhool: All right? That was the high-water mark. And this is a case where Skelly Wright says, “The arbitrary quality of thoughtlessness violates the equal protection clause.”

Pelka: The arbitrary quality of—

06-00:55:17

Gilhool: Thoughtlessness. A phrase that we have used forever after.

Pelka: OK.

06-00:55:26

Gilhool: Whether we used it in *PARC* or not, I don’t know. And it’s funny. I remember walking up or down the steps of the Supreme Court, before or after the argument in *Shapiro versus Thompson* [1968], which was the first Legal Services case to be argued there, and which I argued for Pennsylvania. There were two other cases up with it. And a wonderful guy—his first name is Gary—who had finished from Harvard Law School and was clerking for Skelly Wright, had just written this opinion. [laughs]

Pelka: Oh. So—

06-00:56:03

Gilhool: In any event, after we filed *PARC*, and while we were preparing it, and as these events were playing out—probably in the summer of ’71—the first filing in *Mills* was *Hobson and Hanson* three or something like that.

Pelka: Mm-hm.

06-00:56:31

Gilhool: You with me?

Pelka: Yeah.

06-00:56:31

Gilhool: It was in that docket to open the schools to kids with disabilities. Now, there are numerous fathers to *Hobson and Hanson*, or *Mills*. And I don’t even know what the federal reports say of it. At one point, Paul and David represented the plaintiffs.

Pelka: Mm-hm.

06-00:57:01

Gilhool:

At another point, Pat, Patricia—[pause] hm—Wald, most recently on the International Court in the Hague, about Yugoslavia war crimes. Before that, a member of the Court of Appeals, and chief judge of the D.C. Court of Appeals. And at this time, a Legal Services lawyer in Washington, shortly to be a major figure in Shriver's campaign for vice president with McGovern [laughs] in '72. She was called the Mother Superior.

Pelka:

Hm.

06-00:57:51

Gilhool:

And she was involved. And there was a filing that Pat did. And there's a guy, whom I'm going to be able to call the name of, who was also on one of the versions of the originating papers. When, at the twenty-fifth anniversary of 94-142, when Frist was chair—[chuckles] he was just new to the Senate, and he was chair of the Subcommittee on Handicapped.

Pelka:

Mm-hm.

06-00:58:30

Gilhool:

He called anniversary hearings. And let me think now. Dennis Haggerty and Judge Tom Masterson and I testified. And then we were followed by Pat, and this person whose name I can't call, and someone else from D.C. I think I would say that Paul and David were the intellectual carriers of these ideas from us here in Pennsylvania to Washington.

Pelka:

OK. Paul, you're talking Paul Dimond and David Kirp.

06-00:59:20

Gilhool:

Yes.

Pelka:

OK. So I was going to ask what kind of connection, or whether there were informal ties, or whether you— What was the back and forth between you, doing *PARC*, and the folks doing *Mills*? Lots, ok.

06-00:59:39

Gilhool:

Yes. And the same was true across the country, after that.

Pelka:

OK.

06-00:59:44

Gilhool:

With John and with the others around the country. Mm-hm.

Pelka:

OK.

06-00:59:51

Gilhool:

And a large part of it was the ARC network. Most people, especially the good, sensible ones, sought assistance from Fred and Alan Abeson. You remember,

Abeson later was national executive director of the ARC. In fact, he was the last executive director before Steve Eidelman, the current executive director.

Pelka: Mm-hm.

06-00:60:17

Gilhool: Yeah.

Pelka: OK. I wanted to ask you— This is kinda out of left field, maybe, but Congress has just passed a so-called Class Action Reform Act. Or is working on that. And would that have affected your ability in *PARC* and in *Mills* to have made the kind of changes that you made?

06-00:60:43

Gilhool: No, I don't think so.

Pelka: OK.

06-00:60:45

Gilhool: It's an atrocious act. It's actually— You know, one of its purposes is to take class actions out of state court [laughs] and put them in federal courts, because the current Congress thinks the federal courts will be less welcoming.

Pelka: Uh-huh.

06-00:61:11

Gilhool: Than some state courts have been. At the same time, it has— you know, it's just the most recent development in significant burdening of class actions. But most of that burdening has to do with class actions for damages.

Pelka: Mm-hm.

06-00:61:30

Gilhool: And, of course *PARC* was not a class action for damages. And compensatory education—that wonderful reference that you found—is not regarded as damages, it's regarded as injunctive relief. Equitable relief. No.

Pelka: OK.

06-00:61:50

Gilhool: There are things, Fred, that I'm pulling my punches a little bit on, that I don't know quite how to handle. Let me tell you, subject only to your prior promise that we can look at it before we decide when and how what follows would be publicly filed?

Pelka: Sure. [pause] Do you want me to turn the tape off at this point?

06-00:62:23

Gilhool: Why don't you do that?

Pelka: Yeah. [audio file stops, re-starts] So we're back on tape. You said there were two—

06-00:62:28

Gilhool: Two things, in terms of the content of the decrees that are, I think, worth mentioning. First, the due process hearings that are constructed there, or the hearings, the opportunity to be heard on stuff, that essentially comes out of the Wisconsin and Constantineau due process framework, was contemplated from the beginning, and became a hearing structured presided over by people who knew how to do it; how, effectively, to teach in the schools so that children with retardation would learn, and learn well.

Pelka: Mm-hm.

06-00:63:21

Gilhool: And that lasted for a couple'a years. PARC and the state essentially chose from some really good people from schools, but mostly, really good people from university faculties.

Pelka: Mm-hm.

06-00:63:43

Gilhool: People who *knew* how to do it. And the theory was that they would bring to bear, in these proceedings, all of that knowledge. Right?

Pelka: OK.

06-00:63:56

Gilhool: Now, that became transmuted. And it'd be interesting to look at the Kirk, Buss, and Kuriloff piece in this regard. But by the time of 94-142, it became transmuted in most states, in their implementation of 94-142, into a kind of legalized proceeding. There was no contemplation at the beginning, for example, that lawyers would be present there.

Pelka: Hm.

06-00:64:25

Gilhool: This would be school district people and families, and this educationally witty, up to the state of the art interlocutor. Right?

Pelka: Mm-hm.

06-00:64:42

Gilhool: And— [pause] I struggle often, but I've never struggled systematically. We have lost something terrible—some think we've gained some things; I'm not sure—by the legalization of these proceedings and the extended time that they take, and all of the rest. And we can return to that theme at some point.

Pelka: Mm-hm.

06-00:65:12

Gilhool: Second, I think you will notice that there is nothing in the October or the May or June writing that you could regard as the individualized education program.

Pelka: Mm-hm.

06-00:65:33

Gilhool: Right?

Pelka: Right.

06-00:65:35

Gilhool: That was an invention of 94-142. And it was invented by a particular person, whose name I can no longer call, a mother who— Judy Heumann worked on Senator Williams' staff, and so did this person.

Pelka: OK.

06-00:65:57

Gilhool: And she borrowed the written IEP from some other context. May have been a context having— it may've had *some* relation to deaf education. But in any event, there it was. And even at that, what she had in mind—and this was more in prospect from the point of view of the *PARC* decrees—but what she had in mind, and what 94-142 had in mind, the emphasis was not on the written. And what the emphasis was on—and this, I think, is reflected in the provisions—that people, the adult people who knew the child very well, and who cared for the child, would sit down face-to-face and think about the child's strengths and the ways and means of educating the child.

Pelka: Mm-hm.

06-00:66:53

Gilhool: Right? It was thought of as a face-to-face, collegial, maybe even almost Quaker-like opportunity.

Pelka: Mm-hm.

06-00:67:06

Gilhool: And of course, it's become something very different, too.

Pelka: Mm-hm. OK. Now, the hearings you're talking about are hearings, now, coming out of the IDEA, where educators are meeting with parents, and they're having hearings to determine changes in IEP or—

06-00:67:32

Gilhool: Well, what you're referring to, I think, is better called the IEP conferences, the team meetings.

Pelka: OK.

06-00:67:38

Gilhool: Conferences that formulate, that are meant to design and formulate, and periodically reformulate, the education program for the youngster.

Pelka: Uh-huh.

06-00:67:49

Gilhool: And then what I refer to as the due process hearings is the opportunity—which 94-142 has offered from the beginning, and which is limned in the *PARC* decrees—if there is a change in placement, or if the family disagrees about the design or implementation of the child's education, the opportunity formally to be heard.

Pelka: OK.

06-00:68:19

Gilhool: Yeah.

Pelka: OK. Hang on a second, I gotta change tapes again.

Interview #4: May 2, 2007

Begin Audiofile 7

07-00:00:01

Pelka: OK. This is an oral history interview with Thomas K. Gilhool, on May 2nd, 2007. And you know, to tell you the truth, I can't remember what number interview or tape this is. [It is interview 4, tape 7, side A]. [Gilhool laughs; comments between them about this] We were going to talk about the Pennhurst case. I think technically, it's *Halderman v. Pennhurst State School and Hospital*.

07-00:00:48

Gilhool: It is.

Pelka: To begin with, tell me a little bit about Pennhurst. It was founded in 1908, is that right?

07-00:00:57

Gilhool: Well, it's interesting. You use that word, and some of our students who've been doing research do '08. And I have not gone back to check it, but I always write about it, both in the Cleburne brief and in the history of each of the states that is attached thereto, and in the Pennhurst briefs itself, as 1913, because 1913 was the act of the legislature which expressly said Eastern State School for the Feeble Minded, et cetera, is, oh, created, commissioned, founded— established to segregate the feebleminded, idiotic, et cetera. And so I will need to check that, because enough people like you [chuckles] have said 1908. There may have been a commissioning of it, but the final commissioning took place in 1913. And the public pamphlet which gave rise to it, called *The Menace of the Feeble Minded in Pennsylvania*, in our brief to Cleburne; and in his opinion, Marshall does a great job on the titles of the pamphlets in the several states, all of which originated with the National Conference on Charities and Corrections; and in the case of Pennsylvania, with the Pennsylvania chapter thereof, which was the carrier of segregation and sterilization and et cetera. In Pennsylvania, Governor Pennypacker, in 1904 is my recollection, had vetoed what was the first sterilization bill passed in the country. And it was the only one vetoed. But they turned to the segregation part of the dyad, and if you look at—and I should be able to supply you with *The Menace of the Feeble Minded in Pennsylvania*—it bore, as most of these pamphlets did, the names of many of the leading families. [chuckles] In this case, the Strawbridges, the {Clothiers?}, the Wanamakers, et cetera. And this was, of course, before radio was widespread. And still, I was astonished when I first discovered it, that pamphlets, as in Thomas Paine, were still a major mode of conducting public discourse. So Pennhurst was commissioned. It was Pennsylvania's first institution.

It's funny, by the time of *PARC*, there were eight or so institutions in Pennsylvania. By the time of Pennhurst, or a short number of years thereafter,

there were thirteen. [laughs] They just multiplied in that last decade. And it was always regarded as the flagship institution. And it's population had been quite high; as high, as I remember it, as five- or six-thousand. At the time we focused on Pennhurst, Pennhurst was— I should check these facts for you, and I can. When PARC did its investigation of Pennhurst in 1968, '69, it was probably about 2,500 people. And by the time of trial, in '77, it was about 1,100 people. And you'll remember that in the run-up to *PARC*, one of the things— Well, there's no point in going there.

07-00:05:36

But in the run-up to *PARC*, the Pennsylvania association had gone to the administration, around Pennhurst itself. You'll remember that the [Governor Raymond P.] Shafer administration and the legislature had appropriated twenty-five-million to improve Pennhurst. And PARC went to the administration, including Lieutenant Governor Raymond J. Broderick, to say, "Hey, that really makes no sense, because you can't improve this place," and so on; and persuaded the administration and the legislature instead to set the money aside—and this probably happened by '70, '71—for, as the act put it, to develop a typology of community living arrangements, and to begin to establish them.

And that happened. They spent what I recall as \$20,000 on Floyd McDowell, who wrote a magnificent report which articulated seven sorts of, seven kinds of, seven types of community living arrangements that covered the full spectrum of the disabling conditions that people at Pennhurst—or anywhere, for that matter—had. And by '72-3, they had, when [Milton J.] Shapp was governor, started to create community living arrangements. And that was, in part, driven by a fellow named Stanley Meyers, who had been the Northeast regional guy for the ARC National, and who became, early in the Shapp administration, the— Let's see, what did we call it in those days? Well, to use the anachronism, he was the deputy secretary for mental retardation. His formal title was probably director or— Commissioner. Commissioner, that's what it was, Commissioner of Mental Retardation. OK.

Pelka:

Just to interject, I've got the— What am I looking at here? I'm looking at the *Federal Reporter* second series on *Halderman v Pennhurst*, and the factual findings. "At the time of the trial, Pennhurst housed 1,230 mentally retarded individuals."

07-00:08:44

Gilhool:

Right on.

Pelka:

OK. And then— actually, I'm gonna read just a little bit more of this. "At the time of the trial, Pennhurst housed 1,230 mentally retarded individuals, some of whom also suffered from physical disabilities. The residents are not mentally ill, have broken no laws, and are not a danger to others, although in severe cases, some are unable to care for themselves." So that's a quick description of who we're talking about.

07-00:09:14

Gilhool: What does the judge say about the date of Pennhurst?

Pelka:

Yeah, I was looking for that, and I don't see much on the history. No. There are actually two or three of these that I've got, and it could be in another one. But at any rate, that's what I—

07-00:09:37

Gilhool: And the one you're looking at is the eve of the eve of Christmas of 1977. That's the first opinion {inaudible}. And then the next one, or the first of the opinions on, and orders, that's March 17 of 1978.

Pelka:

OK. You know, actually, what I think I'm looking at at this point is the Court of Appeals, which is, I guess, argued in '79. So this is a recap. I haven't got the original right in front of me right now, but this is a recap of what had gone on before. Now, the original suit was brought in May, 1974, is that right?

Gilhool:

Yeah, I'm sure that's correct.

Pelka:

OK. Now, how involved were you in the run-up to filing that?

07-00:10:34

Gilhool: Not at all. I was, from '71 through— Well, let me see. From July 4th of '72 to July 4th of '75, I was in California, teaching at the University of Southern California Law School, and living in Palos Verdes. And when I left, I had asked Rick Bazelon to represent the Pennsylvania Association [for Retarded Children] with regard to Pennhurst. And I had asked Jack Hagele, H-A-G-E-L-E, to represent PARC in *PARC*, [laughs] in the education case [*PARC v. Pennsylvania*]. Rick was then at a law firm called Dilworth, Paxson, Kalish, Stone and {Dilks?}, and Jack was at Pepper, Hamilton and Scheetz. And Rick very likely had conversations with Dave Ferlinger before it was filed. But I don't know any of that for sure. I remember one summer— Let's see. What date was it filed in '74?

Pelka:

In May, I believe.

07-00:12:09

Gilhool: Yeah. Probably that summer, I remember being back and stopping into Dave's office and talking about what was going on, and encouraging him, and raising the question whether he really wanted it focused on fix-up, which was the way it was filed. You'll remember that *Wyatt v. Stickney* had been decided in '71, I think. And that was widely hailed as the great "right to treatment" case. And it was all about improving the institution. And the first opinion in Willowbrook [*New York ARC v. Rockefeller*], which was, I think, filed in '73, '74, was also that, all about fixing up the institution. And it was in that line that David and his clients had framed the case. I'm pretty sure that by the summer and our conversation, and in the conversation, Dave had become aware of PARC's

great interest in this, and had the expectation that we would intervene at some point.

Pelka: Now, I was going to ask you about that, because it seemed striking to me that PARC joined the case— It was about a year after it was initially filed, I think, wasn't it?

07-00:14:01

Gilhool: Mm-hm.

Pelka: And then the U.S. Justice Department—I forget whether it was before or after PARC; I think it was after PARC got involved—

07-00:14:08

Gilhool: I think so, too. But that would be of interest, and perhaps significant.

Pelka: Were you involved with the parents movement? Had you been keeping in touch with people while you were out in California?

07-00:14:20

Gilhool: Yeah. I came to at least one of their conventions, and stayed in touch occasionally. And I wrote two things while I was out there, one of which is directly germane; and in the course of writing it, would be back and forth with the people at PARC that I did my thinking with. One of them was in *Mentally Retarded Citizens and the Law*. And the paper was called “The Right to Community Services.” And that actually laid out what pretty much was done around the Pennhurst case and beyond it, and is probably worth a look-see. Among other things, it suggested that while the constitutional grounds were strong and the rest, that it was very important that we get to a statute at some point, because the courts would be much more receptive to enforcing a statute. And of course, we had gotten, in '73, to [Section] 504 [of the Rehabilitation Act of 1973]; and in '75, the DD [Developmental Disabilities Act] Amendments, which I must say, nobody ever took seriously, nobody ever thought of them as? enforceable. [laughs]

Pelka: [Over Gilhool] Well, the Appellate Court seemed to take it seriously, but—

07-00:16:05

Gilhool: [laughs] Would you like that story right now?

Pelka: Why don't we do this chronologically? But just when you said that, it just occurred, 'cause—

07-00:16:12

Gilhool: Yes, exactly. And Ray Broderick, at the first session of the Third Circuit Historical Society, which chose Pennhurst for its opening deliberations, was very wry and very funny about how, in his Christmas Eve opinion of '77, he had based his decision in 7, 8, 9 [separate] grounds, every statute, he said he thought, and several variations of constitutional claims. And you know, he

said, “Wouldn’t you know [laughs] the Court of Appeals would come up with something else?” And sure enough, they did. But it was the development of 504, and much later, the ADA, which supplied the statutory grounds. Anyway, that’s an interesting article. The other article was “The Uses of Courts and Lawyers,” which is in the second edition of the President’s Committee on Mental Retardation, *Changing Patterns in Residential Services for the Mentally Retarded*. This is the one that Richard {Coke?} was the co-editor with, along with a wonderful English woman whose name was {Ann?} something or other {Shearer?}. But in any event, I’d been in touch. You might actually want to talk with Rick [Bazelon]. I think what you’ll learn, and what I remember—but I want to be cautious about this—is Rick, who was David Bazelon’s son, and who is quite steeped in all of this, and who later was responsible for a—not much later, actually, late seventies—for a redraft of Pennsylvania’s Mental Health Procedures Act [of 1976]. And he was shy, reluctant. We had had several conversations about it before I came back, and a couple afterward, to frame the intervention in terms of closing the institution and providing community services to all. In most significant part, I think that’s because of the careful and inherently conservative lawyer that he is, as most big firm lawyers are. So the intervention came sometime after I came back.

Pelka: Now, the intervention being—?

07-00:19:31

Gilhool: The intervention of PARC [Pennsylvania Association of Retarded Children]. And when you move to intervene in a case, you file a motion that states what the interests of the intervening parties are, and make various representations of fact about whether others will represent them, et cetera. And you file a full complaint with the motion, that if you are granted intervention, then becomes a further complaint of the triggering document in the case, which defines for all preliminary purposes—and in many ways, really, in the real world—defines for the entire proceeding, trial and orders, as well, what the claims are and what the case is about, and what it’s based in. And that was the intervention which we filed.

Pelka: OK, now, when you say “we,” were you , at that point, representing PARC again?

07-00:20:24

Gilhool: Yes, I was back.

Pelka: OK. How did that happen?

07-00:20:28

Gilhool: How did it happen? [laughs] I don’t know. I mean, on the one hand, PARC’s basic resolution after it’s ’67, ’8, ’69 investigation of Pennhurst was, you will remember, that institutions could not be salvaged, though they had spent the better part of a couple decades trying to improve them; and that we really

needed to end them and close them, and create an alternative system. And the discussion after the resolution to consult counsel was about ways and means to use the courts to advance that. And they chose to do the right to education first. But it was chosen with that ultimate purpose in mind. And interestingly, there was no case—with an exception that I'll describe for you in a minute—there was no case, there was no alternative described in the memorandum that framed their discussions and actions that was the *Pennhurst* case, equal protection, close 'em. There was a right to treatment option, like Wyatt. Though that's anachronistic; Wyatt hadn't happened yet. But the right to treatment action was in a lot of minds. And I can do that, as well, but I'm not sure whether you want me to do it now. Several of us who were involved in this run of cases all participated in the third year of law school; it was the spring—could've been the fall of 1963, and the spring of 1964—with Joe Goldstein and J. Katz, who were the law psychiatry, et cetera people at Yale Law School. And Anna Freud was in the seminar, as well. And there was much talk of a right to treatment in that seminar. And Charlie Halpern, who became a clerk for the D.C. Court of Appeals, and who was there when Judge Bazelon began to articulate in, not the Forest Haven context, but what's the famous mental health institution in D.C.?

Pelka: Oh, the one that Ezra Pound was kept at.

07-00:23:34

Gilhool: Yes, exactly right.

Pelka: Oh, I'm blanking, I'm blanking on it.

07-00:23:38

Gilhool: And another of our classmates and friends who was in this seminar was Bo Burt, Robert A. Burt. And he was Judge Bazelon's clerk the year that the—almost had the name of [laughs] the Ezra Pound institution.

Pelka: [laughs] Yeah, well, they ought to rename it.

07-00:23:57

Gilhool: Right, right. And Peter Strauss, who was also in this seminar, and he had clerked for Bazelon the year before; by now, he was probably clerking for [Justice Byron R.] Brennan, on the Supreme Court. But in any event, where was I going with that?

Pelka: You were talking about right to treatment being—

07-00:24:19

Gilhool: Yes, exactly. And it was— you know, instead of languishing, if there's any reason for people to be there, and thus to be deprived of their freedom, they surely were entitled, under the due process clause, the analysis went—'cause you can't take away freedom without due process—they were surely entitled, as a matter of substantive due process, to treatment to address their condition.

And that's where the name came from, and that's where Judge Bazelon's—as I remember, there were two decisions in the late sixties, and then Wyatt—which Charlie had a significant hand in—framed it that way. In my memorandum of counsel, and in PARC's discussions, we were not much interested in the right to treatment approach, especially because all that did was to pretend and presume to fix up the institutions, and we were interested in getting people out. The cause of action that was the fifth on the list that was described in the alternatives which were before PARC was a state court action around that twenty-five million dollars. It would've relied upon a state court doctrine that is hallowed, of arbitrariness. If legislation does something that's unreasonable, severely unreasonable, and makes no sense at all, then that's not good.

Pelka: I'm sorry, I didn't catch the phrase. It was something of arbitrariness? What was the word before arbitrariness?

07-00:26:28

Gilhool: I wonder. [laughs]

Pelka: Oh, ok. I just didn't catch that.

07-00:26:34

Gilhool: It sounds like federal substantive due process. It's something that's irrational and arbitrary. It's also like [Supreme Court] Justice [Byron R.] White's opinion in *City of Cleburne, Texas v. Cleburne Living Center*, where he found the exclusionary ordinance of Cleburne, you'll remember, to be entirely irrational, to have no ground, no permissible ground or purpose to support it. And so the argument that we limned was exactly that; that the twenty-five-million couldn't do it. Not because it was inadequate in money terms, but because the task made no sense; and that it was therefore, totally irrational, and the money should be spent in other ways. And that's the closest we got to articulating what became the claim in the Pennhurst intervention.

Pelka: Now, the other case you were talking about, was that Donaldson? You said there were two cases, Wyatt—

07-00:27:55

Gilhool: No, Donaldson is from Florida. And Bazelon's decision was actually pre-Donaldson. Donaldson was early seventies, I think.

Pelka: OK, well, I was just throwing that out.

07-00:28:11

Gilhool: Yeah. And a name will occur to me. And there's also another place where you will see it. The other article is "Mentally Retarded Citizens in the Law," the PCMR. That's the Ohio State conference, which was quite famous, and just covered the landscape. It was essentially driven by the possibilities raised by PARC—that is to say, of using the law. And when Larry [Lawrence A.] Kane,

who was on the President's Committee; and Dennis Haggerty, who was a consultant for the President's Committee; and most importantly, Mike Kindred, who was a professor at Ohio State Law School, and who participated, in the early seventies, in getting a Supreme Court committee, and actually, a law office, much like Frank Laski's in Massachusetts, on disability litigation— Mike put together a three day gathering in Columbus, which covered the landscape, and drew, oh, just an extraordinary and precise and rich reach across the country, into people who had been, for a brief time, at least, thinking about every dimension of the law as it affected people with retardation. Developmental disability was hardly a phrase in use then.

Pelka: When was this conference?

07-00:29:50

Gilhool: As I recollect, the conference was '74. And the book appeared in '75. It was Glen Cove Free Press, which was a major publisher in many things, but a major publisher in law, psychiatry, and psychoanalysis. Law schools traditionally—and it probably reaches to the twenties—had paid no attention to other disabilities, including no attention to retardation, but paid *enormous* attention to mental health. And it was chiefly because the mental health context, even more than the prison context, the criminal context, was a superb place to test out, develop, and try to think through notions of constitutional liberty.

Pelka: By the way, St. Elizabeth's was the name of the hospital.

07-00:30:51

Gilhool: Yes, that's— [laughs] Well done! Great, Fred.

Pelka: Well, I couldn't *live* with myself if I hadn't been able—[laughter] I want to back up a little bit, about *Pennhurst*. So you weren't involved with the initial filing of the case; you came in at the PARC intervention. Can you tell me anything about Terri Lee Halderman and the original people who filed on behalf—

07-00:31:20

Gilhool: Yeah, let me think about it. The Haldermans were a lovely family. They were quite angry and worried about the injury and abuse that occurred to their daughter. There were another seven or eight individuals, as I recall, in David's complaint. And there was an organization, to be distinguished from the later arisen— [pause] Oh, you know what I mean. The movement of institutional parents [that is, parents who wanted to keep the institutions open].

Pelka: Yeah. I know there was a thing called the Parents and Family Association of Pennhurst.

07-00:32:18

Gilhool:

That was their [the Halderman plaintiff's] organization. And Alan Taub, whose child was also a plaintiff—a daughter, as I recall—was one of, probably the chief driving force of that organization, and of this set of plaintiffs. And he was a small businessman who was very sharp, very wise, very articulate, moved very well. And again, the presenting circumstances for them, and for David, were chiefly about the abuse that occurred in the institution, and the injury. And hence, it got framed the way it got framed, significantly by the success of *Wyatt v. Stickney* and the way it had formulated the issues. And the change of theory in the case was— It was notable. That is to say, you know, my clients and David's clients understood that it was a shift—at least a shift in emphasis. And maybe there was some hesitation on the part of the Haldermans and Alan and so on. I spent a lotta time with Alan. He was quite active in the Philadelphia chapter of the ARC.

Pelka:

Could you spell his last name for me?

07-00:33:04

Gilhool:

T-A-U-B.

Pelka:

T-A-U-B. OK, Taub.

07-00:34:07

Gilhool:

Yeah. But it was not problematic. That is to say, there was no fight about it, there was no battle about it, there was no— You know, it was all quite congenial. In part, because in those days, as maybe even now in some places, everybody who was active in the field saw the ARC as their organization. And trusted their sense of where things were and where we ought to go.

Pelka:

Let me just pause you right there. I want to ask some follow-up about that. But before we do that, I just wanted to read something again about the conditions. This is from the factual findings. And you were talking about the abuse, and I just wanted to throw this in. This is a quote from the factual findings on conditions in Pennhurst. "Urine and excrement on the ward floors. Infectious diseases are common. Serious injuries inflicted by staff members, including sexual assaults, have occurred. Physical restraints have caused injuries, and at least one death." And I know there was testimony about one woman who was kept in restraints for 720 hours, during a one-month period. I just wanted to get in some details.

07-00:35:40

Gilhool:

Yes, yes. And there was a huge record in the Pennhurst trial of that. We did the injury reports and records for a period of years, probably for a decade. We did the restraint authorizations, all of which were already being documented under federal rules and regulations, ICF-MR [Intermediate Care Facilities for the Mentally Retarded] stuff. And so on. And the Justice Department lawyers bore, carried the burden of, having assembled the documentary record, of then examining in deposition large numbers of people—probably three dozen,

maybe four dozen, maybe more; all of which— well, I bet there are ways to trace that down—from the ward level, all the way up. And they started with the ward level. And that was focused on two things. One on the injuries and abuse, the conditions at the institution; and second, to some degree, on the capabilities of people with retardation. Both what they were suffering, and what they might have been capable of. The record of the trial, which you will remember was an eleven week trial, was of course, transcribed. But when we went to the Supreme Court the many times that we did, the parties have to designate a record and print, not all of it, but large proportions that are agreed upon among the parties. And so there are six relatively slim volumes, about 250 pages, I guess, of the trial transcript. And you can see this dimension of the evidence, as well as the other dimensions quite vividly there.

Pelka: Now, let me back you up on two things here. You said the Justice Department lawyers then had the responsibility to track down— Now, did the Justice Department lawyers come in and do the original research, gathering the abuse complaints, incident reports from the wards?

07-00:38:34

Gilhool: Everybody was involved in that. And probably, that discovery had occurred or was underway when Justice came in. Because that's simple. You ask for documents. [laughs] And they give them to you. But Justice Department had, of course, the deep pockets, among the three sets of plaintiffs. And they, too, had until this time, been focused rather exclusively upon conditions in institutions. So we were eager to have them do the institutional conditions part of the case, because it is depositions intensive. Depositions are expensive. There are essentially three dimensions of proof of any matter in these and most cases. One is documents, the other is depositions of people and observers on the other side, and the third are experts. And on all three dimensions, the Department focused on the conditions of the institutions in this case. Yeah.

Pelka: OK. Now, let's get back to the shift in theory in how the case was framed, going from right to treatment to due process. And there was another aspect, wasn't there? Due process and—

07-00:40:05

Gilhool: Well, you know, in some way, it's a shift from due process, right to treatment, to equal protection. Equal citizenship, equal protection. And that shift is nicely articulated by Bo Burt in his piece called "Beyond the Right to Habilitation," in the *Mentally Retarded Citizens and the Law* volume, from Ohio State. And his essay, which you will enjoy reading, is essentially a contrast of Wyatt and Willowbrook, with *PARC*, with the right-to-education case, which was, of course, equal protection. In any event, we filed our intervention. I think we're both right—and we'll act on that assumption for the moment—that Justice intervened as parties, shortly after. And where am I going with this? And they, too, would've filed a complaint in intervention. And I haven't looked for ages at what their complaint said. But the odds are that it was a straightforward

Wyatt v. Stickney complaint. But in the course of the discovery, and in the conversations with essentially two people—one, at that time, more important than the other, Michael {Thresher?}, who was the director of the Office of Special Litigation in the Civil Rights division of the United States Department of Justice, which had, with Wyatt, begun to do what was actually called then institutional litigation. And they had done so not on the basis of any congressional act giving them the authority to appear in court—and believe it or not, that’s usually required—but rather, on the basis of their inherent interest in the liberty of citizens and, to some degree, their interest in the expenditure of monies which flowed to the states from the federal government for these institutions. And there was much litigation about whether they could properly intervene. And by and large, their right to do so was upheld, though there were some cases that went the other way. And so the Congress, round about, oh, I think, ’76 or ’77, passed the CRIPA statute [Civil Rights of Institutionalized Persons Act]. Now, the question is, what does the acronym CRIPA stand for?

Pelka: Oh, yeah.

07-00:43:11
Gilhool:

Yeah, we’ll figure that out. Which gave them statutory right to intervene. But again, that statute was framed chiefly in terms of constitutional conditions. But in the course of our discovery—and the sense is, that I’m talking about all three parties—we all came into significant conversation. None of this stuff—as I like to tell young folks, the practice of law is really a social undertaking. That is to say—nearly no good lawyer likes to do things alone, and all good lawyers like to check and double check with all their colleagues, you know, what they’re thinking and what their judgments are about the best ways to proceed and so on. And that was true to a fairtheewell, in the run-up to the PARC trial. In part, because Michael{Thresher?} was a very unusual, openhanded, tough lawyer. And he was assisted by a guy who was then very young, Art Peabody, who later succeeded Mike as—you know, I’m doing an anachronism there—as the director of the Office of Special Litigation, and ran it for a couple of decades, from the eighties on, I suppose. My anachronism is that the first director of the Office of Special Litigation was *not* Mike {Thresher?}. He became director in the course of the Pennhurst case. It was someone whose name you know. And it wasn’t Martin Geary, but he both looked like him and had his air, in many ways. And he was something of a figure in Washington legal circles. And it was he who had invented this office. I’m going to have to recover that for you. And he was the director of the office at the time Justice came in. But in any event, that work and those conversations are what took Justice, in the trial, to supporting building a record and seeking relief that would take the institution down and establish community services. Those were quite intensive conversations that involved a whole lot of considerations. And I indicated earlier that it’s the complaint that defines the issues in the case and the rest. On the other hand, the federal rules then say that, in effect, the complaint will be treated as amended by what the

proof shows in trial. And so on. So the development in the Justice Department's position was very important. And we all ended up in the same place, I would say by early '77, when we were framing the issues in the case for trial, which began, as I remember, in— Geez, I used to have the date. I would say April 11th or something like that. And at the same time, Michael was doing the Justice Department work in Willowbrook. And he changed the approach in Willowbrook from the first decision, which was fix up, to the ultimate orders and implementation in that case, which were to take the institution down and build community services.

Pelka: So the Justice Department intervention sounds really quite huge. I mean, both in terms of resources that they were able to bring, which is always helpful; but also, in kind of nudging the framing of the complaint in the direction that you had been—

07-00:47:45

Gilhool: That's right. That's quite right. Yep. And it was huge. And huge and important in this whole movement. Because while it is relatively easy to do a *PARC* kind of litigation, right to education, because we didn't need a huge factual record; the exclusions were established, and we could address capability questions, and ability to teach and learn and so on, with a relatively small number of expert witnesses. But the institution cases necessarily were fact intensive, as Wyatt itself was, and so on. And so the cost burden, not to speak of anything else, was considerable. And the ARCs were never wealthy organizations; nor has the disability movement from beginning until now ever had— [end of side A of audio tape]

Pelka: OK, this is interview with Thomas K. Gilhool, May 2nd, 2007. This is side B of whatever tape we're on [tape 7]. And you were talking about the importance of the Justice Department intervention. So if you could just go ahead.

07-00:49:20

Gilhool: And their importance arose from simply doing the work; from bearing the cost and the energy, and the excellence of work. The Justice Department has always been, at least in modern times, highly regarded. It had an honors program that drew the best people, and the best public spirited people into the Department. They were very acute lawyers. They were used to working very hard. And further, there's a phenomenon in litigation that is near to universal. While it is true that if you get a judge's ear, and if you have a trial in front of the judge and the rest, you can drive decision making and consideration to the point where the judge is dealing with the facts as in front of him, it is also the case that, as in most human undertakings, everybody, including judges, thinks and acts in such a way that there really is a kind of modest presumption for one party or another. And there are two kinds of presumptions that have arisen in public lawyering. One is that the court almost always believes what it hears from the Department of Justice. A similar experience applies to large law

firms. Large, well reputed law firms, as they put in evidence and take positions, there is a kind of credibility that attaches to their work. and judges don't feel like they have to second guess. On the other hand, while that was also true in the early days of Legal Services, for various reasons, that didn't last long. And usually, counsel for vulnerable parties, otherwise disfavored parties and the rest, really have an uphill battle. And it was very important to have Justice in these cases, because if nothing else, they gave validity to the point that these were worthy and important matters.

Pelka: Now, did people in the Justice Department decide on their own to intervene? Or did someone from the plaintiff's side approach Justice to—

07-00:52:07

Gilhool:

I think it was undoubtedly a combination of both. But Justice was, in these days—and the fellow whose name I'm suppressing deserves a great deal of credit for it—they were, as the Civil Rights Division as a whole was, in this time—that is the say, the seventies—very proactive. As the Civil Rights Division was on race matters and gender matters and so on. And that had significantly continued in the Nixon administration. It was not until the Reagan administration that Justice Department's professional activities to advance enforcement of the civil rights laws, and of those dimensions of the constitution became problematic. The Nixon administration might as well have been, you know, anybody else's administration. So— I'm sorry; what was I doing with that?

Pelka: I just asked whether you knew if Justice had intervened on its own hook, or whether the intervention had been solicited.

07-00:53:23

Gilhool:

[Over Pelka]: Yes, yeah. They were quite proactive. They had begun their process of scrutinizing, affirmatively scrutinizing states and their behavior. It was, you know, early behavior, which later became entirely systematic; that is to say, looking at what's happening in the world to see if there were legal violations that they should intervene to address. So yeah.

Pelka: OK. You had mentioned before, and I just want to backtrack a little bit to fill this in, you'd talked about the national ARC and the local ARCs, and your lack of resources. Specifically, was there— I imagine there was interest on the part of the national ARC; but was there specific input? I mean, Gunnar Dybwad, for— Well, he wasn't with ARC at that point, but he was kind of their—

07-00:54:28

Gilhool:

But Gunnar was *very* close to the Pennsylvania ARC. It's fair to say that in his years at Brandeis, you know, he was the major counselor to the ARC movement; not so much the national organization, but rather to those state chapters which had some verve and were focused on trying to make things better than they were. And I used to tell Rosemary [Dybwad] that we all

know, of course, why it was that Gunnar's favorite ARC was the Pennsylvania ARC; it was because of the dirty spoon on Main Street in Harrisburg called "The Spot," that he just *relished* coming back to as frequently as he could. Do you know about his addiction to— What would you call it? These days, you'd call it fast food. In those days, it was greasy spoons.

Pelka: Yeah, yeah.

07-00:55:36

Gilhool:

Yeah. So that was one. The national ARC at this time, and at various times since, as you know, was unclear about where they stood on closing institutions and moving people out into community services, versus either acquiescing or maybe affirmatively avowing fixing them up and keeping them around. Phil Bruce was then the national executive director of the ARC. And they did not take a public position in favor of taking the institutions down and building community services until sometime after the '77 trial. And there were debates and strained tensions inside. And in fact, Phil Bruce was, in the trial, the first expert witness. And the Justice Department put him on. They examined him. In a three party trial, all of the parties get the opportunity to examine. But, you know, you would split up responsibility for preparing the witness and taking the lead. And we were—that is to say, Frank Laski and I, and our clients—were worried about what he was going to say on the ultimate matter. We were quite worried. We knew that on the one hand, he had a personal understanding which was growing, growing, growing visibly, that we needed to get out of these places and into something else. On the other, he had been an institutional superintendent, and a leader of the good guys among institutional superintendents, who were clear and direct and forthright about how rotten things were; some of whom thought we could perfect the institutions, and some of whom thought we were long past the point when we had to acknowledge that we couldn't do that, and hence, get out. And so it was a matter of much thought about how we could shape the circumstances under which he was testifying to minimize the probability that he would opt out on the ultimate questions because of, you know, the political situation inside the ARC. And so we were very self-conscious about being clear, as inevitably he would've known anyway, that the ARC's position was clear. And he knew that, because ARC of Pennsylvania has probably contributed more presidents of the national organization than any other. Eleanor Elkin, who had been president in—let me think—early sixties, was at this time working at the Law Center. Not a lawyer, but we had many subject matter experts in various fields working with us, and she participated in preparing the trial and so on. Jim Wilson was the next Pennsylvania ARC person to be national president.

Pelka: And that's a name that rings bells from *PARC v. Pennsylvania*.

07-00:59:37

Gilhool:

[Over Pelka] Yes, that's right. He was the PARC president when we started the right to education case and so on. But in any event, we made certain that

Phil understood what this case was about, and where PARC wanted it to go, and what the underpinnings were. And as what sounds like a silly tactical matter, but simply tells you that shaping things is not unlike theater, where you try to attend to everything that might affect it— I have no mind's eye recollection, but I would be sure that the leadership of PARC was in the courtroom when he testified. [they laugh]

Pelka: Uh-huh. Probably toward the front of the courtroom.

07-00:60:37

Gilhool: Yes, exactly. In the front row. And Gunnar's involvement in all of this was important, as well, because he had, of course, been an executive director of the ARC. He was enormously respected and revered, even at that young age, in the movement and in the organization. And he, of course, was a very important witness in this case. And his fingerprints are all over the shaping of the case. And we made sure that Phil was quite aware of that, as well. But we intentionally had Justice do it, so that he would understand that facts from his experience and knowledge, that we wanted him to be sure to put before the court, were not special pleading by us, but were straight out on the merits. You follow?

Pelka: Yeah, yeah.

07-00:61:43

Gilhool: Because that's how Justice approached things. And it turned out fine. And I think, in fact, in that six, seven, eight volume piece we see, we ended up putting a whole lot of Phil's testimony there. You know, it was not until Steve Eidelman that the national ARC took and acted upon a sturdy support for community services and closing institutions. And you may remember that that occurred on Steve's actions for the national ARC, with regard to the California Association for the Retarded, which was the name of the California ARC; and which, more than most in the country, though there are some counterparts, was dominated by a kind of pro-institution fervor, or softness, or both.

Pelka: Now, the California ARC was suspended for a time?

07-00:62:52

Gilhool: Exactly. And that was Steve Eidelman who did that. And it was precisely around whether they would adhere to the national ARC's position and resolution that what we needed to do was to close these places and build excellent community services. And that's exactly— you're on the button.

Pelka: Yeah. Now, I'm gonna— How do I phrase this? In the *PARC* case, there's a very conspicuous, and pretty much abject total capitulation by the commonwealth, it seemed, once the case got to court. I mean, as I recall, it was after one day of testimony that the—

07-00:63:37

Gilhool: [Over Pelka] Yes, one day {inaudible}.

Pelka:

—that the state came back and said, “OK, let’s go to an agreement.”

07-00:63:43

Gilhool: They didn’t even come back. I mean, sitting in the—

Pelka:

[laughs] OK. Wow!

07-00:63:48

Gilhool: [laughs] At the end of the day, Allen [C.] Warshaw stood up and said to the court—and he probably had mentioned he was gonna do this—“We’ve had enough. We would like to ask the court’s permission to engage with the other party on whether we can come to terms on this case.”

Pelka:

Uh-huh. So a *My Cousin Vinnie* moment.

07-00:64:13

Gilhool: Yes, yes. Right, right, exactly. [laughs]

Pelka:

But obviously, this didn’t happen in this case. I mean, you’re talking about an eleven week trial. So obviously, the commonwealth was much more invested in seeing this through to the end.

07-00:64:27

Gilhool: Quite right. And we went to the Supreme Court. The Supreme Court wrote two sets of opinions in this case. It was argued in the Supreme Court three times. And there were another score of proceedings, which led to decisions, but not arguments or opinions, in the Supreme Court. Yeah. And—

Pelka:

I was gonna ask if you had a sense as to why— They weren’t challenging the facts of the case, were they? In the sense of, the conditions in the institutions were awful. Was there a lot of dispute about that? Or was that pretty much—

07-00:65:06

Gilhool: No. No, there wasn’t. Largely because the [laughs] discovery had been so overwhelming. You know, they’d pinned it. And it was very difficult for them to dispute.

Pelka:

So they had other reasons, then for—or other arguments, at any rate. But before we get into the arguments, do you have a sense as to what the reasoning was? I mean, was this a fiscal kind of thing, or—

07-00:65:29

Gilhool: Well, it’s all— Thanks for asking the question. It’s not a question I’ve thought about in recent times. Let me try to get my chronologies correct. [Governor Robert P.] Bob Casey was elected in ’86, took office in ’87. [Governor Richard L.] Dick Thornburgh was elected in ’78, took office in ’79. Milton

Shapp was still governor in '77 and in '78. Now, cost was one thing. The Shapp administration was in its last years. They had had some scandals, having nothing to do with any of this, but of a Pennsylvania style corruption variety. And it's fair to say that it was a fairly— How would you say? I don't mean disillusioned. It was, you know, an administration whose morale was quite low.

Pelka: Disheartened.

07-00:67:00

Gilhool:

And so they weren't doing much of anything that was unusual. And remember, it was the Shapp administration, which had taken the position in *PARC*, after the pretrial proceedings in *PARC* [which] were very significantly contested. I mean, strong arguments were made, they were pressed strongly. But after four witnesses, they threw in the towel. I'm going up to Syracuse next week. And Burt Blatt was the fourth witness, and Gunnar was scheduled as the last witness. And we had another six witnesses scheduled, wonderful people, from Columbia and so on. And the two educators from North Carolina, one of them later— Jim Gallagher and whatsisname had testified, and Ignaci Goldberg from Columbia, the grand old man of education, had been the opening witness. Anyway, the contrast in Shapp administration, et cetera behavior in the two cases was marked. For reasons that I guess I've limned as best I can, we had no expectations of anything more from the Shapp administration, except opposition. And undoubtedly, what was seen then as the fiscal cost of such undertakings had a lot to do with it. Remember, the home and community based services amendments were in 1981. And in fact, they grew out of the experience that HHS—HEW, in those days—had in helping implementation of the *Pennhurst* decision. But at that time, there was negligible federal money, virtually no federal money available for community services. As you may remember, [Supreme Court Justice] Ruth [Bader] Ginsburg's wonderful comment in the *Olmstead* decision. She said, Georgia argues that the Social Security Act and Title XIX medical assistance had a preference for institutional services. And she says, "They quite properly put that in the past tense." [they laugh] And then she pursues the home and community based services amendments in '81. So that was heavy. That was heavy for everybody.

Pelka: Now, let me just interrupt. The twenty-five-million dollars that you talked about earlier, was that in some kind of escrow? Or was that—

07-00:69:45

Gilhool:

That was state money.

Pelka: Yeah, it was state money, but was that a factor in what was going forward in *Pennhurst*? I mean, was that ever—

07-00:69:54

Gilhool:

Oh, it was a very important factor, because by '77, a significant number of people who had been in Pennhurst and in some of the institutions were living in the community. And that allowed the plaintiffs, at Jim Conroy's hand and Debbie Spitalnik's hands—but Jim's primarily, but Debbie and some others—to do the twin study, which was really, as you look at Judge Broderick's opinions and so on, the driving, piercing piece of evidence. What we did was to match by disability configuration, and age, and time in institutions, and other things like that, people who were in Pennhurst, among the 1,200 at the time of trial, with people who had been in Pennhurst, and who were out, and who were doing very well in the community.

Pelka:

[Over Gilhool] OK. And that was contemporaneous. And was that fortuitous, or had that been planned all along, as people were moving forward with Pennhurst?

07-00:71:06

Gilhool:

It was not fortuitous. It was a part of the strategy that PARC saw from the beginning. That is to say, getting that money put on the community side was important. One, because it would directly advance their objectives; but two, because they expected that it would show what PARC understood to be true in any event, namely, that folks who were suffering in institutions could flower in the community. And it was no accident that they went to work, in ordinary citizen ways, to get that result politically from the legislature and the executive, so that other things could build upon it. In another way, I don't think any of us had in mind that sooner or later we would be filing this suit. Certainly, we didn't in '71. So in that sense, it was fortuitous. [laughs] But the fortune arose from PARC wanting to cover every base in advancing their objective.

Pelka:

Yeah, yeah. Moving on to the trial then, you talked about the testimony of the first witness. Maybe you could go through some of your recollections of the trial, some of the things that stand out.

07-00:72:44

Gilhool:

Well, it was an extraordinary trial. The judge's pattern in all this litigation was four days of trial and Friday, no trial. So that it was eleven weeks of four day weeks, to allow everybody to try to recover, and of course, prepare for the next week.

Pelka:

And this is Judge Broderick?

07-00:73:10

Gilhool:

Judge Broderick, Raymond J. Broderick.

Pelka:

And he, of course, had been involved with *PARC*, is that right?

07-00:73:18

Gilhool:

Yes. Exactly. He had been a member of the three-judge court.

Pelka: Right. So in a sense, you had a history with him. OK.

07-00:73:29

Gilhool:

Yes. And indeed—now, whether this thought arose before or after—in *PARC*, after the settled orders were presented to the court and approved by the court as preliminary orders, in October of 1971, there were objectors in the court, as is their right. We had filed it as a class action against all school districts, as well as a class action on behalf of all kids with retardation. And many school districts came in to object to the settlement and to say it was wrong and wasn't well based and so on. And in retrospect—and maybe this only arose after our coming to know Judge Broderick even better, in the course of the trial—it may well be that Judge Broderick was the key to holding that court together when they were dealing with the objections. And I think when we talked about *PARC*, I told you about the judge's— He ran for governor in 1970, against Milt Shapp. And Milt Shapp issued brilliant position papers. And Ray Broderick flew into Pennhurst twice [laughs] to see it, and to campaign there and so on. And he had played a role in moving the twenty-five-million, in ways that we've discussed. And Judge Broderick was a great story teller. And so he told a couple of times, in chambers, with all parties there— In those days, you used to meet in chambers to plan the next steps in the case and so on, with the judge. And he would tell the story often of— Now, I'm uncertain. My memory is uncertain whether it was his daughter and her boyfriend or whether it was his son, who was a worker in a community living arrangement in State College, where Pennsylvania State University is located. All three of them were students there then. And Ray Broderick told the story about going to a Penn State basketball game with the people who lived in that community living arrangement, and his son or his daughter's boyfriend. And so he had the *PARC* experience, and all of those other experiences. Anyway. Yeah.

Pelka: OK. Any particular moments during the trial that stand out in your recollection?

07-00:76:44

Gilhool:

Oh, my. It was just extraordinary. And I think you get a sense of it from the appendix, as it's called, the record; the partial record, not complete, but the record of the proceeding in front of the Supreme Court. The testimony— Well, the job in every trial is to present the crucial, driving facts, in as many different languages and ways as you can. Because even if you've had an opportunity to get to know the judge's habits of thought and the rest in the course of discovery and the preparation for trial, you can just never predict what is going to reach into the mind of any human being, [laughs] let alone a judge, and make a difference. So there was, as I mentioned earlier, extensive testimony, chiefly at Justice Department's hands, from direct care workers. And many direct care workers, and indeed, the leadership of this institution, who also testified, were, from their own experience, very much sympathetic to *PARC*'s, and now all of the plaintiff's, objectives in this case. And that testimony, along with the analysis of the documents, was the strong stuff, in

addition to the testimony of parents—our set of parents and the Pennsylvania Parent and Staff Association of Pennhurst, et cetera, the Taubs and the Haldermans and so on. That added up to the trial record that drove the dimension of the decisions which concerned the conditions of the injury and the awful nature—nasty, brutish and short, as we came to say, borrowing from Hobbes—of conditions and of life at Pennhurst. And then on the other side, we put on several “house parents.” It’s interesting to note that retarded people didn’t testify. I’m not sure that we even considered that, which will tell you how distant ’77 is from the mid-eighties, by which time the People First moment had more than begun. But we didn’t seriously consider that. Though there is one important footnote to the participation of people with disabilities. And that is that consistent with these cases as a general matter, disabled people as a general matter, “children,” quote/unquote, as a general matter, early in the case, an order had been entered which, to protect the privacy, if you will—those aren’t the words that were used then; privacy is the way it’s done now, I think much to our detriment—but to protect the privacy of people with retardation. And so initials were used. Sometimes numbers were used. And there was a table and a code, so that the judge and the parties would know who you were talking about, right? And Judge Broderick, after the decision in December and his orders in March of ’78, at one point, from the bench, looked up and said, “You know, I think it’s time we—” And someone in the court had just referred to M.C. or J.M. or what have you, or #197. And he looked up and he said, “You know, I think it’s time we stop doing this. There’s no reason. No one should be ashamed to be retarded. And I’ve learned from this case that people and families have enormous capabilities. And I think it’s time we called people by their names, [laughs] as people.”

Pelka: Well, you know, what that also does is, it literally humanizes— I mean, to talk about case 195, I mean, that could be, you know—

07-00:81:47

Gilhool: Yes, exactly. And I would say that he did that probably in the course of early ’78. And it, you know, was just so cool. Now, the closest we got to that, of course, was testimony of parents, and sometimes other relatives. And we put on several people who had been working in community services. And I’m going to be able to remember, I think, the name of the most vivid witness. She was a house parent. And in the seventies, it was a house parent model that the twenty-five-million and Stan Meyers and the Floyd McDowell design had established. And she testified vividly, and with great verve and élan and affection and delight, about the guys who lived with her in the house in which she and her husband were house parents. And that meant a lot. Now, the systematic evidence on that matter—namely, proving that people in the institution could, with the proper services, make it in the community—the crucial evidence there was the evidence I spoke of earlier, which Temple University’s Developmental Disability Center, it was one of the Kennedy funded centers— Not so much the foundation as the Kennedy legislation that came out of his ’63 address. University affiliated facility, it was then called.

And Jim Conroy, who had graduated from Yale and was then completing his PhD in statistics at Temple; and Debbie Spitalnik, who was on staff there along with Jim, and who subsequently has done many things, including PCMR and the UAF [University Affiliated Faculty in Developmental Disabilities] in New Jersey, did all of the work on that twin study, which I described earlier. And the study was presented in documentary fashion, of course. And the person who put it into evidence was the chairman of the statistics department at Temple University, Jim's thesis advisor, and later, a principal in the NASA statistical center at the University of Colorado, about three, four years afterwards he got hired away from Temple. So that was the second set of evidence that was vivid.

Pelka: Was there rigorous cross-examination?

07-00:85:00

Gilhool: Oh, yes. Yes, yes, yes, yes, yes.

Pelka: And do you recall—

07-00:85:03

Gilhool: Both ways. Both ways. The state had three lawyers on the scene. Bob Hoffman was the junior, Allen Warshaw was the next to senior, and the lead lawyer, I'm blocking for the moment on his name. And they were all assiduous. While one of them had, as you remember, I think, from a previous conversation, early in the tours with experts at Pennhurst and so on, had been so viscerally moved that he had to leave, to go outside to vomit, at the conditions. They were tough and strong. And they were using all of their wiles. OK. Now, the third piece, which at the time, had considerable impact, is that sometime before the trial, the [Pennsylvania] Secretary of Welfare had appointed three experts to look at Pennhurst and to make recommendations to her. This was the Thornburgh administration, and Helen O'Bannon was the Secretary of Welfare. And she had appointed—it's important that I get these names; my memory is— Alex, whose last name I'm blocking on, who was at the University of Pennsylvania School of Social Work; Valaida Walker, later Assistant Provost at Temple University, and then a major figure in the education school at Temple—

Pelka: What was the first name?

07-00:86:52

Gilhool: Alex. And I'm blocking on his last name.

Pelka: But Walker, you just said.

07-00:86:57

Gilhool: Yeah, Valaida Walker. V-A-L-A-I-D-A. She's a distinguished African-American professional. And Ken Thurmann, who had just come to Temple from Peabody, and who was also in the education school, and very much a

disability specialist. And they did their study and wrote their report, and came to plaintiff's conclusions. And we had a big battle about whether we could put that in evidence or not. You know, first getting access to the reports, and then whether, you know, this having been done by the defendants in preparation for litigation; maybe it wasn't something we were entitled to have and put into evidence. But it went into evidence, and all three of them testified for the propositions that were important to the plaintiffs. And there's no doubt in my mind that that had a considerable impact, both on the judge and on public opinion.

Begin Audiofile 8

Pelka: Just a little housekeeping. I found out this is interview number four. I've switched tapes, so the last tape was tape seven; this is now tape 8, side A. This is an oral history interview with Thomas Gilhool. And I didn't do this on the last tape, but I need to do it. You understand you're being tape recorded—

08-00:00:25

Gilhool: Absolutely.

Pelka: And I have your consent to do that.

08-00:00:27

Gilhool: Yes. Throughout, you certainly have my consent.

Pelka: OK. We were talking about the trial and the trial testimony.

08-00:00:37

Gilhool: Yeah. And we had covered the institutional conditions, the testimony, well, anyway, we'd covered three heads, three vectors of the trial testimony. There are two others that are important. One was to the proposition that all could be in the community. The "all" was crucial. Just as the "all" in the Education for All Handicapped Children's Act was crucial. And in *PARC* we understood that from the beginning, because the grotesque history—"the prejudice, once let loose, not easily cabined," as Marshall put it in *Cleburne Living Center*—was such that if there were any fuzzy edges, you could predict that the bureaucracies, whether school bureaucracies or adult services bureaucracies, state or local or what have you, would take whatever even reasonably phrased exemptions or exceptions ad hoc might be allowed for; would take it and would run a truck through it. So the all was very important. And the second vector of evidence was how to do it, the point of which was twofold. One, that it can be done; and two, that doing it well was important. And that had implications for our asking the court to supervise it with great care. Now, as to the "all," all of the testimony, of course, went to "all." The testimony on conditions did, because always, the last set of questions to the fact or the expert witnesses on the institutional conditions were, "Well, what is the remedy for this?" And the experts, without exception said, "Well, take the institution down. Close it, and move everybody out." And in the course of it,

they would testify to, “This can be done with all.” That, of course, was an implication, as well, from the twin study, and from the experience that people had in the community living arrangement side of things. So while it was pervasive, there were also particular witnesses whose testimony was, in a major way, focused upon leaving no exceptions and reaching to all. And you will see in the middle of Judge Broderick’s decision on the eve of the eve of Christmas in 1977, that he articulates this focal turning point, factual conclusion about, this is for all. This applies to all. He articulates it, in significant part, by quoting a crucial piece of Gunnar Dybwad’s testimony. Interestingly, and very surprisingly to us, we had, as a part of the common strategy to present it to the court in as many different languages as we possibly could, we had invoked the help of Derek {Lancaster Gay?}, the director in England of the UK Spastic Society, the counterpart of our United Cerebral Palsy associations. Right? And Derek did it in terms of England, and drew his conclusions with respect to all retarded people, all people with disabilities. And at that session, the first of the 3rd Circuit Historical Society, where the many participants in *Pennhurst* led the conversation, Judge Broderick, in addition to his remarks about the Court of Appeals somehow finding [laughs] other statutes to base this on, after he had worked so hard to be complete and comprehensive, as he wryly put it, he said—and it blew our minds; it blew my mind—“You may be interested in when I came to the conclusion that these facts apply to all people at the institution.” And he said, “It was in the midst of the testimony of Derek {Lancaster Gay?}.” And he described it. And [laughs] I never let him forget that. And I subsequently would kid him, when we were together in the course of implementation and so on, how wonderful it was than an Irishman should have found most persuasive [laughs] the testimony of an Englishman.

Pelka: Now, Derek {Lancaster Gay?}, was he himself disabled?

08-00:06:12

Gilhool: No. He was not. He was not.

Pelka: Now, what was it about his testimony, in particular? Did Broderick say? Or has he elaborated on that since then?

08-00:06:22

Gilhool: Well, it’s worth our looking at the transcripts, which exist, of the Court of Appeals, of the proceedings of the Historical Society. But Derek’s testimony was quite like the testimony of other experts about, you know, what had been the pattern of treatment of people with significant disabilities, and the pattern of segregation, and its origins in state imposed injunctions to segregate, and in eugenics. And then the testimony about the conditions of institutions. [laughs] And then the findings, both from that era, from the many people who didn’t get put in institutions, and who, depending upon what support and assistance they, and to some degree, their families had, were making it in the world. And then the testimony about the folks who were actually in [the community]—

you know, designed and established recently in the UK, as here, though much farther advanced in the Scandinavian countries, of course, which Gunnar had testified to and which Derek also testified to, which showed that all could do it. So there was nothing in content, or even qualitatively [laughs] unique, about his testimony.

Pelka: It was just that tipping point.

08-00:07:56

Gilhool: But it was a different voice. Maybe it was because Judge Broderick had such low expectations of the English [they laugh] that—

Pelka: “Well, if *they* can do it—”

08-00:08:10

Gilhool: Right. Exactly. [they laugh] Exactly. If they come to these conclusions, how can the rest of us avoid it, maybe. You know. And that may have been the mechanism. And that’s what I used to kid him about. You know, how *strange* to look to the English. [laughs] And Broderick was by no means a professional Irishman, but he was *very* Irish, and very proud of it all, and had been an Irish pol in Pennsylvania politics, in the best sense. So that was kind of funny.

Pelka: OK, so the trial was eleven weeks. At the conclusion of the eleven weeks, did you have a sense as to how it was going?

08-00:08:50

Gilhool: Yes. Yes. Yes. I’ll come back to do the last head in a minute. We had high expectations. Nothing is ever a given. But we had such expectations that by December, we had actually prepared a press release to celebrate the opinion, when it came. So that not hours, let alone days, would pass before it was brought generally to public attention. OK? And I had a very disappointing—in fact, I felt hurt and impeached by it—conversation—I’ll think of his name—with a reporter for the [Philadelphia] *Daily News*. Understand that in those days, it was common for the press to follow these trials. And there were virtually, literally, daily stories in the press. And that was important, of course, as I mentioned earlier, because all these things we were trying to bring the court to see, we were eager also to bring the public to see, because again, “prejudice, once let loose, is not easily cabined.” And so one had to reach, if any of this was to last, public opinion on the questions. Anyway, Jim somebody called me about an hour, hour-and-a-half after the opinion was filed. And I think I’d mentioned to you before that Judge Broderick had this wonderful habit, in cases of public moment, of filing the opinions on the eve of a major holiday; and usually, [laughs] at five-of-five on the eve of a major holiday. And my speculation always was that he had not been pleased with the treatment that he had been given by the member of the Fourth Estate when he was running for governor, and by God, he was gonna make ’em work [they laugh] into the holidays. But that was the pattern in the major opinions here,

and in some of his other cases. But Jim, an hour-and-a-half later, probably an hour after we got the opinion, and in fifteen minutes, got to the bottom line, we put the press release out. Right? And he said, “Did you know this opinion was coming?” [they laugh] In other words, raising the question, if not, indeed, accusing me and the court of having disclosed—right?—in advance. And you know, I never felt that in that conversation, nor later, that I caused him to understand, Look, this isn’t space science. [laughs] You know? We were ready both ways. But we knew it was gonna come this way and we— Anyway. That was painful, actually, for me, in a personal, professional way.

Pelka: Oh. Now, the *Daily News*; is there a Philadelphia *Daily News*?

08-00:12:10

Gilhool: Yeah, Philly *Daily News*. Still is. The other, the major evening paper then was the *Philadelphia Bulletin*. And the *Philadelphia Inquirer* was the morning paper. And we were blessed throughout with an extraordinary set of reporters. Dorothy Brown; a guy who now runs the journalism center, critical ethics— Rem Reider—at Columbia University; and another three or four reporters, including, from the *Pottstown Mercury*. There are two Potts in Pennsylvania, one of which is John O’Hara’s town [Pottsville]; that’s not it. The other one, which is Pottstown. I’m sure I’ve got that right, or reasonably sure. It’s very close to Pennhurst. And they had a Pulitzer Prizing winning newspaper there, actually. And that reporter was assiduous, and it was all put out with care. Just incidentally, the best single piece written on the Pennhurst trial was written by Bob Perske. He sat through all of the trial. And, with drawings from Martha, he wrote a piece which he called “The Courtroom as Classroom.” And it was published, in a time before evangelical was a word that denoted much here, in an evangelical journal that was published here out of Germantown. A national publication. And he and I are both searching for a copy of that darn thing, and if we get it, we’ll favor you with it. But it was, as you can imagine, [laughs] given his talents, it was just the most vivid description of the trial.

Pelka: And given his religious affili— I mean, he’s a minister, so it makes sense that he would tailor it toward an evangelical publication.

08-00:14:24

Gilhool: Yes. Well, and you know, evangelical then had none of the connotations that it does now. And it was plainly a social action kind of journal. And it’s name, when I recover it, even suggested that.

Pelka: It wasn’t *Christianity in Crisis*, by any chance?

08-00:14:46

Gilhool: No, it was not. It was not. It was national, but it wasn’t *that* prominent. Yeah. Well, let me just return to the vectors of proof. The last vector worth mentioning was about how to do it; that it could be done, and that doing it well was important. And every piece of testimony went to that. The factual testimony from inside the institution, the factual testimony from community

living experience, the expert testimony, the twin studies, we put on with care; what Floyd McDowell's study had looked like, and what that had then produced. And then of course, in the twin and testimonial reports, the quality and results that came from it. Jim had not yet done his comparative growth and skill reports, which he first did during *Pennhurst* implementation. But in the twin study, we got to some significant outcome measures. And that was very important, as I mentioned earlier, because we wanted not only a profound and deep and biting opinion that is well based in the facts and the law, from the court, on the merits; but we wanted to raise as high as we could, the likelihood that the court would superintend implementation in ways that would assure the quality. And of course, the court did; and didn't finally surrender jurisdiction until everything was very well done. And we'd had many fights about some things that were not, which Judge Gramm, my colleague here at the Law Center, conducted over ten years. I think he [Judge Broderick?] surrendered jurisdiction probably in '94 or '95, *Pennhurst*. The last person was out in the early eighties, and the place was closed in '84. OK. Now, there were two dimensions of all this further worth mentioning. One, I alluded to earlier, about the role of *Pennhurst* implementation in driving the amendments to Title XIX of the Social Security Act, establishing home and community based services. Well, we were in the Carter administration, of course. He was elected in '78. By '79, he was in office.

Pelka: Now, you're talking about President Carter?

08-00:17:44

Gilhool: Yeah.

Pelka: So '76.

08-00:17:46

Gilhool: Yeah, thanks. That's even better. That's even better. So thank you. '76. And of course, around '78, the 504 regulation demonstrations [in 1977] around the country, and in Califano's office had occurred, and so on. At some point, shortly after Judge Broderick entered his *Pennhurst* orders requiring the state to create quality community services, community services needed by each, for everybody at *Pennhurst*, Jimmy Melody called here. And Jim said, "What can we do to help?" Now, Jim was then, as he had been from the beginning of the Carter administration, the secretary's representative to the Middle Atlantic region. That is to say, he was the regional director of HHS. All right? And Jim was the son of a political boss in Scranton, Pat Melody, who ran the county and was on the commission. Jim had been a fifth grade student of my mother's, teaching at St. Paul's Elementary School in Scranton. And Jim was very close to Califano. And so we sat down. And we call him Jimmy, in the Irish tradition, which is especially strong in Scranton. Everybody's called Jimmy or Tommy or Freddy or what have you. And so we said to Jim, "Jimmy, look. What we would like you to do is to make it possible for Pennsylvania to take all of the *Pennhurst* budget and move it to the

community, with the people.” Right? And he brought Califano in, and they did that. They did it promptly. And they did it thoroughly. And the mechanism had to have been the general waiver authority under Title XIX, Social Security Act, medical assistance, which has existed since 1965. And in the event, the Pennhurst budget paid for quality community services for the 1,200 people at Pennhurst, and another 900 or so from the waiting list, all right? And so in ’80, Califano formulated the Home and Community Based Services stuff. And in ’81, when the Reagan administration failed in congress, in their effort to revise Medicaid as a general matter, and to step back a bit from entitlements and so on, the congress passed the Home and Community Based Services Amendments. And that is a piece of the history that is not widely known. The Home and Community Based Services Amendments did not come out of the air, but it came exactly out of the Pennhurst experience, and the attention given to it across the movement and across the state directors association, and so on; and from Califano and Mellody.

Pelka: It’s Melody?

08-00:21:29

Gilhooll: Yeah. M-E-L-L-O-D-Y. Jim died subsequently, at an altogether too young age, after the Carter administration. But almost everything was possible for him after that, and it never eventuated. Now, there’s one other theme that underlies these events that is important for me to articulate. And that is the unions and the subsequent parents’ movement—union based, union paid for—in favor of institutions. Which showed its head here in two ways. The less significant was when Paul— Oh, dear. The woman who has led— What do we call the institutional parents’ group, Fred? What is it they call themselves? It’s just out of my head; it’ll come back. She was in Pennsylvania, and she had two children at Pennhurst. Her pain in putting them there was very considerable. She had, someone recently reminded me, after putting the two youngsters there, adopted two youngsters, going forward. And she remains, to this day, very much the sturdy leader of those forces. And they played some in the implementation. I mean, they appeared to object to the orders and so on. But it was not a significant factor here; in part, because all these things had been fully— You know.

Pelka: They had intervened, in terms of the original trial?

08-00:23:25

Gilhooll: Subsequent. No, it was not—

Pelka: It was after, yeah.

08-00:23:27

Gilhooll: After the trial, is my recollection. It was afterward. And their intervention helped to reinforce the judge’s orders. He appointed a master; he provided that families had to be affirmatively invited to participate in the design of the community services. And that actually happened. And then there came a point

when whatsername's association sought an early version of the parental veto. Right? And we went to the Court of Appeals on that, and the Supreme Court denied cert on that. And the outcome was, as many Supreme Court opinions anticipated or limned, and as California District Court has recently held—not recently, three to five years ago—has explicitly held, in the course of the implementation of the state court orders in *Pennhurst*, that there was no parental veto; that the parents had fully the right to participate and to assure themselves that the services were what, by their lights, and their experience with their own child suggested, they should and must be. But no veto. But that participation became real under Carla's thing [Carla S. Morgan, 2nd master]. And then Mike [Michael S.] Lottman was appointed the hearing master to make determinations in cases of individual objections by families or anybody else—counties, for that matter—to the nature of the particular services. The final line on that was, as you know, Jim [James W.] Conroy and Celia Fineststein's studies of families, when their kids were in institutions, at Pennhurst. My recollection is about forty- fifty percent of families maintained contact, and the others didn't. And these, therefore, were polls of the families that had maintained contact. And when Jim asked— And I just don't remember right now whether it was before trial, or whether it was early after trial. When they asked the parents what their preferences and experience and judgments were, while the kids were still at the institution, 90%, plus or minus said, "We love the institution. It's great. We want to keep our kids there." And then he redid the question, at a point over time, where people had been in community services for six months or better. And it flipped around, as you famously know, from 90% preferring the institution to 90% preferring the community.

Pelka: Now, just to back up a little bit, just to be clear, when you're talking about a parental veto, what they were asking was that they be allowed to say that their children would not be a part of the—

08-00:26:43
Gilhool:

Right. Yeah. That their children would stay in an institution. That that was their decision, not anybody else's. And of course, several decisions, largely by Burger in the Supreme Court, on commitment statutes, and one of them in a very important case that David Ferleger had taken there, whether it was Romeo or whether it was {Cremins and Bartley?}, I'm not sure—it may actually have been both—where they said, "This decision is an objective decision, to be made," they said, "by professionals, based on the facts and on professional expertise," about whether the person can make it in the community. That's the same test, of course, which Judge Ginsburg articulated in *Olmstead*. Unnecessary segregation is prohibited by the constitution, and by the statutes that she attended to. And if you can make it in the community with the proper array of services, then you've gotta go there; unless the person—the person, not the family—says no. I added not the family; she doesn't articulate that. But that's been the fabric of the law. Now, the underlying point that I wanted to get to was not that; but I'm glad we got to that. But it was,

rather, the involvement of the unions, of employees in Pennhurst. We had named, in pretrial, in our list of witnesses and so on, as our second witness, David— and I'm blocking on his last name. He was at Yale. He was a very shy, even timid man, but was recognized in this area, and in many other areas, as one of the most powerful researchers around. He had been engaged, before the trial, by AFSCME, the American Federation of State, County and Municipal Employees, of Pennsylvania, which represented all the institutional employees, and which was led then, as it had been for a decade or more before, and was for most of a decade afterward, by— Oh, dear me. I just had his name, and it's gone. But it'll come back. He is now, and has been for a decade-and-a-half, anyway, Secretary Treasurer— He was national president of AFSCME after Pennsylvania, and then Secretary Treasurer of the AFL-CIO, which he still is. [Richard L. Trumka?]

Pelka: We can find that for you.

08-00:29:36

Gilhoot:

Yeah. yeah. And David published his results. And it's a very famous article. And I'm not gonna be able to get in clear focus the nature of his undertaking, but it was very central. And contrary to AFSCME's hope and expectation that it was gonna show that there are people who shouldn't be out in the community and so on, in fact, on its terms, established the opposite. But when we started to talk to David to get him ready to testify, it was plain that he was gonna testify differently from what he had written. And so we withdrew him and never put him on. And subsequently—rather soon, I'm sorry to say—he died. And indeed— I never looked at the press reports or the rest, but the word was that he had committed suicide. He was an absolutely lovely, but retiring, relatively young person. Now, that's just the first kind of thing about the unions. By the time whatsername's association, now gone national, appeared in the implementation stages of the case, the union, as it turned out, had helped her create this organization, and has continued in Pennsylvania and around the country, to put money into these associations. And the episode I wanted to get you to was, there came a point—and my recollection is that it was before trial and before orders, but it may have been after trial and before orders—when the ARC of Pennsylvania, Stuart Brown in particular, and Frank Laski and I sat down with Jerry McEntee—M-C, E-N-T-E-E—the Pennsylvania president, later national president, later secretary, right? And PARC made him an offer. [laughs] They said, “You stop opposing this, and join us in these remedies and in their implementation, and we will support your organization of community services by the union.” All right? And he said no. And I had occasion, maybe four years ago, in conversation with the SEIU [Service Employees International Union] president, Andy Stern, who, along with the rest of the leadership of SEIU nationally, took over after John whatisname [Sweeny] became president of the national AFL-CIO, or the leadership of SEIU— And SEIU's leadership is almost entirely, but significantly, composed of people who had been social workers in Pennsylvania. Not in institutions, but in public assistance systems and such as

that. And I had occasion to tell Andy that story four or five years ago, when {Max Levertose?} and I met with him and his colleagues. And he just delighted in it—in part, because he and McEntee are significant rivals—and of course, pointed out that had he done the opposite, then all of labor history, let alone the history of services and the situation of the people with disability would've been quite different.

Pelka: And SEIU is now working to— I mean, certainly in the Northeast, I think, working to unionize personal care assistants. I mean, that's, I think, a big push.

08-00:34:21

Gilhool: No, you're absolutely on the button. And that was the occasion of our meeting. Among their highest priorities. They had, of course, done personal care assistants and nursing assistants and all the community health stuff, not so much the disability stuff, in California, very successfully, as they did janitors and suchlike. And yes, since four or five years back, in their highest set of priorities has been organizing workers in disability community services. And indeed, at some point—and I think it's still true—they have focused on California and on Pennsylvania as their priority states. They have not made much headway in actually organizing people in either of those two states. They did succeed in getting from the Alleghany County Council, which includes Pittsburgh and a host of other towns in western Pennsylvania, a disability community services Right to Know Act. And it's *magnificent*. And it requires people to tell. It's very much key to and built around that crucial quality problem that pervades across the country now, and which we lost in the Court of Appeals in the 9th Circuit a couple of years ago in [Judge] Diarmuid O'Scannlain's dreadful opinion in Sanchez versus all the California state officials [*Sanchez v. Johnson*]. But in any event, it's significantly built around the low wages and the high turnover in community services. And you may remember, there are a couple of quality standards that are around. One of them was done by our friend, the woman in Boston who was a member, indeed may have been chair, of the President's Committee on Mental Retardation, under Clinton. And her name is Jan. She did for the National Association of State Directors of Developmental Disabilities Services— Bob Gettings then the executive director; Nancy Thaler is the new executive director at NASDDDS. And she was, at Kencrest, one of the great providers of community services during trial. She didn't testify, but many of her other people did testify. And she did testify in some of the zoning battles that we had in order to get rulings from the state court that community living arrangements were functional families, and could not be excluded from family zoned neighborhoods.

Pelka: I'm going to interrupt you at this point. I think I'm going to close up for this session, if that's ok. What I want to do to maybe close this out, and then as a launching point for the next session, which we hopefully will schedule today, I want you to finish up on Broderick's ruling. And then next time, we're

gonna talk about the appeals process and going to the Supreme Court. And then the impact of *Pennhurst* nationally. So maybe if you could— Broderick came down with his Christmas Eve ruling to irritate—

08-00:38:12

Gilhool: {inaudible}

Pelka: —the working press. And you had been expecting this. You put out the press release. It was a good ruling, was it not?

08-00:38:22

Gilhool: Oh, it was brilliant, yes. Yes. And received great attention nationally, on Christmas morning newspapers. And I have undertaken, but never followed through on, collecting the stories around the country. The one I remember—and it may be apochryphal—was the Austin, Texas *American-Statesman*, which front page headlined, “Court Ruled Institutions for the Retarded Unconstitutional,” et cetera. Yes.

Pelka: And his order was essentially to close down—

08-00:38:59

Gilhool: Yes, and his orders, which are published in FSupp, are March 17, maybe 16, of '78. Yes. And worth taking a look at. And yeah, they were to get everybody out, and to plan carefully, and to do it expeditiously, and et cetera, et cetera, et cetera.

Pelka: OK, let me ask you two questions about that, and then we'll tie up. And now I'm blanking. OK. Well, did you know, first of all— were you expecting an appeals process from the get-go?

08-00:39:35

Gilhool: No. yes and no. And that involves a conversation about the Thornburgh administration. And Dick Thornburgh and Ginny [Thornburgh], of course, came to have, in the accident that killed his first wife, a disabled youngster, who's now quite a young man; and on our recommendation, transmitted through Eleanor Elkin, had hired as the Commissioner of Retardation, whatsername, [laughs] now with the March of Dimes, out of Connecticut, and who had been one of the implementers of Willowbrook, at the point when Willowbrook became community. And so after the thing, we sat them down and we said, “Can we compose this?” And they professed to be willing, but were unwilling to commit themselves to the financial necessities and so on. And this was probably before we had Jimmy Mellody and so on actually committed. But it was in view, anyway. We were always very puzzled about that. And then, of course, all of the appeals, which continued for many, many years, and then came to a conclusion that we can talk about next time, were generated by the Thornburgh administration. And just as you asked the question about the Shapp administration, you know, how come? How come? And I think the answer is twofold. It's, to some degree, the same fiscal

considerations. But my own hypothesis—and that’s just what this is—is— It arises with some frequency. It’s a little bit like we and our colleagues, when we get judges who are disabled, or who have children or other relatives who are disabled, that’s not necessarily good. It’s not necessarily bad, either. But it’s gonna be something, right? Because of emotion and experience and so on. And so your big job is to find out what. I think to some degree, Dick and Ginny Thornburgh thought that they could not—until ultimately, they did—compromise this matter or settle it—and of course, we wanted orders that did it all, or we wouldn’t settle—because they thought they could very well be accused of having done it because of their private interest. And I think that was the mechanism that let all of these appeals go forward and so on. And though they applied to all of the courts, including the Supreme Court, for stays of those orders, while the appeals went forward, we were successful at every point, including in the Supreme Court, in getting the stays denied. So implementation was going forward.

Pelka: OK, that was my second question.

08-00:42:42

Gilhool: Yeah. And we didn’t mind the appeals at all because, you know, we were bullish that they would result in law that would help us.

Pelka: And you were creating facts on the ground while all this was happening.

08-00:42:58

Gilhool: Yes, exactly. Exactly. And it was going forward, and being done very well, by dint of Judge Broderick, and by dint of Carla Morgan, who is a widely unsung heroine of all of this, who was the master during virtually all of it.

Pelka: What was the first name?

08-00:43:17

Gilhool: Carla.

Pelka: Carla. OK. Well, why don’t we— I’m gonna turn the tape off for now.

08-00:43:23

Gilhool: Good. Good.

Interview #5: December 14, 2007

Begin Audiofile 9

9-00:00:04

Pelka: This is an oral history interview with Thomas K. Gilhool. This is December 14, 2007, this is interview #5, this is tape #9, side A. And you understand you're being tape recorded and I have your consent to do that. Okay, great. Now, the last time we talked, which was back in the spring of this year, I believe, we had just finished up with *Halderman/Pennhurst*, with the original decision coming down. And we were about to begin talking about the appeals process, it going to the Supreme Court. Now, was there anything relating to what we talked about before, that you've been thinking about that you want to add at this point?

Gilhool: I was wondering whether it would be useful for me to give you one of the few remaining sets of the excerpts of testimony that run about seven or eight little volumes that were presented at the Supreme Court as a record. That might be useful to be on file. And we did talk some about the crucial testimony and the rest. Two things occurred to me subsequently on the testimony that might be worth saying. Stop me if we said them. One, had to do with the state of the movement, and particularly the ARC as an organization in the disability movement and the movement for community services. Phil Ruse [Phillip R. Ruse] was then the executive director of the ARC and he had, I believe, he had moved the headquarters to Arlington, Texas. He was a Texan, it was located there. He was once an institutional superintendent, and I'm sure we've talked one time or another about the important role that very many very good institutional superintendents had in the whole movement toward community services; that there were a few sticks in the mud, but the best of them, a fellow from Georgia, a fellow from Wisconsin who had been long time president of it, and some others. And Dwayne Youngberg, in Pennhurst itself, who were themselves committed to getting out of institutions and into community.

9-00:02:52

Pelka: Could you give me the first name of Mr. Ruse, the guy from Arlington?

Gilhool: Phillip. Phillip R., as I remember. And Pennsylvania was, of course, on the frontiers of the organization in terms of its position on community services, and ending the institutions. And in some ways, they were the first, apart from Gunner [Dybwad], to actually articulate that as their purpose. And there were other ARC's that were in the same place. But, as a general matter, the national organization had not really come to terms with the issue. And Phillip, himself, would appear and speak in ways that would cause a careful listener to suppose that he was on all sides of the issue. And what caused me to smile in my recollections since we last talked was, we decided that he was a very important witness to put on early, in part because of the judge's respect for ARC and so on, arising from the judge's previous work in the education field

and otherwise. And we decided that it would be best for [the council from the] Department of Justice to examine Phil, not ARC's council, me, or Frank, or Ned Stuckman [Studman?] or what have you, because he would accept much more quickly without so much regard for the political problems it caused him as ARC executive director, their sense of what his testimony should look like. And then we also arranged for the current, immediate past, and next president of the ARC of Pennsylvania to be in the courtroom when he testified, in order, non-verbally, to let him know that we had high expectations of his testimony. And he was very clear in his testimony that everybody could be out, and that if proper services were supplied, it could and should be done. And that reminded me, it was a couple of decades before the ARC became perfectly clear, to put it one way, about getting out of institutions and into community.

9-00:05:55

Pelka: Now what time frame, when you say 'a couple of decades', meaning which decades?

Gilhool: The period when Steve Eidelman was the executive director of ARC. Phil Ruse was succeeded by, I'm not sure, it could have been directly by Ellen Abeson, who had been at CEC and very much involved in the rights education things. And he served as executive director for a long time and then, Steve Eidelman was directly after him. He moved the offices back to Washington, D.C., but- not back to, before Texas, they had been in New York- but it was Steve, as executive director, who on behalf of the national ARC, finally said to the California Association for the Retarded, CAR, which, in significant ways, functioned and thought as an institutional parents' group. And which— Steve was executive director through the '90s, I think, Fred maybe as recently as five, six years ago. You know, it would have been the mid, late '90s, when he said to CAR, "Look, if you want to maintain your association as a chapter of the ARC of the United States, you have to change your position."

9-00:07:37

Pelka: And they were suspended for it, I'm not sure what the technical term would be, but they were disfranchised, or whatever, for a period of time, if I recall.

Gilhool: Yes, exactly, exactly. And it was Steve who finally did that. And it worked. That is, to say, CAR withdrew, they reorganized, it became quite a different crew of people. Much younger, much freer, much more in tune with the rest of the movement, and so on. And it took that long from '77 to the mid '90s for ARC to become clear. So, Phil Ruse's uncertainty about which dimension of himself and of the organization to present was a long-standing dilemma for them. Now, Steve, as you may know, had been the, let me see, the chief in Philadelphia was called the Administrator for Mental Health Mental Retardation, and then there were two under him, one for retardation, and that was Steve Eidelman. Not during the Pennhurst trial, my recollection is, but at the point where decisions came down and implementation happened, Steve was the guy. And he subsequently, in the '80s, became deputy secretary of

public welfare for Pennsylvania, in charge of mental retardation. And he went from there to the Kennedy Foundation, and then to the ARC. I'm quite sure I've got that in the right order.

9-00:09:31

Pelka: You also, last time, talked about a parents' group that was separate from the ARC that attempted, after the original decision in *Pennhurst*, to intervene and win a veto option, I guess it was called. And you were trying to think to provide a little more information about who those people were and we really didn't get into that very much. I was wondering if you'd had a chance to think a little bit about who, precisely, was that, this was an organization now—

Gilhool: Yes, and it's relevant at this point. The Pennhurst Parent and Staff Organization is what it was called. And it was, I suppose in the early days it had a very significant staff component, but by the time of the litigation, in part with Dwayne Youngberg's superintendency, which was not new, but less than a decade, Dwayne and many staff were all in the same place: that it was important since people could be out that they be out. And indeed, many of them, many staff people testified to that effect, ranging all the way from direct care workers on the wards through Chief of Nursing and Chief of Schooling, and other mid-level, top-level administrators.

9-00:11:11

Pelka: This Dwayne, it's Youngberg?

Gilhool: Yes, Y-O-U-N-G-B-E-R-G, he was the defendant in a Supreme Court Decision called *Romeo and Youngberg*. Nicholas Romeo. It was a right to treatment case, and the Supreme Court held that the right to treatment included the right to get out. It was a lawsuit for damages, it was brought by Mrs. Romeo for Nicholas Romeo by David Ferlinger, and it's a very good opinion in the Supreme Court. It's kind of the high water mark of the so-called 'Right to Treatment'. If the low water mark is the first opinion in *Willowbrook*, where Judge Judd, I think, held that the right to treatment did *not* include the right to get out, the Supreme Court holding was very, very useful. And Youngberg was the defendant in that case. Now, let me see.

9-00:12:22

Pelka: Now, he was the defendant entirely because of his institutional...

Gilhool: Capacity, right. Because it was a suit about mistreatment at the institution, and the failure to provide treatment at the institution, and then, further, check the opinion, then, further, as a part of the right to treatment, the right to get out.

9-00:12:49

Pelka: I'm going to interject this, just so that, perhaps you can remind me later on to bring this up, or we could bring it up now, although it's an interruption, but I've begun reading an oral history that was done with Richard Thornburgh in the early '90s, and it doesn't talk about *Pennhurst* at all, really. It's mostly

about his role in the passage of the ADA when he was Attorney General, so that is what they focus on, but of course, he, as governor of the Commonwealth of Pennsylvania, also had an institutional role as a defendant during, if not the initial case, then the appellate process, is that right?

Gilhool: That is very important, and let us to return to it just after this conversation about the Pennhurst Parent and Staff Association.

9-00:13:44

Pelka: I just wanted to say that because when you said that, it provoked that thought in my mind. Getting back to, so this is an organization that had existed before the initial lawsuit was brought.

Gilhool: And from time immemorial, it existed in one form or another. And at the time of the lawsuit, it took on a good deal of energy. Its leader later became a national leader of Voice of the Retarded, VOR. Her name was Polly Spare. She had two children who had been in and were at Pennhurst. Indeed, the personals of these, not for the value of disclosure itself, but they helped explain things in many ways. I mean, as we've discussed before, it was nothing short of heroic that so many families were able to escape the trauma of placing their kids in the institution. I mean, it was no accident that most of the state laws of the '10s and the '20s providing for compulsory institutionalization of the feeble-minded were clearheaded that they were taking the kids away from their families and that the family nexus should be broken and they explicitly provided for no visitation in the first significant period, could be a year, could have been two years, could have been, I don't remember exactly, but our brief in Cleburne puts a lot of that stuff together, will show it for many of the states. And, of course, all of this came out of the Eugenics movement that saw disability itself as hereditary, and significantly a matter of blame, and blame was very much a part of the rhetoric of the Eugenics movement that gave rise to all of these institutions. It was laid all on the tops of families.

Well, the Spares had two children who were sent quite early to Pennhurst, and you'll remember that as late as the '60s, when Frank Mendalascino [Menalascino?] and the University of Nebraska, very much involved in court (?), Nebraska is the first in the country, systematic community services system. He and a co-author who is also a significant figure, and his name is out of my head at the moment, surveyed pediatricians about what advice they gave upon birth, and shortly thereafter, to parents who had significantly disabled children. It is, even now, hard to read, because the numbers, the proportions are so high, of pediatricians who thought that the only sensible, the only good alternative, was the institution. So, all of that is by way of an annotation to how difficult it is for families and how heroic it is when families go through all of that and then come out on the other side, acting as families and as citizens to secure better things for their kids.

9-00:17:28

Pelka:

I just want to make sure I've got that name right. Frank...

Gilhool:

Menalascino, M-E-N, I believe A-L-A-S-C-I-N-O, it could be M-E-N-D. He was an important figure and a president at one point in AAMR, AAMD, as it later came to be called, etcetera. A very, a very telling article and I've wished and have occasionally urged my American Academy of Pediatrics friends to take a look at the state of knowledge and the state of professional advice coming from pediatricians in recent times. It would be stark and interesting to see the contrast.

In any event, the Spares, as I recollect, had actually adopted two children in place of, quote, in place of, close quote, not quoting them, of course, but in place of the children who were sent to Pennhurst. And Polly, and a gentleman from Pittsburgh, later much involved in Western Center, in the opposition there, though our lawsuit in that regard was successful, and similarly implemented very well and everybody got out, including their child. The Spares' children got out too. Judy Gran could probably tell us the particulars about them. But anyway, Polly was the lead of- the spear, if you will- and there were two or three parts to their participation. One part is the part you put your finger on and it arose post-implementation, that is to say, it arose post-judgment by Broderick in December of '77, and post-orders, which were the eve of St. Patrick's Day of '78. And it arose, not immediately in terms of the commonwealth's appeal of the merits of the judgment to the 3rd Circuit, but sometime thereafter. They sought intervention, in order- not their phrase, but the phrase that has come to attach to it- in order to secure a parental veto. And Judge Broderick famously said: "They are welcome to participate", and indeed, the master has established this careful forum for family members and people themselves, and professionals and so on, to participate in the design of services and his orders required that parents participate if they wish, but he was clear it was 'participation', and not a veto. If a person could make it in the community, then the services of the optimum variety, needed to be carefully adumbrated and then provided. And they went to the 3rd Circuit, seeking a veto, and the 3rd Circuit said "no" and wrote a very sympathetic opinion to them, and my recollection is they did not try for a Supreme Court hearing. That's my recollection. In any event, if they did, it was denied. It came back and the master proceeded similarly and as a result of some discussion in the 3rd Circuit opinion, Judge Broderick then appointed a second master, a hearing master, at the close of all of the development work for any given individual, there could be, at the option of a family member, or of the person, a further hearing in front of, it turned out to be Michael Lottman, Carla Morgan had been and was the implementing master. They could have a hearing, a little bit like the due process hearing, but again, there was no veto. That was the latest participation.

There were two previous pieces of participation. I'm going to say this and check it later, and I'll let you know. As you know, we went to the Supreme

Court twice. First, on the grounds supplied by the Court of Appeals that the Developmental Disabilities Services and Bill of Rights Act of 1975 included an enforceable duty which strongly preferred the community for everybody who could make it. And that was decided in '81. And then, it came back to the 3rd Circuit, and this time, it went up on the Pennsylvania state statute, the MHMR Act [Community Mental Health and Retardation Act of 1967], the Kennedy-era act of 1967. That one was argued twice and decided by the Supreme Court in 1984, and it was after those proceedings, when it came back again, with still several grounds on the table, which Judge Broderick had based his initial decision in, most notably Section 504, the several constitutional grounds, particularly equal protection and the various linguistic formulations of those rights, including what he spoke of as the right to habilitation in the community. And it was at that point that we asked the 3rd Circuit to appoint one of their number to conduct conversations among the parties and that resulted in an agreement of all of the parties and the end of the litigation.

Both cases in front of the Supreme Court were, in all three arguments and the several briefings, and the Court of Appeals proceedings beforehand, were pretty thoroughly litigated by the commonwealth and its attorney general. At that point, the Pennsylvania attorney general was a member of the governor's cabinet and appointed by the governor. He subsequently became independently elected, but this was an attorney general who was gubernatorially appointed, and there were two or three deputies attorney general of considerable stature, at least two of whom had conducted the defense in the trial, who participated in it, and they did what I think anyone who reads the briefs and the arguments would suggest, would be a serious and credible job for the defense. But the *real* defense, in the Supreme Court, was conducted by Joel Klein.

9-00:25:33

Pelka:

Joel Klein?

Gilhool:

Klein, K-L-E-I-N. Undoubtedly, in your this morning's *New York Times*, on one page or another, because he serves, as he has, since the beginning of the Bloomberg administration, as chancellor of the schools, for the city of New York. Joel represented the Pennhurst Parent and Staff Organization. He was engaged to represent them. I'm going to have to check this for the particulars, but they did not have party status, and so, I can't remember and my hand doesn't pull up one of his briefs- they must have, maybe they appeared in the Supreme Court as amicus, in which case, with the permission of the court, they were allowed to argue. And I need to chase that a little bit to be sure I'm right about that.

Joel had clerked for Judge Bazelon, the great judge in these matters, who for a long time, several decades, been appointed by Truman, he'd been Chief Judge of the United States Court of Appeals for the D.C. Circuit, District of

Columbia Circuit, for several decades. In the '60s, he had written, chiefly, as I'm sure I've told you this story, during a period when his clerks were classmates of Gillian's and mine, had been classmates of Gillian and mine at the Yale Law School at a time when Joel Goldstein and J. Katz and Anna Freud taught a seminar entitled 'Psychiatry, Psychoanalysis and the Law', a seminar that was present in virtually every law school, probably since the '40s, maybe the '30s. To be sure, its subject matter was disability in a sense, but the reason why it was in everyone's curriculum was that issues of mental health and social action, with respect to it, were seen as kind of testing issues on questions of liberty. It would help you figure out what constitutional guarantees of liberty meant, to take them in this context and look at them. In any event, Peter Strauss, Robert Abert [?], some others who clerked for Judge Bazelon, had come out of that seminar. And during the period he was clerking for them, he wrote the initial and great opinions on right to treatment. They all arose out- I think all, but most of them- arose out of St. Elizabeth's, the historic mental health institution in D.C. And they were, when there came to be a constituency for disability law, lawyers and people interested in it, they were, of course, widely used and applauded opinions.

9-00:29:16

Pelka:

You were talking about the earlier intervention by this parent staff group, I think, is how all this began.

Gilhool:

Earlier to the request for a veto. This was their presence in the case, represented by Joel Klein, and most notably in the Supreme Court, in order to defeat Broderick's judgment, in order to reverse that. And Joel had clerked for Bazelon, the reason why I went to the Bazelon stuff, is that in many ways, he was a sport of a clerk for Bazelon. Nearly all of the other Bazelon clerks- Pat Wright and many others, the people I've mentioned, went on to take important roles, whether from law schools or as litigators, or in some case, both, favorably, to advancing the interest and the rights of people with disabilities. Joel was a sport and took little, at least there was nothing recognizable either in the substance or in his approach to things in the *Pennhurst* case. Once he got involved in the *Pennhurst* case, he began to appear in courts of appeals, and then in district courts all around the country for various institutional parents groups.

9-00:30:37

Pelka:

You said he was a sport? Is that the word you used?

Gilhool:

A sport, yeah. Where does the word sport come from? An unusual, out-of-character, jarring, completely contrasting event [laughter], to all the other events that you expect whenever Judge Bazelon's name is invoked. He had, also, gone from Bazelon to clerk in the Supreme Court for Potter Stewart. Potter Stewart was, again subject to checking, still on the Supreme Court in all of the *Pennhurst* arguments, but more important, his relationship, we learned, and indeed observed, from the bench, he had developed there in a strong

relationship with the Virginian on the Supreme Court, Powell [Lewis F. Powell], and he had created a small law firm that did a fair amount of Supreme Court work and so on. And it's fair to say that he was the craftsman for the defense. He was the person who did the framing of the arguments.

It's important to note that both of the decisions of the Supreme Court on *Pennhurst* were awesome opinions. They broke the mold on two matters of constitutional law and policy that had been very strongly established, and each of the decisions reversed one of those things. Both of the rules that were so radically changed had nothing to do with disability or the content of the case, but in the first one, dealing with the Developmental Disability Services and Bill of Rights Act of 1975, the Supreme Court held that the act was unenforceable, that Congress did not intend that it be enforced, and that it could and would not be judicially enforced. It said, in a phrase that appears fairly early, that the Bill of Rights provision of the DD act were precatory, and not binding. The Congress was merely seeking to express its *hope* that the state might proceed that way. They didn't intend to confer rights and the judiciary would not enforce it. Now, that was essentially an unprecedented decision of the United States Supreme Court.

9-00:34:15

Pelka:

Okay, let me interject two questions here. Prior to that, had the common view of that portion of the act been seen that it did have enforcement?

Gilhool:

Now, that's a terrible, wonderful irony. We had not argued the DD Bill of Rights Act to Judge Broderick. We had not argued the DD Bill of Rights Act to the 3rd Circuit, except at a point during the briefing, the Circuit asked the parties to address that act, and we did. And the 3rd Circuit rested its first opinion, affirming Broderick on that ground. And Judge Broderick said, as I think we discussed, later Broderick said at [a reunion of the] the 3rd Circuit Historical Association, "Can you imagine? I had ten grounds, and they insisted that they would find another one."

9-00:35:21

Pelka:

Okay, so it was the 3rd Circuit that inserted the DD Act, not Broderick.

Gilhool:

Quite right, quite right. And a part of the reason why we held our hand and that act was never put in front of Broderick was that the popular view was that the DD Act was a services act, and it wasn't a very well funded services act. And while it had this lovely language in it, which Elizabeth Boggs had been responsible for putting in, I think it's fair to say that nobody thought that anybody should think that the state had to carry it out. Now that runs a little contrary to the legal doctrine best expressed by Justice Holmes in 1913, riding circuit, in *United States v. Johnson*, in which he said, "If the Congress should even *hint* at its purpose, what it wishes to see happen, then the Court must divine the meaning of the hint and enforce it." That had been the legal view. But on the street, and understand, anybody who watches or works in the

Congress understands that legislative history has a very different meaning to those participants than it does and has traditionally in the courts. So, if Elizabeth told the story of what happened in the DD Act, and the 3rd Circuit told the story of what happened in the DD Act, in the development of the DD Act, they're very different stories. And the chief reason, why we didn't think to raise it, didn't raise it, I'm not sure we even made a self-conscious decision not to raise the DD Act, we didn't think it really had all that much weight.

9-00:37:31

Pelka:

So, basically, you had to go to the Supreme Court and argue a position that...

Gilhool:

That we had not urged before. Quite right. And we made a considerable argument, I, it would be fun in that, and you tell me at some point whether we should attach the briefs here, and there was a strong argument to be made, and let me put it right here, and then we'll come back to the second Supreme Court opinion, and then we'll come back ultimately to Joel Klein and the Pennhurst Parent and Staff Organization. This is a question that I must tell you I began to think about only since the conversation you and I had two weeks ago. One of, in retrospect, and indeed, it's been detailed and adumbrated in all of, in many of the very many decisions about interpreting and enforcing or not, of finding rights in federal statutes or not, all of those decisions which *Pennhurst* triggered. *Pennhurst I* gave rise to three decades of litigation on this stuff, well beyond the disability context, obviously. And by and large, under Rehnquist's leadership of the Court and so on, they found an increasingly great number of statutes unenforceable, either because they had no ground in the Constitution, or because the Congress didn't want them enforced. And those decisions are characteristic of the Rehnquist years on the court, and the Roberts years, even so soon, promise to extend that mightily, and that's a whole new development, as contrasted with the decades before. Why did I get into that?

9-00:39:50

Pelka:

Now you're saying that the decision in *Pennhurst*, the appeal to the Circuit Court, the 3rd Circuit decision, this was the beginning of that retrenchment, so to speak...

Gilhool:

and most particularly, the Supreme Court decision.

9-00:40:08

Pelka:

Oh, okay, that's very interesting.

Gilhool:

Which said Congress could write the words, but that doesn't mean that the courts are going to enforce them. Chief Justice Marshall had said, way back in 1803, in *Marbury v. Madison*, the United States prides itself on being a government of laws, and not of men. If we should fail to find a remedy to enforce a law, then we hardly deserve that proud appellation. In other words, it had been a given from the beginning that what the rule of law meant was that if the Congress hints at its purposes, they are to be taken by the courts as

gospel and made to happen. And in the now, three, almost three decades since the *Pennhurst I* decision, that is very much in question, and statute after statute, the Violence Against Women Act, the Drug Free Schools Act, the AIDS Discrimination in Employment Act, many, many, many statutes have fallen, and indeed, this has been the major jurisprudential battle in court circles for these decades. The Federalist Society was founded to advance the other view. And it weighs very much in the balance as we go forward. It was clear in 2000, and many people chose their presidential candidate because that's what was at stake, and increasing numbers of people do, and it's very much at stake going forward, given the respective fields and their association with the Federalist Society and these issues. Anyway...

9-00:42:07

Pelka:

Now *Pennhurst I*, then, was the first opportunity that the Court had, is what it sounds like you're saying, something they could glom onto to make this argument, is that—

Gilhool:

Yes, that's quite right, Fred. There was nothing in the nature of the case, or its subject matter that would have pointed them to this argument, but they took it, as an occasion, to do some things that several members of the Court wanted very much to do. And Powell turned out to be the crucial guy, and in many ways, it was a surprise from Powell. Powell had been a president of the United States Bar Association, and had been a citizen of Richmond, Virginia, and indeed, on a school board there, and had played an entirely affirmative role in the school desegregation battles there, which in those days, at least, caused people, people understood that civil rights race was the prototypical issue about which the, apparently theoretical issues waged. It was the role of the courts in *Brown [Brown v. Board]* that triggered in various ways this reaction and this effort to render either constitutional provisions or statutes offered to implement them nullity. So it was very surprising, but he was kind of a key guy.

Now, I promise to pause on that long enough and then I'll come back to Joel. The question that occurred to me, almost awoke me with some startlement, some evening, some night since we talked a few weeks ago was "Did we argue?", I asked myself, and I asked Frank Laski this morning for his recollection, "Did we argue that the imperatives, the requirements of the DD Bill of Rights Act, had in 1981, been funded by the Congress, when it adopted the Home and Community Based Service Amendments to Title XIX of the medical assistance title of the Social Security Act?" And the reason why that question occurred to me, and you know, it was a kind of "Gee, did we think of that or didn't we?" is because both in the *Pennhurst* argument itself and the opinion, you can see it, and in later opinions, most relevant, *Olmstead*, you can see it. Just as a common sense matter, obviously, if the question is 'did the Congress intend enforceable rights?', a corollary question in order to answer the first question, a sensible question, is 'Did the Congress provide for the funding of the implementation of those rights?', and a part of the argument-

not a huge part- but a part of the argument was that the DD Act had so little money going to the state, how could it possibly have...

9-00:46:02

Pelka: Okay, this is an oral history Interview with Thomas K. Gilhool. This is December 14, 2007. This is tape 9, side b. You were talking about whether or not, trying to recall whether or not you had argued that Congress had signaled its intent to enforce the civil rights part of the DD Bill of Rights Act by funding the Home and Community Services Act, is that right?

Gilhool: Yeah, the Home and Community Services Amendments, in Title XIX, had provided for medical assistance money to go to the states to provide home and community based services instead of institutional services, which had, from time, from the beginning been funded by Title XIX. That is to say, the institutions had...

9-00:46:57

Pelka: Did you recall?

Gilhool: Both Frank and I, without having yet gone back and looked, but we're pretty clear that we didn't make that argument as such. One, we didn't do it, and I haven't checked the exact dates, but the Home and Community based services amendment was adopted in 1981, Reagan's first year. The decision in *Pennhurst* came in 1981, maybe early in the year, and the amendments were later in the year, so they didn't exist for us to make any reference to in the argument, or in the record, in the trial of the case three years before, or in the kind of supplementary record that you are able to make as you go to a Court of Appeals, and get to the Supreme Court.

We're a little less clear about whether we argued the theoretical point, namely, I've mentioned to you and I'll come back to it in a little bit as we go from Judge Broderick's first opinion into the rest of it in time. Fairly early, probably shortly after the enforcement orders of St. Patrick's Day of '78, the regional secretary of ATW, Jimmy Mellody, called and said, or we called him, I don't remember, 'What can I do to help?', and we said, "What you could most effectively do is to tell Pennsylvania that they can spend all the money they're spending at Pennhurst that comes under medical assistance, Title XIX, they could move that money with people to the community, and of course, in the event that money, without any significant adumbration, was enough to pay for the eleven-hundred or so people at Pennhurst at the point of order and implementation, and for another eight hundred, nine hundred people who were on waiting lists for Pennhurst.

9-00:49:01

Pelka: That happened before the Supreme Court?

Gilhool: Yes. That was well under way by the time of the Supreme Court.

9-00:49:11

Pelka: You're talking about whether or not you made this argument, but going into that particular argument, were you aware that there was a possibility that the court would use *Pennhurst* as a way of...

Gilhool: Yes.

9-00:49:26

Pelka: You had thought about that possibility, you were concerned about that.

Gilhool: Yes. They quickly became framed in the Supreme Court, largely at Joel Klein's hands, in his briefs, as that issue of Congressional intent and power, and whether the statute was enforceable or not, so yes, we were very much aware of. Now, let me go from *Pennhurst I* to the Supreme Court decision in *Olmstead*, which was, what 1999? Thereabout? Justice Ginsburg [Ruth Bader Ginsburg]. The Georgia Case, the ADA, and the question there was 'what does the ADA mean?' And it's hardly exactly the same, but the language in the DD Bill of Rights Act of '75 and the language in Title II of the ADA and in the regulations there under, that Dick Thornburgh promulgated, borrowing from the 504 Regulations verbatim, as Congress instructed him to do. The language is quite similar! And the question was, 'Does this bind the states, does this confer enforceable rights or not?' And the Supreme Court held that it does.

You'll remember Justice Ginsburg wrote two beautiful essays, one that was triggered by her holding that the ADA requires that anybody who needn't be at an institution must be out, and that that was sensible, because it gave people the opportunity to realize all of these constitutionalized values like family and society and participation and the rest. And then, just below it, she does an essay on Title XIX, and Home and Community Based Services. Georgia had argued, well, look, the ADA may say one thing, but they argued, Title XIX of the Social Security Act, medical assistance says quite the opposite. And they cited the Intermediate Care Facility Mental Retardation, ICFMR, provisions of the Medicaid Act, which had been in the act, and still were, since 1965, when it was invented, and which provided federal and state funding for institutions. And from that, they said, "Look, the Medicaid Act has a presumption for institutionalization." Actually, what they said was the Medicaid Act *had* a presumption for institutionalization. And Ginsburg, in a lovely sally, said Georgia is quite correct in putting it in the past tense. Remember? Indeed, it had, but in 1981, she said, it was amended to provide for Home and Community based services, and then she goes on to say, all of this provides the money- not to say, but in effect to say- for implementing ADA. And so, not is there not any conflict between the statutes, but the statutes properly read together tell you that here's a declaration of an enforceable right, and here's a provision for funding it.

9-00:53:20

Pelka: Now what was the vote breakdown for *Pennhurst I* and *Olmstead*?

Gilhool: *Pennhurst I* was, I believe, 5-4. The dissent was Brennan for himself, White, Thurgood Marshall... I'm sorry, Powell or Rehnquist wrote that opinion, I think it was Rehnquist. Powell wrote the state law opinion in '84. One of the *Pennhurst* may have been 6-3. *Olmstead*, there were three real dissents, parts of the opinion only commanded five members of the Court, a part only commanded four members of the Court, but I think it was roughly 6-3. And in the course of thinking through these historical attachments and the rest, we were both recollecting our amicus brief in *Olmstead*, which was done for the ARC of the United States and perhaps, UCP and Easter Seal and so on.

9-00:55:02

Pelka: By we, we're talking about Frank Laski, you and Laski?

Gilhool: Yes, Frank and I were, this morning, remembering that if we made any particular contribution to *Olmstead*, it was the linkage between the ADA and the Home and Community Based Services Amendments, and those provisions are kind of fun, those arguments. We were even at pains to argue, you know, in the field, it's called 'Home and Community Based Services Waiver', and someone suggested yesterday if we can get the Congress back, and the President, we're going to want to change that, but for a long time, we've been saying it's not, it's Home and Community Based Services, they're not a waiver, they're mainstream, they bear the brunt, they increasingly now exceed the flow of dollars to institutions and part of our analysis, of course, rests on Ginsburg's analysis, which in turn, rests on ours. And in the brief, we borrowed some from the National Association of State Directors of Mental Retardation, or Developmental Disability services, and they, twice, had, in a study of how the feds were treating the state's applications for Home and Community Based Services, said, "they'd never turned one down."

9-00:56:31

Pelka: How the who were treating the...

Gilhool: The National Association for State Directors of Developmental Disability Programs [inaudible], now Nancy Peylor's, NASTY. And you'll see it in our amicus brief, in *Olmstead*. But one of their studies of the practices under the act had concluded, if they ask, they get it.

9-00:57:04

Pelka: It sounds as though, what you're saying is if *Pennhurst* had been argued maybe a year later, there might have been a different outcome.

Gilhool: Exactly, exactly.

9-00:57:13

Pelka: Another thing that I find intriguing...

Gilhool: And it took twenty years for the question to come back, and it could be informed by the crucial nature of the appropriation.

9-00:57:24

Pelka: And in the intervening twenty years, of course, there have been all kinds of decisions on acts, as you say, that are not related to disability. The Joel Klein connection to two of the Justices that you talked about is interesting. When you mentioned The Federalist Society, I was thinking, and I'm trying to think if this is right now, was it C. Boyden Gray who was a member of The Federalist Society, and he was Bush's counsel, was that right?

Gilhool: And his undertakings for the ADA were an exception to his behavior as a citizen lawyer.

9-00:58:03

Pelka: And how!

Gilhool: With The Federalist Society and otherwise.

9-00:58:05

Pelka: And how! I'm just wondering how- in the back of my mind, I'm wondering whether that connection to the ADA somehow translated into a more favorable atmosphere.

Gilhool: Oh, quite right, Fred. I mean, that's on the button.

9-00:58:28

Pelka: Assuming that I'm right that Gray was...

Gilhool: Oh, he was. He was Bush Sr.'s General Council, he was the go-between between the movement and Bush Sr., and hence, had a crucial role in evoking Bush Sr.'s strong attachment to ADA, both going into the sign-in ceremony while it was pending, and afterward, in Bush Sr.'s constant pleasure in celebrating it as an important act that he is very proud to have had a hand in making happen.

9-00:59:07

Pelka: And again, this is more a personal connection than an ideological argument, but Gray had this personal relationship, as I recall, with Evan Kemp at the head of the EEOC. It's interesting, because it seems as though relationship trumps ideology.

Gilhool: Yes, yes, as in human affairs, we are lucky it should, right? You're quite right. Evan and Boyden Gray had played bridge together for a decade, better. And I may have told the story, stop me if it's of record in the interviews already, but early, well, mid '80s, probably, when the movement had, you know, flowered to the point where there were several dozen people located in Washington, let alone around the rest of the country, who were spending a large part of their talent on all of these matters. And I wonder if this grew out of a meeting with George and Madeleine Will at a point early on of what later became People for Human Rights, I think. Tom Lerner (?), and Frank and I, and so on, and Gunnar [Dybwad] was there, Evan was there, this is irrelevant, but I

remember that he took Evan apart. Evan spoke in terms of the wants of people with disabilities, and George said, "I don't want to hear about wants, I want to hear about needs!" Nobody is entitled to get their wants respected, but anyway, it was around that time, in the mid '80s, that the people, chiefly, the Washington people, of course, because that's where things were at hand- John Lancaster and Justin Dart and others said to Evan, "Look, you're so conservative, compared to any of the rest of us, and we very much need a figure on the Republican side of things. Why don't you become a Republican and be that figure?" And it happened. Evan did switch his party registration and became a figure to the Bush White House, to Boyden Gray, and more generally. Anyway, you're quite right.

9-01:02:21

Pelka:

It just astounds me to be able to trace the personal backdrop, underpinnings of all of this. I mean, on the one level, we were talking about issues of law and argument and history and the record, but beyond and behind all of this are just certain coincidences, really, personal relationships...

Gilhool:

In some ways, they're not coincidences. From early on, in this rising movement, we talked about, you know, you'd reflect sometimes on what are the strengths and what are the weaknesses of where we are in the movement, and so on. And one of its great strengths was that it was purposed in equality, and that is kind of the essential American commitment, and there is great strength and being purposed there, but the next one always mentioned was there's hardly an American family that does not have the experience of disability, and so, it reaches across the citizenry, and while you always worry, as with institutionalized parents, and we used to particularly to worry if we ever ran into a judge who had a disability or the experience of a disability, since that can, given the history of things, could have affected people's then current views in many different ways, we always worried about how, we would figure out how they affected them, so that we could put on the record that, you know.

But those were and are the two essential strengths of the movement that make it so powerful, and Evan's disability and Evan's presence there and his relationship with Boyden Gray, around bridge, etcetera, given the reach of the movement, there's a sense in which it's not surprising that that kind of thing happens. And as always, just to teach some humility, it's very important that that kind of thing happens, because particularly, when you're working against stereotype, and you need not merely an intellectual, certainly not merely a legal, you need an emotional experience, most often, the literature tells us, to overcome stereotype, to purge it, to understand that it ain't where it is [laughter], and that's not where you want to be. And those personal attachments are very important, absolutely very important.

9-01:05:19

Pelka:

Where were we before I sidetracked?

Gilhoot: I think where we were was, I was about to say, so, Joel made all of those arguments which had resonance irrespective of the disability field, and prevailed. And he did so on behalf of the Parent and Staff Association. There's another connection. Who paid for it? And the answer to that question is, we believe, Pennsylvania AFSCME. American Federation of State, County, and Municipal Employees. Now that in turn relates to the first event. If the third one is the [?] of parental veto, and the second one was the engagement of Joel Klein and the framing of these arguments by the Parent Association with the assistance of the union, the first was...[pause]

9-01:06:37

Pelka: You had talked, in the last interview, about a meeting you had with union leaders, and now I'm blanking on the name.

Gilhoot: Harry McEntee, M-C-E-N-T-E-E, who, at that time, was the president of the Pennsylvania AFSCME, and who has been the national president now for a couple of decades, and who is secretary-treasurer of the AFL-CIO, and that meeting happened after the enforcement orders of St. Patrick's Day '78, probably some distance into implementation. While things were pending, while they were being argued and decided in the Court of Appeals, and before the Supreme Court had taken the cases and those processes were underway. And at that meeting, the ARC, by us and, by their own voices, sat with McEntee, and said, "Look, why don't we get together on this? We will if you will." And surely it lingered in the backs of the ARC, the minds of leaders of the ARC, and our minds, that the union was supporting the Pennhurst Parent and Staff Association. I doubt if we yet had the advent of Joel Klein and all of that, but anyway, we knew that that's where they were, and we said, "Look, you support the orders, we'll support the organization of community services workers." That's very important to us to sustain their wages. And he said "no". That was the thing.

The first place where Pennhurst Parent and Staff Association had a presence also involves the union. There was a superb and young researcher at Yale University, who worked for a professor of psychology there, who was the first director of Head Start in the Johnson administration, who had, in a real sense, invented Head Start. And he had had from his early days, like so many psychologists, a kind of research interest in retardation and in institutions and so on. And his protégé, whose name I am now blocking, did a piece of work in '75, 6, early 7, that was an empirical examination of, as I recall it, and the language is probably anachronistic, it probably wasn't written in these terms, but as we would talk about it now, an empirical examination of the difference in quality in life in institutions and in community. And it was a piece that when we read it, we thought 'wow', and in our draft of the pre-trial statement, where we listed all of the witnesses we were going to present, including the expert witnesses, and the attached documents, we listed this person, in our draft, as second or third witness. But before we filed it, we talked to him, and discovered that his idea of what it was his research showed, was exactly the

opposite of our own. And so we withdrew him, and I can still see that empty space there. And I have a hunch we submitted it with that empty and just renumbered. Irv [Balla] turned out to be and was then, and his work was then, it turned out to be very much a part of Voice of the Retarded and Pennhurst Parent Staff Association stuff.

9-01:12:01

Pelka: Now, as I recall, you did mention this also, I think, last time- and the idea was that it was this parents organization that had commissioned this work, is that right?

Gilhool: That's what I'm trying to recollect. Ed cooperated with it at some point, he and Ed got together- Ed was kind of an old school guy, and so was always happy about institutions, right into the current time, and from time to time, would plague us. But yes, at some point, it became a close and visible relationship with the institutional parents organization, and also with the union. And it just occurred to me, one of the early ways we had sight of that. We, early on, as we were preparing for trial, it's my recollection, we got a copy of a letter and Irv Balla- B-A-L-L-A, Irv Balla's writing, which Pennsylvania AFSCME had circulated to many of its members, including the institutional members, and that was one of the early clues that there was a relationship here. I don't know that we ever established that they had paid for the research, or anything of the kind, because the research was likely done either with a Kennedy Foundation grant, or with an NIE or what have you grant, an HEW grant of some kind.

9-01:13:56

Pelka: But this professor being sympathetic to institutions may well have been on their radar, or they may have been on his radar, and somehow, that connection was made.

Gilhool: Exactly, exactly. So, those are my three thoughts about the roles played by the Pennhurst Parent and Staff Organization.

9-01:14:19

Pelka: With ramifications far beyond Pennhurst, certainly, even disability rights law, in general. Going to the heart of civil rights law across the board. Is that generally acknowledged, do you think, or is this something that you and Laski and a few others are kind of privy to?

Gilhool: Which part of it? That of relationships and etcetera?

9-01:14:49

Pelka: The role of *Pennhurst*, let's say.

Gilhool: Oh, yes. On the legal side, on the constitutional legal side, the jurisprudential side, standard law school casebooks would say that, that it was *Pennhurst* that triggered all of these questions, and then, further, as you read the opinions in

those cases, the Violence Against Women Act or what have you, their use of *Pennhurst* is very clear. Yes, that's clear. The underlies that we've spoken about, the institutional small 'I', relationships and so on, that's less widely known, I guess, except that the wonderful guy who is the current president of SEIU, State Employees... isn't that terrible?

9-01:15:53

Pelka: I want to say 'international', but it really doesn't sound... international union.

Gilhool: International Union. Absolutely. The largest fastest growing union in the United States now. It declared a couple years ago, by god it was going to organize community services workers, that produced in Alleghany County, the first disability right 'to know' ordinance, requiring providers to make available what they pay people, what their turnover is, how many people they moved from work jobs to real jobs, etcetera. That union, its president, who has most of its leadership, an old Pennsylvania social worker, in his case, working out of Harrisburg, whose name I'm now blocking on. When Max and I told him the story about McEntee and that offer, first he was shocked, and then he just laughed and laughed and laughed at how, in his judgment, and in retrospect, how foolish that was, on McEntee's part. Now, that, of course, is against the backdrop of SEIU and AFSC[ME] and being significant competitors, in many ways, the same work force.

9-01:17:22

Pelka: It sounds like we've pretty much covered with *Pennhurst 1*.

Gilhool: Right. It would be sensible to go to *Pennhurst 2* [two].

9-01:17:31

Pelka: Do you want to do that now? How are you doing on time?

Gilhool: Our good friend, Yasu, whom you will remember from our New York conversation, is coming to the United States for five to eight days, this afternoon at 4:30, so at some point, I have to rent a little car.

9-01:17:49

Pelka: Okay, then let me ask you one quick, dumb question, and then we'll close up and schedule for another time, if that's okay. A while back, you were talking about the connections at the Yale seminar on mental health law. And you mentioned a Pat Wright. This isn't Patrisha Wright that we know.

Gilhool: Certainly it is. She was not in that class. She had, however, been the first person in Legal Services in Washington D.C., as a young lawyer. I would want to check it before writing it, but she was, I believe, a clerk for Judge Bazelon, and then, of course, was active in the second rights education case, and etcetera. She's done a great deal in the disabilities world, and has a piece in *Mentally Retarded Citizens and the Law*, etcetera. That is herself, one of the most wonderful people found anywhere.

9-01:19:03

Pelka: Yeah, she's amazing. She's just amazing.

Gilhool: She used to be called 'Mother Superior' in Sargent Shriver's campaign for Vice President in '82, you know. She was the 'Mother Superior'.

9-01:19:16

Pelka: In '72, you mean.

Gilhool: Right, '72.

9-01:19:26

Pelka: Okay, I'm going to turn the tape recorder off now, so we're done for today.

Interview #6: January 4, 2008

Begin Audiofile 10

10-00:00:01

Pelka: Okay, this is an oral history with Thomas K. Gilhool. This is interview 6, this is tape ten, side A, January 4, 2008. Just to restate it, you understand you're being tape recorded, and I have your permission to do that.

Gilhool: Yes.

10-00:00:21

Pelka: Okay, as I recall, we left off last time, talking about the *Pennhurst* case. Broderick had ruled, it had gone to the appellate court, the appellate court had upheld it, on the basis of the DD Bill of Rights Act that had gone to the Supreme Court. The Supreme Court had basically overturned it on that basis, and returned the case to the appellate court, and I believe, that's where we left off.

Gilhool: Got it, and then, the Court of Appeals rested its affirmants from Broderick on Pennsylvania State Law. And in doing so, they took seriously, maybe overtook seriously, maybe it was an invitation that was in fact, at least intended by some, to be a trap, the court in saying the DD Bill of Acts right was merely precatory, and not intended by Congress to confer rights or to be enforced, said, and decides the court below ought to look at the state law. And that hint was initially, at least read, as another merely routine repetition of what had become a well established standard in constitutional law, namely, that courts should avoid making decisions on constitutional bases whenever they can, and should prefer to make decisions based on federal statutes, or upon state statutes. And indeed, the choice of state statutory grounds was seen as not only avoiding unnecessary constitutional decisions, but avoiding unnecessary federal statutory decisions. And that acting standard was a very important part of what [US Supreme Court Justice Felix] Frankfurter or Alex Bickel would have called the passive virtues, that is to say, an important part of judicial restraint, so when the case went back to the Court of Appeals, they rested their decision on the Pennsylvania Mental Health Mental Retardation Act.

As I recollect Pennsylvania was the first state to pass a community mental health, mental retardation act, following the Kennedy presidential address to Congress in February of 1962 or 3, I'm sorry, I don't have the briefs in front of me. Kennedy had called upon Congress to act, to reinforce families in their ability to care for children with disabilities, and to reinforce communities in their ability to retain and advance people with disabilities in communities and to avoid and overcome, reverse institutionalization, which had been, of course, so widely practiced into the turn of the twentieth century, driven by a

stereotype, an invidious stereotype initially, and then driven by federal funding.

10-00:05:07

Pelka:

I was just struck by your saying this ‘may have been’ or ‘might have been’ a trap. And I’m thinking, of course, the 11th Amendment, the Supreme Court, then, injected 11th Amendment issues into the subsequent appeal, is that what you’re referring to?

Gilhool:

Yes, that’s exactly what I’m referring to. The opinion of ’81 on the DD Act, when first read, just seemed to be a plain, and seriously intended, instruction, suggestion or instruction, by the Supreme Court: Look, decide this case on state law grounds. Look and see if you can decide it on state law grounds, treating such a decision as a legitimate one. And it wasn’t that the Supreme Court later reversed because the Court of Appeals got state law wrong, rather, the Supreme Court reversed the state law grounding by the Court of Appeals for the reason that the use of state law to avoid, by federal courts at all, was they newly declared, itself, unconstitutional. The federal courts had no jurisdiction because of the 11th amendment the Supreme Court held, to base its rest injunctions against a behavior in state law itself.

10-00:06:56

Pelka:

Now, did you have an inkling that this was coming, or was this completely out of the blue for you all?

Gilhool:

Did we expect to win in the Supreme Court? We certainly did. Did the United States expect to win in the Supreme Court? And, they, of course, since trial, we had been litigating this case in tandem, shoulder to shoulder. They certainly did. Was there a visible effort, movement among legal academics, and some practitioners, to get the Supreme Court and the federal courts out of the business of resting decision upon state law? You know, I don’t think there really was.

You ask a fine question and I cannot recollect with any satisfaction, the subjectivities on that question at the time. Certainly, I think I’m right about this: there were three arguments, in the Supreme Court, oral arguments. The first round on the DD Act was argued once, and the state law grounds was argued twice, and when a court asks for re-argument, that is a signal that there is some stuff that is relatively new or original that they’re deeply concerned about. And certainly by that time, it was beginning to look like there might be something going on. It’s a bit of a wry retrospective, for me to say that what we all read in the first *Pennhurst* opinion, as a routine and standard, and entirely legitimate invitation to the Lower Court, to base their decision on state law, may, in fact, have been a set-up to advancing the Rehnquist jurisprudence, the jurisprudence of the Rehnquist court in this regard. I really would like to look at the index to the legal periodicals of the time, to see,

because I'm a bit dismayed and disappointed with myself that I don't have a more present memory of how we saw that stuff.

I do remember that there was no question in *Pennhurst 2* about whether state law required community services, indeed, the language of the statute was, whatever services are needed shall be provided, that's a bit of a shorthand, but it was as explicit as that. The Kennedy message, of course, was strongly communitarian, and against the institutions, and it gave rise to, in '67, is my recollection, to a funding statute for the states, for community based mental health and mental retardation [services], they were conjoined at that time, which encouraged the state to enact statutes, in accordance with the principles set out in Kennedy's address to the Congress, and it was indeed, in 1967, that Pennsylvania had enacted that statute. And most states have. I was curious, almost every state regards its statute as the first. California, even though theirs was amongst the last, continues to regard the Lanterman [Developmental Disabilities Services] Act, which, it was initially a very straightforward four page, five page, simple, clear statute, now grown to a couple of volumes, and just impossibly complex, California continues to think that their statute is unique in the country, when in fact, all of the statutes for the states were cut from the same cloth. In any event, where do you want me to go from there?

10-00:13:01

Pelka:

You personally argued these cases before the court, is that right? Now [US Supreme Court Justice Antonin] Scalia had by this point, joined the court, is that right? Because we're talking about the Rehnquist Court, now? [Chief Justice Warren] Burger is gone, okay?

Gilhool:

Wait a minute, no, forgive me, it wasn't the Rehnquist Court, but the *Pennhurst* case is regarded as kind of a signal of the agenda of what became the Rehnquist Court. Burger was still presiding, [US Supreme Court Justice Harry] Blackmun was of course on the Court. I realize that I should have these opinions in front of me, as well as the briefs. I'd give you a more faithful analysis.

10-00:13:52

Pelka:

I'm just wondering, if in your recollection, you recall a point when you're being questioned before the justices, if there was a moment when you thought, "Hmm... where's this question coming from? Something is going on here that's beyond the specific details of this particular argument."

Gilhool:

I'd like to look at the arguments and see. That's worth doing. I don't have any present recollection on that. That's a very good question.

10-00:14:41

Pelka:

Were you able to provide any input to the appellate court during this process? I'm a little unclear on this. Were you able to go to them and say, would you please just decide it on the grounds that we argued it and not attempt- that's

putting it rather crudely- but we gave you all kinds of reasons to rule in our favor.

Gilhool: In fact, when it came back, with that suggestion of the court, my recollection of the Supreme Court, my recollection is that we *encouraged* the Court of Appeals to decide it on state law grounds, as simplest, most straightforward, most likely to be affirmed by the Supreme Court, raising the least fuss.

10-00:15:39

Pelka: Since this was, after all, the Supreme Court's suggestion.

Gilhool: Yes, that was the suggestion, and it was the most restrained way to do it. The series of constitutional grounds that were in the case would predictably have been hard fought. The statutory ground, which from the beginning, we had urged as the most compelling was, of course, section 504. It would be fun to look at our briefs to the Court of Appeals and answer the procedural part of your question. When it came back, we all briefed it again, in the Court of Appeals, they didn't really sit down and redecide it, it was briefed, and then again, argued. And again, it was the Court of Appeals en banque, Courts of Appeals usually take appeals in panels of three judges. On the first round of appeals, I can't remember whether there was first a three judge court which heard argument and then asked for en banque. I think, in fact, it was en banque from the beginning. Fairly unusual then, as now, but a sense of the...

10-00:17:25

Pelka: I have a copy of the *Federal Reporter* here. Court of Appeals, Third Circuit argued January 9th, '79, which would be the first, yes?

Gilhool: Yes.

10-00:17:39

Pelka: Reargued en banque September 6th, 1979.

Gilhool: October 6th, '79?

10-00:17:46

Pelka: September 6th.

Gilhool: So it was argued first in front of three, and then en banque. And that had to have been on the court's motion. Is there any indication there of who the initial three judges were?

10-00:18:09

Pelka: [Judge James] Seitz, chief judge, dissented in front of an opinion in which [Judge Ruggero John] Aldisert and James Hunter III, circuit judges, joined.

Gilhool: That's on the January 9th, 1979 thing?

10-00:18:28

Pelka: Yeah, let me look. Yeah, January 9th.

Gilhool:

Okay, so they must have set it down for three judge consideration, Aldisert, Hunter and Seitz. Seitz had been the great man in *Brown v. Board of Education*. He had then been a federal district court judge in Delaware, and of the cases consolidated in *Brown v. Board of Education*, one from South Carolina, one from Kansas, one from Delaware, one from another state, his decision was the only decision which had struck down school segregation. And he had later risen to the Third Circuit and then was chief judge. Aldisert was...

10-00:19:28

Pelka: Let me stop you right there. There's probably no way you can know this or could have known it then, probably, but I was just wondering if the fact he had such a prominent role in what was such a powerful decision that was so controversial. What am I trying to ask? Whether people like Rehnquist, Scalia, were looking at that and saying, and again, this is a crude way to kind of put it, but kind of in your face, you...

Gilhool:

Maybe, but I doubt it. Judicial thinking, even when, in fact, the action is very purposive, tends not to be fought through in such ad hominem terms. On the other hand, if you turn your question around, and the question becomes whether Chief Judge Seitz, because of the previous experience, and hence his, of which was personally and professionally, every indication is very proud, but if the question is 'might he have been sensitive to giving a decision the weight, that in en banque court, all of the judges sitting would give to a judicial decision', I think the answer is yes, and that may have moved him in that direction.

Aldisert, it's a complicated thing. He was an FDR—Truman in voice[?], but I think he was actually an FDR appointee. In any event, he was a Truman appointee, but he was in FDR, he was a New Dealer in his youth. I had drawn him on several three-judge courts involving public welfare matters, in which fact, he, it would have been '71 or thereabouts, wrote the opinions, favorable to my clients, striking down a couple of statutes in Pennsylvania inhibiting the extension of public assistance. But by now, a decade later, he had become—you wouldn't recognize him as a New Dealer, in either the substance, or in the nature of his judicial analysis. As that may suggest, he had been on the court when three-judge court decisions, not three judges on panel, but three judges made up of Court of Appeals judges and the district court judge, judge or judges, judge before him, in that case, originated were common. That is to say, the federal statute provided that whenever any state statute was being contested on US Constitutional grounds, it had to be a three-judge court, not a simple single district judge, because you shouldn't strike down a state statute except with that kind of extra weight. In any event, that suggests that Aldisert

may have been sensitive also to the usefulness of having the whole thing. Hunter was a relatively new appointee.

But there was another dimension of Aldisert. Aldisert was the uncle of a significantly retarded youngster, perhaps a young adult by now, child of his brother, a doctor in Pittsburgh. In some ways this is then the phenomenon that I mentioned to you before, that we had always been concerned to know if we could, to find out if we could, whether any of the judges before whom we were offering these matters, had the experience of disability in their families, so that we could try to figure out how that affected them. It turned out, it was the case that the president of the ARC of Allegheny County was Helen Aldisert, Judge Aldisert's sister-in-law. And Aldisert dissented from, perhaps several, perhaps all of the decisions of the affirmative in the Court of Appeals, that is to say, they were not unanimous, and Aldisert, each time, wrote opinions against Broderick's decision, and the ARC, of course, was a member of the Pennsylvania ARC, our client, our organizational client, in the case, and a very active chapter of the Pennsylvania ARC.

10-00:25:34

Pelka:

Was there an attempt, at any point, to ask him, I mean, I don't know, again, the legality of this, to recuse himself, because having that...

Gilhool:

No, we never considered doing that, but we were aware that he was problematic, and we became doubly aware that he was problematic when he dissented [laughs], because Helen made it clear that he was, you know, much of a cut[?] with the common stereotype driven family response to disability. He really felt sorry for his brother, that he had this terrible burden of having a kid with retardation and etcetera. Those were conversations that probably took place subsequent to Aldisert showing his hand.

10-00:26:35

Pelka:

It's very interesting to trace these kinds of personal connections, interconnections, whether we're talking judicial matters or policy.

Gilhool:

And Burger, of course, had- the chief justice in the first round, anyway- had personal connections as well. They never came sharply into focus for me, but were probably, historically, and now as a matter of history, sharply in focus. It was widely thought, and we thought we understood, that he had a daughter who had a mental disability, not retardation, and that the daughter was a frequent figure in his office, stopping by and the rest, and it was always of enormous interest how that played here and it seemed, from the record, to play very well in cases like the Romeo decision, which we spoke of last time, where Burger wrote an opinion, it's my recollection, and in a couple of very important cases, where Burger did write the decisions that said families are *not* to have the absolute say in whether their child goes to an institution or not, and there are objective standards that the state has an interest, and families have conflicts of interest and therefore, that there must be objective

procedures, as well as an objective standard, before anybody can be sent to an institution, and hence, deprived of liberty. If you read those opinions against his potential parental role, they become doubly interesting, because it's certainly not the institutionalized parent veto that VOR and such people have occasionally urged and courts have pretty much, following Burger's opinions, rejected. Then the other piece of that is, I do not recollect it ever being said that Burger's youngster, who was an adult during all of this period, had ever been in an institution, but rather, she had been, very much a part of the family and in the community.

10-00:29:41

Pelka: Now, has anyone that you know of explored this particular aspect?

Gilhool: No, I don't know of that. And I cannot profess to have read what must now be a considerable number of biographies of Burger and an even greater number of analyses of the Burger, Blackman, etc. Court, many of which have addressed such personal matters, but I don't remember seeing, I haven't read all of them, and I don't remember, in those that I was familiar with, ever seeing these matters addressed, but it sure would be fun to find out, wouldn't it?

10-00:30:30

Pelka: Yeah, yeah. Moving it along a little bit, so, it goes to the appellate court, the appellate court sends it, or the Supreme Court takes it, they send it back to the appellate, the appellate reaffirms their decision, but on the state grounds, that goes back to the Supreme Court, the Supreme Court strikes that down on the basis of the eleventh amendment, give or take, it goes back to the appellate court, yes? What happens then?

Gilhool: We wrote a letter to the court on behalf of our client, suggesting that the court appoint one of its members who had not participated in the case to that point, and that was, in a sense, a highly particular suggestion though we did not mention him by name. One judge, Arlen Adams, had disqualified himself from the case. I don't remember whether he said or whether it later became clear, he had disqualified himself because he had a kind of relationship of informal advisor to Frank Rizzo, who was mayor of Philadelphia during this time, and Philadelphia, along with the four suburban counties, was one of the defendants, along with the Commonwealth of Pennsylvania. And therefore, the suggestion that they appoint someone who had not participated was, in effect, a particular suggestion, that they appoint Arlen Adams, to meet with the parties, and see if the case could be composed. And they took the suggestion, but did not appoint Arlen Adams to do it. We were interested in Arlen Adams doing it, because my client, and I, from other work, knew him as Secretary of Public Welfare of the Commonwealth of Pennsylvania, in the Scranton administration, and quite attentive and informed on these matters, generally, and he, of course, had been the third member the Court of Appeals sitting member on the three-judge federal district court that handled the *PARC*

case. So we had a high regard and expectation that he would try to superintend discussion in a proper direction.

But in any event, the court, instead, appointed Max Rosenn. Max R-O-S-E-N-N, who had succeeded Arlen Adams as Secretary of Public Welfare of the Commonwealth of Pennsylvania by appointment of Bill Scranton, governor, and then, Ray [Raymond P.] Shafer, Scranton's lieutenant governor and successor. It's possible that Max Rosenn was appointed entirely by Shafer. In any event, Rosenn's chambers were in Wilkes-Barre, and we all traveled up to Wilkes-Barre and met with him, three, four, five times. And he brought the parties to a settlement and, I remember his picking up the phone a couple of times to call the governor's office. The governor at that time was Dick Thornburgh. And indeed after, let's see, when did Dick Thornburgh become governor? '78- he becomes governor after trial, and before the orders. Well, I'm not sure now, I'm sorry, I think he was elected in '78, so he didn't become governor until '79. So he became governor. We had made an effort with the Thornburgh administration to settle, way back at the beginning of the Thornburgh administration, while the appeals were pending or just after the first decision in our favor, by the Court of Appeals. I can picture the meetings around the table in our office. Jennifer Howse was the Deputy Secretary of Public Welfare for Retardation. She had been first master in Willowbrook implementation, and those had fallen apart in part on the Commonwealth's refusal to pay attorneys' fees to the law center that were in the least bit, respectable, which was important to the law center and important to our client to sustain future work in disability and so on.

10-00:36:25

Pelka:

The law center being PILCOP?

Gilhooll:

Yeah, right, right. But this time around, the conversations succeeded, and again, the sticky point was attorneys' fees and Judge Rosenn's couple of calls into the administration solved that. I took several months of conversation for us to resolve that. That was the end of the appeals on the underlying merit and the agreement was then, Pennhurst would be closed. Everybody there would move to the community. All the money that we had spent on Pennhurst would be spent in the community, and would maintain Judge Broderick's roughly one-for-one: for every person who left Pennhurst, somebody would go from the waiting list or home who needed services to confee (?) services and so on.

10-00:37:36

Pelka:

What did I ask you, this may be jumping ahead a little bit, but contemporaneous to this, or almost contemporaneous, you also had, not you, personally, but there were deinstitutionalization cases that were focused, not on people labeled mentally retarded, but people who had been diagnosed with some sort of mental illness, various cases. Was there any coordination between those two aspects of the deinstitutionalization movement?

Gilhool:

What cases do you have in mind? Let me say, as a general matter, we never did mental health cases, and that was for two reasons. One, my sense and our clients' and so on, was that they were two different states of the art, if you will. And we simply didn't have the expertise on the mental health side, hadn't collected it and so on. And then second, in part because the Kennedy initiatives had had other things, including the birth of the institutions in common stereotype, and in very much a similar stereotype in mental health and in feeble-mindedness or retardation, had been conjoined at the hip. And shortly after the Kennedy initiative and the Kennedy legislation all around the country, states enacted and localities through states began to draw federal money for community based services. In fact, they were called base service units in most places and they were typically both. And in the mid, still by the mid '70s, and certainly in the late '60s, the facts on the ground in most states, certainly in Pennsylvania, the same would have been true in New York, and most other states that I'm familiar with, and by reports, states that I wasn't familiar with, most of that money flowed to mental health. That is to say on the one hand, mental health associations were much stronger and more influential, and whatever other considerations did it, let me see, let me see... anyway, where I was going with that, Fred, is there was always, it seemed to me a way that may not survive analysis that there really would be a conflict for a lawyer who was representing both retardation organizations and mental health organizations, because in a sense, they were positioned to fight over the same dollars. Of course, such conflicts can be easily overcome, not easily, but can be set aside if both organizations knowingly, if they agree we'll seek to maximize money or something like that, but in any event, we had personally stayed out of those. The coordination among retardation cases was very much real, I'm trying to—*Wyatt [v. Stickney]* had a mental health dimension, didn't it, and indeed, may have started at a mental health institution?

10-00:41:49

Pelka:

Yes, I believe that's true, and the reason I ask is because you know, there's often the observation made that deinstitutionalization was more or less two-pronged, two aspects to it, and I think there's a prevailing opinion that the mental health side was less successful than the mental retardation side, less successful meaning that the outcomes weren't as good, people have called it not deinstitutionalization but trans-institutionalization, issues of homelessness, and it seems, from my very superficial look at this, that the mental health decisions seem less meticulously constructed.

Gilhool:

I think that's observably so. My sense of the underlie is that there is much less mental health litigation than there was retardation litigation, and that relates, in some ways, to your first two points, which are, I think, the driving ones. Nursing homes had just been funded under Title XIX, just as retardation institutions were funded under Title XIX, right? And that started in '65. Mental health institutions were *not* funded, by the feds, directly under Title XIX, except if the person was under 21 or under 18, I think it was 21 at the time, and over 65, and the states had to bear all of the dollars for in between.

But however you do it, there was an enormous financial incentive for the states to get out of mental health institutions where they bore the great percentage of the cost and into nursing homes and the figures are legendary about the proportions of people who came out of mental health institutions and went directly to nursing homes, and indeed, that accounted for the rapid growth of nursing homes, as much as their need altogether. So that is the case, that did not happen, or at least, did not happen observably with retardation institutions until recent decades. Judy has been focused in Illinois, for example, and Steve Gold in other states on the numbers of people with retardation in nursing homes, joining those who long ago left mental health institutions to go to nursing homes, and then, the increased number of folks with physical disabilities in nursing homes.

So that was one dimension, and the other dimension that you spoke of was the homeless business, and that is the difference in homelessness among former mental health institution residents and former retardation institution residents, is very large, and has been measured, and I have been of the view, that it is the function, chiefly, of the judicial implementation of decisions on community services rather than institutions. The courts were not present much in the formulation of community services on the mental health side, but as in Pennhurst, and then, Rhode Island, and Connecticut— see, that’s interesting, the main case may have been, at least initially, in mental health care, New Hampshire was retardation, and then Michigan, and then, etcetera. The pattern which Broderick, in *Pennhurst*, and a second judge in Willowbrook, had set up, of very careful implementation, and court-appointed professionals responsive to the parties, all the parties, and to the court, to assure that nobody was lost, to assure that quality of services, and so on, was a mode of public administrate of the creation of essentially, a new set of social institutions that was pretty unique and was pretty effective, pretty effective. I’m sure I told you the tale, or you’ve heard me tell it, of a guy who was Philadelphia administrator of mental health and mental retardation, Dick Searls, Richard Searls, he was Steve Eidleman’s boss, when Steve was the mental retardation guy. I used to call Richard every fortnight or so because he had asked the police to collect on a regular basis, and send to him, and to the mayor’s office, the information on people who were homeless, and he carefully tracked how many people, you know, to find out whether anybody had been in Pennhurst, etcetera, and in contrast with Byberry and with the other mental health institutions.

10-00:48:26

Pelka:

I’m sorry, Byberry?

Gilhool:

Yeah, Byberry was the famous Philadelphia, Pennsylvania, although there were many others in Pennsylvania as well, mental health places that were quote deinstitutionalized. But in contrast, nobody from Pennhurst ever showed up among the homeless. And the judicial administration really did it. Now, that’s not to say, that there weren’t battles about this judicial administration.

From the beginning, there were battles between the plaintiffs and the state bureaucracy, but there was... [end side 10 A]

Gilhool: [begin side 10 B] in my mind with the timing of things, but there did come to be a time, let's see if I can get this right, when the Secretary of Public Welfare in the Thornburgh administration, Helen O'Bannon, wanted out from under and rather than applying to the court for it, she began to do or decline to do things that were required by the orders, and we moved for finding of contempt and sanctions and after extensive hearings and a couple of appeals, I can't recollect, she was found in contempt and was fined for as long as it should continue, a certain amount per day, which went into the court's coffers, and which the court directed would be spent to maintain the master's office. And that, in fact, is what kept, in fact, that may have been her contempt, was not paying the expenses of the master's office, despite the court's order to do so, and that was hardly the substance of the master's offices were, but was crucial, of course, to sustaining it.

Just one other piece, there was a treasurer, the Treasurer of Pennsylvania then, was elected, and it was a gentleman who had been in the legislature for a long time named [R.] "Budd" Dwyer who, on inquiry by PARC, as to where the secretary was getting the money to pay the fine, reported that she was taking out of program funds for retardation and PARC and we asked Budd Dwyer whether that was appropriate, and he ruled that it was not appropriate, and that it should be taken out of administration funds of the secretary. [laughs]. And that was kind of fun.

10-00:52:09

Pelka: It's just remarkable, looking back on some of the, just the detail of some of these orders, the appointment of masters, the day-to-day really, week-by-week oversight that the court had through the masters in this deinstitutionalization process, and I'm trying to think if, I guess if we're talking about, for instance, court-ordered bussing desegregation in the '70s, that might be analogous, but beyond that, there doesn't seem to be, I'm trying to think of other aspects of the law where the courts took that hands-on an approach for such an extended period of time.

Gilhool: On the private side, there were antitrust agreements that involved the reorganization of corporations or suchlike, where that kind of oversight, similar oversight occurred, and occasionally, maybe some shareholder derivative actions, though they would, shareholder actions of various kinds involving corporate, but in those days, they were mostly state court matters. They became federalized in securities fraud and stuff like that later. And there were similarities there, but it was the civil rights decrees that, not only in schooling, but in the rest of the race civil rights litigation, employment and public accommodations and so on, that provided the closest analogy, and yes, it was fairly unique and Owen Fiss [Frist] wrote a wonderful, long article once, entitled "Against Settlement", which appeared in the *Yale Law Journal*,

in which he made the case that the judicial system contributes significantly to rational purpose-tested action, by hearing all sides and composing a record and not prematurely coming to judgment until you've tested the facts and are pretty clear about them. And if you go back to, it's really funny, if you go back to [Max] Weber and his theories of bureaucracy, the whole point of the bureaucracies, of course, which in his lingo, and in mine, tends to be a complementary word, was to be sure that the purposes of laws were, in fact, implemented in a more complex, modern world and it was a part of the bureaucracy's job to have the knowledge that led to good decisions, you know, the construction, the design and construction of systems that would function and work and produce on purposes.

10-00:55:45

Pelka:

As national intelligence estimates, for instance.

Gilhool:

Yes, and while during the poverty days, in most major states, anyway, you used to think of state bureaucracies as having achieved those objectives, of sensible design that produced, that could and did, some nudging. Since then, of course, one thinks of bureaucracy in exactly the opposite way, and in that context, the function of the courts in introducing a systematic reflection and careful judgment, and taking account of all interests not to stop things, but to advance them, which is a considerable difference, is really quite unusual, quite remarkable, and very much worth attention, I think, if we ever get back to questions of how governments can be brought better to function, to serve the purposes declared by the law and the people when they sought the laws, if that makes any sense.

10-00:57:04

Pelka:

I wanted to ask a question about a comment that you made quite a while back, really toward the beginning of these conversations. You had expressed some disgruntlement with how the *Pennhurst* case has been seen historically, and I believe this came in the context of you talking about some sort of conference that you'd attended, and someone had been giving a lecture on...

Gilhool:

...eccentric people.

10-00:57:37

Pelka:

Maybe you could elaborate on that. What were you talking about when you said that?

Gilhool:

Let me see, let me see, let me see. That observation was triggered by a session in Washington, at American University, on the new UN treaty, and Aryeh Nieyer, N-I-E-Y-E-R, or something like that, who has, I think for some time, been the executive director of the Soros Foundation and who had been at the ACLU, delivered a luncheon address and celebrated Willowbrook as if it had been the source of the move from institutions to community services and along the way, the use of courts to make that happen, and yeah, I was quite exercised. I still haven't written to him, though I intend to. And I didn't in

part, because he did it in the context of celebrating the memory of Bruce Ennis, who died recently and who had been at the Mental Health Law Project and then at the ACLU, and so on. It was the ACLU that had originally brought Wyatt and Stickney [*Wyatt v. Stickney*], and I had two problems with it, I think. One, the ACLU's instinct had been the right to treatment and to improve the institutions, and indeed, that's where *Wyatt* was focused, and as you know, didn't really overcome that, until the last five or six, ten years, and that's what Willowbrook was also initially brought for, and when the Justice Department changed the plaintiff's agenda in Willowbrook, in the direction of providing community and taking the institutions down, the first judge in that case had ruled that there was no legal grounds available to do that. And then it was a subsequent settlement of *New York State ARC vs. Willowbrook* that had introduced the master and the community remedies in that case. And I guess what I'm defending or offending about is *Pennhurst*'s role in first effectively articulating a claim to community services and that's why I wanted to write to Aryeh and tell him I love Bruce too but that his history just wasn't right on.

10-01:01:31

Pelka: Now, Bruce had been one of the counsels in *Donaldson* [*O'Connor v. Donaldson*], right? And that was "right to treatment". Was that a "right to treatment" case?

Gilhool: Donaldson...

10-01:01:46

Pelka: *O'Connor v. Donaldson*, whatever it was.

Gilhool: Very important case, it was individual case, and it was a "right to treatment" case, and it was on the mental health side. I'm not sure I can go any further than that. It was a Burger opinion, and that had been Bruce's case when he was at the Mental Health Law Project.

10-01:02:18

Pelka: Interesting overlap there between the mental health side and the mental retardation side as we were talking about before. I wanted to kind of close up *Pennhurst* at this point, and our next big and final agenda item for these conversations will be the 504 trainings that PILCOP participated in, as I recall, is that right?

Gilhool: Yes, there were four grantees, originally. The country was divided into four areas.

10-01:02:52

Pelka: Were you involved personally?

Gilhool: Oh, yes.

10-01:02:55

Pelka:

Okay, so I want to talk to you about that, but that's a whole other topic, so this might be a good place to break. Do you have any final grand overarching thoughts that you'd like to record on *Pennhurst*? How do you, for instance, see the significance— you talked a little bit about this, vis-à-vis Willowbrook — looking back on *Pennhurst*, maybe you could kind of sum it up for people who will be looking at this oral history in the future.

Gilhool:

Well, the *Pennhurst* experience and the flag of *Pennhurst* really drove the creation of community services across the country. It tends to be celebrated, for better or worse. We're under 30,000 now, I think, people left in the institutions and we're getting a real purchase on getting people out of nursing homes as well, and the extraordinary growth in community services that was driven by *Pennhurst* and its progeny, about thirty or so cases, in other states, that thirty, thirty-five, Dave Braddock lists them all, regularly updating them in his annual report, *The State of the States in Disabilities*. Did you see this morning's *New York Times*? The story on the UK based, London, I think, Imperial College study of respitol and haldol?

10-01:04:54

Pelka:

No.

Gilhool:

Just fascinating, Fred. The study concludes that they are totally ineffective in dealing with aggressive behavior, all the stuff that they're used for, in nursing homes for elders, and in institutions and in community services for people with retardation and other intellectual disabilities and, you know, the whole run, anyway, it concludes that from a study of those things and placebos, that the placebos actually worked just as well, and in fact, better, in reducing the target behaviors, and they conclude that what really does it is the attention which placebo or pill, doesn't matter [which], brings to the person. Are you with me?

10-01:05:53

Pelka:

Yeah, yeah.

Gilhool:

And it's just a beautiful demonstration, and of course, it raises the question, how, in the presence of continuing stereotype, thus far is still inadequately reduced stereotype, do you evoke that attention? Maybe placebos are just the way to do it, you follow? In any event, this historic change which remains still problematic, one, because of turnover, and two, because of—it's hard to say—the bureaucratization of community services, harder and worse than I think anybody would have predicted, the struggles for power by providers, etcetera. So, in any event, it made a huge change which, much like the change in education, is worth something only if the movement has constant and continuing success on the constant battle to affect the day-by-day reality, which requires constant purposive attention if it's not going to turn into the same sort of dismissive relationship between people with disability and people who are not, that has characterized things historically. So, that's my initial

thought about summing it up. I'll let you know when we get together again if any other thoughts have occurred to me since.

10-01:08:04

Pelka:

Okay, great. I'll turn the tape off for now.

Interview #7: March 31, 2008

Begin Audiofile 11

11-00:00:01

Pelka: This is an interview with Mr. Thomas K. Gilhool. This is March 31, 2008. This is interview #7, tape #11, side A. How are you doing?

Gilhool: Okay, okay!

11-00:00:13

Pelka: Oh, good.

Gilhool: I talked with Dennis Haggerty on, gee, I think it was Friday evening.

11-00:00:19

Pelka: Oh, yeah.

Gilhool: And he told me that you guys had had a wonderful conversation.

11-00:00:23

Pelka: Yes? Yes, indeed.

Gilhool: He also told me- did he tell you?- that he had spirited away the archives of the National Center on Law and Disability- or Handicapped, it was probably was then- from the Notre Dame days of the '70s.

11-00:00:40

Pelka: Oh, no, he didn't tell me that. He told me that he had quite a lot of material relating to PARC—

Gilhool: It's maybe the first time he's admitted to anybody that he had done that. And he put that at Elwyn [a private institution in Pennsylvania]. Dennis, of all the wonderful people in so many scenarios, always had a bit of an ambivalent relationship to institutions, and he put the archives with Elwyn.

11-00:01:24

Pelka: Elwyn is now, it's a facility in Pennsylvania.

Gilhool: In Delaware County. And it was one of the original and signal and leading segregationist institutions in the turn into the twentieth century. Most of the institutions and institutional superintendents who led the movement were public. I've never looked carefully at Elwyn's history. It may have had a public dimension as well, that I just don't know- much like Vineland in New Jersey later private was at the time, also a leading institution in the place where what's-his-name, who imported Benet's IQ test to the United States. I forgot his name. He was one of the leaders of the Eugenics movement, I know, was public at that time, but later became private. Did Dennis tell you

the story about he and Eileen going into a nursing home sometime in the last couple years, and lasting about three weeks?

11-00:02:52

Pelka: No, no. We pretty much stuck to *PARC* and issues related to that. He did tell me the entire, or at least a more complete telling, of the John Stark Williams story than I'd ever heard before, which was quite, quite stunning. Gunnar had told me about it. He was at that final meeting and gave me his perspective on the final meeting, but Dennis was with that from the beginning of *PARC*'s involvement, all the way through.

Gilhool: Yes, he led the investigation. Carried it through, and did that presentation which Gunnar loved to remember, to the board, the committee, whatever. Yeah, and did he tell you the story about forcing Leopold Potkonsky [?] to resign? Isn't that a lovely story?

11-00:03:53

Pelka: Yeah, it was very interesting, sort of behind-the-scenes stuff.

Gilhool: Such a great touch. Did he tell you- it would have been a stretch for your conversation- about his defending a minister?

11-00:04:10

Pelka: As a matter of fact, he did. He did tell me that story. And I neglected to tell him that Elvis Presley recorded 'How Great Thou Art'.

Gilhool: Oh, oh, wonderful! I will keep my eye out. Does Amazon do records?

11-00:04:28

Pelka: Yeah, yeah, you could probably—

Gilhool: What a great present that would be for Dennis.

11-00:04:39

Pelka: Yeah, yeah. Well, anyway, getting back, I believe what we were about to do, according to my notes—

Gilhool: Let me tell you one other thing. Dennis told me, for the first time, and I'd never had a clue, in part because we were in California during the relevant period, that he'd spent a considerable amount of time at Coatesville, which I remember as a state mental health institution, but it was also a veteran's hospital. There was a veteran's hospital in that town. And then at the Friends facility up in northeastern Philadelphia, on the boulevard, from major depression, which it took him three or four years to get through.

11-00:05:30

Pelka: He told me about the depression. He didn't go into the details of where he was, or the kind of treatment. I thought that was remarkable. He told me he'd felt depressed because he felt he hadn't really achieved very much in his life,

and that was just stunning. And I told him, “Well, you know, you’ve got historians tracking you down”: that should indicate something, you know.

Gilhool: That’s very nice. Lovely way to put it.

11-00:06:03

Pelka: I was quite, quite taken aback. But of course, depression doesn’t necessarily actually relate to real events. I’m not putting that very well, but it doesn’t necessarily correspond to what it is you think you’re depressed about.

Gilhool: That’s for sure. Hence the relative success for many of cognitive therapy. Good, good.

11-00:06:31

Pelka: Well, we were going to discuss the 504 trainings that were, I believe, coordinated by PILCOP [Public Interest Law Center of Philadelphia] in the mid to late 1970’s, if I have this right? And your role in those, and that’s how I wanted to begin, if that’s okay.

Gilhool: Good. I have one chapter that I’d like briefly to address that occurs before that, and it was suggested because it relates, in a certain way, to the design of the 504 trainings. Round about- I just made a list last night, all I have to do is find it- round about 1973, ‘2 and ‘3, the President’s Committee on Mental Retardation determined that they were going to do a second edition of *Changing Patterns in Residential Services for the Mentally Retarded*. Is the first edition of that book, which was 1968, familiar to you?

11-00:08:14

Pelka: Uh, yes, but it’s been a very long time.

Gilhool: Right. That was edited by Wolf Wolfensberger at Syracuse, and contained a writing by Gunnar and many, many other writings. And it first put in focus moving out of institutions and into community services. And Wolf did his conceptual historical piece at some length- 70, 80 pages, as I remember- and I think, for the first time, formulated and published therein his theory of normalization. In the early ‘70s, I think it’s probably fair to say, sparked by *PARC* and the run of education cases and the new movement, they decided a second edition would be valuable. The two editors were Richard Koch, an MD, then at UCLA, running the West Los Angeles Regional Center for California. And do I have the phraseology right? There are about twenty, twenty-four regional centers in California, and it doesn’t mean “center” in the institutional sense. They were created when California enacted the Lanterman Act [Lanterman Developmental Disabilities Services Act of 1968], about five years after Kennedy’s mental health, mental retardation address to the Congress, which as I remember was February of ‘63, and the Lanterman Act, I’m pretty sure, was about ‘68. Californians, in their usual conceit, are quite sure that they passed the first of the states’ MH/MR acts, community focused, after the Kennedy message. But, in fact, they were quite late, and most other

states had done it by '68. Pennsylvania's which was perhaps the first, probably the first, was 1965, and they were indirectly responsive- directly responsive, really- to the Kennedy address, but tapped directly from the Congress' adoption of, what was it called, Fred? A national act which commissioned what in Pennsylvania became Base Service Units, and in California, became Regional- I may have that phrase wrong- Regional Centers. Essentially, loci for, from which to develop community services, which, of course, for the first decade, were most strongly into mental health, coinciding with the very large- deinstitutionalization that occurred then. Though the largest number of people in mental health institutions didn't go to community, but went to nursing homes, since medical assistance had just been invented, and they were prepared to fund the states to do nursing homes, and [inaudible] after the regional centers, and struggling funding streams there. It took a while to really develop community finance strategies.

11-00:12:37

Pelka: I'm looking at my chronology here. You're probably talking about the Mental Retardation Facilities and Community Health Centers Construction Act?

Gilhool: That's probably it!

11-00:12:50

Pelka: Of 1963?

Gilhool: Nice, exactly, promptly after Kennedy's address. In any event, Richard Koch was the very distinguished leader of the Los Angeles Regional Center, and subsequently went to New York. Indeed, he may have been in New York by the early '70s, when he was doing the work in putting this book together. Place on Fifth Avenue, that had been somewhat notorious and which he changed significantly. He and Ann Shearer, who was an Englishwoman, were the co-editors. And her presence as an editor was sort of in recognition of the fact that in the first edition- in 1968, there had been a section with, as I remember, four or five, Europeans writing, including Gunnar's good friend, Bengt Nirje, from whichever of the Scandinavian countries it was, reciting their experience. And by this time, that caused the President's Committee to be attentive to the international stuff, and hence, Ann showed up, as a co-editor. I hadn't reflected before on, I mean, those were the years when Gunnar was so active with the International League, now called Inclusion International. And anyway, it reminded me of the UN treaty so recently formulated and being ratified widely, but not here.

In any event, I wrote a piece for that volume, which I cannot now remember, was published either in '73, '74, or '75. The Ohio state conference, *The Mentally Retarded Citizen and the Law*, which was also a President's Committee, publication, though they published *Mentally Retarded Citizen and the Law* with Glenn Cove Free Press, the second edition, like the first edition, of *Changing Patterns in Residential Services for the Mentally Retarded* was a

Government Printing Office publication. In any event, and that was published, I know, in '75. And then I'm a little unclear whether they were written together, whether they were published in the same year, or sequentially. Anyway, I wrote a piece there called 'The Uses of Courts and of Lawyers'. It was an effort to, more or less, systematically, analyze the learning from the legal services programs and to some extent, civil rights litigation more broadly. I speak of it as the first generation of OEO's [Office of Economic Opportunity] legal services programs for the poor and several generations of civil rights lawyering. And to seek to bring into bear for the use of people with disabilities, their families, friends, and organizations. It spoke to themes that are very familiar to you from our conversations, and from everything that happened, and not really at my hand, in the disability law undertakings, namely the systematic and long-term representation of real clients, especially organizations, the uses of litigation, negotiation, legislation, public engagement, and so on. A part of that learning from the legal services experience was brought to bear on the 504 training. I had, indeed, the summer of the *PARC* trial here, in front of the three-judge court, I became the co-director of the legal services training program. Let me see... LSTP, we used to pretend. STP was then a major product with huge advertising, about making cars go better. You're too young to remember STP. We called it Legal STP. Anyway, it was a training program for legal services lawyers in general, but where we started was with new lawyers, hoping to reach them within preferably the second half of their first year of practice.

11-00:19:11

Pelka: Now, this was under the auspices of PILCOP?

Gilhool: No, it was funded at Catholic University Law School by the United States Office of Economic Opportunity Legal Services Program. I think Sargent Shriver was still very much in charge of the poverty program. Clint Bamberger had been its first director. Bamberger was a very distinguished lawyer, albeit young, a partner at Marberry and Madison- that's wrong, Marberry and Madison is the famous case. But anyway, Piper Marberry, the very same Marberry, a law firm in Baltimore, and had, was expected to be elected attorney general of Maryland, after his initiation at Shriver's hand of the legal services training program. But it was the year, in which a fellow named Mahoney, popularly derided as the ax-wielder, ran a significantly racist campaign off the boards. And Spiro Agnew, to the surprise of everyone, was elected governor of Maryland, and just subsequently became Nixon's vice president, of course.

11-00:21:00

Pelka: Bamberger- could you spell that for me?

Gilhool: B-A-M-B-E-R-G-E-R. Clinton. And he went to Catholic University as Dean of the Law School, and when we had some conversations about funding the legal services systematic training effort with new lawyers and old lawyers in

legal services, he became the residence of it. A fellow named Dick Carter and I were its co-directors.

11-00:21:37

Pelka: Carter or Harter?

Gilhool: Carter, C-A-R-T-E-R. Richard. He retired just recently as the director of continuing legal education for ALI-ABA, the American Law Institute dash American Bar Association, which is the common law codifying arm of the legal profession. Very distinguished, and before that, he had run continuing legal education and training for the American Bar Association. All subsequent to this undertaking, the legal services training program, Dick was then teaching at Catholic University, and I had just come off the *PARC* case. And we resolved to make the training as experiential as we could, that is to say 'clinical', as the docs would say, though not in people's own hospitals or law offices, or what have you, but rather, to do role-play, in a serious way.

11-00:22:57

Pelka: Okay, are you talking about the training for the new lawyers?

Gilhool: I'm talking about the legal services training program, because this is what set the model for what came in the 504 trainings. So, anyway, that said, the 504 training was, of course, in the immediate aftermath of demonstrations in Washington, to free the 504 regulation, which had been written and, which was, for reasons I now cannot remember, being held in captivity by that great guy who was Carter's Secretary of HEW [US Dept. of Health, Education, and Welfare]?

11-00:23:46

Pelka: Califano.

Gilhool: Califano. Joseph. And the demonstrations which occurred in his office and across Washington, and across the country were, as you have written, really the beginning of the modern Disability Rights Movement. People acted together in numbers and impact and effect, which were to that date, unprecedented. Shortly after the success of those demonstrations in securing the regulation, HEW put out a request for proposal for training, in the uses of 504. And I don't have much memory about how articulate, how much of a framework that request for proposals put on what became the training. I just have no memory on that front, and I meant to consult Frank to see if he's got any.

11-00:25:12

Pelka: Frank Laski?

Gilhool: Yeah, yeah. In any event, we bid for the Middle-Atlantic and New England states. DREDF [Disability Rights Education and Defense Fund] bid for the Western and Midwestern states, and an outfit, which I always turn to your

book to identify correctly, in North Carolina, led by a really wonderful guy whose name I'm now suppressing—

11-00:25:52

Pelka: It wouldn't be Ron Mace—

Gilhool: Yes, Ron, and another wonderful guy whose name I'm also losing, who subsequently fell in love with Sharon Mistler [Phil Calkins], and they married, and Sharon died some decade ago, now, almost. This wonderful fellow continues to live in Northern Virginia and sails the high seas. He's paraplegic.

11-00:26:36

Pelka: I know who you mean, and I'm blanking on the name, too. He was at the UN conference that you were involved with.

Gilhool: Exactly, exactly. I can picture the two of you, right, at that table- the three of you. Anyway, they did the Southeast. And we went state by state, gathered fifty or so individuals from diverse organizations in the disability world- in each state- for what then, and perhaps now, would have been regarded as a long time, an extended weekend. We opened on Thursday night and worked Friday, Saturday, and Sunday, until the late afternoon, which was, for many people, a shift from the usual one-day weekend, or one-and-a-half-day weekend kind of conference.

11-00:28:00

Pelka: Now, who all was involved specifically in pulling this together?

Gilhool: Well, the training here was Frank Laski, Ned Stutman, and in a way, I'll mention in a minute, his wife Suzanne. Jim Raggio, Sharon Mistler, I guess we had come to know Sharon in the course of the 504 demonstrations, and we hired her for several things, but most particularly, for work on the 504 training. She had physical disabilities. She was raised in Oklahoma. She had a sister with retardation, so she knew all of disability in a personal way. And we hired Debbie Yager, who had then very recently been one of two, maybe three, very stirring founders of Disabled in Action of Pennsylvania, who had become significant clients of the Law Center, and later, actually, made their offices here for several years, until the Independent Living Movement came to Philadelphia, and they set up an Independent Living Center and moved out. But anyway, Debbie was hired for the logistics of the training, as well as for other participation. Oh, and Nancy Zollers was very much involved in the training.

11-00:30:15

Pelka: Could you spell her last name?

Gilhool: Z-O-L-L-E-R-S. She and Frank met here at the Law Center in these early days and married.

11-00:30:40

Pelka: Now, just to back up a little bit. At this point, what, if anything, was happening in the way of 504 enforcement or 504 litigation?

Gilhool:

Nothing. It was fresh, it was brand new, it was a clean slate. This was literally months after the regulations were promulgated, right? And that was the very point. It was to gather and arm a constituency to make use of 504. The very first- I haven't thought about this in a long time- Court of Appeals case, using 504, was a case in which Frank and I wrote an amicus brief: it was in the 8th Circuit, it was argued in St. Louis. There are two transportation cases, one from the 7th circuit, which is Chicago, and one in the 8th Circuit, St. Louis up to Minnesota. This was a case from Minnesota. *Lloyd vs. Transportation Authority*, I think that's right. And a great judge of the 8th Circuit took the occasion to announce that 504 was a civil rights statute and in those days, that meant, in the jurisprudence of the day, in the not written, but yes, written in opinions, but the rules by which the federal courts fly. That meant that you had to plead those cases with great factual precision, much as you did fraud cases, for not dissimilar reasons so that a court could know from the get-go whether there was really stuff here or not. Second, that the act was to be construed generously, interpreted generously, in order to achieve its remedial purposes. That second has, of course, become highly problematic, in the federal courts in the last couple of decades.

11-00:33:34

Pelka: So, the trainings essentially were—

Gilhool:

I'll get a year for you on that. That was '72 or '3, I think.

11-00:33:46

Pelka: You're talking about *Lloyd* [*Lloyd vs. Regional Transportation Authority*]? I think that was '77.

Gilhool:

Oh, my God.

11-00:33:51

Pelka: Certainly if you're talking about enforcement of 504... I think it was '77.

Gilhool:

I think you're right, and who would know better?

11-00:34:00

Pelka: Well, I wouldn't say that. [laughter]

Gilhool:

I go to your book for the particulars on each of these whenever my memory fails, which it increasingly does.

11-00:34:10

Pelka: But essentially, Dennis Haggerty used a phrase that I thought was really kind of neat, in a sense, on talking about the National Center on Law and the Handicapped, but he said that 'we saw ourselves as running around the

country setting fires for other people to then stoke'. And that sounds essentially like what the 504 trainings were going to be. I mean, you were arming constituencies, as you say.

Gilhool: Yes, yes, yes. And really, I can do a footnote later on the National Center, but yes, that was exactly the point.

11-00:34:53

Pelka: Where was the first training done? Was that done in Philadelphia?

Gilhool: The first training was done in Wilkes-Barre, Pennsylvania. We started here at home. The second one was done in Boston at the airport, as you're driving out, at that hotel on the right. They typically were at hotels, and everybody was locked in for that space of three and three-quarters days. I've mentioned the great diversity, and there was significant diversity in disability, in age, race, ethnicity, the lot, because we reached to all of the traditional organizations and the new guys on the block then were the gatherings that had grown up at the time of the demonstrations.

11-00:36:18

Pelka: Okay, so like Disabled in Action. Was the ACCD [American Coalition of Citizens with Disabilities] up and running by that point?

Gilhool: ACCD was just sort of, well now, let's go back. ACCD, as I remember, came together during and for the 504 demonstrations, though it may have been during and just after the 504 demonstrations.

11-00:36:46

Pelka: You know, actually, as I think about it, I think it would have to be before, because Frank Bowe, who is the executive director at ACCD, put out a call for those demonstrations.

Gilhool: Right on, good, good. Frank was the first executive director and Eunice Fiorito, do you know Eunice?

11-00:37:06

Pelka: Yeah, I knew her, yeah.

Gilhool: Did she die?

11-00:37:10

Pelka: I believe so, yes.

Gilhool: Oh my word.

11-00:37:14

Pelka: You're talking about from New York, yes?

Gilhool: Yes, from New York. The Mayor's Committee on Disability, and then for a long time, in Washington, at HHS.

11-00:37:30

Pelka: Now the cross-disability—

Gilhool: Let me stay with ACCD for a while. They were very much involved, and indeed, you know, we put together a council for the design of the training, and it was led because of the age and because the organization had become the central organization to the developing movement. It included ACCD and ARC and Cerebral Palsy, and I think Down Syndrome was alive then, Paralyzed Veterans of America, the two blind organizations and the two Deaf organizations.

11-00:38:24

Pelka: What were the two Deaf organizations? NAD?

Gilhool: NAD and... am I wrong, were there two?

11-00:38:32

Pelka: I don't know, I don't know. I'm just trying to think of what the other one would have been, because I know ACB and the NFB would be the two blind organizations.

Gilhool: I think I'm probably wrong. Al Pimentel was the person from NAD on the committee, the board, so to speak.

11-00:38:57

Pelka: Was Fred Schreiber involved at all?

Gilhool: No, not directly. I think Frank, actually, may, no, I'm really sorry, I had the boxes pulled out on this a couple of months ago, and I went looking for them this morning, and they've gone back. When I find them, I'll send you the list of the committee and the personnel and a couple of the illustrative things. In any event, the grant was for four years, as I remember, and [at] about the two and half year [mark], we transitioned possession, management of the training to ACCD. And Frank and colleagues.

11-00:39:55

Pelka: Going back to the first trainings, do you recall any particular surprises? Did material, did stuff come up that you hadn't anticipated?

Gilhool: No.

11-00:40:11

Pelka: Were there any particular problems—

Gilhool: And chiefly because, you know, integral to this whole process were people steeped in this, from across the disability organizations of the time. And we

spent a good number of very intense months developing it. What I remember most about it is that that's where Jim Raggio and, I should be able to call her maiden name, but I can't, now Cathy Raggio, Secretary of Disability for the state of Maryland in the administration that's about a year old, who just announced a few weeks ago, that Rosewood was going to be closed, at last, finally. She and the governor did. Anyway, that's where they met. She was running United Cerebral Palsy of Luzerne County, and they fell in love and married and their two boys are now fully grown. That's what distinguishes, the first training in my mind. [Laughter]

11-00:41:35

Pelka: Were there any particular problems that came up? I guess what I'm trying to get at, is whether either logistically or conceptually, there were difficulties in getting this across?

Gilhool: Oh, the logistics were a nightmare. You know, this was before most hotels knew what accessibility was, and you just can't imagine the genius of Debbie Yager and her persistence and insistence in cutting through all of that. And it was not easy, but I don't remember- I wonder if Debbie would, or Frank, or Jim- I don't remember any places where it had gone awry.

11-00:42:37

Pelka: How many people would participate?

Gilhool: There would be fifty, plus or minus, people from the disability world, and there would be the committee, the board, the advisory committee, the board of ten, and the six, seven of us, so... sixty-seven, seventy people, and partly that was to make, for all the obvious reasons, but also, to make the role-playing exercises real. The role-play essentially- the group of fifty was divided into four or five, and got a scenario, and then had to plan the negotiation, including their purposes and how they were going to get there, and then, conducted the negotiation, played it out. We, at various places, we rented actors or college students or graduate students, in places where there were acting schools available, we used them to play officials on the other side, and so on. And each role-play was attended by an interlocutor, a coach, if you will, who observed all the way through and then engaged conversation among all of the players in evaluation of what had happened.

It sounds simple as the dickens, but it was an extraordinarily powerful model which had been developed in the legal services training program and had become quite common in the clinical legal education world. Clinical legal education was then taking the law schools by storm, and most everybody had practice programs with a strong curriculum accompanying them. And the role-plays that I remember were with school-boards, school-board presidents and superintendents, with town councils, mayors, etc. around curb-cuts, with governors or state secretaries, around education, around, what do we call it? In Pennsylvania, we call it labor and industry, bureau of vocational

rehabilitation, and so on. I think, probably we had developed, and these kept getting refined, because some worked and some didn't. We developed six or seven scenarios that we used, and at various times, we also role-played meetings with editorial boards of newspapers. In the legal services program, we very quickly discovered that almost all new lawyers thought, and after a few hours, said at the training gatherings, that their clients nearly always lied to them, which, by the way, is learning that theatre lawyers in Los Angeles and corporate lawyers in New York and so on also recite, from time to time. But we spent a lot of time in the legal services training program on that problem- to cause them to understand that what they saw as a lie— [end of side A]

11-00:47:30

Pelka:

You were trying to get the people in the programs—

Gilhool:

In the legal services programs, new lawyers, my clients nearly always lie... that that was a marker that the client saw the world, saw the institutions that were interacting and whatever had happened, where the problem was defined, and saw problems differently from what new differently classed lawyers did, and so it was a trigger, it had to be treated as a spur by the lawyer to really get into the client's head and figure out what the client was seeing that was so different from what the lawyer expected or believed in a routine way would probably have been the case. And that was crucial, and what we discovered, that the analog to that in the 504 training, we weren't dealing with an advocate—client situation. The analog was shyness, or put in another way, uncertain self-confidence. Assertiveness, or purposefulness. And they're two different things, aren't they? And so, I'm not sure, I think, actually, we did this for the first time in Boston, so it would have been the second. Suzanne Stutman, who is married to Ned Stutman, who practiced here at the law center with all of the people named above, who had been district attorney in Bucks County and had had a single practice there and had done a great deal of work in a very short period of time as a young lawyer for the Bucks County ARC. He left the Law Center in the mid '70s to go to the Civil Rights Division of the Justice Department, and very soon, became involved in the Holocaust Unit of the Department of Justice, which pursued those people from that time who had been hiding themselves around the world and so on.

11-00:50:31

Pelka:

And assets, I would imagine, expropriated property, whatever. You're talking, in a sense, about internalized oppression would be one way you could put it.

Gilhool:

Very nice, very nice. And Suzanne is a psychologist, and she developed, with lots of conversation, with the people I've mentioned earlier, a presentation and some interactive exercises going to that problem.

11-00:51:17

Pelka:

Now how would that be manifest? How did you observe people being uncertain?

Gilhool: In the role-play negotiations, in the first run, people would not press. Somebody playing a school bureaucrat or a state bureaucrat would offer a dodge, and sometimes, people would not take it, but sometimes they would. And when we asked people in the conversation, the critiques afterward 'why?', it became apparent that it had to do with the- it's not the unexamined life, right?- it's the unpracticed life as a citizen that many people with disability had led to that point. I mean, for many people, the 504 demonstrations were the coming out. And while there were many people who had been at it for a good while, and had significant experience, many people were young people with disability, or maybe even middle-aged people with disability who had not had the opportunity before to push public officials and the bureaucracy around to achieve their purpose.

11-00:52:43

Pelka: You know, I want to just interrupt you, just to throw this at you, and you can elaborate on this. I can't remember the name of the person, but I was reading an interview that was done of someone who attended one of those early 504 trainings, and this was out on the west coast, I think, but the first two impressions she had was one: she had never seen so many disabled people together in one place at one time, and two: she'd never been in a fancy hotel, and she was overawed by both of those things for the first day or so.

Gilhool: Oh, that's beautiful, and that rings absolutely true. Just incidentally, I have no memory, but Frank may, I think the three sets of us who were doing this thing in various parts of the country had worked quite closely to share models and things of that kind. In any event, that report is just exactly on the button. So, to go to, what was the phrase you used?

11-00:54:07

Pelka: Internalized oppression.

Gilhool: Yes, yes, yes! You know, I mean, we know so much about prejudice and stereotype and its internalization, and there was such a great literature by this time of all of that, with regard to race and a hidden literature with regard to disability, but some of it pretty blatant. Yeah, yeah, that's a lovely way to put it, and that may even be how Suzanne put it. You might want to talk with Suzanne, because it was brilliant, and it was very well received, and it, and the combination of over four days, and all of these projects had follow-up, I'm just remembering, Fred. The contract was to do the training and then to provide technical assistance in the several states, and so people had the opportunity to practice in play and then to practice in reality this different command of self, or self-command of the world, giving faith to what you were feeling, and what you felt should be happening, etcetera, etcetera. Anyway, Ned died, maybe two years ago, and Suzanne is living on a street, I have the address of it, in Washington D.C., and it's still listed under Edward Stutman, S-T-U-T-M-A-N.

11-00:56:05

Pelka: Let me back up just a second. So, before your first training, before you conducted the first training, you had obviously solicited input from various aspects of the disability community, but had anyone articulated that this might be a problem before you began the first training? Or did this pretty much come to you as a surprise when you began doing the role-playing?

Gilhool: I don't know, I don't know. Well, at some point in the design of the thing, significantly influenced by the conversations with the board of disabled persons who were already veterans, we formulated three teachings that we wanted people to get, not just in the head, but at the tips of their fingers. Never take no for an answer. If one way doesn't get what you want, try another way. And always go to the top.

11-00:57:29

Pelka: Now two of those, I imagine, would be quite radical for somebody who had not had an experience of being able to control at all their environment.

Gilhool: Yes, yes, exactly. Which two do you choose?

11-00:57:45

Pelka: Never take no for an answer and always go to the top.

Gilhool: Right, right. The second one is pretty radical, too, which is do not accept defeat. There's always another way. Think of it, develop it, go with it, right? So, as you immediately analyzed it, plainly we knew, as we knew with young lawyers, right? Not because they had had the experience of oppression, except in that they were young, and had — only reason, they'd been first year law students, where the oppression was made up in order to do something or another. In any event, yes, very different set of people with very different experiences, and implicit in where we wanted the training to help them get had to have been, at some level, an understanding. I use this analysis with regard to teachers, but it certainly would have applied at this time to people with disability. That is to say, they tended to be gentle and shy. It was the adaptation to the powerlessness and the rest.

11-00:59:36

Pelka: You may have already answered this question, but I just want to make sure that I've got this straight. In terms of selecting the people to attend the workshops, how was that done? You reached out to local community groups and they selected people to come? How would a person with a disability in Boston, say, have been selected to attend this workshop at the hotel in the airport?

Gilhool: One of the cuts at it was the array of people from Frank Bowe to John Lancaster to Sharon Mistler herself and so on, who both, from their organizational attachment, as well as from recent events in the 504 demonstrations and their wanderings beyond whatever organizations they may

have been attached to, knew people, and that was a very important cut. The second, obviously, was to reach the, usually statewide, but not always, chapters of the traditional organizations, and then- do you know Meg Kocher?

11-01:01:03

Pelka: Yes.

Gilhool: Do you see her?

11-01:01:06

Pelka: I haven't in a long, long time. She is in Ohio now, I believe. [Actually, she's in Indiana].

Gilhool: No kidding.

11-01:01:11

Pelka: Yeah, she's in Ohio, I believe one of her kids is going to Harvard, but I'm not sure, I could be wrong on that. Or maybe she's graduated by now, I'm not even sure.

Gilhool: Wow. If you get a clue, phone, email, address, even one for forwarding, she became the spark-plug of the Massachusetts organizing, right? And some one or two or three people fulfilled that role in almost of all the states. Not that it was formal, it was very much informal, but very energetic and very wise. And I'm not sure that such a person or persons came forward in the recruiting, though I know Meg did and hence there's the third hook of how people got there. Sometimes they didn't come forward until later, but that was another way in which the training was peopled.

11-01:02:24

Pelka: Okay. What's interesting about this is that what you're talking about are probably the most self-motivated people within the particular communities that you're entering, and what you're finding in even this cohort of people is, you said that they tended to be gentle and shy. Which actually, as I remember, Meg, pretty well describes her. She's a very soft-spoken person.

Gilhool: You know, one of the stories that we frequently told, I passed it on and everyone used it or had variations on it, when I was teaching at the University of Southern California in the early '70s, after the legal services experience, and just as public interest law firms were beginning to be, Joanne Chandler, whom I had previously met, came to Los Angeles to sit down with me because she was very worried. She had graduated at the top of her class at the University of Chicago School of Law. She had been refused a job by California Rural Legal Assistance, CRLA, one of the two, three most effective legal services in the country. This would have been the late '60s. And then she had joined a three-person, three-men public interest law firm in San Francisco called Public Advocates, in my memory. Bob Gagnaza, Tony Klein, and a fellow who later did much work in disability, I'll think of his name. And she

came to me, just distraught, because, she said, “I think I’m going to have leave the practice of the law.” She said, “These guys, they are so good, they know everything, they hold press conferences, they are so flamboyant, they all have the same style.” And what I said to her was, “You’re experiencing it in a very tough context. What I hope you will learn is the truth, namely that you can be a superb lawyer, a superb advocate, whatever your personal style, so long as you reflect on that style and figure out how you use it consistent with your own style,” we would have said in legal services training, to satisfy these three commandments, you know? And that you can be un-tough, un-flamboyant, you can be gentle and shy, and in some ways, even more disarmingly ‘refuse to take no for an answer’, etcetera.

11-01:05:57

Pelka: Just to be clear, this person you’re talking about- Joanne Chandler- was she a person with a disability?

Gilhool:

No, except that she was a woman in what was in the late ‘70s, in the California Legal Services world, a man’s word. As indeed, now that I reflect upon it, it was in Philadelphia. You know, the women’s movement was barely two years, three years old. The modern women’s movement. What’s her name had written only in 1964, that great book, *The Feminine Mystique*.

11-01:06:29

Pelka: Betty Friedan.

Gilhool:

Nonetheless, it was a shock at that time, to hear what she had to say, although the psychological and the integration of personal style and professional purpose is something that....

11-01:06:49

Pelka: Now, how did you change, or did you change the training then, after running across this obstacle?

Gilhool:

We began to be more explicit about such things as the tale I’ve just told, and we asked Ned whether Suzanne, whom all of us knew as a spectacular therapist, an engager of human beings, to design and do a session. And we tried it out for the first time in Boston, and undoubtedly, it was modified, but it kept going throughout the session, the training.

11-01:07:34

Pelka: I’m just wondering about the specifics. You would sit people down and say what?

Gilhool:

I don’t know! I do not know. [laughs] I remember standing in the corner or in the trellis of a doorway in awe of what Suzanne and the people assembled were doing. But my memory doesn’t rise to describing it to you, and that’s why I mentioned that it might be most valuable to talk with her.

11-01:08:10

Pelka: I wonder if there was any sharing of personal experiences, if that was a part of it.

Gilhool:

I think probably so, Fred, yeah, wouldn't you think so? I think so. But I don't remember. Nancy Zellers may remember, Frank may remember, and they both lived together in- what is that town called, the one with all the trolleys?
[Break]

11-01:08:42

Pelka: Great, we're back. Oh, one thing I didn't do when we began is I need to ask, I just need to say that you understand that we're being tape-recorded, and I have your consent.

Gilhool:

Yes, indeed, you do.

11-01:08:54

Pelka: Okay, I always have to check. During the break, I was looking for the interview I did with Meg Kocher, and can't locate that, but the person I was talking about was Johnny Lacy and she went to a 504 training in February of 1978, and she went to the Claremont Hotel, which I gather is in San Francisco or southern—

Gilhool:

Well, it's probably in Pomona. It may have been the Claremont Inn, a very famous place. Gillian's grandfather and grandmother as well as, the recently to die at 96, aunt, and Scott O'Dell, when they were married lived there.

11-01:09:56

Pelka: Oh, okay, well this is the comment that I was thinking of. She's talking about her first day of the training, "I was just overwhelmed by well, number one, I was overwhelmed that this luxurious kind of place was being occupied by a bunch of disabled people. That was the first thing."

Gilhool:

And that was very self-conscious, you know? For us and I'm sure the other programs.

11-01:10:21

Pelka: Meaning that you—

Gilhool:

This was to be first-class stuff. You know, you're first-class people, and this is a first-class undertaking of citizenship. It should be surrounded, it should have all the earmarks of the best.

11-01:10:37

Pelka: She goes on to say. "That was the first thing. And this comment was one that I heard throughout the place. It was the first time I had ever seen so many disabled people in one place in my life." So, anyway, that stuck in my mind when I read that.

Gilhool:

I should tell you, I did for you the lineage of the design of this training in legal services, but there's another lineage that is just as important. And that you just triggered- that is, the welfare rights organizations, whom I represented here in Philadelphia in, God save us, the late '60s and who apart from other extraordinary, from their extraordinary talents, approaches. Early in Pennsylvania, they negotiated a recognition agreement with the Department of Public Welfare that gave them access to every public assistance office, to assist people in seeking public assistance benefits, and shortly thereafter, they began to say to people, "We will help you if you will agree that you will help others and that you will join us in training"- now I'm sure it wasn't put that way- "to know public assistance law and the regulations and the system and in the ways and means of getting stuff for others." And that happened pretty much all across the country. California, Chicago, all over the country, there were welfare rights organizations in the late '60s, usually functioning in some relationship to legal services programs, and of course, they had an extraordinary effect. In Pennsylvania, they doubled public assistance grants from [\$]1800 to [\$]3600 for a family of four, then the poverty level for the first and the last time—we're back to a third of poverty now—and achieved other things in their public strategies in making the stigma go away. It was just extraordinary, in the Reagan revolution, of course, and the Clintons crushed all of that.

But, in any event, that very much was lineage here, and I was reflecting on the heads of learning, that the training was designed to evoke and support. Obviously enough, a command of 504 and its regulation and its history and, etcetera, etcetera, but still more, a command of processes in two senses. One, for example, the difference between promise, warning, and threat. Well, preceding that, the difference between being a repeat player and a one-shotter, which has two dimensions: one, not acting alone, always acting with colleagues, in part against the learned behaviors we spoke of earlier, of making this a social experience, of being able to think and check one another, and talk things out, and overcome one's fears and worries and figure how to do that, you know? But in the context, then, of being repeat players, there for the long haul, not going to go away, where it's not just this negotiation or this undertaking, public action, but you know, we're going to be here for a good while. And in that context, the distinctions between promise, warning, and threat- the literature showed us the obvious, which is threats are only effective before they're carried out, and they lose their power, once you have to carry it out, except, of course, as repeat players, if you're going to do threats, you have to carry them out, so you can come back and the next one can be effective. And the usefulness of clothing threats in a different interpersonal garb, namely promise and warning. You know, we promise you that if you don't do these curb cuts, you will see the following three, five consequences. You know, more easily swallowed and acted upon is a promise than is a threat, and etcetera, etcetera.

And the third head of learning, Fred, was the political and social setting in which you were acting. As I indicated, the trainings were on a statewide basis. In some states, like Pennsylvania, we did two or three, probably in New York State, too. Sometimes, we did a training and then the leadership at that training from within the state did trainings elsewhere in the state. So the third head, what is his name? The name of a guy, a sociologist, whom you will recognize. He's become a very conservative guy at one of those think tanks in Washington, but he had published, happily for us, just about 1968, a series of books state by state, published in regional volumes- forty and fifty page essays on the political history and the contemporary politics of a state. Not just economic, but also bureaucratic, and with significant insights from who the people were in the state, and what set the parameters of expectation and so on. Those books will occur to me. I do not know of a current analogue, by the way, of those books, but they were invaluable. In advance of the training, we put the relevant chapter- Massachusetts, New Jersey, etcetera- in the hands of all of the people who were coming, and the only other materials we put in their hands, I think, were the 504 materials, that we put in their hands in advance.

Let me get back to that initial distinction, just to mention that there was a very important essay in the *American Political Science Review*, probably in the late '60s, more likely the early '70s, by Marc Galanter. G-A-L-A-N-T-E-R. Indeed, my recollection is that it was a two part piece, and it won the American Political Science Association's prizes of the years in which it was published, and it was entitled "Why the Haves Always Come Out Ahead", isn't that lovely? And where he got to was this difference between one-shotters and repeat players, and he was talking about the uses of courts, and the difference in achievement by one-shotters at using the courts and repeat players at using the courts, and the surrounds as well. Marc's son, oh, isn't that terrible, [he's a] very close friend, was at the Clinton Justice Department, in the Solicitor General's office, and then, in the Civil Rights division, left shortly after Bush [became president], joined Drew Days at Morrison, Foerster, the San Francisco based law firm, but the Washington office.

11-01:20:45

Pelka:

What was that again? The Morrison?

Gilhool:

Oh, I know it. Seth Galanter, son of Marc, and a superb lawyer with whom I had the pleasure of litigating very many cases, particularly in the 8th Circuit, some years later, and we and my colleagues now, that I'm pretty much out of it, consult with him and work with him quite a lot. Anyway, that essay we also put in people's hands and used its thoughts.

The fourth thing, in terms of the heads of learning, concerned public actions, whether demonstrations or editorial boards, or newspaper or media strategies, or what have you, public opinion strategies. And what we played with, in the exercises and in the conversations and so on, at the training, was what is now

called ‘framing’, you know? And typically, we would start the training session, and in the early ones, I pretty much did it, with the history of disability, the state imposed segregation and degradation rivaling, even exceeding, that of Jim Crow, as Marshall put it in [*City of Cleburne, Tex. v. Cleburne [Living Center]*]. And then the other side of it, the triumphs of the movement, and so on, in order to get to things like nearly every extended family has the experience of disability, and why you can’t count on how any given person from such a family will now regard questions of disability, and you’re going to need to find that out. There was enormous strength in it. The tap root of the disability movement in the country’s commitment to equality, which we reviewed with great particularity, from Jefferson’s commitment through de Toqueville’s observation that equality was really what moved the whole country and accounted for the nature of all of our small ‘I’ institutions, through Lincoln who said that the declaration that all are created equal was of no use in effecting our separation from Great Britain and it was put there not for that, but for its future use, so that, as fast as circumstances permit, we could actually get to equality. Anyway, that’s probably five heads of learning, but that one, obviously, was designed to understand why you may feel as you feel, great range of feelings, where it came from, that it didn’t arise from your genes, or from any defect of your own, that it was really imposed with great particularity by the state legislation of that era, and the Eugenics movement of that era, and then at the same time, the enormous strength of the movement, in numbers, in its widespread common nature, and in its enormous strength in being attached to that central American commitment.

11-01:24:49

Pelka:

Let me back you up just a little bit. You were talking earlier about the welfare rights organizations being something of an antecedent and contributing to structuring the 504 trainings. Now, I would imagine they also would have run across the same kind of internalized oppression that you were talking about. Did you mean that some of that also carried over, the awareness of, and tactics for dealing with this?

Gilhool:

Yes, and we would talk explicitly. One story we would tell to do it would have been the 1965 Philadelphia riot. We were the first riot in the country, and we were the first one, also, that didn’t lose a life. Each day, the state Secretary of Public Welfare and the Commissioner of Public Assistance, family assistance, as it came to be called, would look at the arrest records, and they were so pleased to note that nobody receiving public assistance had been arrested. And then, it struck them. People receiving public assistance are so down, so beaten down, so reflexive, so pushed out of it, that they didn’t even participate in the riot, and that, in fact, is what, in Pennsylvania, gave rise long before the wonderful man, who traveled the country, organizing welfare rights organizations, came out of Columbia Social Work School. Long tall drink of water, African American, but it was that experience that caused the bureaucrats in Pennsylvania to give money to the Philadelphia Health and Welfare Council to hire a full-time organizer, Terry Dellmuth, out of Amherst,

and formerly a banker, to organize and staff and support the welfare rights organization.

11-01:27:06

Pelka: What was the last name? Terry?

Gilhool: Terry Dellmuth, D-E-L-L-M-U-T-H. But that tale, as well as others, got it to the point that look, that's what happens, you know, when you're the subject of stereotype and prejudice. Most human beings internalize it, but that the reasons why it happens are illegitimate, although powerful and with much official blessing, but that they can be set aside, overcome, with a lot of a hard work, and internal personal toughness, and with the ability to talk with others similarly situated, and think it through, work it through.

11-01:28:06

Pelka: Were you aware of any immediate impacts after the 504 trainings? I would imagine you would have, after each training, some kind of an evaluation... how it went.

Gilhool: And then we would undertake the technical assistance, which Sharon and Debbie were in charge of, so to speak. All of us participated, and yes, as you can imagine, we tracked actions and victories across the states, because we were in the business of reporting, regularly, to ATW. I wonder which unit these grants came out of. I don't think it was the Office of Civil Rights, although it shortly became the Offices of Civil Rights and ATW, a very, very much, including on race matters, very much a prime evoker and mover and supporter of all of this stuff, but I just don't remember what office it came out of. I suspect these grants came out of the Office of the Secretary. But I would bet, that in their archives, in the National Archives, there are probably the applications for renewal, you know, it was a four-year grant, but you had to report every year, etcetera, etcetera. Successes, victories, effects, failures, to some degree, were, I'm sure, reported.

11-01:29:47

Pelka: Anything that stands out in your mind, in terms of immediate aftereffects?

Gilhool: No, but the effects were pervasive, virtually from the beginning. Remember, going on at the same time, was the Transbus battle, and the Transbus battle was both national and local. It started as local, here, and in Denver, and in New York, but it became pervasively local, and that was largely through the undertakings of the network which was created by the training programs. The other thing that was going on was the *Pennhurst* trial and the first orders. '78, you'll remember- you have to watch me on my '78s and '68s- '78, you'll remember, was the effective date of the Education for All Handicapped Children Act, and so, you know, the very significant activity, state by state, and around the country, that arose after the Houghton[?] clarion call of the 504 demonstrations on all of those fronts: transportation, community services, education, was significantly infused and buoyed by the networks that came

out of this training, but again, I'm sure our reports and DREDF's reports and North Carolina's reports probably recite some of that, which would allow you to track the growth of the movement, from 504 demonstrations and training, to those extraordinary numbers which you have in your book of the state by state hearings- the hearings conducted by, what is it called? anyway, the hearings conducted by Justin Dart.

11-01:32:11

Pelka: The Committee on the Empowerment of [Task Force on the Rights and Empowerment of Americans with Disabilities]—

Gilhool: Yeah, on the ADA. They were done by, what was Justin Dart's outfit called? It was not a president's committee, but it was something like that—

11-01:32:23

Pelka: It was a congressional committee. Well, he had a couple of hats, but I think what you're talking about is the—

Gilhool: But your book recites the extraordinary numbers, and the hearings sometimes, two or three hearings in each state, which built the head of steam that made ADA inevitable.

11-01:32:46

Pelka: So you see a direct connection, then between the 504 trainings and—

Gilhool: Oh, yes, yes. It's the same people. It's, you know, the movement continued to grow and grow. The continuity of persons and gatherings, nationally and state by state, was notable.

11-01:33:10

Pelka: Backing up a little bit, when you were talking about technical assistance, did this take the form of legal assistance, or were there people coordinating—

Gilhool: Sometimes it did. And it's likely that some of the anti-institution suits, some of the education due process hearings and suits, and some of the transportation lawsuits came out of and were formulated with networks, these networks in the several states, that's very likely. Something else was on my mind in responding to that question of yours. Oh, but the primary emphasis of the training, while, it was very much about the uses of the law, and that to build on the common American 'if it's the law, it must be good, it must have-power', was not so much the uses of the law in formal proceedings, courts, or even administrative proceedings, but it was the uses of the law in public action, and in negotiation. I meant to mention, way back when we were talking about one-shotters and repeat players, and it crosses over to this business of what was your wonderful phrase, again?

11-01:34:40

Pelka: Internalized oppression.

Gilhool: Internalized oppression. One of the things we were sure to say and to attempt to evoke an allegiance to—

Begin Audiofile 12

12-00:00:02

Pelka: This is an oral history interview with Thomas K. Gilhool. This is March 31, 2008. This is Tape #12, Side A. Okay, I'm sorry, you were using Cesar Chavez—

Gilhool: Chavez never sent into a negotiation without really doking (?) it out, but to the point, he always had, at least the number of people at the table for his side as there were people on the other side of the table. And if possible, one or two more, and that was for several purposes: one, to match the power, in a very close, very important interpersonal sense, and two, they would assign responsibility for watching and gauging the thought, the reaction, where each individual on the other side was. They would assign one of their team to watch one of their team. You know what I mean? And in the unpacking after any negotiation, then they, of course, would report, you know, what did you see? What did you conclude about whether Agent Y of the growers in that case, or of a department, or a town council, or what have you, in our case, where did Agent Y come? And you'd be looking for people who looked like they were going to come with us, or might come with us, and why? What had moved them to do so? You know what I mean? That was all a part of the debriefing, the unpacking of any given negotiation, that somehow [was] close[ly] related to repeat players and one-shotters, and not being alone.

12-00:02:14

Pelka: I guess that the sense that I get, and I wanted you to elucidate, which you have, is that the 504 trainings had a lot more significance than simply workshops on- we have this part of a law and here are the regulations, and go out and do whatever- I mean, these were seminal events in terms of bringing together the community and then, catalyzing the community.

Gilhool: Yes, yes, and helping the community to see and master what its potential and now, not so latent and increasingly visible strengths are. We could use a set of these now.

12-00:03:06

Pelka: I was going to ask how you saw the impact, sort of down the road. I mean, you talked about the influence this had on the eventual struggle for ADA.

Gilhool: Yes. But don't most of us, on reflection, worry that we ain't got much from ADA? I mean, John Lancaster is notorious- virtually every conversation, within the first five minutes, he will say, "You know, the same 30% of people with disabilities have jobs now as did in 1989, no more", etcetera. The thought has not pressed itself on me as it does now, but John and I had a conversation, a little bit like this, but it didn't quite get to it, Fred. About a year ago, Steve

Gold did an analysis of which centers for independent living, were engaged in and effective in bringing people out of nursing homes and institutions, into independent community living, and he found ten, maybe twenty, independent living centers were very effective, and then, the bulk of them, pretty damned ineffective, including many with fine reputations, totally ineffective. And the Independent Living Movement was quite pissed off about Steve's data, and John was under great pressure to disown it, and we had a conversation about whether this could be made the opportunity for bringing the ten who were doing very well together, in regional groups, with those who weren't into it and weren't getting it, for some training, and how to do it.

12-00:05:19

Pelka: Did you get a sense as to why those ten or twenty centers, out of the, I don't know how many, three hundred, four hundred or so—

Gilhool: Yeah, three eighty-four, I think, maybe more. Three eighty-four, maybe the Japan number, and Japan had twice the population, so we have double the number that Japan has, because we've got the same density or distribution of Independent Living Centers, but it may be 384 here, and 184 there, I don't know.

12-00:05:51

Pelka: Did you get a sense as to why those particular centers were the most effective?

Gilhool: No. Because there were many uncharacteristic successes, for example, the person who succeeded Justin Dart at the National Disability Council, that's his name, that wonderful woman, Max Lapratosa [?] from here worked with her, went from here to work with her, I can't remember now the name of her center in Chicago.

12-00:06:22

Pelka: Are you talking about Marca Bristo?

Gilhool: Yeah, Marca Bristo. Bristo?

12-00:06:28

Pelka: Bristo, I think it is. B-R-I-S-T-O. And it's- Chicago is, Access—

Gilhool: Access For Living! Yes, beautiful. Anyway, they were getting nobody out, right? They, unlike most, weren't pissed to have that pointed out. They were challenged, but no, it wasn't clear why ten were working, and the others weren't. What the others all said was, "Our state bureaucracy is impossible!"

12-00:07:06

Pelka: Right, which is probably true, but—

Gilhool: Which is itself a diagnosis of the necessity for a certain kind of engagement, in learning to get past that expectation, that sense of fate which these training sessions were designed to overcome. But it didn't happen, and I haven't been

back to John on this matter in a while, but I don't think it's happened, I must ask Steve, but if you think about employment or about community services, and God knows- if you think about education, that's probably the closest place where it is happening, in different institutional, small 'I' forms, this kind of training and trading of strategies and tactics and postures and framings and so on. You know, the whole movement needs a rebirth with this kind of training, and I wonder whether we shouldn't begin to talk about it seriously with our friends around the country, about whether we can't make it happen in the next administration.

12-00:08:21

Pelka: That does speak to, when you talk about CILs citing bureaucracy as the reason. That's taking 'no' for an answer.

Gilhool: Exactly, and look, haven't we seen it in every movement, waxing and waning, less in the environmental movement, and in the human rights movements, you know, we get to a point of stasis and impossibility, and Lord knows the politics of the last several decades have certainly conspired to make that a not unreasonable view. But part of it is, it's just natural to movements for citizenship, for social change. And they need to be renewed from time to time.

12-00:09:31

Pelka: Just out of curiosity, do you recall which were among the most effective CIL's for getting people out?

Gilhool: I wish I could tell you. Steve could tell you in a minute, he's got it right in front of him. He hasn't been here, I suspect he's in Texas or abroad.

12-00:09:50

Pelka: Any final thoughts on 504 trainings? Anything stand out that we haven't talked about that you think needs to be discussed?

Gilhool: I'm looking over my notes.

12-00:10:06

Pelka: I'm pretty much at the end of my list of questions here, so.

Gilhool: Got it, got it. And another thing is occurring to me. I do have a note on something that I didn't do with you, that I would like very much to do with you. Back to that 'Uses of Courts and Lawyers'. That appeared, it was published by [the] President's Committee in *Changing Patterns in Residential Services for the Mentally Retarded*. And before its actual publication, was widely circulated, just at the point when, I think I have this right, the DD Bill of Rights and Services Act of 1975 was directing the formation, state by state, of protection and advocacy agencies. And a part of what I was doing in the piece, in bringing the experiences in other parts of the movement world to bear, in terms of disability, was, of course, in shaping institutions and law-based institutions and the networks they related to, that were popping up

around the country, and these about-to-be protection and advocacy schemes that were supposed to institutionalize that and bring public support to it and so on, and I was reflecting last night, while making this note, and maybe it relates to our continuing training, though it would be a tougher nut, I'll tell you. I think my judgment is quite widespread, I know that Frank shares it, and Nancy and others I respect around the country, but my observations for a good decade now, have been that the P&As are markedly uneven- that some states have P&As who are bold and brave and wise and adept, and others, many have P&As that are mild, and not gentle and shy in the nice sense, but just scared to death to do anything, and resolve, my analysis is for survival reasons, tied to the political structures of their state and state agencies, resolve not to do anything. That caused me to reflect that the Parent Training and Information Networks, remember them?

12-00:13:15

Pelka: Oh, yeah.

Gilhool: That Martha Ziegler led for, what, the first two decades? Remember Martha?

12-00:13:23

Pelka: Oh, yes.

Gilhool: You know she came to Pennsylvania three, four years ago, to work with Jerry Miller's project on juvenile institutions and transforming that whole set of things, you know? To infuse it with attention to disability and so on. But in any event, the PTIs [Parent Training and Information Centers], and again, my experience, and so it's limited by that; while my observations are systematic, I'm not sure that my survey is systematic — the PTIs are something of a contrast to that. Now, they, of course, were limited from the beginning. They can't litigate. So they have to use other modes of advocacy, whether it's negotiation, or public actions, or what have you. It may be a benefit, just like right to work laws are a benefit to the union movement. [laughter] Footnote, my daughter, Bridget, was a union organizer in Texas, a right to work state, and she and I quickly observed from her experience there, that the public employees union was much bolder on public issue matters than most unions, and they would go to bat with the legislature and so on, regularly, and after a while, we began to suspect that that was because they were relieved of the duty to grieve for individuals, and the duty to grieve for individuals contributes to unions settling in their strategic foci for the least common denominator, protect their people rather than advance their people's situations, am I making sense?

12-00:15:18

Pelka: Yeah, yeah. It's sort of the longstanding debate between service provision and advocacy that you find in the Independent Living Movement, I would think. I'm sorry, go on with your point, though.

Gilhool: That's so right, and of course, in the ARC movement, I mean, I remain, I get expressive of frustration to the point of anger every quarter of every year by finding friends from the old ARC days who are running, as they did with less trouble then, but who are running service providers and so, for example, in Pittsburgh, oppose a county ordinance to require freedom of information and public reporting of such things as average salaries, turnover, compared with executive salary, numbers of people moved from workshops to competitive employment and so on, because of that dissuetude. And God knows that the providers, as a general matter, who were started by people out of the '60s, in the birth of this movement, full of purpose and mission, they're mostly now in the business of I'm not sure what, but it has little to do with establishing friendship and active citizenship in the lives of the people who they are charged with supporting and assisting.

In any event, the PTIs, it seemed to me, and I'm looking at Martha's era, probably. I spent in 1977, on the occasion of that dreadful reauthorization of IDEA [Individuals with Disabilities Education Act] which had passed in the spring of 1977, and repealed the 'all' from the Education for All Handicapped Children Act, providing that people could be thrown out of school for various reasons, just throw parents all around the country to go marching on their 'inside the beltway' colleagues on how they could ever have signed off on that.

12-00:17:39

Pelka: 1977?

Gilhool: 1997, and of course, they got to the 'all' back in, but in any event, where was I going with that? I addressed, at Martha's request, each of the regional gatherings, there were probably eight regional conferences, etcetera, on the history of all of this, and so on. My sense, then, was unlike the P&As, that there was, again, with ups and downs, pluses and minuses, there were much more well-informed flexible sets of strategies to make things really happen there than there were in the P&As.

12-00:18:41

Pelka: I wonder if you could find any correlation between the effective P&As and the effective ILCs, you know, state by state.

Gilhool: Boy, and add PTIs into the mix. That would be really fun to look at. And Steve stayed on the ILCs, which he has constantly in front of him, unless he's given up in the last couple of months. [laughs] That'd be fun. And Cathy Boundy at the Education Law Center in Boston, do you know Cathy?

12-00:19:19

Pelka: No.

Gilhool: Spectacular person. She's worked closely with Paula Goldberg, leadership of the PTIs. She would have a sense of their productivity.

12-00:19:28

Pelka: How do you spell that last name again?

Gilhool: Boundy. B-O-U-N-D-Y. Wonderful, wonderful person. Yeah, that correlation would be worth looking at. I mean, for example, if we were able to bring off some whole hog, let's look at this again and think about how we can revive, reinvigorate what it is we're getting, that analysis would help us see which states, what we ought to draw upon to train, which states that are doing pretty badly.

12-00:20:07

Pelka: One of the crucial elements of the 504 trainings, of course, was the funding. I mean, somebody had to kick in the money to be able to pull this together, and I highly doubt, in the current circumstances, that the federal government would—

Gilhool: I think that's right, mostly in that second sense, that NAPAs, whatever their current name is, they still have quite a lot of money. Well, what's his name, the lovely young man who leads it, there is a shyness about doing visible and systematic things, though he's extraordinarily adept at getting important things to happen, interstitially, unobserved, without his fingerprints on it, because of the current climate, long since climate, same perhaps for PTIs, I don't know.

12-00:21:15

Pelka: Okay, any last thoughts on all this?

Gilhool: No, no. I do have a wish which I speak with some trepidation, to talk to you, for the archives, about *City of Cleburne, Texas v. Cleburne Living Center*, about the 1997 experience, about *Olmstead* and about our trilogy of cases in the 8th Circuit, which in this era of federal courts driven to avoid the enforcement of federal statutes as often as they can, and very often, a good three dozen statutes by now, essentially saying in the Supreme Court and the Courts of Appeals that this act cannot be enforced by the federal courts. That trilogy which Seth Galanter and I did at the turn into 1999, '98, 2000, 2001, essentially held IDEA enforceable, at district court- not district court, a panel of the Court of Appeals of the 8th Circuit, and also, held 504 unenforceable. We went to the Court of Appeals en banque and they sustained 504. It still stands now, eight years later, though the courts have found other ways to avoid effective enforcement in many cases. Those cases have almost uniquely, across general welfare statutes, to use the phrase from the Constitution and from the funding clause of Article One, have been taken out of judicial enforcement, contrary to Marshall's dictum in 1803 that we pride ourselves in being a nation of laws and not of men, and we will cease to be so if the courts fail to provide remedies for violations of those laws. We are still in a rather unusual situation across civil rights and social justice movements, in having statutes which survive at least the threshold that has destroyed Title VI and the Age Discrimination and Employment Act and some of the women's acts,

etcetera. Anyway, I would like, if on reflection, you think it would be useful to treat of those four or five things at some point.

12-00:24:18

Pelka:

Okay, okay. Let me turn the tape recorder off at this point, since we're finished with this portion of the interview, and thank you again. I'm going to turn that off—

Interview #8: April 16, 2008
Begin Audiofile 13

13-00:00:04

Pelka: Anyway, you wanted to talk about Cleburne.

Gilhool: Yes, I do, let me do it. I don't have either the opinions or our brief in front of me.

13-00:00:15

Pelka: I have the opinion.

Gilhool: Good. What's the name of the young man from Texas who argued the case?

13-00:00:21

Pelka: The young man from Texas who argued the case...

Gilhool: Or, let's see, respondent, I guess it would say.

13-00:00:29

Pelka: [mumbling, reading, flipping pages] Argued...

Gilhool: He represented Cleburne Living Center. After the head notes, they usually list the counsel.

13-00:00:37

Pelka: [reading] Robert W. Porter, Jr.

Gilhool: No.

13-00:00:40

Pelka: [reading] Court of Appeals.

Gilhool: Keep going. It will say 'argued,' probably.

13-00:00:46

Pelka: No, I don't see it, I don't see it. After hearing, after re-hearing, well, what I've got is I've got the Supreme Court decision-

Gilhool: Yeah. And right before the opinion starts, but after the head notes, it gives you the counsel.

13-00:01:01

Pelka: Okay, I'm still not finding it. Respondent, Cleburne Living Center, Inc.

Gilhool: Were represented by...

13-00:01:10

Pelka: Oh, okay, here it is. Earl Luna, Texas, Dallas Texas for petitioners, Renea Hicks, for respondents.

Gilhool: Say it again? Hicks, Hicks, yes, what's his first name?

13-00:01:23

Pelka: Renea, if I'm pronouncing it. R-E-N-E-A?

Gilhool: Renea!

13-00:01:27

Pelka: Renea. Okay, I'm sorry.

Gilhool: Renea Hicks, thank you, that's wonderful.

13-00:01:32

Pelka: Okay, hang on a second. This is an oral history with Thomas K. Gilhool. This is April 16, 2008. This is interview #8, tape #13, side A. And you understand that we're being recorded and you are okay with that.

Gilhool: Indeed, indeed, indeed. My wonderful memory said Richard Koch when we were talking about, in our last interview, rather than Bob Kugel, and we were talking about "The Uses of Courts and Lawyers" as the co-editor of the President's Committee on Mental Retardation's revised edition of *Changing Patterns in Residential Services for the Mentally Retarded*. Bob fits the biography I described in so far as it was he who went then to Fifth Avenue in New York, but he went from Kansas and all of my characterizations of the other fellow applied to Bob, in terms of his virtues and etcetera. What my memory is not serving on and I haven't had an opportunity to check is that, I think in fact, he ran a regional center out of UCLA in Los Angeles before he went to the University of Kansas. Anyway, that's one correction. It's so frustrating, because the day before, I'd just written something, in which I used Bob Kugel's name correctly.

13-00:02:59

Pelka: Well, you know, at some point, you will have an opportunity to look at the transcripts and go through them.

Gilhool: Yes, and I am delighted to tell you that I found the first set of transcripts yesterday. So, I will actually mark them up.

13-00:03:18

Pelka: Good! And congratulations on your celebration that's coming up, I've received another notice about that, so that's very lovely.

Gilhool: We're going to have some fun with it. And we may be extending some of the symposia into the fall. Don't suppose yet that we're finished asking you to come. [laughter]

13-00:03:42

Pelka: All right, all right.

Gilhool: If you were able to come on May 14th, needless to say, wonderful, but you had said last time that...

13-00:03:50

Pelka: Doesn't look likely, but getting into Cleburne...

Gilhool: Dick Cohn is coming. It was such a pleasure to get up to date with him. I encouraged him, oh well, go ahead.

13-00:04:09

Pelka: Anyway, getting into Cleburne. Am I pronouncing that correctly by the way?

Gilhool: Cleburne. *Cleburne, Texas vs. Cleburne Living Center.*

13-00:04:16

Pelka: Okay, now as I understand it, the case began because the managers of a living center had purchased a building and they wanted to set up a group home for thirteen people. I'm not sure whether that means thirteen residents plus staff, or...

Gilhool: It means thirteen residents, yes. These were the days when 'small' was anything under sixteen or fifteen, whatever that dividing line in the CMS Medicaid Funding was. They considered small four to sixteen. Things have changed. They changed quite rapidly after that, actually, in the smaller direction.

13-00:04:59

Pelka: So the city of Cleburne had a regulation or an ordinance that said they had to apply for a special permit, and they had to go to a hearing, and they had to get input from the neighbors. And this had to happen every year, as I understand it.

Gilhool: That may be! That's beyond my memory, but it wouldn't surprise me.

13-00:05:22

Pelka: So the people who wanted to set up the group home went to court. They went to the federal district court, is that right?

Gilhool: Yes.

13-00:05:31

Pelka: Okay, as I understand it, the district court sided with the city.

Gilhool: That makes sense.

13-00:05:38

Pelka: It was then appealed.

Gilhool: Through the Fifth Circuit. As I remember that, it was then called still the Fifth Circuit, from running from Texas to Florida.

13-00:05:47

Pelka: And the appellate court sided with the plaintiffs.

Gilhool: They certainly did.

13-00:05:52

Pelka: They not only sided with the plaintiffs and said that the ordinance was unconstitutional, but they went a little further than that, so why don't you pick it up from there?

Gilhool: They did. The Court of Appeals, buying into the equal protection analysis that prevailed at that time- the mid '80s- this analysis had rose in the early '70s, maybe the late '60s, and has, it's hard to say, it's diminished since. But I would say I was critical of it for a long time, from the getgo, both as bad law, bad history, bad analysis, and because the three-tiered system of equal protection, examination of official state classifications came to be reduced to- you get strict scrutiny only for race, you get intermediate scrutiny for gender, and for ordinary economic and etcetera regulation, you get reasonable basis, rational basis scrutiny. That is to say, if you wanted to prevail under strict scrutiny, you would prevail unless the state showed an overwhelming strong interest. Middle was middle, and rational basis, the least scrutiny of the offending state classification, was if you could think of any reason that would sustain it, then it would be sustained.

13-00:07:50

Pelka: And strict scrutiny, as I understand, at least at that time, applied basically to issues of race or gender.

Gilhool: Not to gender, actually. Gender was middle scrutiny.

13-00:08:01

Pelka: Oh, okay, okay.

Gilhool: It was slightly better. Well, it was significantly better. Actually, the opinion in Cleburne, it's a very short opinion, by then Chief Justice Burger for himself and Stevens. If you paged to after White's opinion, you will see it. And they wrote, I think, felicitously and correctly, that of course there are different intensities of examination of the justification or not for a classification that treats different people differently. Of course there are, it said, but this mechanical three-tiered system really makes no sense. What does make sense is to apply, to approach the equal protection question in historical terms, and to look at whether and the degree to which the people disadvantaged by the state classification have been disfavored in our history. There are three or four short paragraphs and a couple of footnotes that weave together there in just a very important statement of what I think, when we get the courts back sometime in the future, the federal courts will likely become again, the prevailing spirit of enforcement of the equal protection clause.

Let me go back and set the stage and then come back to what happened in the Supreme Court and the opinions, because it is they, and particularly Marshall's opinion, that are especially notable. This problem of exclusionary zoning, zoning excluding the residence of people who had been called 'feeble-minded,' people who had 'retardation,' people who had various visible disabilities as well, was quite widespread around the country, and was one of the early problems which arose in moving out of the institutions and into community services. Here, in Pennsylvania, in the course of *Pennhurst* implementation, it was not rare, it was quite common across the eastern states which we followed most carefully. The ordinances would sometimes be expressed in direct terms, naming numbers of disabled people, sometimes in indirect terms by saying, "No house can exist in a residentially zoned area if it has, say, five or more unrelated people," and obviously, that reached to juvenile rehabilitation facilities, etcetera, etcetera. And while the Cleburne number is quite large, in accordance with the times, the thirteen people, it presented problems for places of four or three, or what have you, depending upon what the local ordinance had to say. In Pennsylvania, and in many other states, we were successful in beating that back in state courts, where usually, it would be enforced, by arguing that the five or six people in a community living arrangements for people with retardation, for example, were a functional family. They were the function equivalent of a family, and you could not, we argued for public policy reasons, for reasons of analysis of what families are, and what community living arrangements are, you could not fairly distinguish between related people and unrelated people.

13-00:13:45

Pelka:

Just to interject- in Cleburne, I think, also, the area that they, these folks were going to set up this group home, already had existing fraternity houses, apartment buildings... there were other living arrangements where thirteen or more unrelated people were living together that apparently the city had no problem with.

Gilhool:

Yes. Exactly, and that was marshalled well, and may indeed have been recited by White in the opinion for the court.

13-00:14:27

Pelka:

I'm sorry, I interrupted you.

Gilhool:

No, no. So, Frank [Laski] and I early on got a call from Renea Hicks, and worked quite closely with him. He was just a superb fellow who had been or was at the Protection and Advocacy Agency in Texas, which was staffed by a further set of superb people, including a wonderful guy who later was on the executive committee of TASH [The Association for Persons with Severe Handicaps], and another couple wonderful people. In any event, we all worked together on the brief to the Court of Appeals, which resulted in the turnaround that you characterized earlier. Then, the losing side took it to the Supreme Court. The ordinance had its origins, about 1929, as I remember, and

in fact, the record of its formulation and passage in the city of Cleburne and elsewhere in Texas, showed a direct link in language and otherwise to the Texas statewide statute, which established the institutions in Texas to segregate people with retardation, ‘feeble minded’; ‘imbecile’; ‘idiotic’; ‘palsied’, etcetera, etcetera. So, in any event, what we undertook was, in part, directed to sustaining the strict scrutiny, and in part, directed to any other theory of equal protection, including the better one, which Burger and Stevens spoke to in their opinion.

13-00:17:11

Pelka:

Okay, let me interrupt for just two seconds. You’re saying that the ordinance, this particular ordinance in Cleburne city, related to the establishment of residences for feeble minded people, whatever the language was, that was directly linked to the establishment of the larger institutions in the 1920s?

Gilhool:

Yes, yes. And we discovered the links in the Texas archives, and they were set forth in our brief, which I wish I had in front of me, so I could read to you directly the link, but I will- you know how much I want, each time as we talk, to fill the library also with papers. This brief is actually probably something that you might want to take and see if the library wouldn’t like to put next to the interviews, because what we undertook to do in the brief to the court, was to examine and systematically set forth the history of state imposed segregation, in each of the states and the link between the Cleburne exclusionary ordinance, zoning ordinance, and the state-imposed pattern regime, as Thurgood Marshall called it, of segregation and degradation, which rivaled in its virulence even that of Jim Crow, as Marshall said. That was the very point of our undertaking with the court, and we spent ourselves, moving around the country to state archives to pull out the materials from that time. *Pennhurst* had made it clear what the history was, you’ll remember that it was 1913 when Pennsylvania by statute established its first institution and said, explicitly, that it was to segregate the feeble minded, imbecilic, palsied, et cetera. And it had been driven by a pamphlet entitled “The Menace of the Feeble Minded in Pennsylvania.” And as we pursued the archives of other states, we found, and indeed, there had been a couple of dissertations that had been written at that time, that had also found similar pamphlets across the country: “The Menace of the Feeble Minded in Connecticut”; “The Feeble Minded, the Hub to Our Wheel of Vice in Ohio,” and so on. So it was driven by the same animus and what we sought to do was to collect that history, and that’s what we did, and what Thurgood Marshall did in an opinion for himself, and Brennan, dear me, and who was the third person concurring and dissenting?- was to take that history and turn it into a beautiful, maybe two and a half, maybe even one and half page essay, on the history of official segregation of people with disabilities. It’s a piece of our history arising from Eugenics, driven by the extraordinary immigrations at the turn from the nineteenth into the twentieth century, and the fear, even the hysteria that accompanied them, and resulted in just an extraordinary chapter in our history that was, and still significantly is widely unknown. The history of Jim Crow is

well know, though it is not widely recognized that Jim Crow was essentially a function, not of the immediate years after the Civil War, but of the 1890s and the 1900s.

13-00:22:38

Pelka: You're talking about the opinion- this is Marshall, Brennan, and Blackmun. I think I'm looking at the language right now.

Gilhool: Right. A couple of pages in, after the reviews. That and current standards of equal protection, he does [in] his essay. The historical work- Frank and I did some of it, Tim Cook and Judy Gran did the bulk of it, traveling into various states.

13-00:23:21

Pelka: I'm sorry, Judy who, now?

Gilhool: Judith A. Gran, G-R-A-N. Judy is still here at the Law Center, and is a major figure in COPA, the Council of Parent Attorneys and Advocates, who had their tenth convention just a few months ago, and which is an extraordinary array of lawyers and advocates, very many of both parents of kids with disabilities, that is focused on schooling stuff.

13-00:24:03

Pelka: There's a paragraph that I thought maybe I might read, just from this, if that's all right? This is from the Marshall, Brennan, Blackmun opinion: "For the retarded, just as for negroes and women, much has changed in recent years, but much remains the same; outdated statutes are still on the books, and irrational fears or ignorance, traceable to the prolonged social and cultural isolation of the retarded, continue to stymie recognition of the dignity and individuality of retarded people. Heightened judicial scrutiny of action appearing to impose unnecessary barriers to the retarded is required in light of increasing recognition that such barriers are inconsistent with evolving principles of equality embedded in the Fourteenth Amendment."

Gilhool: And then he may say, "Prejudice once let loose is not easily cabined." Or that may be at the bottom of the preceding paragraph. Yes, it's just an eloquent, elegant high clout opinion of Marshall's.

13-00:25:15

Pelka: What I find interesting about that is that in the majority opinion, or the opinion for the court, there is a really kind of, I think, peculiar- it struck me when I read it- section in which they talk about the objections to heightened scrutiny of legislation or regulations or ordinances dealing with the retarded, and one of the objections they have is that, generally, such heightened scrutiny is used for constituencies that have no political power; however, we have seen recent legislation that, on behalf of people with mental retardation, so therefore, obviously, they must have some political power. I was looking at that and thinking, well, you know, the Civil Rights Act of 1964- does that

mean we no longer need to apply heightened scrutiny to race-based ordinances, regulations, whatever?

Gilhool:

Yes, yes, good eye. Very good eye. Exactly right, and that's a part of what Marshall was responding to, and that argumentation, including to the Civil Rights Act, has, of course, had some even larger influence in recent years in the United States Supreme Court's, both constitutional decisions on equal citizenship or equal protection, and also in the Supreme Court's decisions about statutes, about whether statutes are truly based in the Constitution, are proportional and focussed, targeted in their remedial aspect- proportional to the problem, and so on. And O'Connor, God save us, which opinion was it- actually dropped a footnote which recited the Civil Rights Act provisions of the several states on disability. Because - as the federal courts began to make statements about equal protection and the exclusion of kids with disability from schools and so on, many states- Massachusetts was the first in the education front- began to adopt their own statutes. And as the Congress acted to create civil rights acts on behalf of people with disabilities in Section 504 of the Rehabilitation Act in 1973, and of course, in ADA, the states also tended to add disability to their state civil rights acts, and O'Connor formulated exactly the argument which White did.

That analysis, and your interrurum (?) notice, that if that applied here, why wouldn't it apply to race, has actually been, in significant part, realized. The United States Supreme Court, in a decision, six to eight years ago, held that the effects regulation of Title VI of the Civil Rights Act of 1964 were not enforceable by the courts, and in fact, well... because the legislatures had act to remedy. So that was a straw in the wind, what's interesting about, in some ways, about the three opinions here, White's opinion, in particular- that it's full of straws in the wind, and later jurisprudence could have gone a couple of different ways, and in fact, has gone a couple of different ways, and none of it is still yet fully resolved. What "rational basis" used to mean was that the statute will of course, be upheld, and what "strict scrutiny" used to mean is that it will shortly be struck down. And White said "rational basis," if there is a rational basis for this ordinance and its classification, and the effects of its classification upon people with disability- then it must be upheld. Back when I was arguing the residence requirement for public assistance in the United States Supreme Court in 1968- a case called *Shapiro vs. Thompson*, opinion by Brennan which struck down the Elizabethan Age durational residence requirement as a condition of eligibility for income assistance. The way the test was applied was, if you could imagine any rational basis for the statute, for the classification, for the different treatment of the subjected class and other people, if you could imagine any reason for it, then you had to uphold the statute. White applies a very different rational basis test, because he examines each of the proffered and as I remember, some of the imaginable justifications for the classification and subjects them to a reality test. Now that is not rational basis analysis. It, in fact, is more like the middle scrutiny in that

ignoble three-tiered test, which had been applied with regard to women, gender, etcetera.

So from one perspective, you can say that the court was unanimous in applying a heightened scrutiny under the equal protection clause, and then the second piece of analysis is that you can do on those opinions, is that the three in concurrence and dissent, Marshall, Brennan, and Blackmun, added to Stevens and the Chief Justice Burger, is five. So a majority of the court, you could quite properly say, held that heightened scrutiny, without specifying the mechanics of the analysis that heightened scrutiny would then evoke, but heightened scrutiny, a majority of the court said, and held- would have held- was in fact, the standard. And then you look at the four who signed the White opinion, and look at what they actually did, which was to test the hypothetical justifications against reality, and they did a brilliant job, from Renea's brief, and ours, of taking each one of them apart and finding them quite irrational. Someday, that will come back.

13-00:33:59

Pelka:

In the meantime, you know, as I was looking at this opinion, this was pre-Scalia, pre-Clarence Thomas, pre-etcetera, so, yeah, "straw in the wind" is the way to put it. There was another part to the argument against heightened scrutiny that I thought was interesting that I wanted to run by you. Now I'm forgetting who exactly was writing this, but if we require that legislation and ordinances having to do with the mentally retarded in quotes, need to meet this heightened scrutiny, then what do we do about legislation such as the Education for all Handicapped Children Act?

Gilhool:

Which is meant to favor them.

13-00:34:51

Pelka:

Right. What do we do about the DD- this is probably prior to the DD Bill of Rights Act, but...

Gilhool:

It's not actually. The DD Bill of Rights Act had already been found unenforceable in the court, in the *Pennhurst* decision in 1981. The DD Bill of Rights Act was itself 1975.

13-00:35:13

Pelka:

Okay, okay.

Gilhool:

I think the answer to that is- and it is one of the considerations that should drive a sensible mind to the Burger-Stevens equal protection analysis the answer to that is that classifications as in education, which advantage people with disability, are not flawed under the equal protection clause, because they are justified by the historical treatment of people with disability that form the backdrop and indeed the motivation for congressional enactments like the education act. Indeed, those enactments were designed to remedy exactly the denials of equal citizenship and equal protection which state action had

imposed upon people, which same denials, one would have argued, would have been, directly offensive to the equal citizenship and equal protection clause. Indeed, that's what the thirty or so cases which preceded the Education for All Handicapped Children Act, most of them federal court cases, had held. So again, that was by White, a kind of interesting debating point, but doesn't really hold water for the aforesaid reason. You know that Scalia and Thomas in the race cases- the two Michigan cases that were up there the year before last- for example, would have taken the position that no use of race is permissible. And so far, at least, that by a thread of one vote there- and it was O'Connor's- has not been accepted, and plainly is inconsistent with any sense of history and its interaction with the possibilities and the limits on the uses of the law.

13-00:38:23

Pelka:

Applying that to disability rights legislation would absolutely gut it. If you were to apply the same standard and say nothing having to do with disability, you know, any legislation or ordinance having to do with disability in that same way, is constitutional, then pretty much anything that exists in disability rights law would go.

Gilhool:

Yes, yes. Your analysis of it, I think, puts into stark focus why the three level, so-called, tests, scrutiny formulations under equal protection, make little sense. They render it altogether more mechanical than either the real world or law which, since the beginning of the common law at least, undertook to take account of the real world conditions affecting real people. The foolishness that such mechanical tests can be reduced to.

13-00:39:41

Pelka:

There's another sort of foreshadowing in the opinion I thought was interesting. Let me see if I can find it. "Fourth, if the large and amorphous class of the mentally retarded were deemed quasi-suspect for the reasons given by the Court of Appeals, it would be difficult to find a principled way to distinguish a variety of other groups of have, perhaps, immutable disabilities, setting them off from others, who cannot themselves mandate the desired legislative responses and who can claim some degree of prejudice from at least part of the public at large." I read that and went, "Yeah? So?"

Gilhool:

Right, right. After the tests got going, you know, well, the first question that arose after this way of analyzing things came into focus, were the women's equal protection cases, which started with Frontiero, Frontiero vs. somebody or other, and following them, there were decisions to the United States Supreme Court examining classifications based on illegitimacy. They were assigned to the middle level of scrutiny, quasi strict, and the classifications generally fell and what you saw there was, since you do have to examine them against historical circumstance, and you discover that the proffered rationalization, or even the imagined rationalizations don't measure up, and that they are in the main, a cover for stereotype and prejudice, which in turn,

don't measure up to facts. And the other piece, of course, that's constant through equal protection analysis, is that the persons disadvantaged by the classification, were who they were, not by any action of their own; they weren't black because they chose to be black, or their gender wasn't whatever it was because they chose it, nor disability, nor illegitimacy, etcetera. And so there's that. To White—it's very interesting—Burger, who was regarded as a conservative, though his opinion here, and his opinion in the race school case, *Milliken 1, 2, and 3*, show what a different era it was. He was prepared, as would anyone who embraced the mid level to look at the real historical facts, and to weigh them when considering the offensive classification.

13-00:43:08

Pelka: Earlier on, you had said you wanted to look at this case and talk about the kind of carryover into contemporary disability rights litigation. Do I have that right?

Gilhool: Let me see. It was always very surprising to me, surprising in retrospect, because I did not understand it was happening while it was happening, but the ADA legislative history, which as you know, is very extensive, and which, by and large, especially in *Olmstead*, had carried the day against efforts by the states to render the federal statute unenforceable, the ADA legislative history contained, apparently, no reference whatsoever, to the *Cleburne* case. There were extensive hearings all over the country, you detail in your '97 book, the numbers of those hearings and the rest, and Justin Dart's undertaking, and the movement's undertaking to ask everyone to come forward to those hearings and tell about the social, cultural, the societal discrimination that people had experienced, and to tell also of the official state action based discrimination which they had experienced. And that record has been more or less successful in sustaining the enforceability of the ADA. This historical record was never explicitly brought to bear on the legislative history. I don't know whether it was because the major sponsors of the ADA all knew these opinions so well that they didn't feel- what is the analogy, it's like why is education never mentioned in the United States Constitution when it was formulated in 1787, and when we know that Madison and Adams, and even Alexander and Jefferson and etcetera, though he was in Paris, regarded and were very articulate about the crucial role of education in citizenship and in public matters. It may be that both of them are alike in that they are ever present, quite unavoidably linked with what was going on in the constitutional convention, that nobody, you know, it was part of the landscape. They didn't feel any need to mention it and being addressed in another way.

13-00:46:57

Pelka: Certainly, there were people from the DD community who were involved in—

Gilhool: Yes, and Tim Cook; there was many people, Bob Bergdorf and Tim Cook were among the handful of people, half dozen or so— [tape break, end of Tape #13, side A, beginning of Tape #13, side B]

13-00:47:19

Pelka: You were saying, Tim Cook and Bob Bergdorf were among the handful—

Gilhool:

I would say, I haven't named it out, but about six people who had a very significant hand in the formulation of the very language of the act. And you will remember the findings of the Congress and the statement of purposes and so on, and it is explicit in saying, I don't have it in front of me, either, but the findings of Congress in the act itself noted the long history of discrimination again people with disability, and then the statute explicitly says and this statute is meant by Congress to enforce the equal protection clause and is based, also, in the funding power and the commerce, and any other part of the Constitution that might provide a basis. Tim, and Bob both, but I know Tim explicitly, this is what he had in mind when he made those references.

13-00:49:02

Pelka:

There's a part of the opinion that just seems to beg for the ADA. It's the continuation of that same paragraph. If we're talking about the mentally retarded as a protected class, or quasi suspect class, whatever, then, how do we stop, how do we keep from going to people with other disabilities, and they go, "One need mention in this respect only the aging, the disabled, the mentally ill, and the infirm. We are reluctant to set out on that course and we decline to do so." That seems to me, an invitation to say, okay, well, then Congress will do it.

Gilhool:

That's quite right! ESL (?) on the button, exactly right. And Congress did. Twice. Yes.

13-00:49:56

Pelka:

That is interesting, that Cleburne isn't a part of that history, I wasn't aware of that.

Gilhool:

Yeah, and it would, of course, need to be tested. I spent a lot of time, as you have, in the legislative history and I haven't found it. I have not found it. Someone else may, but I think it was very much present in [Senator] Tom Harkin's mind and [Senator] Lowell Weicker's mind and so on, and it was discussed in other ways, but anyway. The answer to White, of course, would have been, 'Well, yes. Follow where constitutional themes and values would require to follow, and yes, of course, whether court or legislature [are] used to do it.' I suspect, for White, it may have been an invitation to the Congress.

13-00:51:06

Pelka:

When they were talking about immutable conditions, or whatever the language is, if you follow that road long enough, it would seem to me, you also begin to talk about gay, lesbian rights.

Gilhool:

Oh, yes, quite right. And the Supreme Court opinion out of Colorado, which measured against political matters, was a very surprising opinion, which

struck down an action of the Colorado legislature, it may even have been a referendum which disqualified gays...

13-00:51:59

Pelka: From being foster parents, or something, was that it?

Gilhool: No. Damn it, I can't get it in focus, Fred.

13-00:52:06

Pelka: Okay, that was a Colorado Supreme Court...

Gilhool: No, no. It was a United States Supreme Court decision. And it ruled on behalf of gay and lesbian gender or sexual preferences, ruled on behalf of them, starkly so, and it was not a close decision. If you look at that opinion, it is framed in terms that are reminiscent, that are just what you just said, and which arise from the equal protection analyses that are so beautifully set forth in Burger, Stevens and in Marshall, Brennan, Blackmun. Yeah, so it actually has happened, but then, it has also evoked a whole lot of legislative stuff.

You know, one of the themes and in one of the briefs, to the United States Supreme Court in the *Pennhurst* case- we had at the very middle page, where the staples, the publisher's binding would cause it to open, we had a kind of visual representation of the interaction between courts and Congress, and we set it forth in order- this was the DD Act 1 [one], which incidentally, none of us ever regarded as a statute that was anything but a modest, minor funding statute, terrible irony in that regard, 'cause that's about what the Supreme Court held, but it was a departure from so many modes of analysis which would say you need to look at the words, take the words seriously, and it isn't your business to second guess Congress. If they said it, they must have meant it. But throughout all of this, that's what you see. I mean, the three dozen or so cases on opening the schools interacted with the Congress, and then the Congressional undertaking, you know, finds its way back into courts for adumbration and interpretation, and in the instance of that statute, unlike some others, for enforcement. And that's a relationship which, for my generation, is one that the American legal process derived enormous strength from. You know, tying judges, on the one hand, to reality in the lives of everyday people, and tying Congress, on the other hand, to values which had been constitutionalized, and each of them, in their own way, got focused, you know, playing out enactments and decisions. It's a fascinating back and forth that my generation, and I think, the new generation, again, is very much possessed of. That is the way things should operate- that the institutions are checks on each other, but they are also inspirations to each other. You know, culling the attention of one and the other.

13-00:56:17

Pelka: Or gods. Gods to each other. [laughs]

Gilhool: Yeah, yeah.

13-00:56:23

Pelka: Are there any other comments you care-

Gilhood: Let me see if I can give you, in three or four sentences, a couple of other things. *Olmstead* is of course post-ADA, and it is the major opinion that gives life to ADA. What is fascinating about that opinion is how historically attuned it is. The background which Ginsburg makes the foreground is very cognizant and influenced by the history of the relationship between state and people with disability. And it is that on many counts. And in that wonderful two-sentence thing, when the Congress enacted this thing, it was doing two things, first and second, it recites the history of stereotype and segregation without using those words, and the cases it cites as illustration are not disability cases. They are consistent with the theme you were pursuing earlier. They are race cases and they are gender cases and the rest, as if to make a whole of both constitutional and statutory analysis, and that these themes apply to all people to whom they apply. The other wonderful thing about *Olmstead* is, you'll remember that Georgia argued, and Ginsburg said that Georgia argued that how could the ADA require integration and citizenship, people citizenship living in the community, when in the Medical Assistance Act, Social Security Act, Title XIX, the Congress had shown its preference for institutions? And she says, Georgia is correct to use the past tense, because, she points out, the funding solely of institutions that existed for such a long time, under medical assistance, from before '65 actually, until '81 was amended with the Home and Community Based Services Provisions in of '81

And then the other interesting thing there is the ease with which she says and finds it to be the case, as indeed Congress and ADA had said it was the case, that the Congress fully intended to enact into the ADA with the further reach that the ADA provided, the central imperatives of section 504, and that was kind of cool. And there's a wonderful passage where it finds the meaning of 504 and hence, the meaning of the ADA from the United States Department of Justice briefs to the United States Supreme Court in the *Pennhurst* cases.

Anyway, *Olmstead* is another of those Supreme Court opinions, where, in Cleburne, it was the ARC of Texas, and then the ARC's of the country, and then it was the UCP's, and the People First. In *Olmstead*, it was actually People First who were our clients, and those two cases are not unusual, but cases in which amicus briefs had enormous effect on the formulation of the opinions and of the decision.

And I wanted to mention just two other things. One takes us back to the education act. In 1999, 2000, 2001- may even prove to be the height of the Supreme Court's inclination to render acts of Congress unenforceable, either on Eleventh Amendment grounds, or on Tenth Amendment grounds, or because the Congress didn't have any strong basis in the Constitution, any power or authority to enact particular statutes. I don't know why I'm doing this. We had a trilogy of cases from Arkansas in which the Eighth Circuit, first

a panel led by a very conservative guy, Judge Loken from Minnesota upheld the enforceability of the education act, in an opinion which had pretty much carried the day around the country. That is to say, the Education for All Handicapped Children Act—IDEA [the Individuals with Disabilities Education Act]— has not been plagued by the unenforceability decisions of the courts that have plagued the Civil Rights Act of 1964, and another 35, 40 statutes, in part because of the strength of that opinion. Loken, at the same time, said, well, 504 isn't enforceable. The Eighth Circuit, en banque, in an opinion by Richard Arnold, the first is *Bradley vs. Arkansas Department of Education*, and the second is *Jim C. vs. Arkansas Department of Education*, the court, en banque, upheld the enforceability of 504, and thus far, at least, those opinions have been followed across the other circuits, and we have escaped, thus far, the plague of nullification that the judicial revolution of the last thirty years has brought to so many other undertakings of Congress.

13-01:03:57

Pelka: Judge Loken- could you spell that?

Gilhool: L-O-K-E-N.

13-01:04:01

Pelka: K-E-N. Okay, and what was the second Arkansas case that you mentioned?

Gilhool: *Jim C. vs. Arkansas Department of Education*. That was the en banque 504 sustaining of the enforceability of 504.

13-01:04:18

Pelka: And then, also backing up, who in People First do you recall working on that amicus brief?

Gilhool: Oh, wow. Oh, boy. The two women, you know them. Oh, my.

13-01:04:49

Pelka: Valerie Schaff, maybe? I'm just going to throw names out.

Gilhool: No, no. Still very, very much at work, and active. They were successively or with an intervening term of someone else, the chairs of SABE, Self Advocates Becoming Empowered. Oh, my, and I can see both of them.

13-01:05:22

Pelka: Bonnie Schultz wouldn't be it. Oh, boy, I'm blanking.

Gilhool: Yeah, yeah. Their pictures are on some walls around here. I'll find them and supply their names. I was talking with Chester Finn yesterday. One of them is his immediate predecessor as chair or president of Self Advocates Becoming Empowered. Oh, it's just terrible. One of them may actually have gotten some funding to open a Washington office, maybe two, three, four, five years ago. I'm sorry. I just can't do it.

13-01:06:06

Pelka: We can find that later. Any other threads that you want to tie up?

Gilhool:

The only other thing that I want to put on the agenda for future historians is the 1997 battle, which more or less saved 94-142. Curious, just having some conversations with people where two of the same themes got repeated and one of these conversations in the last couple of days was Legal Services. It was 1997 when Congress and the administration imposed the current strongly limiting conditions on Legal Services, prohibiting them from representing organizations from doing class actions, etcetera. The pattern was like the IDEA pattern, that is to say, people inside the beltway, the people who were focused on the Congress and bore the responsibility day by day for lobbying, became in both instances, quite convinced, in the instance of IDEA that the bill that had been passed unanimously through the House in June of 1996 probably, [the] reauthorization bill, was the best they could get, even though it repealed the 'all' from the Education for All Handicapped Children Act by authorizing the school districts to exclude certain children, the heavy actors and the rest.

13-01:08:08

Pelka: This was because of supposedly behavioral issues.

Gilhool:

Yeah. Disciplinary issues, etcetera. And as with the Legal Services conditions, except there was no revolt there, the folks who live with this everyday, you know, were sufficiently dispirited to suppose that that was the best they could get. When news of it hit the country, even though it had been enacted by and adopted by one house, a wonderful woman from Illinois, three wonderful women from Ohio, a wonderful woman from Minnesota, Martha Ziegler from Boston, rose up in rebellion and organized a kind of continuing march on Washington that resulted in fourteen joint hearings presided over by [Senator] Trent Lott's chief of staff and the scrapping of the House bill, and eventually got back the 'all.'

Anyway, just an extraordinary chapter and one that puts in relief one of the many problems that arise when a movement after its initial successes becomes, in many ways, institutionalized with divisions of focus and function often not terribly well-defined between folks in Washington and folks in the country. Between and among people with disability, families with the experience of disability, on the one hand, and professionals or if you don't find it, too much of a contradiction, movement bureaucrats. And I think it is one of the most fascinating things of this fourth or fifth decade of the modern disability movement, to see how, in many ways, the richness of the movement has brought us to the point where there are all kinds of wonderfully intriguing plays, among and between different parts and different roles and so on in the movement.

Anyway, '97 was among the first times where that became highly visible, and that will be a continuing matter. In some ways, Charlie Laken's observations of that- the difference, in posture that has grown between direct care workers, on the one hand, and agencies- service agencies- on the other. At the beginning of this movement, the service agencies were a part of the movement, and indeed, many of their founders and leaders had left positions in banks or in stock brokerages or in corporations, and so on, driven by the excitement of the movement of the '60s and '70s, and their sense of purpose diminishes and their sense of bureaucratic necessities increase, and they're in a different place than are the people who ostensibly work for clients, but work for them- the direct care workers- and those developments will, of course, how they are ultimately resolved, will have a lot to do with the quality of life, which all of this actually sustains on a day-in-day-out, year-in-year-out basis for people with disability. But those tensions between, you know, others in the movement, and "nothing about us without us"- the enormous explosion led by people with physical disability, and now extended so strongly into developmental disability of self-directed stuff that '97 is a good illustration of all of that.

13-01:13:15

Pelka:

When you talked about people leaving professions, you know, bankers, whatever, Elizabeth Boggs immediately sprung into my mind, as someone who gave up a career, as a mathematician, yes?

Gilhool:

Yes, yes, exactly. A brilliant one, with a brilliant academic, and perhaps, even business career ahead of her. And she, of course, did it very early, though you're quite right in placing that in a movement context, because my sense, always, and I may not be entirely accurate in this regard, is that she came to this movement in the late '40s, early '50s, when of course, the movement was a-formulating, at least in the retardation world. As Gunner used to say, significantly influenced by returning veterans, who then found themselves parents of kids with disabilities, and who found themselves going into these institutions and being horrified, and remembering that they weren't much different in aspect from the institutions that they had liberated in Europe at the end of the war. Yes, and Gunner and Elizabeth and many other people, including superintendents of institutions, came to it then, with an extraordinary sense of purpose and great energy. Many of those superintendents became significant leaders a few decades later of the 'out of institutions, into the community' movement. Some, however, did not, and were lost to the formal, the bureaucratic attachments that had overtaken their movement's sense of purpose. And I had not thought before, but that in some ways, replicates what's happening now among providers of community services and what has happened in so many places among educators.

13-01:15:26

Pelka:

And in the independent living movement.

Gilhool: Yes.

13-01:15:29

Pelka: The last time we talked, you were talking about normalization and the advent of normalization, and you were trying to remember where in Scandinavia this first sprung up. In the meantime, I was listening to an oral history that Elizabeth Boggs did, I'm not sure exactly when, I'd have to check on the date this was recorded, but she runs down the beginnings of normalization, and it's a fascinating story, I'd never heard this. She puts it in Denmark, and her take on it is that during World War II, when the Germans occupied Denmark, the Danish folks working in mental retardation, of course, knew what had been happening in Germany to people who were institutionalized, and so they made the decision to basically empty out all their institutions, and they sent all of the residents who could possibly live in the community out into the community, either back to their own families or into foster families, and the kids, or the people who simply couldn't survive in the community as it was, were sent to a newer institution that she said was out in the middle of the Jutland somewhere, very rural, and they figured well, maybe the Germans will never find it. And they never did. But what happened was at the end of the war, when occupation is over, and they're thinking of reopening all these institutions, they discovered, much to their surprise, that these people were doing very well out in the community, and in fact, had progressed and people who had been written off as being uneducable had made great strides, which was a surprise. She says that was the germ of normalization, of people sitting down and saying, well, you know, maybe we don't actually need to put these people in these places.

Gilhool: Isn't that spectacular? And you know, Wolf Wolfensberger's heritage may actually take him to that, you know? As to be sure, Gunner's did.

13-01:17:40

Pelka: Oh, yeah.

Gilhool: I'd never thought of that in terms of Wolf. Of course, the historical connections between the American Eugenics movement and Hitler's Nazis were explicit. As you were speaking, I was remembering a play on the life of Paul Robeson. A magnificent play. Robeson was played by a professor at Rutgers who, at that time, frequently appeared on television as a great singer and dramatist, I can't remember his name. It has a scene where Robeson arrives by train in Berlin and is not, as he had expected to be, met by his German agent or manager, and tries to find him, goes after him, to discover that his agent manager's daughter, a little person, had just been seized by the Nazis and sent off.

13-01:19:12

Pelka: I'm surprised that Robeson would be going to Berlin at that time, but-

Gilhool: Well, this was quite early.

13-01:19:19

Pelka: Yeah, yeah, I guess.

Gilhool:

'37 or '36. No, it was early. Judy Gran points out, frequently, and I never remember whether they started out with the disabled or they started out with the union leaders, but that's where they started.

13-01:19:43

Pelka: Okay, any final thoughts?

Gilhool:

Not a thing.

13-01:19:49

Pelka: Thank you so much.

Gilhool:

Thank you so much for this magnificent undertaking, and as all of your work, I'm sure it will be enormously productive.

13-01:20:00

Pelka: Well, I would love to be there for the celebration of your work.

Gilhool:

Don't worry it. If you can be, it will be wonderful, and if you can't be, we'll miss you.

13-01:20:11

Pelka: Well, we'll certainly be thinking of you. Say 'hi' to Gillian.

Gilhool:

I will, and love to your spouse. Give her a hug for me.

13-01:20:17

Pelka: Okay, well thank you so much.

Gilhool:

Thanks.

13-01:20:20

Pelka: Take care.

Gilhool:

Bye bye.

13-01:20:21

Pelka: Bye bye.

[End of Interview]

Fred Pelka

Interviewer/Editor

Disability Rights and Independent Living
Movement Oral History Series

Fred Pelka is a freelance writer specializing in disability rights politics and history. He is a 2004 recipient of a Guggenheim Fellowship to support research and writing of an Oral History of the Disability Rights Movement. He is the author of *The ABC-CLIO Companion to the Disability Rights Movement* (1997) and *The Civil War Letters of Colonel Charles F. Johnson, Invalid Corps* (2004). He has a bachelor's degree in English from the State University of New York at Buffalo and has done graduate work at Boston University (in journalism) and Emerson College (in fine arts).

Mr. Pelka is also the author of numerous articles on disability issues and was a frequent contributor to *Mainstream: Magazine of the Able-Disabled* and a contributing editor at *On the Issues*, a women's political quarterly based in New York City, from 1989 to 1995. In 1995, he researched and authored a major study on the problems of blind computer users for the National Council on Disability.

His disability rights activism began in 1983 at the Boston Center for Independent Living, where he served on the editorial board of Rollcall, the BCIL newsletter, from 1983 to 1994, and was elected to two terms on BCIL's board of trustees. He was also a long time member of the Massachusetts Coalition of Citizens with Disabilities (now defunct) and has been a researcher/writer for Justice for All, a disability rights listserve organized by Justin Dart, Fred Fay, and Becky Ogle, since 1997.

Mr. Pelka has conducted literally hundreds of interviews for use in his articles and book. He has taken the lead for the Disability Rights and Independent Living Movement Project on interviews in Massachusetts and Washington DC.