Marca Bristo
EXECUTIVE DIRECTOR OF CHICAGO’S ACCESS LIVING, COFOUNDER OF THE NATIONAL COUNCIL ON INDEPENDENT LIVING, PAST CHAIR OF THE NATIONAL COUNCIL ON DISABILITY

Interviews conducted by
Mary Lou Breslin and Sharon Bonney
in 2002 and 2005
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Marca Bristo, 2008

Photo by Lisa Winn
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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—Marca Bristo

Marca Bristo has been involved with the Disability Rights and Independent Living Movements since the late 1970s. She helped found Access Living, the first independent living center in Chicago, Illinois, in 1979. She co-founded the National Council on Independent Living in 1982, and she served as chair of the National Council on Disability from 1994 to 2002. On both local and national levels, she has been a strong advocate for consumer control of independent living programs, for cross-disability networks, and for disability rights legislation.

Born in 1953, Marca Bristo was raised in the small town of Castleton-on-the-Hudson in upstate New York. In her oral history she reflects on her family and childhood experiences and how they shaped her understanding of right and wrong and her attitudes about disability, injustice, and political activism. While earning a BA in sociology from Beloit College in Wisconsin, she studied and worked hard, and also partied hard. Eventually she realized she was addicted to alcohol and entered a recovery program. She identifies alcoholism as her first disability.

Bristo trained to become a midwife by attending Rush School of Nursing in Chicago, Illinois, graduating with a BS in nursing in 1976. A diving accident resulting in spinal cord injury ended her plans for midwifery. Following her accident, she spent about nine months in rehabilitation at the Rehabilitation Institute of Chicago [RIC]. When she began her reentry into the community, she first experienced discrimination in housing, transportation, and access. Not recognizing these experiences as discrimination at that time, she believed them to be the inevitable consequence of living with a disability and using a wheelchair. A trip to Berkeley, California, in the late 1970s changed her perspective on disability forever. After meeting and talking with activists there, she realized that people with disabilities had much in common with one another. Moreover, this trip helped her reject disability stigma. Having found her “disability activist” voice, she returned to Chicago and joined RIC’s independent living committee.

Marca Bristo went on to establish Access Living in Chicago, one of the early centers for independent living in the nation. She has served as its president and executive director since its founding. In 1982, she co-founded the National Council on Independent Living [NCIL], a cross-disability membership organization of independent living centers. She was elected president of NCIL in 1986, running on a women’s slate. In 1994, Bristo was appointed chair of the National Council on Disability [NCD], a federal agency that advises Congress and the administration on disability policy. Under her leadership, NCD convened a 1996 Disability Summit which produced the report, Achieving Independence, and completed an in-depth examination of the effectiveness of the federal disability rights laws in Equal Protection under the Law. Ms. Bristo’s oral history ends with reflections on nearly thirty years of involvement in the disability rights and independent living movement history and thoughts on future directions.

The interviews took place in three sessions. Mary Lou Breslin conducted the first two interviews on May 27 and May 28, 2002, at the Rehabilitation Institute of Chicago, and Sharon Bonney conducted the third interview on May 10, 2005, at Access Living in Chicago. The three-year hiatus was a matter of busy schedules, traveling, and difficulty coordinating dates. The transcript was audited and lightly edited by Regional Oral History Office staff and read and approved by Bristo with only minor changes.
The oral history with Marca Bristo 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 US Department of Education. Funding from DBTAC-Pacific ADA Center for interviews on the antecedents, implementation, and impact of the Americans with Disabilities Act enabled us to complete the interviewing and process 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/.

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Sharon Bonney
Mary Lou Breslin
Interviewers

Berkeley, California
April 2010
Interview with Marca Bristo

Interview 1: June 27, 2002
[Audiofile 1, Side A]

Breslin: Why don’t you say a little bit about where you were born and tell me a little bit about your family.

Bristo: Okay. I was born on June 23, 1953, the third child in a family that lived in upstate New York. I grew up in a little village called Castleton-on-the-Hudson, right south of Albany. I lived on a farm. My father was a farmer, and my mom was a farm wife. I have an older brother, Paul, and an older sister, Gail. We had an extended family that was pretty traditional in its family values and all that kind of stuff.

Maybe a couple of things that were a little unique that shaped my early disability perspective—I didn’t know it at the time though, it’s one of those things you only catch in hindsight—was that my father became ill from working with the animals. He acquired some type of illness from the cows. And he survived it, but we had to sell our farm when I was quite young. We lived pretty poor, and that was a really difficult period. Even before that, my mother had lung cancer when I was four, and had one lung removed at age four. Then it metastasized when I was eight, and so she had a third of her other lung removed. At that time I just thought of her as “Mom.” Those things had an early impact on me, because later I have come to recognize that my mother lived with disability her whole life, but we didn’t call it that. And my dad died early to lung cancer, so—.

Breslin: How old were you when your father died?

Bristo: Eighteen. We moved from that initial village, which was real WASPy, upstate New York and actually very homogeneous in almost every respect, to a little village near the Vermont border called Greenwich, New York for a year, because my dad needed an income. And we lived there just for a year. We moved from there to Utica, New York, where we lived for another year, and moved from there to West Winfield, New York, where my mom still lives, which is about twenty miles outside of Utica, New York, between Utica and Cooperstown. It’s a very small town. So I moved a fair amount as a kid.

Breslin: How old were you during all these moves, or when was the last one?

Bristo: The first move was entering fifth grade, the second move was entering sixth grade, the third move was entering seventh grade.

Breslin: Were these moves because your father was looking for work?
Bristo: Yes. The first move was really out of necessity. He wasn’t able to really earn enough of a living after he had to sell the farm. So he took a job working in a feed and agricultural supply company, and it just was not enough for us. So he moved to run a hardware store, a big hardware store, and he didn’t like it. Then he got a job offer to go into a plumbing and heating supply store. And these were white collar jobs for a guy that was an outdoors person, you know, he lived outdoors. As a farmer, his whole life had been around hunting and fishing and all those kinds of activities. Putting a suit and tie on wasn’t a good thing for him. So the final move was for him to reclaim his own life by going into business for himself as a contractor, as a general contractor.

Breslin: That was in West Greenville?

Bristo: West Winfield.

Breslin: Tell me a little bit about life in West Winfield, about your school days.

Bristo: Well, okay, I want to maybe even precede that. I didn’t know this at the time, and I don’t know how to sequence these things, but my family was a Methodist family—family values prevailed—and we moved from Castleton when I was ten, so it was like 1963 or so. The civil rights movement was happening. My brother was a senior in high school and didn’t want to move with us, so he stayed with my grandparents and then went straight from there to college. And he was the big brother that I looked up to. In many respects my brother has had a deeply profound impact on my life, my whole life.

For starters, during that period, he went to a small college in Pennsylvania, Alleghany College. It was during the civil rights movement era. I was seeing it just as a kid, running through the living room when the news was on; that was how I was being exposed. And learning a little tiny bit about it in school. But to be honest, in that part of America, you weren’t really seeing that in school. It wasn’t something that people talked about the way they do now. So my brother would come home from college, and, because I idolized him, he would have all these stories that idealistic college kids have about what was happening, both with the antiwar movement and the civil rights movement. I then started to pay a little more attention to the news—the way the war and the civil rights movement came into our living room. At first I really remember, being a kid, that it was just that, news, and I couldn’t switch the TV station to what I wanted to see. But the more my brother came home and started sharing with me his world view, the more I started to see it in a different way. So in many respects, growing up in white, upstate New York, where if anything there was sort of a pro-war movement, and him coming back
home with this whole new way of looking at things was really shaping my world view.

Another thing that happened after we moved from Greenwich to Utica and Utica to Castleton, where we finally settled, was that my father became very involved with Rotary. There we started hosting foreign exchange students. So from seventh grade all the way through when I left home, we had an exchange student almost all the time living in our home. And that really started to get my mind going about America. So this combination of what I was hearing from the students and what I was hearing from my brother started to make me question authority, question the rhetoric, question everything earlier than my friends and in a different way.

Then my brother went to Fisk University as an exchange student. Through that experience, he had a mental breakdown, an emotional breakdown. He was there when Stokely Carmichael was down there, and when the South was kind of on fire. And he was one of—gosh, I’ll have to check the record with him, but I think there were three other whites that were on Fisk campus at the time.

Breslin: Do you remember the year?

Bristo: Yes, this would have been roughly ’65. We can check exactly what it was, and I can do that. He was, at the time, moving towards studies in divinity. I don’t know if his life course at that time was taking him into that sphere professionally. But he went down there because of the impact that the civil rights movement was having, and the migration of students to the South to help out in the civil rights movement. Although he didn’t go in the same way as a volunteer to work on the lines like a lot of people did. He went as a course of study. And while he was there, some riots occurred and his roommate was killed, kind of in his arms.

Breslin: Killed by the police?

Bristo: No, by a sniper, who knows where it came from? I don’t think anyone really knows. But it really devastated Paul, and I don’t really know the sequence of events, because my family shielded me from it. But I know he then, for a period of time, went back to school and tried to make it there, and ended up in a psych hospital for a while. He never really recovered from it. He dropped out of school, got a job working in a welfare office, did some really good work there, and then ultimately he went on to become a flight attendant. And I’ll pick his story up a little later, because it weaves into my own story in a very deep way.
During the same period of time—but I’m not accurate about whether I learned this before or after Fisk, it’s in the same two-year period from when I was in maybe eighth grade till when I was in tenth grade, somewhere in that era—Paul came home one day and said, “I’m gay.” And I thought, “Oh, good for you.” It was before the word had meaning. I really did think he meant he was happy.

Breslin: Having a good day, having a good time.

Bristo: [laughs] And he must have known by the look on my face that I had not a clue what my big brother was telling me. But I was still in high school, I don’t know what grade.

Breslin: Do you remember your age at the time?

Bristo: I would say I would have to have been about fourteen or fifteen. Fourteen or fifteen. And what I didn’t know was that my family had known this for years, that apparently Paul had known he was gay since he was a kid. I never understood this until later, but my brother and my father had a very problematic relationship. There was no like beating or anything, but they were always fighting. In hindsight, now I’ve come to know that what was going on was my father found out when he was a teenager that he had a gay kid in farming, upstate white America, where that’s just not done. It somehow became a public issue within the schools because an older guy was caught with my brother and another guy somehow—I don’t know all the details—but then they were talking about gay kids in schools. Back then, oh my God, it was equivalent in sentiment to the kind of lynchings that were occurring in the South. It was simply not done.

So the conflict in my family over that issue was something I had lived with a long time, and when Paul kind of proudly declared he was gay, it was like it came out of the blue to me. And it was only over time that I came to understand that the tension in the family had been driven by that. Then my brother was involved in the very, very early organizing of the gay rights movement in New York, and was on the very first big gay parade. I don’t know all the details, but—.

Breslin: This was in New York City?

Bristo: Yes. So in that era when Bette Middler was kind of coming out in support of gay rights really, really early, he worked with her in a nightclub for a period of time.

Breslin: Would this have been around the Stonewall period?

Bristo: I don’t know.
Breslin: I haven’t quite got the dates clear myself.

Bristo: I can find out, and fill in some of these blanks. I know that this was all happening between—let’s see, he went to college in ’64, and he must have dropped out in ’69. So it would have been from ’66, ’65 to ’70. Not even ’70, ’65 to ’69, right in that period.

Breslin: Well, that was an amazing time to be in New York City.

Bristo: And what basically I’m trying to convey here is as a little girl growing up, my idol was living in the civil rights movement. First, as one of the white students who understood the wrongness of our system and who was seeking a personal understanding and an activist way to become involved in both the protest and the reconciliation, and second, as a man who was coming to terms with his own gayness in a period of history when it wasn’t even vaguely acceptable. I watched the impact that those things had on him, and the strength, even though, as I said, parts of it crushed him, the strength with which he embraced it, ultimately. His gayness actually became a source of his strength for kind of reclaiming himself, when he finally came out and really started to own this and not hide it. I remember the girlfriends he would bring home from college, it was all a sham, the girl he went to the senior prom with—. Now, of course he has talked to me all about this stuff in more depth. That, coupled with watching my mom’s role in our family as sort of the—well, she was perceived, because of all the illness, to be the weak one. Later, when my dad died and wasn’t there to create the image that she was the weak one, she was the strong one. She is still alive fighting that same kind of disability now with strength and grace, so in a strange way I never saw Mom as disabled until later. But of course, then I did, and these things all kind of shaped my early views.

Breslin: Do you remember what your reaction to your brother was when he first told you that he was gay and when you understood what that really meant?

Bristo: I was proud of him. At first I was confused. I just didn’t get it. And then I thought, “Oh,” I accepted it pretty much completely. Then I was proud of him, proud of him for standing up for what he believed in. Remember also, he was my idol. I looked up to him. So I kind of was taught to question authority, to protest, to stick up for your views. My father very, very much believed in education, as my mom did, and in speaking your mind, being your own person, don’t let anybody tell you what to do. And so they imbued in me, my whole family, those things. But also a strong sense of leadership. They pushed me towards finding that part of me. Really young, in little silly ways when I was in, probably, what grade would this have been? It all merges together. I’m going to say tenth grade.
Breslin: That sounds right.

Bristo: Somewhere around that era, the state came in and declared that they were going to cut all our trees down because of some disease the trees had. And some of the families were organizing to say “No” to this. So I organized all the students and they would come over to my house, because we lived two houses away from the school. They were going to strip trees right in our yard, in front of the school, and down the whole main street. And I can remember organizing, leafleting all my classmates, this is in a little, tiny upstate New York town. We would all have our organizing meetings in our kitchen, at my house in the morning. Then on the big day when the trucks all came to cut them, we all went out and circled the trees and wouldn’t let them in. Well, then the cops came and said, “We’re going to arrest you and take you all away.” And I climbed the tree and I wouldn’t come down. So I was like the student that got arrested. They dropped the charges, but it ended up that we passed a law and they didn’t cut down all the trees. They cut down a couple that needed to be cut, and then for a long time the state had to go through a completely different process before they could cut down trees. So it was a real lesson to me that if you take your sense of injustice and you organize people that you can make a difference in a real, practical way. That was my real first memory of activism. It had nothing to do with any of this, but—

Breslin: Well, it’s an interesting leadership story. Did you parents support the tree-saving effort?

Bristo: Yes. Well, first off, my mom was there that day, and when she saw me going up the tree she reports she said, “Oh my God!” So she was amused, embarrassed, and then when she realized that the cops were there she was more like, “Oh my God, what am I going to tell your father?” But as she reports it, she thought he might be upset that I got arrested, but he wasn’t. He actually wasn’t. We all had to go down to the Town Hall for the bail hearing or whatever it was. I thought I was going to be in enormous trouble, and I wasn’t. So yes, they did support it.

Breslin: Did your father reconcile to your brother being gay?

Bristo: No, not completely. He died—I think if he had lived I know he would have. I know that he was a person of that era of history. But I believe in my heart, knowing the kind of person he was, that over the long haul as time passed, there would have been a reconciliation. They may not have stopped bickering. You know, their personalities were such. But he died before that. He died way back in, gosh, I want to say ’71. So he died right while we were still really in the middle of it, of lung cancer.
What else did I want to say? Oh, this is all pre-disability, of course. My exposure to disability during that period, other than what I’ve already shared, was quite limited. My sister, Gail, when we lived on the farm, her best friend used a wheelchair and was a post-polio survivor, Toni. Toni would come over to our house all the time, and Gail would go to her house and they’d have sleepovers. And she went to the regular school even though it wasn’t accessible. So I remember Toni as just being Gail’s good friend.

I had two cousins who were “mentally retarded” at the time, people who had Down Syndrome. Both of them, for most of the time in my young life, lived at home with their parents. As they got a little older they were put in state institutions. Their mom later fought to get them out of those state institutions into smaller group home settings, well before group homes were much anywhere. So I kind of watched—. And they were part of our family. Family celebrations, Stevie and Michael would be there. We would go to their house for holiday dinners and they would be there. I loved them like anybody else, they were just my cousins. I will say that when all my buddies came over, from time to time these cousins would do things that caused embarrassment to me. So, the good part was that they were part of my family, and therefore I was exposed to disability from a young age, and it was something I accepted. But on the other hand, I was still living with the stereotypes of and the prejudice against disabled people, and was guilty of it myself. I would feel, when we were just us, it was fine. But when we were in a more public setting—

Breslin: It was embarrassing.

Bristo: Sometimes. Not always. But just certain things that they might do I would feel an embarrassment. I remember feeling that my aunt was strong, I guess, that I would look at her life and think that she really had a hard life in figuring out how to do all this, and that I respected her for doing it. I never questioned the boys being in an institution until they got out, and until the state made its change. I don’t know if she fought to get them out, I think the state started to change its policies and she was one of the first to get on board to move them out.

Breslin: Do you by any chance remember which institution they were in?

Bristo: No, I don’t.

Breslin: Because this is the same period as the Willowbrook deinstitutionalization movement in the late sixties, which would have been in upstate New York.

Bristo: I can find that out.
Breslin: It’s not terribly important, just wondering if they might have been part of the group that was deinstitutionalized—

Bristo: In Willowbrook, I can find that out. I don’t know.

Then moving forward now into West Winfield where I spent the longest period of my adolescence, in that high school, as far as disability, there was a guy named Harold who was sort of the town mascot, if you know what I mean. He was a person with a cognitive disability, and again, on the one hand he was a part of our town, and that was good. He lived there, he lived with his mom, he wasn’t in an institution, he had the run of the place. You saw him everywhere. On the other hand, the teenagers made vicious fun of him. Now, I don’t ever remember personally participating in making fun, and I do remember from time to time getting pissed off at my friends who were. But the culture was, on the one hand he was accepted, and on the other hand he was made fun of. And he didn’t know he was being made fun of. I mean, maybe he did. But that was one very deep impression that I had. Then the second was my school. I remember this so clearly, two things, the kids who would be picked up and put on those special buses and taken away to “Bozes.”

Breslin: Was that—?

Bristo: Segregated, vocational, special ed, external places. There were those littler buses and branded in my mind was, “Those kids.” Those special, those different, those other, and that they were shipped out. Then there was also a classroom that I remember being at the end of a corridor, downstairs, sort of in the least desirable part of the building.

Breslin: Darkest, dankest part of the building. [laughs]

Bristo: It wasn’t literally the basement, because I don’t think we had a basement. But it was way at the end of the corridor, off where nobody ever went. That was where the kids that were disabled in the regular school were put. I don’t remember any kids with any disabilities in my class, ever. And that’s the way I went through life, pretty much not too aware of it, except in those little places, which was a series of contradictory messages. My dad also had a good friend who was an amputee, when we lived on the farm, who would come to visit a lot. And I can still remember that.

Breslin: And this was the period of the Vietnam War escalating, ’65 onward. Were there disabled vets coming home from war that you can remember in the community, and do you have any recollection of thinking about them, or thinking about the politics of that?
Bristo: No. I remember—well, what I most remember about the war was my boyfriend graduated from high school and came home and announced, “I’ve signed up for the marines.” And I said, “You did what!?” I thought he was crazy. Because the antiwar sentiments had begun to creep into me through my brother, and it was starting to grow. The long hair was coming—. It was starting to become socially acceptable to protest the war, even in upstate New York. Even while a much bigger number of people were doing their patriotic duty and going off. There were a lot of people drafted, I remember the dodging of the draft. I remember my brother being happy to have gotten the release, he was deemed ineligible for the draft because of his psychiatric history.

Breslin: Was he thrilled—

Bristo: Yes. And all of us thinking, “Oh, that’s why I had that period in my life, thank God!” [laughter]

Breslin: God, really.

Bristo: But I don’t remember a lot of people coming home with disabilities. I remember vaguely a friend—a former boyfriend of my sister—who I think had a head injury coming home, but you didn’t see or hear much of them. More what I remember is people going. You know, it’s a small town. Lots of people went, but they were are still there, and not too many of them were coming home hurt.

Breslin: Do you remember or recall whether there were African Americans or other minority groups in the community?

Bristo: No, there were none.

Breslin: None.

Bristo: There was one family, one family. One. There weren’t, to my knowledge—I didn’t even know any Jewish people where I grew up. They weren’t there. It was white, rural—I don’t want to over-label them—you know, there’s a stereotype that if you’re white and rural you’re redneck. Yes, there were some people who would fit that. But by and large, no, they were just middle-American, working-class, lower-income, or lower-middle income, regular people, who all happened to be white and the same. There wasn’t a lot of difference of opinion. It’s mostly Republican. I remember that my family stuck out because we were Democrats and everybody else was Republican. So I remember feeling different on a lot of levels in that respect. I should mention, we lived two doors from the school. And our home was central. You know what I mean— everybody came to our house. It was
the hangout for everybody. For my sister, for me—not my brother, because he grew up somewhere else. But it was the place the kids would come before school and hang out until school happened, then when school got out and in between activities they came and hung out. So my home was always very welcoming and accepting and tolerant. I had a pretty cool family in that respect. They really loved us and allowed us to grow. We didn’t have really rigid rules. We had rules, but not really rigid rules. They encouraged us to take risks, and—.

Breslin: Was your mom a stay-at-home mom?

Bristo: Yes, except during the period when we were on the farm, where she worked harder than anyone I know. She got sick, and her health really prevented her from doing much for a very long time—she was in the hospital almost every year with pneumonia my whole life, until we moved to this last home, and maybe there there was a climate change difference slightly. But for most of my life she would go off to the hospital. And I know—this isn’t relevant to your interview, but as I’ve come to try to understand my psychological make-up better, I know that that had a big impact on me. Seeing my mom go to the hospital, and not really knowing if she was ever going to come home. Visiting her—in those years you couldn’t go to her hospital room. You’d go to the hospital and wait downstairs. And, if she was well enough to come down, we’d get to see her that day, and if she wasn’t we’d just send a note up to her or talk to her on the phone. And—Sunday dinner was a big deal—after church Sunday dinner, family reunions. We used to do it at our house, but then as my mom got sick we did it at my grandparents.

[Audiofile1, Side B]

Breslin: I remember you mentioned just a moment ago that you really missed your mother when she was ill and you were growing up, and she was being hospitalized. I’m wondering if that had any influence on your decision to be a nurse, or if it didn’t, how did you come to that decision?

Bristo: So I’ll skip over a period, and then we’ll—

Breslin: Well, we can actually, let’s just go forward with—

Bristo: No, let me answer your question. What influenced my decision to be a nurse might have on a subconscious level been that. But I never wanted to be a nurse, I wanted to be a midwife. And what influenced my decision there was that in college I became really interested in biology. I didn’t want to be a doctor. And then as I told you, the women studies movement had taken hold. The first women studies
program on my college campus was being set up by my sociology professor, and she asked me if I would help her design it. So I was sort of a student—not really intern, but I kind of worked with her to gather books, decide what the curriculum would be, and helped her. It was the merger of those two things, my interest in biology, my desire to be supportive of the women’s movement’s goals, and not having a clue what else to do. I wasn’t one of these people that could just, when I graduated, not know. I needed to have something more concrete. So I spent a lot of time in that senior year really thinking, “What do I want to do?” Then this program was introduced to me at—this was at Beloit College in Wisconsin. They had just entered into an agreement with Rush Presbyterian Hospital here. Rush College of Nursing was starting a new Bachelor’s program, and in order to recruit students they were allowing people who had two years of baccalaureate education to transfer those two years, so that you could get your Bachelor’s in nursing in only two years. Well, they came up to our campus to recruit people, and it was a timing thing. I was sitting there struggling with what I wanted to do. I knew I wanted to do something, generally, that dealt with the biological sciences. And I was really motivated by the women’s movement. And as I heard this, somewhere out of the blue—I don’t know where the idea of midwifery came from, whether I read a book or I don’t know—but that’s what my life goal became at that time. So I came down here to get a nursing degree in order to become a midwife.

Breslin: I see, all right. Well, let’s back up just a little bit and talk about your decision to go to college, and sort of the process of selecting a school.

Bristo: Oh, boy. Okay. I mentioned that I had exchange students living with us all the time. When I became a junior, I decided I wanted to be an exchange student. There’s something here that’s quite irrelevant to everything—but it’s a corny part of my past that I almost can’t not put it in. [laughter] I crack up over it when I think about it now. I was a cheerleader and dated the captain of the rival football team during that period. And I quit being a cheerleader in protest over something. I don’t remember what. But I remember, this coveted cheerleader role, and I quit in order to make a statement. I can’t tell you what the statement was right now [laughter], but I know at the time it was—

Breslin: It’s the intent that is important [laughs]—

Bristo: It was a hot issue at the time. [laughs] However, then—you’re going to crack up over this. This is so funny, when I think about it—we started a color guard at my school, which at that time, in upstate New York, was really a big thing. Sort of like, what, acrobatics, you know what I’m talking about—?
Breslin: Gymnastics—

Bristo: Gymnastics is now. There, then, that was the “gymnastics” of the day.

Breslin: And explain what a color guard is for people who might not know.

Bristo: It’s a marching unit without a band. [laughs] And you compete. So it’s banners, imitation rifles, and an American flag. [laughs] But it’s all competition, and it’s real military.

Breslin: Synchronized movements.

Bristo: Oh, yes. And you’re rated—you know. You may have six people who have rifles, and you’re flipping them up in the air, and there are people on the sidelines to look at them and see if the rifles spin exactly at the same moment, you know what I mean? Synchronized, perfectly. I was the captain, the saber-carrying captain. You know, I did sports also. I did hockey, and basketball, and track. I was really good at discus and shot put and the fifty-yard dash. But something about this color guard—and now in hindsight I know what it was. It was one way to organize something. Starting something brand new, which I have now come to understand is something I know how to do, organize things. But second, it was because I was drafted to be the leader. And this is a pattern that happened in my life subsequently. I didn’t try out to be the leader. The coach came and said, “You’re going to be the captain.” And I wouldn’t have tried out to be the leader, because I wasn’t confident enough in myself to believe that I was a leader. It wouldn’t even have dawned on me to do that. My self image, even at that time, was not high enough to put myself out in that way. But he saw something in me that I didn’t see in me. So once he said, “Do it,” I said, “Okay.” Then, boy, did I do it with a vengeance. I was like, really—you’ve got to imagine this drill sergeant thing, Mary Lou, and I can say this to you—

Breslin: I can envision it. [laughs]

Bristo: —because I think you and I sort of have, at least, we have, I think the tenor of who we are—there’s a little bit of the drill sergeant in both of us.

Breslin: A little bit of the “Get it done!” “Get it done now!” [laughter]

Bristo: Yes. Without a smile. [laughter] No, because smiling you couldn’t do it. You would get ranked off for smiling. If you had a smile on your face, you lost points. So sometimes I think maybe that’s why sometimes my style of leadership has a sternness to it, sometimes, or something. But anyway, I was the captain of the color guard, and won
the state trophy one year, and it was kind of a big deal. But I bring it up because it was really my first test of leadership. I had to organize the practices, I had to keep these teenage women, young women focused on what we were doing, when we all really wanted to be out with our boyfriends. But somehow our parents had conned us into doing this, and then there was this esprit de corps. We got to travel, we got to go to hotels, you know, it was fun. And my parents were very involved in this. They were part of the family team that traveled with us and helped out.

So from that experience, I don’t remember how I decided it, but it’s almost like one day I just woke up and said, “I want to be a foreign exchange student.” I went to my parents, who had no money—we were living pretty broke—and I knew we had no money. My parents said, “Go ahead and apply, honey; we’ll find a way.” I got accepted. And you know, this is something I don’t know whether they told me this, or whether I made this up, but in my mind I remember thinking, “Okay, it’s either the money they put into your wedding when you get married, or you’re a foreign exchange student.” [laughter] Like, one or the other.

Breslin: You have two choices, you can travel or get married.

Bristo: Well, getting married wasn’t in my repertoire. But I probably made that up. The point was that I definitely knew it was a big financial hardship, but they let me do it anyway. I applied, and I wanted to go to Japan—no, I wanted to go to Sweden. My most recent foster brother was from Denmark, and that’s right, it was that foster brother that had said “You should apply, you should apply!” And then kind of convinced me that I should apply to go to his part of the world. But I thought, “Well, I know a lot about Denmark, so I’ll apply to go to Sweden.” So I applied, and you get to designate where you want to go, they don’t agree that they’ll send you there. So I applied to a Rotary International exchange program, and said I wanted to go to Sweden, and they accepted me, and they accepted another woman in my class, Sally Robertson, who wanted to go to Japan. Well, they didn’t have placements in Japan or Sweden, but they ended up getting our names mixed up, and they sent her to Denmark, and they sent me to the Philippines.

Breslin: [laughs] Oh, my God!

Bristo: Because they thought, “Well, Japan and the Philippines—”

Breslin: “If it’s out on the Pacific Rim somewhere—”
Bristo: So, I didn’t even know where the Philippines was. I had to get out my map and look at it. When they told me this, I was excited, but then I was terrified, because—I don’t know why—if you look at a globe or a map, Sweden’s closer. [laughter] And all of a sudden I’m like, “Wait a minute! I’m going halfway around the world away!” So I spent what should have been my senior year in the Philippines, which was—no particular disability stuff there.

Breslin: But was it transformative in some other way?

Bristo: Oh, my God, yes. More than anything. More than anything. Remember, my boyfriend is now in Vietnam. I’m in the Philippines. And we’re writing letters to each other from the same place. He’s defending our country in this war that he believes in. I’m in the middle of all the Filipino anti-American demonstrations. The city of Manila and the University of the Philippines is where I wanted to go, but they had a policy there that, because American girls were considered more mature, they put them in college, first year college. They had a history of recognizing that if you were put in high school, the girls from the United States and other parts were too mature, and they didn’t fit in. So they automatically put you into the first year of college. I wanted to go to the University of the Philippines. They wouldn’t let me because of all the anti-American demonstrations that were going on there.

When I say I didn’t have any particular disability experience, I have to qualify that. One of the families I lived with—was a seventy-year old couple from China, Chinese-Filipino couple. They had ten kids, adult kids. The one adult kid that lived with us in this big mansion was their daughter, who was forty, or forty-five, who had Down Syndrome. So—and oh, we were very close. So there’s been actually a lot of Down Syndrome in my life, with a lot of depth of affection over the years.

Anyway, so I went to the Philippines. That was transformational in so many ways. First, being that far away from home. Growing up, just having to be on your own, cope with your emotions, figure out how to live in a foreign culture. Well, it was complete—everything was new. Well, in hindsight of course, it gave me all this great life skill that I carried with me. Not being afraid of meeting new people, being a good public speaker, because you had to do three-million speeches to a million different Rotary Clubs, boarding with other people that you didn’t know, it just was awesomely important, personally.

Breslin: Was it—did it work out for you to be a better placement, do you think, than if you had gone to Sweden? Have you any way to assess that?
Bristo: Oh, yes, because I was right in the middle of—you know, the part of
the world that was—

Breslin: Geopolitical upheavals.

Bristo: Oh, my. You know, we had all those bases over there at the time.
Marcos, Ferdinand Marcos was in power. Martial law was declared
pretty much when I was leaving. The streets were on fire, literally.
When I got there I was assigned first to a family, a so-called family.
This was—do I want to say this—I’m going to say it, and if I want to
edit it out, I will. He was the president of International Rotary,
worldwide. His family lived in California. He lived in the Philippines.
He had two homes in the Philippines. His office was set up—he had a
downtown office, and he had an office in his home. So when I got
there I thought I was the luckiest kid in the world because I had two
houses, I had three personal maids, I had my own Mercedes limo with
my own driver assigned to me only. I had the maid that did my
laundry, I had the maid that cooked my meals, I had the maid that
accompanied me wherever I went. Well, little upstate New York girl
who had no money was now thrown into privilege—and it was so
upside down. Okay, first off, I thought these people were poor and we
were wealthy. Well, now I was in the lap of luxury. But I would drive
to school past squatters of unbelievable poverty—like I never knew
existed. There is this one whole part of Manila that is a garbage dump
on top of which literally people have taken scraps and made homes.
They live on the garbage. It’s still smoldering. You can barely breathe
and that’s where their homes are. So other than my disability and then
becoming a mom, there is nothing that changed my life more than this
experience. It was life-altering, and in the most profound sense. My
world view of America changed [snaps fingers] overnight. I went from
questioning the war, but otherwise being a patriot, to understanding the
“ugly American.” To really seeing how other people see our foreign
policy, and why they don’t like it. And at the same time, I was
escorted through the halls of power. I had breakfast with Marcos. But I
also saw all the corruption firsthand. Firsthand corruption.

For starters, my foster father, remember his family lived overseas? I
was seventeen, he started making advances towards me. I didn’t know
they were advances at the time, I thought it was cultural. And he kept
telling me it was cultural. “It’s cultural that we always lay in bed in the
evening together. My whole family does it. It’s sort of like the couch,
you know? And it’s cultural that we celebrate the woman’s body.”
Now, you know, he never did anything horrible to me. But one day his
secretary was in his office, and she uncovered a travel bag filled with
slides of all the other exchange students that had preceded me, nude,
five of them. All of a sudden I was like, “Oh, my God!”
Breslin: Did that make you think that you should leave, or—? What was your reaction to that?

Bristo: First I was terrified. Terrified. This is my feminism before I knew it was. It was my outrage at this.

Breslin: At what he did.

Bristo: I knew it was wrong, and I wanted to expose him. And the secretary was terrified she’d lose her job—he had been requiring sexual favors of her and she felt her job was on the line, so she went looking for something and found it. She knew something was awry. So I went to the head of the program. Remember, he is the international president of the whole association. Not just of the chapter. I went to the head of the exchange program and brought the slides with me. And they handled it in the following way. They immediately took me out of the home and gave me a new placement, quicker than they would have otherwise. And then they hushed it up.

Breslin: And what did you learn from that?

Bristo: That the good old boys have a lock on things, and that power protects itself, that justice is only half-hearted.

Breslin: Did you have an anticipation there would be a different outcome?

Bristo: Yes, I thought that they would throw him out! I thought it would go up through the echelons, and at least he wouldn’t be the head of the foreign exchange program—I thought he would pay a price. He paid absolutely no price, except that the people in his club knew about it. But they didn’t throw him out of the club. I would still have to go to events and he would be there. You know, he violated me and he got away with it. It taught me—you know, on the one hand they did the responsible thing, that they took me out. They never made me think that I was lying, you know, how could they?

Breslin: You had the evidence.

Bristo: But then they protected him. And I did, for a while, think, well, maybe this was a cultural difference, that they just did things differently. That’s what they were telling me, that, “Shame in our culture is the most extreme form of punishment, therefore he’s already experienced it. And nothing else we could do is more than what has already been done, because it’s out.” And so I moved on to my next family. Then I lived in three other families after that, so I lived in four families, each one completely different, showing me a really different side of the
country. It was quite a year. I know these aren’t all important things—but they do add up.

My first real exposure to death there, my foster brother, not exactly, but in the big extended family, the kid of one of the adult kids, he was my age, or a little older, was a pilot with the air force, and he also was a recreational pilot. I wanted to go to the south of the Philippines, and so he surprised me, and not knowing that I had just planned a trip by boat with all the other exchange students—again, this is an interesting thing. I had all these opportunities to put my organizational skills to use—I planned this whole trip for us to go on a boat all over the Philippines, contacted all the other Rotary families to find places to stay, and got like eight of us to go on this trip. I was just what, seventeen at the time, sixteen, seventeen. So he came home one day all excited to say, “I planned this trip! We got the plane, we’re going—” And I said, “Oh, I’m so sorry, I just planned this other trip.” His plane crashed, and he was killed. And I lived with his family and went through his death with them. They kept the body on vigil for twenty-four hours. So that whole experience of death in a different culture, and family, and sustenance, and religion, that was really intense—and seeing it the way the Filipinos did—it was just such a different approach to death than the way we did it.

Breslin: Did he die flying the plane that you would have been with him in?

Bristo: Yes.

Breslin: So there was a certain amount of fate and paradox.

Bristo: Yes, oh!

Breslin: In the circumstances too.

Bristo: Yes. And you know, as a disabled person, you look at, like, I broke my neck, that’s a pretty big deal. But that and one other time in my life—that later I’ll tell you about—that I just should have been dead and I wasn’t, and then this happened. So I have a pretty heavy non-religious, but very intensely spiritual side of me. I am one of these people where—I know this is controversial in the movement—but I really do believe things happen for a reason. Not all things happen for a reason, but I do think that big things do. There is something bigger than all of us, sometimes, that puts us in places. I have always believed that I was put in this place for a reason. I know not everybody believes that. A lot of people think that’s really crazy, but in my heart that’s how I feel. Now, maybe it’s just the way I accepted it. But I didn’t come to feel this way until a long time later.
Breslin: This is hindsight operating to some extent, too.

Bristo: Yes, yes. Like all these things that led up to making me who I am, yes, there was a randomness to them on the one hand. But each thing has given me unique gifts and talents. And then to break my neck, it’s like all these things then came together and I was, I think, given a gift to do what I’m doing that was built upon all that preceded. And I think each one of us that have been real leaders, you’re not just coincidental leaders. Something, somewhere, contributed to you being one in the unique way you are.

Breslin: And as you get older, you can look back and analyze what has happened in a way that makes it make some sense to you, I think.

Bristo: Because a lot of it is just guts, right, it is courage. It’s standing up against criticism, it’s stepping out, it’s the time and energy. And then it’s tactical ability, it’s organization—it’s all these things. I’ve never thought about it the way you’re making me, but my planning those trips down in the Philippines took a lot of chutzpah, negotiation, we had to convince our parents, the foster parents, that we should be able to go all by ourselves.

Breslin: And in that culture it’s harder even than in this one.

Bristo: Oh, my. Yes. And while I was there I saw political corruption from the inside, right inside.

Breslin: What’s an example of that?

Bristo: The best example I can remember is after we saw the president, the day we all went and had breakfast with Marcos.

Breslin: Now, was this because your first foster family was connected to the Marcos family?

Bristo: No.

Breslin: Or was this part of the Rotary—?

Bristo: More part of the Rotary. But someone in Rotary was. It wasn’t him, it was someone. Even in his own country, Marcos at that time was controversial. You know, he had his “citizen police.” My foster father in my third family was one of those citizen police. Well, they were just vigilantes. He dressed all in white, he had his gun. At night he left home and he would go around the city with his gun. I don’t know what the heck he did. But I always thought it might not be good.
Breslin: Or maybe, well, it probably was legal, but definitely not good.

Bristo: Well, he was part of Marcos’s posse—

Breslin: Part of his system.

Bristo: —to keep people oppressed. And it was all fed by the American military. I mean, this was the deal that the United States had at this point. Marcos would let us have these bases as long as we’d let him do whatever he wanted. And you know, as history later showed, he just raped the treasury. And I observed it in these lavish parties that they would have. One of my girlfriends’ father was in the American military in Subic Bay, and I went up to her house for the weekend. We went out one night, and we went out to one of the military base bars. We weren’t supposed to, we broke all the rules. But oh, my God! The disgust I felt at watching American military servicemen with these young, thirteen, fourteen, fifteen-year-old nude dancers, putting dollar bills up their pants. Really! And then watching them take these teenage girls out, wherever they went, to do whatever they were doing with them, it was nauseating to me. Yes, it was no wonder when I came home that I was a different person. You can’t see all that and not feel like, “This is wrong, this is wrong.” No matter what we say in the name of defending democracy, there are big elements of it that were just wrong.

Another example was, after we had breakfast that day, one of the top members of their parliament cabinet, not cabinet, Congress, a member of Congress took us all out. We didn’t even really know where we were going but we were in one of their limos, and they took us into these illegal gambling casino places that weren’t supposed to be there but were. You had to kind of go through this little peephole door and they had to clear you in. And they gave us lots of money. They just said, “Here, here’s a thousand dollars, go have fun.”

Breslin: What on earth did you make of that as a seventeen year old, you must have been—?

Bristo: Well, having just left that family situation, what I made of it most of the time was that these guys were trying to get in my pants. So I was terrified. I lived with a certain sense of being sexually assaulted.

Breslin: Having to defend yourself against assaults, sexual assaults of different kinds.

Bristo: And it toughened me. It also was very socially acceptable—this is so bizarre. Men drank excessively. Women drank calamansi juice, except for us Americans, who they thought it was just culturally appropriate
to let drink. So the women never drank alcohol, but the exchange student girls were lavished with alcohol. So here I was at seventeen, I go to a Rotary event and they put a Jack Daniels down in front of me. And it was heaven, you know? Later, as I’ll tell you, I am a recovering alcoholic, and it contributed to that in some ways. I started drinking hard liquor early. Not all day long or anything, but in those settings. Nobody thought twice about it.

Then the final thing that happened, of course, was that the worst typhoon to ever hit Manila hit. Two, back to back. The first one came, and then the second one was even worse. Well, the first one happened while I was on that trip, on the boat. So it was like terrifying. My mom thought I was out on the open seas and was trying to find me through the Red Cross because the phones were out and there was no way to communicate. It took her two weeks to find out that I was alive.

Breslin: Were you actually caught in the storm?

Bristo: No, we weren’t.

Breslin: Too far south.

Bristo: But the funny thing is, I was pretty well sheltered. As I’ve told you, I had a driver—. And we wanted to be more independent, myself and my girlfriends. So I had finally convinced my third foster family, the old Chinese guy, who was the most conservative of all, to let me take public transportation. Public transportation in the Philippines at that time were called jitneys—

Breslin: They still are.

Bristo: They were carryovers from Jeeps, but they were really fancy, all decorated. And they’d have the locations of where they were driving. There are public ones and there are private ones, and they’re hard to differentiate if you’re a newcomer. So he had given me permission to take a jitney with my girlfriend from my current home to my former home. It was probably a good forty-five minute ride to get there. We left, and when we left he said to us, “The typhoon is supposed to come at 1:00, so just make sure you’re there by then.” That’s how commonplace typhoons are. He let me take my first jitney ride the day of the typhoon—but the typhoon came early.

Breslin: And bigger than ever.

Bristo: Oh, yes. So we’re out on the street. We’ve got our little umbrella that went, whoosh, right upside down. And we’re in the typhoon, and it comes first with just lots of rain, and then the winds come. So we’re in
the rain part first. So we’re like, “Oh, my God.” So we’re hailing a jitney. The jitney comes and we get in, and we’re taken off and it’s raining, and all of a sudden we realize we’re not in a public jitney, we’re in some private person’s jitney! In the middle of a typhoon.

**Breslin:** Which is totally forbidden, right?

**Bristo:** Oh, yes, you’re not supposed to do this. But now the roads are getting—it’s becoming impassable. So this private jitney took us to his mother’s house for tea to wait out the storm.

[Audiofile 2, Side A]

**Bristo:** Anyway, we finally made it to where we were going. But by the time we got there all the roofs were off. My home, the water was up to our knees. When we got there, every building—every, you know, like most all the fancy houses were wiped out. But like the hospital wasn't, the church wasn't. It was very bizarre. Electrical wires were everywhere. It was terrifying, just terrifying. So it showed me a national disaster in a way I've never, ever even since then.

**Breslin:** Never experienced, even here?

**Bristo:** No.

**Breslin:** I think that traveling internationally is the most transformative experience I can think of.

**Bristo:** Totally.

**Breslin:** For everyone, the younger the better, because it changes the way you think about everything you thought you knew about.

**Bristo:** But there's such a difference between tourist traveling and this.

**Breslin:** Oh, tourist traveling doesn't count.

**Bristo:** Tourist traveling, you don't come away with it.

**Breslin:** No, you have to travel for work or on exchange—

**Bristo:** Or with a family, or something that makes it a little unique. Anyway, so I was in the Philippines a year and during that year my sister's daughter was born. I missed the birth. Then it was time to apply to college. And of course I'm in the Philippines, and the college application process is happening, and my brother said he'd help. So he did a lot of the research and gathered up all these college catalogs and
sent them over to me, recommended schools to me. Strongly recommended that I go to a small school, both because he thought I'd fit in better since I had lived in small towns, but also because he thought I'd get better scholarships. So I applied to the four or five that he had recommended, and I ultimately decided to go to Beloit College in Wisconsin.

My reasons for going to Beloit were so ridiculous. I had come back from the Philippines a completely changed person. I felt like the world traveler. In its rawest form, young women my age in my hometown, when they graduated, there was so little there. Most of them either got married, and by then I was able to see that a lot of the marriages, not all, but a lot of them didn't work out in that era. Or they went into clerical jobs or other jobs that were not what I wanted. I don't mean to put these things down now. At the time, I put them down. At the time I thought, "That's not for me," I was better than that and I wanted something better. Now I look at it quite different. But not then. In fact sometimes I go back there and there's a nostalgia associated with the simplicity of life, the real sense of community and family that lives in small town America. And many of my friends made a really good life, so—. But then I just wanted to get out and go far away and felt like I was entitled to that, because I had just come away from all around the world.

So I had applied to these schools, not even really thinking of the geography. But I went to look at them, and—this is so funny— I'm almost embarrassed to admit that when I actually got in the car to drive to look at the school, literally, I pulled out the map and in my mind I was going to the state of Washington.

Breslin: [laughs]

Bristo: But really, once I pulled it out, "Oh, Wisconsin!"

Breslin: It was one of those "W" states. [laughter]

Bristo: Here I had been all around the world and I still had my American geography screwed up. So I was interested to find out I was only driving half way across the country.

Breslin: Let me just stop you there for a second, just one question in relation to the Philippine experience. Had you had any experience traveling in the US before you went to the Philippines?

Bristo: No.

Breslin: Had you traveled in the South or—?
Bristo: No. I had never even been on an airplane.

Breslin: So your trip to the Philippines was the first airplane—?

Bristo: Yes. And oh, I can tell you, my first airplane was one of those itty-bitty nine or ten seaters, in Utica, New York that took me to New York City, by myself. So I went up in one of those little itty-bitty airplanes terrified, all alone, in New York City, where I had to switch onto a flight to go to Las Vegas. In Las Vegas my aunt met me, she lived there. Here husband was the head bartender at the Sands Hotel. So that was my first travel, I went to Las Vegas to visit my aunt on the way to the Philippines.

Breslin: Had you been to New York City before?

Bristo: No. Wait, well, once. My brother, when I was sixteen, took me to New York City for a weekend. So I had been there once.

Breslin: Big US cities and, then, overseas for the first time.

Bristo: Yes. But I had gone to New York City, and I had gone to other little cities in, you know, Syracuse—but mostly with my family to a state fair. We went to Cape Cod, but with my family on vacation. Even our vacations were mostly family. We went camping, but that was almost the only thing we ever did. We did stay in a cabin once in Cape Cod. But the rest of the time we did old-fashioned tent camping, not with the fancy equipment. Up in the Adirondack Mountains. That was pretty much it, I lived in a very insular, upstate New York rural American world. So when I went to the Philippines I stopped in Vegas, went to one of the casinos.

Breslin: Casinos.

Bristo: My aunt dressed me up and made me look like I was old enough. Then got on the airplane after visiting Hoover Dam—the next day!—I got on the airplane and flew to LA and then to the Philippines.

Breslin: So you've made your college selection based on primarily your brother's recommendations.

Bristo: And the desire to be far away and have a different life.

Breslin: Right. Just the distance and difference.

Bristo: Then when I visited the schools, of all the other ones, Beloit was the furthest away and it was an alternative college experience. Beloit was not like your average college. It was very similar to Antioch. It
operated in a different way, it had trimesters. You spent the first three trimesters on campus. Then the next five, you did two vacation terms, two on-campus terms, and one field term—field study out working somewhere—and then the last three on campus. And field study was a very big part of it. And there were a lot of what you would characterize as hippies, and I would also observe psychedelic drugs. So, like, when I drove onto the campus, there were a ton of people tripping and doing all this stuff.

Breslin: So this was '68, is that right?

Bristo: Nope. I went there in '71. What happened, why my dates are a little confusing is because my senior year in high school was from '70 to '71. But that is the year I was in the Philippines, '70 to '71. When I got to Beloit, they have a big international studies program there, so they allow me to transfer most of my academic credits from the Philippines to Beloit, which expedited my graduation. So instead of being at Beloit for four years I was there for three. So I graduated with the class of '74, even though I really started with the class of '75.

Breslin: All right, let's talk a little bit about Beloit, because you had said that one of the most influential aspects of your college experience was being exposed to women's issues and a sort of feminist perspective.

Bristo: Right.

Breslin: Why don't you talk a little bit about what you were thinking about doing with yourself when you entered and being exposed to the feminist movement and any other influences that came about.

Bristo: I had no idea what I was going to college for, none.

Breslin: Well, you were trying to get away from home and—

Bristo: Yes, and get an education. But I was a real liberal arts person. I went to college at a time when it was totally okay to have no career goal. Remember, we're in the late sixties, early seventies, exploration, finding yourself. So there wasn't the pressure that kids have now to go in and have a career goal. Nobody did. We just all kind of went to school and hoped that while you were there [laughs] something would click. But I don't know any of my friends except for a few people on the pre-med track who knew what they wanted. Everybody else was pretty much there with the same sense. I wanted to have the college experience, get a good education, and use it in some way, but I didn't know for what.
What I recognized the day I got to college, however, which was very interesting, was that even with all this world travel I felt inadequate. Because I grew up in upstate New York in lower-middle class America, and at that time Beloit attracted kids from all over the country, and quite a few from around the world. They were rich kids, most of them.

Breslin: It was a private school.

Bristo: It was a private school. But there were some of us on scholarship. I was not psychologically ready for the fact that I didn't go the kind of high school where the kids had already read Homer's *Odyssey*. I didn't even know about it.

Breslin: Kids that had gone to prep school, probably.

Bristo: Yes, or like where my kids are going now. My son is entering ninth grade, his summer reading is the *Odyssey*. You know, I didn't even know that book existed by the time I got to college. My kid is reading it in ninth grade. So when I got there and they laid on the schoolwork, and everybody else seemed to have all this and I didn't, I felt just, oh my God, how am I going to compete here? So I went through this intense period of feeling just completely inadequate academically. Even though I wasn't. I did really well. I mean, I wasn't like an A student, but I was a B+, A- student. And I'm diligent and worked really hard. But I felt like I had to work for every grade. It wasn't easy for me. I did get good grades, and I worked really hard.

But I had another track in my life going. This is the part I don't know how much I want to go into. You said at one point you didn't know how frank I could be because you were the one doing the interview. There's elements of this that make me be more frank because it's you.

Breslin: Well, you should feel free to say whatever you like, and as I said—[tape interruption]

Bristo: It's no surprise that everybody during this era, and I'm sure I'm not alone in this, but there was a lot of drug experimentation, sex experimentation. It was, you know, the free love, try things period.

Breslin: It was the sex and drugs and rock-and-roll period in history.

Bristo: Yes, yes, and so I was definitely a student of that. So I had my daytime student self that was very diligent and worked really hard, and then my nighttime student self that was studying something else. And there was this big contradiction that coexisted in the same person. On the one hand I was a very serious student, and on the other hand I was
becoming a lush, I guess is the right word. I was usually the last one at the bar. We had a campus beer house—they don't exist there anymore, you have to be twenty-one now in Wisconsin—but at the time you could drink before then. So was the one that closed the town every night. I was also in work-study, which most of my peers weren't. So somehow I justified all this excess because, unlike the rest of the students, I also had to work. So it does make up who I am, in that I somehow was able to compartmentalize me and later on in my life I discovered that I had an alcohol and drug addiction problem. It was blossoming during this period.

It started earlier when I was, as I've mentioned to you—[tape interruption] But I was always able to drink more than everybody else, tolerate it better than everybody else. Never got drunk, because I was an alcoholic, right? When my friends were drunk, they would go home, or they would feel ill and therefore would stop drinking. I had such a high tolerance to everything, pretty much, that it barely affected me. And therefore, I got away with it for a very long time.

Breslin: Let me just ask you about that for a minute. Is that your retrospective analysis?

Bristo: Yes.

Breslin: What was happening for you actually at the time you were doing it initially? Did you have this insight, or were you going along with what everyone else was doing, or—?

Bristo: Did I know I was an alcoholic in the making? Absolutely not. What was happening for me at the time is that I worked really hard all day, had a job, and then partied like crazy at night. Drank a lot and experimented with drugs—but not as much as most of my friends. I didn't like psychedelics, so I didn't use them very much. Speed was, you know, all this stuff was a central part of college life then. Not a little part of it, at least in my school. It was as essential as turning in your papers on time. Whether you had pot, where you got your pot, it was part of the culture.

Breslin: I think so much a part of the culture that it's odd to even have any second thoughts about talking about it, but everybody does because there's now cultural opposition to it. At the time it was what distinguished us from the world that we thought was oppressive.

Bristo: What I find, as a woman, is that I don't have any problem talking about the drugs, maybe because I am in recovery—I mean, I've changed. But the sexual stuff, even though during that period it was very acceptable, people had multiple partners, you didn't have to be in love to be
romantically involved or have sex. So I didn't feel myself to be outside of the ordinary. But now that feels different. I don't know that people look back on women who were as sexually active as some of us were then in the same way as they look back at people's drug history. I'm not sure about that.

Breslin: Do you think that's a function of being a mother—does that have any relationship to that issue for you?

Bristo: At the time, no, I don't think it does.

Breslin: No, in retrospect.

Bristo: Oh, now does it relate now?

Breslin: Yes.

Bristo: Yes, sure.

Breslin: As a mother do you think your view of your own sexuality is different?

Bristo: Sure, because I feel different about it now. For all the time I was in it, I didn't have any regrets about it at all. In fact, you wore it as a badge of honor, because you were like guys, right? It was sort of the ultimate equalizer. If men could sleep with whomever they wanted with no commitment, so should women. It was a political statement on some level. And I was proud of it. Now I do think, in hindsight, back on some of the judgments I made then that I would do differently—that I wouldn't want, not just for my daughter, but for myself.

Breslin: So your current thoughts about your decisions spring from someplace other than being a parent.

Bristo: Yes.

Breslin: It's actually evolved—

Bristo: Evolution in me, yes. Things that I feel differently about. I do think that—well, and it may also be AIDS and other things—that the concept of responsible lovemaking wasn't there.

Breslin: It was just pleasure.

Bristo: Well, it was pleasure and a political statement.

Breslin: And power.
Bristo: Yes, yes. It was those two things. Now I feel different. Now I think that you have a responsibility to another person with whom you have been intimate—to how it affects them, not just you. And that, you know, I wonder how many people I hurt along the way. And certainly how many people hurt me.

Breslin: That you remember. [laughs]

Bristo: It has affected who I am, sure it has, because I was hurt a lot of the times along the way. But you went along acting like you weren't hurt because—I don't want to say it was cool—but because you weren't supposed to be hurt. It was supposed to be casual. But it did hurt when you really cared about somebody and for them it was just a one-night stand. So now I ponder about how many times did I perhaps treat a person that way and hurt them. I don't know. That has been part of my growth as a person in recovery, where you're taught to kind of take ownership for your actions and make amends for them and to try, as you go forward, to be a different person. And it's not laden with all this values crap. You know, it's more—What do you feel makes a person a good person? It's not that I think sex is bad. It's more how you treat your fellow person, and that that is an important demonstration of respect or lack thereof.

Breslin: It's more transcendental than the kind of cultural demands of the moment.

Bristo: So that was a big part of college, that whole experience, where the women's movement was really, you know, I guess it was youth and that the women's movement in my mind meant converting to sexual revolution, show your power that way. But I changed my views on that over time.

Breslin: What else stands out in terms of Beloit years that you recall as particularly important?

Bristo: In my own development, a couple of professors and several friends. I was a sociology major because of the impact a couple of professors had on me. The head of my department was a guy named Don Summers who was brilliant, just brilliant. He really made you think. He had us read what a lot of people would say are really esoteric readings, and force you to think in ways that I had never been forced to think before. That really affected a lot of the way I continue to look at things.

The other thing is the discipline of college. Beloit was a hard school. You had a hundred assignments going on at once. They weren't light. You had lots of books to read in the same week.
schedule—you had to get a certain sense of discipline to handle multiple priorities. I remember almost nothing I learned in school, you know. You ask me what books I read, I can't tell you. You ask me what were the main esoteric ah-ha moments, there's a few, but some of that's alcoholism, I don't have good long term memory on things like that anymore. But what I really learned is planning, how to set priorities, how to accomplish a lot of tasks at once, how to write, how to communicate, how to have a belief that someone else doesn't and argue my point persuasively. So those are the things I got out of college that have served me well here. Critical thinking, analysis—how to research an issue and delve into it—that's what I got more of than anything. Other than what I've already talked about this, it brought together parts of me and moved me towards Chicago, okay. And that's the biggest thing.

Breslin: So, it was destiny of some kind.

Bristo: Yes. I never wanted to live in a big city. Here, I'm a farm girl. I went to a college to avoid the big city. I went to a little school to not be in a big university. These were all life plans, right? I'm a small-town person whose life was destined to be in a smaller community and never would have picked Chicago. In fact, was terrified to come to Chicago. I had only been to Chicago once, other than at the airport and the place the bus picks you up to get you up here.

Breslin: [laughs] You hadn't actually come down to Chicago during your—?

Bristo: Oh, I forgot one other thing that's really big, most people don't know about me. God, this is so funny. My birth name is Marcia.

Breslin: That is a well-kept secret. [laughs]

Bristo: Yes, my birth name. When I got to college—remembering that the drugs, sex, rock-and-roll counterculture was going on and people had purple hair and your wardrobe was purchased at the Salvation Army, thank God—I never could have kept up as a kid without a lot of money on work-study. If I had to go to college now with the kind of wardrobe requirements, I would never have made it. Also, my brother's year, he had to wear a suit and tie to dinner in the dorms. So I was lucky in that respect.

We landed in O'Hare airport, and then we would take the subway. We had to get to Jefferson Park station, where the bus would pick us up, Greyhound bus, to take us to O'Hare. So at O'Hare they had upper-level students meet us. They knew when we were arriving. Then they took us to the bus, and then we took the bus up to Wisconsin together. The guy that met our group was this wild hippie with tie-dye
everything, whose name was—to this day I don't really know what his name was. I'm sure I did somewhere along the way, but I've forgotten it—Cinnamon Bear was his “name.”

Breslin: That was his name? [laughs]

Bristo: That was his name, and I never knew him as anybody other than Cinnamon Bear. And the people that were in this one circle, all had these alternate names. Which of course, in the sixties, people had alternate names. Not everybody—but they did, you know.

So when I got on the bus and we were doing our introductions, this guy said, "Okay, what's your name?" And I told him—no, he picked up the sheet, and he was reading off our names. He looked at my name and he goes, "Oh, that won't do. That won't do!" in his real exotic kind of way. So he anointed me, you know, like this—"I anoint you Marca."

Breslin: Is that right, that your name was changed in the bus on the way to college?

Bristo: Yes.

Breslin: I love it.

Bristo: Then when we got to college, he was one of the people that was supposed to be sort of the bridge between me and others. So he would show up at the orientation like a buddy.

Breslin: Yes, a big brother of yours, a mentor.

Bristo: And he had a small group of us. So as we were being introduced to the teachers and the other students I’d go, "No, no, no, my name is—" And he’d say, "No, no, no, her name is—" And so it just stuck. And it's a funny little thing because most people in the movement don't know.

Breslin: Don't know. When did you start writing Marca on your documents and your papers?

Bristo: You know what, I don't even remember. It had to have happened at Beloit, but I don't have a recollection of doing it. It just stuck. So, I mean, I will say, I had to have been receptive to it. I never grew up thinking I didn't like my name. It never dawned on me to change it.

Breslin: [laughs]
Bristo: You know, it just happened. It's the funniest thing because I don't even have the guy's real name in my memory to go back and say, "Hey, do you remember me?"

Breslin: But he's responsible for changing your name!

Bristo: If I could see the pig book, you know, the picture book, I could pick him out. Or I could probably track him down through somebody else. But Cinnamon Bear named me Marca.

Breslin: That is a great story. Well, you know what I think we should do—we have just about five or six or seven minutes left on this tape—why don't you say just a few words about the decision to go into a nursing program and we'll break, and then we'll revisit that after lunch.

Bristo: Okay. Well, this is short. It's what I said to you, I was really enjoying biology and women's studies. And a Rush University recruiter came to the college campus and was telling us about this program. Somewhere along the way nurse midwifery—remember Our Bodies, Ourselves—came to me.

Breslin: Yes.

Bristo: That book was out and hot. So I kind of wove it all together and decided, "Okay, I'm going to be a midwife." And it was like, click! And then I said, "Okay, how do I do it?" This opportunity was there, so I applied, they accepted me, and I came.

I came down here in order to get two years of nursing under my belt. I researched the midwifery programs beforehand, discovered there were two types of midwifery, lay midwife and degreed midwives. The degreed midwives—most of them have Master's degrees—would give me the widest range of opportunities to be in charge and not report to a man. This was all borne out of not wanting to be a doctor, because I didn't like the medical model of women's healthcare. Isn't that interesting? I was rejecting the medical model that had been done to women before I ever even knew about a medical model in disability. And Our Bodies, Ourselves, wasn't that Irv's [Zola] wife's—?

Breslin: I don't know, it could be.

Bristo: I think Irv's wife [Judy Norsigian] was very involved in that.

Breslin: Could very well be. It was the Boston Women's Health Collective that first put it out.
Bristo: Yes, and I think his wife was involved in that, maybe was one of the original authors.

Breslin: Very well could be.

Bristo: Funny how our lives come together. But that book was present and I decided I did not want to be part of the male medical machine. Therefore I would be a midwife. And I wanted to be a midwife that didn't have to take orders from a doctor. So I had concluded the best way to do it was to get a rapid Bachelor's degree so I could immediately go into a Master's program. What I wanted to do was home birth. So I was anti-establishment. And that's in the medical universe, I wanted to give women a different option for giving birth. I had never wanted a kid. In fact, I had, like all of us, I had gone way out of my way and used all sorts of birth control to not get pregnant. I never perceived parenthood in my future. I wasn't big on kids. But I was really big on this, and I thought it was something I would really love.

Breslin: So you applied and were admitted to Rush, and that's Rush University College of Nursing?

Bristo: Yes.

Breslin: And is it a stand-alone university, or is it affiliated with—?

Bristo: No. Rush University is a university. It is a medical university. It's one of the four medical schools here in Chicago. It's big, it's well known, it has got a huge campus on the west side. Its nursing school had died many years ago. It was like a hundred-year-old nursing school, certificate kind of program. And they had just regenerated it. So I was in the second graduating class of the rebirthed nursing school, and it was called the Rush College of Nursing.

Breslin: This was, again, in 1974?

Bristo: '74. So I moved to Chicago, entered there, where I continued on this anti-establishment path.

Breslin: [laughs]

Bristo: I mean, this is the little spark that traveled with me everywhere. From the day I went up in that tree, this carried with me. And some people say, "Well, how come you got involved?" Then I see all these other people who never get involved—they stay home. I say that some of it has nothing to do with my disability. It's either my personality, or my upbringing, or a spark in me, who I am, that preceded. And all of these
things made me who I am. But that activist spark, triggered by my brother in some ways and nurtured by my parents, who supported me and sent me off into the world, then made me question what I saw in the Philippines—

Breslin: It's was a package.

Bristo: Yes.

Breslin: It accumulates.

Bristo: I became very notorious in nursing school because I refused to wear a uniform. I felt it was a continuation of the stereotyping of women as servants to the male medical establishment. And I'm so proud, because nobody wears the uniforms anymore. They are just out. But I was the only one in my nursing school. My classmates, to this day, crack up because they say what they remember me for is that I refused, the whole time I was there, to wear a uniform. Never wore one. And that I used to carry my pen on a string of rubber bands. [laughter] In fact, in my psychiatric nursing rotation I got called into the office by the head of nursing and head psychiatrist. They never do this with nursing students, you know, you're just a piddly little nursing student. So I knew something was up. They called me in and they said—

[Tape Two, Side B]

Bristo: —“We understand that you have a problem with a uniform, but we've received several complaints and several of our male patients are having a gender identity crisis. Could you please lose the work boots?”

Breslin: [laughs] They couldn't live without the uniform!

Bristo: Because you remember in that era how women wore work boots, right?

Breslin: I do, I do.

Bristo: So I did, I gave in on the work boots, and I put on a different pair of shoes.

Breslin: All right, it seems like that's a good place to stop for a minute.

Bristo: Yes. [tape interruption]

Breslin: So Marca, why don't you just talk about whatever else you would like to say about the nursing school experience.
Bristo: That's where my other disability kicked in kind of full speed. During college I felt that my drinking was pretty much like everybody else's, and after college, during nursing school I started to become aware of the fact that I was drinking more than my friends. I wanted to stay out later than they did. [laughs] If I couldn't find somebody that wanted to drink with me I would have alcohol at home more, even when I really couldn't afford it. I sometimes would not feel great on the days of exams and things like that. But it wasn't at a level at all of thinking I had a drinking problem. Some of it is more in hindsight, too, that I think back on that period as out-of-the-ordinary drinking. I didn't do anything about it or even think I should do anything about it. But it was a period of time where I would go to school, study and drink in the evening, do my clinical, go home, stay up late and drink some more, and start all over again the next day. So that kind of rat race started then.

I ultimately graduated. We had some rebellion during the school years. I remember organizing a protest, five of us, against the dean when he was trying to do something, I can't remember. It had something to do with the fight in nursing between baccalaureate nursing versus associate degree nurses, and we didn't like what they were doing and protested it. So that little protesting continued even there. Myself and the four other women who I became good friends with were all a little outside the margins. You know, we were marginal nursing material. Very smart, but we were not your traditional nurse types in any sense of the word. We stood out, and we therefore magnetized.

I graduated from nursing school and went straight into a job right at the same place in labor and delivery. That was a period of time where I loved my work. It was really challenging. I never really liked the emergency side of labor and delivery, you know, but I loved birth.

Breslin: What's the emergency side, what is that?

Bristo: Crisis management, you know, I was so worried about the baby [laughs] that sometimes I didn't operate well under that kind of pressure. And I earlier said to you that I'm not very technological. It really became clear to me in nursing. The parts of it I didn't like had to do with the machinery. I didn't enjoy that. I liked the people part of it, and the human side of it. I loved the birthing experience, and I loved being right there in the middle of the action. But I didn't really like the technical stuff.

Breslin: The tools of the trade.

Bristo: Yes.
Breslin: Can I just ask you, you had originally thought that you would be a midwife, but it sounds like you found yourself actually in a traditional delivery setting there.

Bristo: No, you can't get into a midwife program unless you've done at least a year of labor and delivery or obstetrics/gynecology. So I was on the career path that you had to go through at that time. So I was putting in my time in order to become a midwife.

Breslin: I see.

Bristo: I hated the politics of the profession of nursing and—I hate to be so harsh, but I'll be blunt about it—the hierarchy where mostly women, nurses, did all the work and got almost none of the credit with very little of the pay. Now, I did like the sense of community that you found within the hospital, but not so much the profession. A hospital is much like a small town. You've got different parts of it. So there was a strong sense of belonging and identity that came out of being in one particular place, even in a place as big as Rush. I graduated from there. I'm working there, and I had been working there. You do a three-month stint over the course of the summer while you're waiting for your licensure—maybe it's more than three months, but you get a license called RN License Pending while you're waiting for your license to come back from the state. I did all the time at Rush in labor and delivery.

I then decided I was ready for a change, so I started looking elsewhere and moved over to Northwestern.

Breslin: When was this?

Bristo: '77. So I graduated in, it would have been in the summer of '76. I moved over in the summer of '77, like May. So I worked for about a year at Rush, then I came over to Northwestern to Prentice Women's Hospital here. I finally had my license.

Oh, I've got to back up. That's the career path. The social path, when I moved here to Chicago, I kind of left a lot out there. I didn't have any family here, and I couldn't afford an apartment here by myself. So I did what most young people did, I went to the Reader—Chicago's free weekly newspaper. [tape interruption].

During the period after I moved to Chicago to come to nursing school, I didn't talk to you at all about the social side of life and what was going on there. I didn't have a roommate, I moved out here from college. I escaped an abusive relationship with sort of the love of my life, a boyfriend, who had it in him but never demonstrated it until
once and then he did. That was really hard. Making me a statistic, because I guess most women have this in their pasts—a lot of women do—but most people don't talk about it. It has only happened to me once.

So I came down here and my first apartment was with that boyfriend. Then he moved; he had to go back to college. So I moved in with another friend from college and lived with her and her sister, and then needed to move from there because her family was coming back. I got an apartment—. So I kind of went from apartment to apartment largely with Beloit network people, but then eventually those friends ran out. Like when one of their boyfriends moved in, it was time for me to move.

So I went to the Reader and ended up in one of the suburbs for a while, and ultimately in the end wanted to be back in the city and started looking around for where to go. We had been hanging around after work in some of the clubs, and I made just an acquaintance with one of the bartenders. I was visiting a friend who owned a head shop at the time. And that bar waitress, who was a friend of hers, came in. I was standing there looking through the Reader for a roommate, and Jill said, "Well, I'm looking for a roommate, do you want to look together for a place to live?" So the two of us decided we would look for a place together.

Then we found a great place with three bedrooms for $300 a month, but we couldn't afford it. So we had to find a third person. So, I don't remember even where we found Delores, honest to God, but I think she answered an ad. So the three of us, Jill, me, and Dolores moved into this apartment on Lill Street. I became really good friends with Jill. I lived there for the better part of a year, before my accident, with Jill and Dolores. Jill remained being bartender at this bar called the Single File. At the Single File was this blues band that was really popular called Ójala who started to become part of my social network.

Breslin: Say it again?

Bristo: Ójala. I think it means dream, I'm not sure.

Breslin: Ójala.

Bristo: Yes. That band became sort of a galvanizing point for a whole network of us. We were friends of theirs. You might call us groupies, but we weren't. They weren't big enough to have groupies. We were just a social network. But we went there after work from my job. I worked the night shifts and we'd go over afterwards and hang out in the bar
and watch these guys. They were awesome. They were just wonderful. They played from place to place.

So I'm now working at Northwestern in labor and delivery, I've been there about a month, not quite a month. I had left my other job and gone on a vacation in between jobs. So I'm living with Jill, and I decide to take another vacation. The first vacation is not that important, forget that. But the second vacation, in between jobs I took six weeks off and decided to go traveling. I went out to O'Hare, I didn't know where I was going, I just had a credit card or a check, or money, I don't—probably traveler's check. Went out to the airport and looked up on the board and said, "Where do I want to go?"

Breslin: [laughs]
Bristo: Had my backpack.

Breslin: That's the fantasy fulfilled. [laughs]

Bristo: All by myself. Which was kind of bold for me, because I didn't really like being by myself. But I figured, okay, this will be different. Nobody else could go at the time, and I didn't want to not go because no one else could go. And ultimately decided I would go to Jamaica. So I ended up at the airport in Jamaica in line waiting to go through immigration. There were two, a man and a woman with backpacks, hippie-looking people, standing in front of me. They're fiddling through their stuff, and one said to the other, "Do you have the proof of where we're staying?" All of a sudden I went, "You need proof of where you're staying?" They said, "Oh, yes, they're not going to let you through unless you can tell them where you're staying. But it doesn't have to be real. Just as long as they know it exists, they're not going to check. So just tell them——"

Breslin: Give them a hotel name or something.

Bristo: Right. So they said, "You can just tell them you're staying with us." So I did, I said, "I'm staying at that place." They weren't staying there either. So we made it through to the other side of customs, and there I was standing around, and they said, "Well, where are you going?" And I said, "I don't have any idea." They said, "Well, do you want to come with us?" I said, "Where are you going?" They said, "Well, we're hitchhiking down the road a ways, and we're going to stay at this place." I said, "Sure." So I just attached myself to this couple, who weren't a couple. I thought they were. The guy ended up being sort of a boyfriend for the period that we were there. [laughs] They were chiropractors who were on holiday. I ended up having this incredible trip in Jamaica. We just hitchhiked all around. We did the old
Rastafarian thing where we hung out and listened to great reggae music. It was really a great experience.

The first vacation that I didn't tell you about was to New Orleans with Jill, where I had heard my first reggae music ever, The Inner Circle. And that's what ultimately took me to Jamaica. I thought, Jamaica, reggae, okay, I'll go there! So I'm now in Jamaica, and we were staying in the jungle under some trees. We put all of our backpacks up in the trees at night and during the day when we would go down to the city. And there was this big celebration going on. And when we came home one evening, everything was gone, or rifled through. My sleeping bag was gone, my traveler's checks were gone except for what I had in my pocket. It was really kind of devastating. So I decided, "I've got to go home."

So I went back to the airport, bought a ticket, but I didn't want to go home yet. So I went and visited my girlfriend in Boston. And—is this related to anything disability specific? Not really.

Breslin: It's fine.

Bristo: I went to see my girlfriend in Boston who was staying with a record company. They lived in a commune. It ended up, the musician that was staying there, ended up becoming really famous, so that's the little tangent there. Sort of really famous. George Thorogood.

Breslin: Yep.

Bristo: Yes. So I spent two weeks in Boston with George Thorogood and Sally, my girlfriend from nursing school, who was living in Boston, and going to Red Sox games—is it Red Sox? Whoever it is that plays in Boston, they were big fans—and becoming really good friends with them.

So then I came back home, started back at my new job and was still going out in the evenings to the bar. It was the weekend, and I was by then starting to feel as if I was in—I didn't intellectually get this, but—the rat race of work, party, work, party, work, party, which really meant work, drink, work, drink, work, drink. I was home that evening—it was a Saturday night—and I said, "I'm staying home. I'm not going to drink, I'm going to stay home and read a book. This would be good for me."

Jill and Curtis and Thomas, the musicians, and Char came in and said, "Come on, we're going to a party, let's go!" "Ah, I don't want to go." They said, "Oh come on, we're not going to stay very long." So I went. We went to this party somewhere on the north side of Chicago. I had a
beer or two, I wasn't drunk. I had a beer or two. It was quite boring, none of us were having any fun. So we left, and Char, the singer in the band said, "I've got to go get Chauncey." That was her dog. "He needs to go out for a walk." So we went and got Chauncey and decided to take him for a walk over by the lake. So we were out by the lake, and we were just sitting there—Chauncey was doing his business, and we went out on the end of the pier—with our legs dangling over the pier. And Chauncey comes running up, and the shoes that I've just hitchhiked through Jamaica in that were of strong memento value to me got knocked in the water by the dog. He just like bumped into them and they went floating in the water. I'm sitting up on the pier and I'm looking at those sandals thinking, "There goes all those memories." I didn't say a word, I just got up and took off my clothes—I was completely naked [laughs], in the City of Chicago up in Rogers Park. I can't believe I did this—and just dived into the lake. And the lake looked really deep—

**Breslin:** It *looked* really deep.

**Bristo:** It *looked* really deep. And later on, a long time later I discovered that it was like a foot and three-quarters, it wasn't even two-feet deep. But I was from upstate New York, there lakes were deep. I had really never even been in Lake Michigan the whole time I had lived here. I hadn't been swimming in it. So I hadn't understood that these lakes are shallow and have sandbars. We were far out on a pier, the waves were big, it was a warm summer evening. And all the signs were gone that said, "No Diving, No Swimming," and all the ones on the dock were faded. Not that I would have paid attention to them necessarily, who knows, who knows?

**Breslin:** You might have stepped in instead of dived in.

**Bristo:** Yes. Keep in mind that the pier was way up high. I mean, it was a big drop. You couldn't step in. So when I dived in, I didn't know what happened. I thought everything went black. But I felt like I was in total command of consciousness. I didn't feel unconscious at all. But it was dark. Now, maybe it was dark because I was under the water. And I had this awareness of being out of my body. Then I had this incredible flashback—like a movie of all these different things in my life—the little girl playing in the front yard under the willow tree jumping through the water sprinkler, my mom out milking the cows, all these little things, like a movie. I think that I was right at that edge between life or death, or I thought I was dying anyway. I might have just knocked my head and had a little concussion, who knows. But all through this, while it's going on, I'm aware of being a sentient being, you know?
Breslin: Was your head underwater at this point?

Bristo: I don't know.

Breslin: You don't remember.

Bristo: I had no awareness one way or the other. What I do remember is that all this was going on and I'm thinking, something's wrong, something's wrong. Then all of a sudden I see my friends up on the pier and they're all looking like this. [startled expression] Then I was aware I had gone under the water. Then I'm like, "This is not making any sense. Why am I under the water?" And I had this literal message—it wasn't God, it was me, saying to myself—"Bristo, you've fucked up this time. Get your act together. If you're going to get out of this, you've got to get in charge of your situation." It was like [snaps fingers] as if I was speaking to myself, it was a wake-up call to myself. I popped up above the water the second time and said to my friends, "Something's wrong, I need your help." And they just kept looking at me. Then I got mad and I said, "I'm serious! Something's wrong, I need your help." At that instant, my friend Thomas—I remember seeing him hold the deck, you know the side—lowered himself down—his feet weren't touching—dropping to the water. And I looked at him, and the water wasn't even up to his knees.

Breslin: Oh, God.

Bristo: Then it all came to me. Then, right then, what was so intense at that moment, I'm in and out of awareness, I'm having no pain or anything, but I'm commanding everything. [laughs] I said, "Just get me out of the water, and do it gently." So they kind of floated me up to the shore, which was a long float, and they got me to the shore and laid me on the beach, and they're all like going a little crazy. "Curtis," I remember Jill said "Go get the phone, call somebody." Then this medical student comes walking along the beach—

Breslin: Wow, that's amazing.

Bristo: By now I'm having little videos go through my mind. It's so bizarre, I'll never forget this. During my nursing, as a part of your graduation you have to do a major paper at the end, and I did it on diabetic ketoacidosis. In it there is a form of coma, and I was researching it. In the course of researching it I came across this old textbook that had two different forms of neurologic problems, decorticate and decerebrate positioning. It was an old medical textbook with those little medical drawings in black ink. I'm lying on the beach, Mary Lou, and these two little visual images of decorticate and decerebrate positioning came in my mind. And I looked down at my legs, I can't
tell you now which one it is, but I was doing one of them. My legs were up, and I knew, right then, your spinal cord, your spinal cord. So I'm laying on the beach being almost a nurse to myself.

Breslin: You knew enough to know—

Bristo: I knew that I had a spinal cord injury. The med student comes along, and I'm now kind of hysterical. But in between calm and hysterical, going back and forth. This guy comes over to me [laughs] and he looks at my friends and says, "I'm a medical student." And they were like, "Great!" He comes over and he looks at me and he says, "Well, if she's carrying on this much, it can't be that bad."

Breslin: Oh, that's good.

Bristo: And I just started screaming, "You mother—get out of here!" And he ran away. [laughs]

Breslin: Were you pretty really aware at this point of what was going on around you?

Bristo: Well, I remember all of this like it was yesterday, so I had to be aware. But what they report to me is that I was like lucid and then not.

Breslin: Not, yes.

Bristo: What then happened, Curtis had run to call the medics, and the ambulance came and they got me in it. I don't remember getting in. I remember being inside of it with my friend Jill, hearing the siren from the inside, feeling like you're in the siren, and looking at her just crying, and just, oh, my God, just crying. And I'm saying, "Jill, it's going to be okay." [laughs] And of course a lot of people relate to this where on some level you're already digesting it for yourself, and other people are freaking out, and you start taking care of them instead of you.

Breslin: Right.

Bristo: There was a lot of that in the early phase.

Breslin: Yes, it's true, especially in an accident situation where people think that they had some contribution to it even if they didn't.

Bristo: Or else they think, "Oh, my God, I could never cope with this if I were them," and they're projecting their reality onto your own. And in some ways it's worse from where they see it than where you are with it. Even at that early phase.
Anyway, they took me to St. Francis Hospital in Evanston to the emergency room there. All the while I'm saying, "I don't want to go to St. Francis. Northwestern has a spinal cord unit. I want to go—" "I'm sorry ma'am, we can't take you there, we've got to take you to—" I was kind of a pain in the ass from the minute I got in.

Breslin: It sounds like it. [laughs] You knew your own treatment situation.

Bristo: They got me to St. Francis, they rolled me in, St. Francis said [laughs] "She's got a spinal cord injury, send her to Northwestern." So they put me back in the ambulance and took me down to Northwestern. The irony is that when I got to Northwestern they pulled into the ER and they opened the doors and there is a doctor there, getting me out, and the doctor, this person looks at me and goes, "Oh, my God, Marca!" It was one of the doctors that had just finished her obstetrical rotation with me. I knew her. Her name was Jill, just like my friend, who was Jill. And she starts crying—of course she's taking care of the situation, but she has also got tears coming down her cheek while she's doing it. I don't even remember her last name anymore, I just remember feeling comforted that it was a human being I knew there and feeling like I was in a place I knew and that things would be okay.

After that everything went hazy. I went into the intensive care unit and then into the spinal cord unit.

Breslin: At Northwestern.

Bristo: At Northwestern. In an intensive care unit, that's where the medical model kicks in.

Breslin: Well, that's where you need the best work.

Bristo: Right. That's what I was going to say, I felt like they were awesome. Right down to bringing the telephone in to me and making sure that I was able to speak to people. Then of course the parade of loved ones start coming in. And the heart-crushing experience of looking at my mother, it makes me cry now to think how much pain I caused her. [crying]

Breslin: It makes me cry to hear you tell the story.

Bristo: Just the pain it caused her. [crying]

Breslin: So did she come out then to be with you?
Bristo: She stayed. Remember I told you I lived with some friends and she moved in with them. They became sort of like my extended family. It's so funny, I haven't cried about this in a long time. [crying]

Breslin: Do you want to take a break, or do you want to go on?

Bristo: A break. [tape interruption]

With my mom, I saw how much pain I had caused her. Even though it wasn't my fault, still it was my mother and the roles were reversed there. I wanted her to be okay. After all these years and all the pride and everything she feels about what I've done, I still know on that most fundamental mom level—

Breslin: It's still very upsetting to her?

Bristo: Sure, sure it is. Even though she totally accepts me without pity. There's none of that, I don't feel pity, none of that. But on another level it's her little girl, and for her to see something tragic happen to her, it's still upsetting—even after all these years of her knowing that not only am I okay, I can't even conceive of going back in time. I'm one of those radical people that if there was—like Max said—a pill, I wouldn't take it. That's beyond her ability to grasp.

Breslin: We'll stop one second, let me just ask you about the actual injury. You have a cervical injury, which—?

Bristo: Yes, I have a C7, C8 incomplete injury.

Breslin: That accounts for the hands.

Bristo: Well, C7, C8 accounts for the hands. The incomplete accounts for things like I have spasticity, and I have spotty sensation. None on this side, a little on this side.

Breslin: You're gesturing to your outer thighs?

Bristo: No, all over.

Breslin: Oh, all over.

Bristo: I don't feel anything on this leg at all.

Breslin: The right leg.

Bristo: On this leg I feel pins or needles or vibration when I do that.
Breslin: That's the incomplete part.

Bristo: So the incomplete means there's still some enervation but it's not very useful except in certain things. One thing for me that I always felt lucky about was in my vaginal area. I still have a lot of sensation, and that's really out of the ordinary I'm told for my level of injury.

Breslin: Yes, that's a bonus, if there are bonuses.

Bristo: I don't feel much anywhere around my breast, just a little bit.

Breslin: Were you involved with anybody, seeing somebody at this point?

Bristo: No. I was sort of not involved with anyone steadily. I had a lot of very good friends. The boyfriend that I had had from college, I was no longer with. So I wasn't involved with anybody. I had a person who was kind of a good friend who decided after my accident he would be my boyfriend. I didn't even really like him that much. But I was kind of, well, I don't want to say desperate, but needy, and he was there, and filled that vacuum for me.

Breslin: Yes, temporarily.

Bristo: He was kind of loyal and showed up. But then he did a really evil thing. He dropped me in the middle of this experience and became boyfriend to my girlfriend, which was really hard. Really hard. I mean, I didn't blame her, I blamed him. I felt like—A] I wasn't head-over-heels in love with him in the first place, B] he kind of filled this presence and was there for me and then he just sort of got tired of it and left.

Breslin: The reason I was asking the question was some people have relationship difficulty.

Bristo: That changed, yes.

Breslin: So from intensive care to—

Bristo: Okay. Then I went to the spinal cord unit, where the medical model really started to hit me. I didn't have the words for it, of course. Those words wouldn't come for a long time. But I just wanted to give you two concrete things that I went through.

Breslin: This was spinal cord injury unit at Northwestern, not rehab yet?
Bristo: Yes. First the internal journey that disabled people who are traumatically injured go through. Elizabeth Kubler-Ross's work on grief is partially applicable.

[Audiofile 3, Side A]

Breslin: You were talking about your loss.

Bristo: I was just saying that the experience, the grief and the loss that you go through when you lose a major body function such as walking and, in my case, bowel and bladder, there is a lot of grief. So you go through a lot of those phases. Except my experience, and what I think a lot of the literature later documented is that in Kubler-Ross’s type of grief, each phase has sort of a beginning and an end eventually. And when you go on living after something like this, they repeat themselves. So you move in and out of them, it's not as linear. What you find, though, is that you spend less time in each phase as time goes on to the point, at least in my own case, where it's infrequent now that I touch those phases. But they never entirely disappear, I've found. So I think when a person loses a loved one, eventually some peace is made and you're all kind of done. For me, I still go through periods of anger. Now I think the anger is more at the situation. But I have to be honest that there are times where I can't separate whether it's the anger at the world around me, or anger that I still have to deal with this shit.

Breslin: [laughs] Right.

Bristo: You know? And we don't talk about that in the movement too much, except when we're one on one like this.

Breslin: We talk about it a lot amongst small groups of ourselves.

Bristo: Yes, yes. You know, there's no need to let the universe in on all of that stuff. But I do think there is a need for us to let each other in on it. Because sometimes people get the impression that those of us that have jobs and work and live don't go through this stuff, but in fact, of course we still do. I think for new people coming up, now that there is a movement, they can sometimes get a false impression of us as no longer feeling the sadness or anger or denial or whatever.

What I have found is the periods shorten, and you don't cycle through them as regularly. For me, that's how it was. But during that early phase, you're just in the kind of catastrophe of the whole moment. But pretty soon I was able, on a very basic level, to accept it. I didn't want any baloney from the doctors, and they didn't give me any. I continued to be a nurse throughout this, which is both a good and a bad. I knew a little, but not enough. On the one hand, I became a much more
immediate steward of my own care. I paid much more attention to what they were doing. [laughs] I monitored them. I gave them a hard time. But I also took better care, I think, right away. I was active in my own care. For example, I have a catheter. I already knew how to put a catheter in. It was not a big deal. It was harder to do it through a mirror, but—

Breslin: It's not alien entity that you've never seen before.

Bristo: So there were certain things that I already had some grasp of that made it a little easier on the one hand. But it also meant that I was objectifying myself for a period. I kind of was my own patient.

Breslin: Let me just ask you about training in terms of being prepared for any of this, even if you were objectifying yourself. Did the nursing training give you any hint of what this might be about?

Bristo: No. During my education, we had one, as I recall, one-hour session on rehabilitation. And the person who came to talk to us for that hour talked about renal rehabilitation. Now, we did study what is a spinal cord injury, but in terms of the life after—nothing. So we got the medical stuff, but in a scant way. Then when we got to the rehab section, the person, the guest speaker who came in that day talked about renal rehab.

I did have experience, however, on the floor with things like the circoelectric bed. I operated them. So it wasn't as scary to me, because I knew, well, I wasn't going to fall out. I had put people in them and turned them around. I had seen Crutchfield tongs. I had never been around when they were put into someone, but I had taken care of someone with them. I knew that they come out. I knew that they didn't go into your brain, you know? So in that respect the knowledge was helpful for me. It wasn't quite as scary.

Breslin: Just describe the tongs a little bit. You and I know what they are, but for the reader.

Bristo: Yes. In the emergency room, at the very beginning they need to stabilize your spine. So during the period while they are both determining how severe the damage is and assessing do you need surgery or not, they need to stabilize your head and give you medication that will take the swelling down while they determine whether they’re going to put you in some sort of a long-term stabilization structure or whether you’re going to have surgery? Crutchfield tongs are these tongs with screws that are screwed into your head, off of which they hang lots of weight, like fifty pounds, I don't really know how much the weight is. But a lot of weight that
dangles and keeps your head perfectly straight. During that period, in order to not have you get pressure sores, you lay down on what looks like an ironing board, and the bed actually revolves on a wheel so that they can turn you from your stomach to your back without really moving you and without disturbing your neck. The weights stay on.

I went from Crutchfield tongs into what's called a halo frame, where I got four more holes in my skull, and you're put into a device that looks somewhat like a halo. You've probably seen them, but it's a body frame, four screws in your skull, and it's attached to a piece of Plexiglas—

Breslin: Like a modified Milwaukee frame, yes.

Bristo: Maybe, that has cutouts for your breasts. Now, this device is kind of important for two reasons. One, I never had a lot of pain, so I was really lucky. I just didn't have a lot of pain, ever, with all this. They put the halo on, and I had two horrible experiences with it. There was a doctor at Northwestern's spinal cord injury unit who was a world-renowned physician. He came on the floor one day and I had the halo on. It was relatively new. I might have had it on for one day. It looks like a big vest and it's lined with fleece, and your boobs hang out from it. I had no other clothing on, that's it. So I'm lying there—and during this period you also go between shivers and sweats. This is part of a high-level cord injury, you get cold sweats until the swelling goes down. It's the worst—if you talk to a bunch of quads they will tell you invariably, the worst part of breaking their neck is the sweats because there's nothing like them. There's no experience to compare it to that anybody else has ever had. It's unique to this. They're cold, icy, shivering, drenching body sweats. They also create a sense of confusion and disorientation when you're in them. They're just horrible.

So I was in the middle of one of these sweats. So I'm agitated to start with, and this physician walked in with a whole group of maybe eight or ten visiting physicians from I believe it was India; I'm not sure where they were from. He walks into the room, doesn't say a word to me, takes the bedcovers, pulls them off of me and says, "This is a halo frame." I'm a twenty-three-year-old young woman lying naked in great discomfort, and the doctor didn't even acknowledge I was there. I was not even a condition. At that moment I was a device. I had arm movement, so I pulled the covers up and I screamed at him to get him and his entourage out of my room. He was there at RIC [Rehabilitation Institute of Chicago] last night.

Breslin: Oh, was he? Have you had dealings with him since then?
Bristo: Oh, yes, professionally.

Breslin: Have you told him this directly?

Bristo: No, I have never told him this. But I have never let it go, I have never forgotten it. And there's a certain feeling that what goes around comes around. They, RIC, had this spinal cord injury grant—well, Northwestern had the grant. RIC was a part of the grant and gave the grant its genuine credibility. But the actual first applicant was Northwestern, so they maintained it all these years. When Judy Heumann became the assistant secretary at the Department of Education and Kate Seelman was the head of NIDRR [National Institute on Disability and Rehabilitation Research], they decided to infuse their grants with better peer review that had a consumer perspective in it, and better requirements for consumer participation in all their grants. And we, Access Living, which you'll hear about later, had been a part of their grants for several years. They were up for renewal and we were in it, and we had made the case that we were doing more work than they were paying us for. So we told them we wanted more money. RIC agreed, RIC built it in. When it came over to Northwestern, the Northwestern people cut us out completely. The grant went in, for the first time in, I want to say, thirty years, I don't know, a really long time, Northwestern lost this grant and were formally told that it was because they didn't have any meaningful consumer participation or demonstration of involvement in the project.

Breslin: As you said, what goes around comes around.


So that was experience one. So I went from being in this intensive care unit where people were really attending to my person even though I was amidst high technology. That was quite awesome. I didn't feel like an object even though my body, in some respect, was surrounded by this machinery. By the time I got to Northwestern there was less machinery, but I was made to feel like an object by this doctor. However, I will say that the staff there was wonderful.

And the second thing I wanted to reflect upon, which is the early experience of an acquired disability, was how much I didn't know about disability and how it came crashing down on my head. It doesn't happen in the first day, the first week. For me it was probably a week or ten days out. It was those late night hours when you're finally all alone and all your family has gone home and there you are all by yourself and you can't sleep. They had TV sets hooked up to these beds, and what are you going to do—lay on your stomach to look at
the floor or lay on your back and watch TV? So I was on my back watching TV. I was really depressed. It was one of the only times that I can really remember feeling sad and depressed. Depression wasn't the way I experienced this mostly.

I'm lying in the room watching TV, and a Breck commercial comes on. And there's this sexy babe in the shower—

Breslin: Swinging the hair around—

Bristo: Washing her hair. And the soap is falling off of her beautiful body. And I'm not aware yet of any body changes, but I looked at her, and I thought to myself, "Oh my God, I'm never going to be able to wash my hair again." "Oh my God, I'm never going to look like that sexy babe in the shower again." And I just started to cry. It was both a fear of losing my sexual identity, and I really did believe at that moment in time that I would never be able to take a bath again. So I was already beginning to think about the life after, before the institution was ready to answer my questions. They were nowhere near that, and that's why people talk about the medical model failing us. When you're living it, you don't think about rehab when you get to rehab, you're thinking about it right at the beginning. You may not be ready to take in a lot of instruction and training, but it's already happening, and painfully.

Breslin: You hadn't met a person with a disability who had been through this at that point.

Bristo: No, no, zero. And back in that era, even if they existed, you didn't see them on the streets in Chicago. They weren't a part of the terrain or the landscape.

Breslin: But I meant that there wasn't anybody who came to your room as a newly injured person to say, "I know you must think this is the end of the world, but here's my story..."

Bristo: No, it didn't exist yet here in Chicago. I will tell you, when I got over to Rehab later, some of the staff were making it happen, just informally. But there was nothing to make sure it happened for people. And there weren't what I call ambient disabled people. We just weren't out there, which we are now more. So on some level now, people have seen people in grocery stores, or going to the movies more than back then. Maybe still not enough, but you can drive through the city of Chicago and on almost everyday you'll see folks in wheelchairs on the street doing something. And wearing regular clothes. So you have some idea now that, "Oh, they must do it, somehow." But I didn't know at that time, I really didn't. And if you think back to the early history that I've talked about, those kids on those buses were taken
away to special places, the ones in the classroom were down this hall, so whatever was there was shielded from you. I didn't have the benefit of being exposed to it, which is why inclusion has become such an issue to the movement. Because there's the non-tangible aspects of including us that is a beacon of hope—well, not even hope, that's hokey—of practical reality.

Breslin: It's a normal part of the social structure.

Bristo: Yes. If you're shielded from it, you don't have any way of knowing anything about it at all. To me it hit home that day when I'm thinking, "I can't wash my hair now." Well, at that moment this cleaning lady came into the room. I'll never forget, it was a cleaning lady who came into the room. She saw me crying, put down her mop, and she comes over, she goes, "Honey, what's wrong?" And I somehow managed to get it out of me. And you know what she did, she sat down, she held my hand, and she said, "Oh, there, there." First off she just said "There, there," and she took the time to be a real person with me, and she said, "You know, I don't know too much about this, but Mary Sue [or whoever was on the nightshift] she does. I'm going to go get her." And she walked out and got the nurse on the nightshift and brought her in and sat her down. It turned out to be a nursing student.

Breslin: Oh, boy.

Bristo: A nursing student who—I know her now. Her name was Laurie Hardesty. I think she has got a different last name now, but Laurie comes in. Now she can bond with me on some level because she's a nursing student. She comes in and she goes, "What's wrong?" And I told her. She didn't know too much, but she did tell me, "I know that people wash their hair."

Breslin: She could confirm that!

Bristo: Yes. [laughter] And then she said, "I'm going to go get more information for you." And as only a nursing student would, she went out and came back in with all you ever wanted to know about personal care.

Breslin: Life after—the personal-care aspect—

Bristo: Just on one little narrow thing. And we became dear friends, really dear friends. She would come and see me. Even after she got reassigned she'd come back and visit me. When I moved over to the Rehab Institute she came all the time. Ultimately she got a job working at Rehab. I mean—and this is another thing that I'll later talk to you about—I didn't have the benefit of being aware of this at the time, but
the impact that these kind of life-altering events have on people around you—now, oh, my—it's so profound. Have you ever thought about that? The way you have touched people? I never tried, I didn't want to, it just happened. In this circle of my friends, this young woman went into rehabilitation nursing. The woman that was with me the night of my accident, the singer, decided—she was a singer, a bar singer, that's what she was doing—to go back to school because she wanted to become a midwife. Never even thought of it before my accident. She is now a midwife in Cleveland. Delores, my other roommate, decided she wanted to be a physical therapist and is now a pediatric physical therapist. Now, good or bad, I know that that is really incredible. It's not me, but disability can really change people. I only have the benefit of that now. Of course, when you're going through it you don't think of it like that.

Breslin: Yes, that's hindsight, but it's still important—there's a relationship between their friendship with you and your injury and the direction that their lives took.

Bristo: Right.

Breslin: Definitely a relationship.

Bristo: So it's now time for me to leave for the Rehab Institute—this is a great story. It's time for me to leave Northwestern, to go to the Rehab Institute. I have a roommate in the spinal cord unit whose name is Chris. Chris, I'm going to forget her last name for a while. But Chris has a spinal cord injury, she's five years younger than me, she's eighteen, she's from Joliet, and her parents are here. My mom ultimately needs to go back to New York. She's out of money and she's got to go back home. I'm now left here alone. I don't have any family here. Mom has gone back home. And Chris's mother, Joyce, decides she is going to be my "Chicago mom." She kind of takes me under her wing. So she's now got these two girls, and my mom is leaving. So we decide we want to be roommates at the Rehab Institute. We're both going over, and we get our room assignments before we leave. I've been assigned into a four-bed room without her, with three other seventy-year-old ladies. And I flip out. I am in tears. I mean, she's my anchor. This girl and her mom are all I have other than my friends. My friends from nursing, from labor and delivery, come in while I'm all pissed off about this. My nursing friends with whom I had been working with for only a month not even one month, go back over to Labor and Delivery all pissed off saying, "There's got to be a way we can pull some strings for Marca." So they're getting ready to arm this campaign against the Rehab Institute. What happens, they come over and look on the board and what's up there? "Monica Betts." The board is all the people who were having babies.
Breslin: [laughs]

Bristo: Henry's wife [Henry Betts, director of the Rehabilitation Institute of Chicago] was getting ready to have a baby. So they're now like— somebody said, "Well, Henry Betts is here, you ought to talk to him." So I now only know this from Henry. But the way it was described to me by Henry—whom then I had never met, I didn't know him from Adam, and I never knew he did this until a long time later—was that apparently they were rolling Monica from her room into the delivery room, when these three nurses surrounded Henry, who is all ready to go into the actual delivery with Monica, and said, "You've got to help our friend Marca!" [laughter] Henry says he leaves his laboring wife Monica, leaves her as they roll her into the delivery room, goes over to the hall telephone, picks up the phone, calls over, and says, "I don't know who this woman is, and I don't know what she wants, but do whatever it is she needs." And hangs up the phone and goes back in and Monica had her baby.

Breslin: And the room situation got resolved.

Bristo: Oh, sure. I'm now in the room with Chris. And the funny thing with Chris—Simmons was her name, Chris Simmons—was that I was sharing a room with her and she was a Jehovah's Witness. So the Jehovah’s Witnesses would come in everyday and pray over her to heal her. They always wanted to come over and pray over me, and I was more or less an agnostic, and so I basically said, "No thanks, thank you very much." Well, did I have my second doubts when Chris walked home and I didn't! [laughter]

Breslin: There was a miracle for Chris but not for you!

Bristo: But when I say walk home, I mean she walked home with those long-arm crutches that, you know, who the heck should be walking in them anyway.

Breslin: It's impossible to use them.

Bristo: Anyway, I'm now at the Rehab Institute, and I can fast forward through this. On the one hand, I was the “good patient” because I was performing well, doing all the things you are supposed to. On the other hand I was the ornery patient, because I was bucking all the rules as I had all my life, right? So they had curfew. "Oh, come on, why do we have to have a curfew?" So I broke the curfew every night, remembering that Rehab encouraged us to get back into life. Even though they had a policy against fraternization with patients, you start to become really good friends with your therapist, and so we'd go out all the time. You're not technically supposed to do that, but we did.
[laughs] So I would break curfew all the time after a while. My friends would come get me, we'd go out and party. I thought that was what real rehabilitation was, to go right back to what I was doing as if I wasn't disabled anymore. So I was on the outside pretending to be doing—well, not pretending—I was doing what you were supposed to, to get back into life. But what was going on inside me was, I was shrinking. I could just feel my world shrinking and me shrinking. By now you've heard enough that a lot of my social networks were around drinking and music. So I was going back to the same places with the same people, not total strangers, and being treated completely differently.

Breslin: Now, this was while you were still in rehab.

Bristo: Yes.

Breslin: So you hadn't had to deal with the transition to housing, and—

Bristo: No, I hadn't, not at this point. But at first you get the, "Rah, rah, here she is!" You know, the sort of—[sighs] you know what I mean, the sort of center of attention poured on you. For a while it feels good, but then after a while you start to realize you're not getting past that. You're still being treated, "Oh, isn't she cute!" Particularly the male-female dynamics were all different now. The very same people that used to hit on me and annoyed the hell out of me were now like looking over my head. I wasn't even there. Or I'd be there with a girlfriend, and maybe even a girlfriend that wasn't as attractive as me, and the guys would come over and talk to her, and I wouldn't even be there. They wouldn't even talk to me or look at me. Oh! It made me angry!

Breslin: [laughs] That's quite a shock, isn't it?

Bristo: For me, it made me angry. But I didn't know what to do with that.

Breslin: Did you understand it immediately?

Bristo: Yes. How can you not? I mean, one day one set of things are happening, and then the next day it's like you're not there. After the period of "Rah, rah, rah!" like, the homecoming queen phenomenon—once you get out of the hospital and that diminishes—you're not quite the center of attention anymore. Then you realize it was serving a purpose. It was filling up your emotional needs. You were feeling loved and attended to. When that left, there I was, kind of alone. I wasn't getting the normal social interactions and feedback like I used to, except from my really good friends or if I arranged the social event myself. But the stuff that I was getting—it stopped. I started to feel so
empty. But I filled it up with alcohol. And I filled it up with socialization that I created. I kept myself busy.

I jumped ahead. So I'm still at the hospital. The therapy stuff is pretty pro forma. I worked hard, had a lot of laughs and a lot of tears. The halo came off and I had to—well I don’t need to go through all that…

Breslin: It's the usual rehab I think. If there are any particular high or low points you want to point out, do, but basically I think it's pretty understood.

Bristo: Well, the high point was that I—[laughs] I'm not going to say the name, because the person still is employed here—but my absolute first sexual experience after my accident was with a person who worked here. I mean, we just like hit it off really well. Where did we do this? We borrowed somebody's apartment.

Breslin: You were still a patient.

Bristo: I was still a patient.

Breslin: [laughs] Good job!

Bristo: I was still a patient.

Breslin: Excellent work!

Bristo: And I have to tell you, I know it wasn't the first time this person did this. I didn't feel at all belittled or patronized or anything like that—it was totally sexual, sensual, and quite wonderful. But I could also tell that this person had been there before, because he knew things about spinal cord injured women's sexuality that I didn't know! And he showed them to me, you know? And I'm thinking, "Man, they should put him on payroll!" And for a while there was this whole trend of sexual surrogates, right? I haven't heard much about it anymore. But—I'm joking.

Breslin: Well, except that [laughs] it's one of the missing pieces in terms of rehab.

Bristo: Yes, and of course it's totally against all the rules. That's why I will probably, whatever you say, seal this part, because I don't want anybody to try to figure out who this was and get him in trouble. We're not close or anything, but we see each other still when I come around over here, and we always wink at each other. You know, it was a really healthy, wonderful thing. And I don't want to say I'm indebted to him or anything like that, but—
Breslin: It's a nice transition into understanding you can have your sexuality back.

Bristo: Yes, and it was a gift to give me even before I left the hospital. And you know, he wasn't doing it because it was a favor. That was clear to me. He was really attracted to me. And also being able to know that I still had it in me to reciprocate. Because I was, "How do you do this?" you know? And people don't still talk about this too much. I mean, you do when you're in sexuality workshops and stuff, but in the movement—

Breslin: Or you're sitting around the dining room table with your friends, but—

Bristo: Yes, or in those rare instances where people are actually there to talk about sex and sexuality. And I did a fair amount of that in the early years.

After I left here—well, let me talk about how I got out of here. Remember, my mom lives in upstate New York, my brother at the time was living in Phoenix, my sister lived in upstate New York. I had no family here. The apartment I shared with Jill and Dolores had seven steps to get in. While I was in rehab they had to move because they didn't have enough money to support it and they hadn't found a third roommate. So all of my stuff was put into the basement in storage. Therefore I was homeless while I lived here. The other thing I forgot to tell you was because I was in between jobs and my accident happened on May 29—my insurance at Northwestern was to kick in on June 1—I had no health insurance. There was no COBRA at the time. I had no health insurance when this happened.

Breslin: And this was 1977.

Bristo: Yes.

Breslin: Just for the record.

Bristo: So I came into Northwestern, and the social workers there immediately began the process of trying to sign me up for public aid. Of course they kept saying, "Don't worry about it, don't worry about it." But my mom and I were both going through this very expensive process not having a clue how we were going to pay for my stay on the—

[Audiofile 3, Side B]

Bristo: Spinal cord injury unit. The woman who lived upstairs from me in my apartment was a lawyer. I didn't know her well, but she had come over to visit me. She was a new lawyer. She came to me in the hospital and
said, "You probably have a personal injury suit here. Do you want to pursue it?" Well, I didn't know anything from Adam, and I said, "I can't think about that now." She said, "Well, would you mind terribly if I at least go gather the evidence for you so you can do it?" I didn't really know that what she was doing was ambulance chasing. [laughs] I really thought she was doing it because she was a friend. And she might have really been doing it for that reason. The good thing is, she went out that day—not the day after but within a couple of days—so this conversation actually had to have happened really quick—and took photographs of everything.

Breslin: No signs, no whatever, yes, all the right things.

Bristo: Right. She did all those things. Then I stopped thinking about it and told her to go away and leave me alone. And she did, she went away and left me alone. She asked me if she could interview people, and I said, "Sure, go ahead." I didn't even think of that for a really long time. Remind me to come back to it later because it's quite a few years later before I even start to be aware of it, even start to process it.

So it's time for me now to start thinking about leaving. I've developed a lot of friends here. I was kind of a unique patient because I was a nurse and I worked right next door. So the medical staff, the doctors who were next door were visiting, by now Henry had known who I was, even though he never really came to visit me to my knowledge; if he did I don't remember that.

Breslin: I was actually interested in having you reflect on your first relationships and interactions with him, but he was not your doc here, he was not part of your medical team.

Bristo: No, my doctor was a doctor by the name of Dr. Joel Rosen, and my resident was a Dr. Bill Adair. Bill is still practicing locally out in the suburbs.

Breslin: So you're thinking about getting out.

Bristo: Yes. It's time to leave, and I have not a clue where I'm going to go. So I said to my social worker, "What should I do?" She said, "Well, there's this guy that works on the—" gosh, was he on the ninth floor, the fifteenth floor, I don't know where he was, "named Jack. Go talk to him, he'll help you find a place." Well, this was the period that the Rehab Institute had hired Helen Goodkin, and Helen had just done this little book or was working on this little book called Access Chicago. They had hired Jack to run this project, a one-person project called Access Chicago, which is why Access Living is not Access Chicago, because we probably would have called ourselves Access Chicago but
it had preexisted and was gone by the time we came around. So he was in a little one-person office here somewhere in the building and he was in a wheelchair—. Oh, I forgot an important thing, I'm sorry.

Breslin: It's okay, back up.

Bristo: One day I was in my room and I had this great recreational therapist named Sharon Green. Sharon was a stitch. She was the funniest person in the universe. An African-American woman, we became really good friends. We maintained that friendship for a really, really, really long time afterwards. Sharon was dating this guy by the name of Jim DeJong. I never had heard of Jim DeJong. So anyway, I was in my room one day kind of blue, all lonely, out of my chair, just laying there, still not having a good grasp on what's going to happen afterwards when this guy rolled into my room really fast.

[interruption] So he comes zooming in like a whirlwind, and he comes up to my bed and he goes, "Hi. Sharon Green said to come by and say hi to you, so hi. I can't stay now, I'm on my way to the Bears game, but I'll be back, I promise. I've got to go." And he took off. And do you know it, that was it. I have to tell you, that was it. [claps hands] That was the moment in my rehab where everything changed. And all it took was a thirty-second interaction.

Breslin: Is that the first time you actually had met somebody from the outside world?

Bristo: Well, you see, I had seen them on the elevator, but they were a blur. I actually probably thought they were all patients. But remember, when you're in the hospital—look around here. What do people wear? Sweat suits, right? Stupid-looking clothing and sweat suits. So in my head I thought I was going to wear a sweat suit for life! [laughter]

Breslin: Still hadn't come to the fashion statements yet?

Bristo: And me, I'm still wearing this dumb halo, so I'm still looking like, atrocious at this point. This preceded the little sex incident. So Jim came in and said that, and I was like, "Whoa, who is he?" Well, Jim is very handsome and very friendly. He did come back, and he ended up being one of the people who I started, with Sharon and others, going out with and part of my tight social network at that point. That's where everything began to change for me.

Then around the same time that I was getting out, Jim Charlton was being transferred to rehab. Sharon called me and said, "There's this guy in the hospital. I think you guys might hit it off." So I came down and said hi to him. He lived in Wisconsin, and so he went home to Wisconsin after he got out, but briefly would come back for rehab
outpatient checks. So he called me up one day and said, "Would you mind if I stayed at your house?" So that started my really dear, dear, dear friendship with Jim, which has lasted solid as gold to this day. And Charlton during that period stayed at my apartment several times when he would come in.

Breslin: And he's currently—
Bristo: At Access Living.
Breslin: Access Living as a director?
Bristo: No.
Breslin: No.
Bristo: Jim was executive vice president and director of programs at different times, and then he decided he wanted to partially retire, so he works very part time. He said to me when he did that he was tired and burnt out, but he still wanted to stay part. He wanted to write novels, but he wanted to work part time. He said he'd do whatever I need him to. So he does special projects working in the development department primarily. But he sort of does whatever we need him to do.

Breslin: So tell me about Jack and escaping.
Bristo: Yes, okay. So that had happened with Jim. Then I got the referral to Jack, so I went up one day on my lunch break and said, "Hi, they told me to come here and you'd help me find a place to live." Jack said, "I don't know who told you that, I'm not going to do that, I can't do that. What I can do is give you this list of apartments, and you can go check them out for yourself." And I was so mad at him. This is where I get so in touch with all the people who get pissed off at Access Living, which they do all the time, because we're not doing what they think we should. I have to put myself back into that moment, because I was furious with Jack. I thought he was useless. "What the heck, why did they send me to him if he's not going to find me a place to live? That's what I need." Already I had become dependent upon the system to give me what I needed. And here, I'm the feistiest, demanding—but I truly did expect that that was just going to be there for me. First off, I didn't have any idea about accessibility. I just thought it should be a service that they gave me, period, "Thank you very much." Well, maybe it should, maybe it shouldn't, but what Jack was trying to teach me—before the idea of independent living existed, of course—was that if you do it yourself, you're going to be better than if I do it for you. He didn't have the places anyway.
Breslin: Yes, like there were a lot of choices.

Bristo: Right. So he gave me this list, and I looked at it, and I said, "I can't afford those rents!" Well, the list he had given me were the high rise buildings that were moderately accessible. Some of them had Section Eight. But the Section Eights were all full. So I immediately hit up against all the stuff that now has occupied a whole lot of living and breathing days. All the discrimination—I didn't see it that way yet, not at all. It just was problems, obstacles, problems. And basically, at that moment in time, that's where the macho part of disability comes in, when you're, in that era, taught, "You have to suck it up, accommodate—kind of adjust. Adopt a good attitude, and just move on, even though half the world is now shut down to you." And being a "good" patient or a "good" disabled person was to do it with a smile, and not be pissed off about it. They really drilled that into us in a subtle way, that to be a good patient or successful patient meant you were supposed to smile, have a good attitude, go on and tackle the world, and figure out a way to make it work.

Breslin: Yes, and tackle the world solo, by yourself, alone with no support and no recognition that the world is not necessarily going to be able to come around and do what needs to be done.

Bristo: Right. The other thing was, the moment in time I was in the hospital, healthcare wasn't in the crisis it is. I ultimately did get approved for Medicaid, just the medical part, not the benefits, just the medical part. It was now time—my rehab was finished. I was complete. There was no more they could do for me. Now, this is backwards now, totally the opposite now. My body was ready to go home, but I had no place to go. So my social worker, Jeanette Taylor, went to battle for me and said, "We need to let her stay longer." So they wrote up whatever they need to do to say I needed to be there longer, and they extended my stay by a month. They couldn't do that now.

Breslin: Yes, you would be in a nursing home someplace today.

Bristo: Well, to start with, I was already there for a solid three months. Now a person with my level of disability is out in a month.

Breslin: Yes, that's hard to imagine, but I know it's true.

Bristo: So you wonder why Olmstead is so important. These people, the well-intentioned people here—and I believe they are well intentioned—fail because A] the resources aren't out there, B] their social work staffs have been cut so far down, and C] they are squeezed in time to get people out the door so quick, they have no choice but to develop relationships with whichever is the best nursing home. And it sucks.
So anyway, I went up to Jack, "He gave me the list, the list was useless," I went back into his office and had a little temper tantrum and told him what good was he, what was he there for if he wasn't going to do it. He basically said, "Well, you know, have you thought of a roommate?" And I said, "Yes, but I can't afford these rents. And the people I know don't have that money." Remember, I was in the 100-a-month-bracket, $100.

Breslin: That was $100 a month, yes.

Bristo: Yes. So he goes, "Well, I might have an idea for you. Come back in a couple of days." So I went back in a couple of days, he goes, "Well, I don't know what you would think about this, but the woman who is the head nurse on the fourth floor is looking for a roommate. I think you guys might kind of hit it off. Would you like to meet her?" I said, "Sure," and I wrote down her name. And I just tucked it away, a few days passed and I ignored it. Then all of a sudden this woman walks into my room, "Hi, I'm Dina, Jack said we'd be a great team. Would you like to be my roommate?" And I said, "Well, okay." I mean, it was just like that. And we were fit to be together so well.

Breslin: It was a marriage made in somewhere, in heaven?

Bristo: Jack and Dina were in a romantic relationship, and she more or less had moved in. I think Jack may have wanted more independence than that. But I don't know if it was at a conscious level that this was happening. Ultimately they stayed together for quite a while, and then they broke up. We became, the three of us became really good friends, and I managed to continue my drinking at Jack's house on a regular basis. We watched three year's worth of losing Bears games every Sunday over lots of Jack Daniels.

So, the two of us got an apartment. And that was my first experience with discrimination, though I still didn't see it as discrimination. Remember, in those days places like this called them "architectural barriers," right? And "attitudinal barriers," right, those were the two things, if you came to a lecture they'd talk about. "The architectural barriers and the attitudinal barriers that disabled people—" as if no one owned inaccessibility, do you know what I mean? As if no one has responsibility—

Breslin: In some third dimension that nobody is responsible for.

Bristo: Yes. So we went looking for apartments, Dina and I. Dina was in some respects the very best thing for me. She was a rehab nurse of the hard-line type, you know, "Do it yourself." "I'm not—if you think we're going to move in together and I'm going to be your personal assistant,
you've got another think coming. If you need a PA, you get a PA. I'm going to do my share as your roommate, but I'm not going to take care of you." You know? And she was hard line about it. [stomping sound for emphasis] My week to wash the floor, "It's your turn, I'm not washing it for you." Now, she could get something out of the cupboard and all, but that was just what I needed. I could have just as easily slid into her taking care of me.

So Dina and I went looking for apartments. In addition to all the ones we just plain couldn't get in, we then started getting into the ones you couldn't move in, or they were great but I couldn't get in and out of the bathroom.

**Breslin:** Or you couldn't afford them.

**Bristo:** We had already bit the bullet on that. My grandmother had decided to give me a little bit of a supplement. Actually, it ended up going for a down payment for a car later, but not very much. And I had social security benefits that were going to start coming in. So I had a little bit—and all my friends, all my musician friends had done all these music benefits and raised money for me. So I had maybe about $2,000, finally, in a little bank account. I'll come back to them. Because I wouldn't have gotten through this on my income were it not for those friends who did all that stuff. So the third place we went to that I remember was perfect. There was absolutely nothing wrong with it. It wasn't really made to be accessible, but it would've worked. We went back down to say we wanted to rent it. And they said, "Oh, dear, you just missed it, we just rented that unit." We had just come off the elevator. There's no way in the world that they had just rented it. And Dina didn't buy it for a minute, and she started hollering at them, and they more or less threw us out of the building. There was nothing we could do about it.

Then the next one and the last one that I remember would've more or less worked, we were leaving the building, and the manager was overheard by us to say, "They're going to mark up the elevator." They whispered to each other. I actually remember that. You know, but again I just sucked it in, didn't think that there was anything really wrong with—well, knew it was wrong, but I just thought I had to accept that stuff. We ultimately found an apartment that we took the bathroom doors off of and hung curtains up, which in those days is what everybody did. In the early days, nobody ever peed in private. You know, it's a new thing for us to be able to pee in private. That's new. And that's something that I don't think the world grasps, how valuable it is to be able to do something as basic as urinating in private, because you've done it with a curtain or with the door open...
where everybody can see because you can't close the door. We still have to do that today in half the places.

Breslin: Where was your apartment?

Bristo: 345 West Fullerton.

Breslin: [laughs] You remember it!

Bristo: Well, I lived there forever. So Dina and I stayed there together for a really long time. That was a great experience and a great relationship. It was my first apartment. And life started slowly to come back together for me. I didn't have a job. By then—they had kept my job open for a while, and then they came over and said, "You know, we can't keep it open anymore," and they closed the job.

Breslin: How many months had elapsed from your injury to actually getting out of rehab?

Bristo: I was injured in May and I got out in October.

Breslin: Okay, so you're six months into the injury.

Bristo: And I'm out now.

Breslin: And you're out, and now you're thinking about working.

Bristo: And—no, I'm not thinking about working. Right now I'm thinking about how to get through a day. So—. My very first recollection of really sort of survival with disability was I had decided—I was lonely. I'm home, all the attention is kind of dying down. Your really good friends you still hear from, but not like you used to. And all the other people who were there through the crisis have gone back to life as usual. You don't have any more visitors, you're not in the hospital, you're not around people all day. You're home alone.

Breslin: And you can't get into people's apartments to visit, and transit is impossible.

Bristo: There is no transportation. I haven't even really gone out yet much. I have no way to get around, I'm dependent on my friends to take me anywhere, anywhere. So I decide, "Okay, this sucks. I'm not going to stay like this. I could sit here and just get miserable, but I'm not going to do that. So what I'm going to do is invite some people over for dinner." I thought, "Well, that will be good, because I haven't really cooked much in this apartment yet." So I invited everybody over. They all said, sure, they'd come. And I said, "Okay, now I have to go
grocery shopping." So there was a grocery store one-and-three-quarters blocks away. So I pushed to the grocery store and—here's the grocery store, here's an alley, I live over here. I come up, I got over to here, I'm doing okay, but I'm exhausted, because—

Breslin: First time on a street.

Bristo: It's kind of a hill. I get to the grocery store, there's a curb. I said, "Well, fuck that curb!" I was really mad. I said, "But I'm not going to let it stop me, I'm going to do this." That whole "grit your teeth, grin and bear it." So what do I do, I go out, go push around the block, come all the way over here, well, duh, there's another alley right here. The grocery store is in between two alleys with curbs. It didn't dawn on me.

Breslin: No driveways?

Bristo: There was a driveway. But it didn't dawn on me at that moment in time to go back to the corner and look to see if there was a curb cut. I didn't know that much about this yet. So I went home.


Bristo: And I had all these people coming over for dinner, and I couldn't reach them, and I went into my apartment and just started to cry. And you know that despondency started to set in, that, "How am I going to do this?" And my friends all came over and said, "Oh, no problem, we'll go get the groceries." So they went and got the groceries and one of them cooked. The good thing about that was that that started a Thursday night thing that went for years called the "Guest Chef" series at my house, where somebody—

Breslin: Somebody shows up with food or makes dinner.

Bristo: —brings—and makes it. And it became something everybody, eventually all my friends knew and all started to hear about and invite their friends, so my house became, at least once a week, the place to be. Because somebody would be cooking great food over there, and people, you know, "It's my turn next week." It started to become a social central. So I started to creatively weave together a social network myself.

And Sharon Green, the therapist, this is another byproduct of how the accident impacted other people. One of my friends from college, Michael Vadeboncoeur, had come to see me practically every day in the hospital. He was a good friend with one of those many Beloit College roommates I'd had in the city. We became good friends here in
Chicago, though we weren't good friends in Beloit. He lived here, I lived here. And Michael came—I don't want to say every day, but almost every day, and we became the best platonic friends.

Breslin: New people rise to the surface, isn't it interesting?

Bristo: Oh, my God. He was there all the time for me. He was, you know, my chauffeur, he was the person that when I needed something I knew I could always call on. When I was in the hospital and I wanted to get out I'd call him and he'd take me. He was just there, solid. Well, he met Sharon, and they fell madly in love, and they're now married with a fifteen-year-old.

Breslin: Fate. Synergy. [laughs]

Bristo: I know. It was so cool. So, where was I going with—

Breslin: Well, I think you were making the point that your house became a social environment and that kind of compensated for this business about—

Bristo: Yes, and then there was something I was going to tell you about what happened with Michael, and I don't—. Oh, okay, so now it's time for me to start really exploring life. And Dina and Sharon, these two rehab professionals who are really with it, who are now my main social network, start leaning on me. "Come on, you can do this," you know, they started getting in my face, and I'm starting to get pissed off at them. So Dina says, "Well, why don't you learn to drive." I didn't know how to drive. I used public transportation.

Breslin: Oh, you were not a driver before your accident.

Bristo: Never, never. And I'm chicken. I didn't want to drive, because I was a chicken. I didn't want to be a driver. I'm the only person I know that didn't like driving. In upstate New York everybody drove their cars really fast and often very drunk. It wasn't something I wanted to do. So I was loving public transportation, and we, of course, didn't have any that was accessible. So Sharon said, "Well, they teach driver's ed down at rehab." So I went back to my voc rehab counselor and said, "I want to learn how to drive," and they signed me up. And the medical vehicles, Medivans, would pick me up and take me down to driver's ed. At that time it was $100 to get in the Medivan, $1 a mile, $100 to get back in it, and another dollar a mile. So to get me back and forth for one driver's ed lesson was costing tax payers something like $220, every time.

Breslin: It was a medical visit.
Bristo: Yes. And the only way I could get it was as a medical visit. But all along I'm still just kind of going about life like this. So I learn how to drive. Joann Holmes, a rehab driver's ed person, taught me how to drive, God bless her. This is what gets lost when we try to convey what we mean by "the medical model." What gets lost is those incredible people who worked within a rehab paradigm, but who had an independent-living mindset.

Breslin: Well, they were on the same page in terms of trying to get you ready to be what you could be using the tools that were available.

Bristo: When you interview Carol Gill, or whoever does—

Breslin: Yes, I would love to, I'm not going to do it though.

Bristo: Oh, well, this is the one thing that is the biggest thorn in Henry's [Betts] side. We all joke about it but on some real visceral level the fact that we, the movement, elected to choose the language "medical model" and hold it up as the pariah broke his heart. And we've all communicated with him thoroughly about what this means—

Breslin: It kills him because he thinks it's so revolutionary and from his perspective a lot of it was.

Bristo: Well, no, because he thinks what we're doing is saying that medicine failed us—that they did it wrong. But they didn't get it.

Breslin: And, well, they didn't get it.

Bristo: They didn't get it. But they got what they did.

Breslin: They got the part they got, they didn't get the other part. Neither did we, for a really long time. [laughs]

Bristo: Right. But on some level when I weave this all together, Sharon and Michael and Dina and Joann all got it. Those people got it. They were my peer counselors even though they weren't disabled. They were the ones. They didn't get the full paradigm because they didn't get the barrier removal stuff. They didn't get the discrimination piece, but they got that you could go on with life after disabilities if you developed new skills. What they didn't get is at the point after which skills can't help you anymore, and there is still work to be done.

Breslin: The rehab process stops and there is still more out there—

Bristo: Yes, yes.
Breslin: —and they never really figured that out.

Bristo: And that's the part that Henry still doesn't grasp. Carol [Gill] wrote an article about this which caused Henry to write like a six-page letter to her.

Breslin: Is that right? You're talking about the paradigm article?

Bristo: Yes.

Breslin: Really?

Bristo: Or maybe he heard her give a speech, I'm not sure, ask her. But he wrote her this really long, stern letter, and they continue to talk about it. I don't mean they are still fighting over it. Ask her to see his letter; that would be a good thing to get into your archives.

Breslin: Well, it's interesting that you say that because I did this lecture here yesterday, and of course the Supreme Court decisions are a product of that model. The influence of that model throughout all public policy is obvious.

Bristo: And a lot of the people in the room still believe that those things are right.

Breslin: Yes. He was here and heard it, and I'm sure it must have hurt. I mean, I toned it down from its original iteration because I didn't want to really upset anybody more than was necessary, so I really did tone it down. But I knew that it was hurtful for him, I was mindful of that.

Bristo: I think he's gone beyond that. I think that he understands that, in spite of all that criticism, what he did helped get us to the point of where we are.

[Audiofile 4, Side A]

Breslin: Marca, we had just concluded talking about your experience learning to drive.

Bristo: The whole point of the driving experience of course was to start to re-expand my world, which had shrunk so much, as I described before. It took some pushing to get me to get the courage to do it. Also I wanted to try to get a job. I had a vocational counselor whose name was Tim Snyder here at the Rehab Institute. They had a state VR [vocational rehabilitation] person on-site full time here. So I'm a little confused on the chronology about whether this interaction around voc rehab happened while I was still in the hospital, or after I went home,
because once I got home I also had outpatient rehab. But the experience is the important thing.

I had gone through all the ridiculous tests that they do for vocational assessment and had said from the very beginning that my career goal had been to be a midwife. I had kind of taken a quick look at whether I could still be a midwife and got real with myself and said, you know, it really wasn't a realistic career goal, to be the kind of midwife I wanted to be. I recognized that maybe I might have been able to be some kind of a midwife somewhere in a high tech facility, not really doing the actual deliveries, maybe teaching it or something. But the home deliveries that I had wanted to do, I knew everybody's homes were not accessible. [laughs] They probably wouldn't want me as their midwife, and I might not be safe as a midwife, given all the weird positions you often had to get in.

So I reluctantly and very sadly gave up that career goal. It was a big deal for me. It didn't take a lot of time, but emotionally it was a real loss for me. Because it had taken me a long time to figure out what was I going to do with myself. I'm the kind of person who needs some sort of a goal, and I lost it. And I felt really adrift at sea with not a clue what I was going to do.

As I started reconnecting with my friends who were in nursing, they all kept saying, "Well, just because you can't be a midwife—you can still be a nurse." I, of course, came face to face with the fact that I didn't really want to be a nurse. I had never gone into nursing to be a nurse. But it seemed like my choices were limited, and it was better than nothing. So I went to my voc counselor and said I wanted to get my master's degree in nursing. Much as he wanted to be able to help me, he pulled out all the books and the policies and said, "Well, the state of Illinois doesn't pay for a master's education." I said, "Well, that's ridiculous." He went to some supervisor somewhere, and basically came back and said they didn't really think I had good career potential as a nurse—after all, I used a wheelchair. And that made me mad. This was probably my first real example of self-advocacy as a disabled person, but it was my personality and my history that got me to this point and made me do it, not any awareness of disability rights. I just said, "Well, that's ridiculous. What am I supposed to do? Go home and just live on social security? I want to work, I can do this." And then their evaluator said I couldn't, that there wouldn't be a job.

So I called up the woman who was my main obstetric-gyn nursing instructor, Nancy, whose last name I'm going to forget. She worked at a south side hospital where I did my nursing rotation for ob-gyn, I won't remember her name or the place right now. And I called up the woman who was the head of nursing at Northwestern, which was my
employer for only three and a half weeks, or thereabouts. I had only met her in passing in orientation, but she had come to visit me in the hospital because this whole network of nurses had told her about me. So I had gotten a little sense of her. And I went to Judy, whose last name I'm going to forget right now, and said, "Judy, I want to do this, and they're telling me I can't. Am I right, or are they right?" And Judy and Nancy independently said, "Of course you can practice nursing. You can teach, you can do research, you can be an administrator, there's a million things you can do as a nurse. That's ridiculous, who told you that?" I said, "Well, these people." She said, "Well, can we help you?"

So I came back to Tim and I said, "Tim, I want to fight this, so what do I do?" He said, "Well, there's this appeal process, and I'm more than happy to help take you through it." Tim was an enlightened VR counselor, who happened to have a disability too. He wanted me to win, and so helped me organize my appeal. I had to bring these people, Nancy and Judy, into a meeting with some high-up muckety-muck at VR, and they just bowled him over. They just came in and said, "This is the most outrageous stuff we've ever heard! Of course she can be a nurse! She's already invested in this. She's already become a nurse."

Breslin: "She's already a nurse."

Bristo: Exactly. They just shut them right down. I won my appeal and they approved funding for my master's degree despite the policy of the state, which was a big deal. Then I applied to master's programs, I got accepted at Loyola University where I was going to get my master's in maternal and child health. And I started back to school.

Breslin: Oh, you did.

Bristo: I did. I started in the Loyola University Master's maternal and child health program out in the suburbs here in Chicago at the main Loyola campus. In the interim I got my driver's license. So I now have a driver’s license. I have to remember the chronology here. This is really hard for me to remember. I did this backwards, I missed something. I forgot the part where I went back to work.

Breslin: [laughs] You have in '77—

Bristo: No, but I'm trying to figure out, when did I do the master's thing? Before I went to work or after I was working? It's a blur. Isn't that funny? I think I went back to work—. Yes, this is what happened, duh. I went back to the same people I had worked for and said, "I want to come back to work." It went up through the supervisor's channel, and Judy and the former supervisor [whom I didn't like at all when I
originally was over there] got together and said—Judy basically said to them—Judy Rice—said to the supervisor of the unit, "We want you to rearrange things here so that she can work here." So what they did in hindsight was ADA concepts. They did job sharing, they pulled apart several jobs, and put one back together, taking the tasks I could do and putting them in my job description, and taking the things I couldn't do and putting them in these two other nurses' job descriptions.

Well, it worked out great, because the tasks I could do were the tasks they didn't like to do.

**Bristo:** And the tasks that they liked to do, I couldn't do. So they created a new position that was a family planning and sexuality health practitioner, or RN; it wasn't a nurse practitioner degree. That's right, so I was back here working at Prentice, in the clinics now though, no longer in labor and delivery. I had gotten my drivers license in order to take that job. So between October, when I got out of the hospital, and January, when I took that job, I learned to drive. October, November, December, I'm taking driving instructions.

My grandma gave me a down payment to buy a little Volkswagen Rabbit, and I got hand controls on it. That's where Dina came in again to kind of give me the boot I needed. I got the car home, and I had learned, well, two things. I had learned to drive with power steering—well, they didn't tell me that Rabbits don't have power steering and, never having driven a car before, I almost totaled it the first—

**Breslin:** You've never driven, and you've never driven with hand controls.

**Bristo:** Well, I had driven with hand controls because that's what I learned on, but I learned with power steering and had never driven any kind of car before to know that there was such a thing as a car with no power steering or what it would feel like. But the Rabbit didn't have power steering and nobody told me that. So I got behind the wheel the very first day and went to turn the corner into this huge three-way intersection, and the car didn't turn! I'm like, "What's going on?!" Michael, that's where Michael came back into it. Michael was with me, and he just said, "Turn the damn wheel!" [laughs] He kind of lunged over and helped me get through that.

But then I got home after that daring first day out, and now it was time to figure out how to get the chair in the car.

**Breslin:** You hadn't purchased this car with an eye to whether or not you could get your chair in and out of it?
Bristo: No. Jack could do it, he had a Rabbit, so I figured I would be able to—[laughter]

Breslin: "Oh, I see. Okay!

Bristo: I wasn't smart enough to know I needed to do that yet!

Breslin: And they didn't teach you in drivers training how to deal with buying a car?

Bristo: Yes, they did. But I hadn't put two and two together yet. I just assumed all cars would work, and Jack had a Rabbit. It never dawned on me that some cars wouldn't work. Didn't even enter my frame of consciousness, and nobody told me that some cars would not work for my purposes. Fortunately, I was a good copycat, and Jack's chair and my chair were similar enough. So, with greater effort than Jack because I'm a quad and he's a para, I learned how to do it.

But the first day that we were out in my driveway, oh, my gosh, you would have thought I was a teenager being told to do my homework or something. It was really awful. Dina sat in that driveway with me, and she would not let me leave the car until I had done it. I mean, remembering this, it was really quite difficult—I was ready to completely give up, throw in the towel. I would have given up if it had not been for her really, really, in your face kind of way of encouraging me. So I did it, and then I was able to drive.

So I learned to drive so I could get the job. Then got the job. But the common theme here is, look, I'm putting myself through all this stuff that I would never have done before I was disabled. I never wanted to drive, now I have to drive. I never wanted to be a nurse, now I'm going to be a nurse. So the trend here is I'm kind of reforming my life rather than questioning everything. But up to that point I'm pretty much taking it all on myself. And that's what rehab kind of left me with.

Breslin: That's what it leaves everybody with, I think.

Bristo: Yes. Like you've got to go out and conquer the world. And never ever did any of this seem bizarre to me. It made me mad, but it just made me work harder, kind of motivated me on some level.

So I went back to work. I'm working in this women's health clinic, and I'm bored as can be.

Breslin: Now, let me just make sure that I understand the dates. This is 1978 to 1979?
Bristo: Yes.

Breslin: Is that right?

Bristo: Yes. Approximately January. I'm now back to work.

Breslin: So it's been ten months or so?

Bristo: Let's see, I broke my neck on May 29, and I'm back at work in early January.

Breslin: Nine or ten months.

Bristo: Something like that. And at first it was good because I was challenged. But you know, after a month, after two months, I had learned virtually everything I could about family planning. All the different kinds of birth control pills, and IUDs, and the risks—. And I'm dealing with an inner-city clientele that didn't really care about all those side effects and how this and that worked. So I'm like overkilling everything, right, because I'm so bored. I helped on some research projects, and I did a lot of sexuality counseling, abortion counseling, those kind of things. But after a while I was feeling so under-challenged and I also felt I just stood out like a sore thumb. I had my white medical jacket on, because that's what I wore at the time, and the doctors and the nurses for the longest time did not know what to do with me. They didn't know how to react to me. The doctor who was the director of the department, nice old gentleman, every single time he saw me for the whole time I worked there he would say, "Hey, you got a horn for that thing!?" [laughs] I mean, I really adored him on one level, except for I wanted to punch him on that level. I know he never took me seriously, even when I had serious things to say. I was a pretty good diagnostician. I had been an A student in nursing and was good at what I did. But I was overqualified for what I was doing, and I was so bored.

Out of the boredom, during the same period, the Rehab Institute of Chicago had started to set up an independent living committee. One of the nurses, who was my outpatient nurse, had been using me to see inpatients. She must have known enough about me as a person, as a disabled person, that if she asked me to come and do peer counseling, I would probably say no. So she asked me in my nursing role if I would be willing to come over and talk to some of the women patients about birth control. I said, "Sure, I'll do that." So that's how I met Susan Nussbaum.

Breslin: [laughs]

Bristo: She asked me to come see this "angry young girl." [laughs]
Breslin: I can imagine. [laughter]

Bristo: Well, you know Susan—she's kept that wonderful label—I mean, you've got to love Susan. I came over with my, you know, gizmos and my rap, and Susan took one look at me and said, "I don't want to talk to you! Who asked you to come here?" But we ended up over time developing a friendship. But when I think back on that, it was so funny.

I did have quite a few people over there who they would call me in on.

Breslin: You had said that you don't think you would have responded to the request if you had been asked to provide peer counseling, and why was that?

Bristo: Well, first off, there wasn't such a thing called peer counseling at that time. But if they had asked me if I would just come talk to another disabled person, I would have said, "I don't know anything. You guys have all the answers, I'm barely surviving out here." But they asked me to come as my professional self. I came into the movement through the backdoor. I came in through my professional self, not through my disabled self. When people say, "How do you get people in?" I answer, "Any way you can. Surprise them. Coax them. Fib to them." Whatever you've got to do. A lot of people newly disabled resist being anywhere near other disabled people.

That wasn't quite what was at play here for me, I didn't think I had anything to offer. This is my revisionist thinking now, I didn't understand it at the time. Now when I look back at it, I realize I was convinced that they were the professionals and I was the patient, that they knew everything and I didn't. So when they would ask me to these independent living committee meetings, I said no, over and over. Mary Keenan, an RIC nurse, would call me up every month and say, "There's another meeting coming up, you sure you won't come?" And I'd say no. I was very in touch with the fact that I wasn't going, primarily because I didn't think I had anything to offer, but secondly—I hadn't been honest with myself yet—I didn't want to hang around with those disabled people.

Breslin: Yes.

Bristo: That became really clear to me in the hospital. Even though my friend Sharon was a recreational therapist and we were really good friends, I never did anything with recreational therapy. I didn't want to go on those “out-groups,” where they would take groups of us to places, because people would stare. And I felt, well, bluntly, I felt like those kids on the bus that got shipped off elsewhere. There was something
about being in a group of disabled people that, for me, meant that you were more disabled. Or you must be disabled, that's really what it is. I was still, at this point, pretending I didn't have a wheelchair, and still sorting through it all. All my social friends were non-disabled people, all of them except for Jack Catlin, Jim DeJong, and Jim Charlton, and a little bit of Susan at this point. For some reason we hit it off as people and all became friends. So I did have a peer support network that was homemade and that worked for me. But none of them were any more in tune with the movement than I was, because it hadn't hit Chicago in any meaningful way yet, to be honest.

Now, there were groups of disabled people in Chicago at this time. I didn't know about them yet, but they were coming to those independent living committee meetings, and since I had never been, I didn't know that they existed. Margaret Pfrommer's group, COPH [Congress of the Physically Handicapped], was the biggest one. Augie Christman, Rose Wilson, Margaret Pfrommer, those are the people who I remember most in that little era. Then there were all the professionals—the Jewish Vocational Services, the Goodwill Industries, the Easter Seals—all these people. Several of them had been invited in by Rehab to help advise on this process. I didn't know what the process even was about, because I had never gone to a meeting.

Breslin: When you say Rehab had invited them in, you mean RIC.

Bristo: Yes.

Breslin: And are you speaking specifically of Henry, or somebody else?

Bristo: No. Helen Goodkin. Now, Helen, you have to get the history from them, but as it has been told to me, Helen was brought in. She had been involved with the Women's Board. She had been brought in to help the Institute begin to think beyond its own walls. So they did this accessibility thing. They worked on the first legislation for a state accessibility code. It was largely bricks and mortar accessibility stuff. Then Jack was hired and Helen worked with Jack, kind of. As Jack matured, Helen let go. So Helen then left, Jack ran Access Chicago. He started doing pretty much transportation and architectural advocacy.

Breslin: All right, stop for just a second and explain to me what Access Chicago is.

Bristo: It isn't, it's gone.
Breslin: I know. But what it was in the context of 1970-whatever, ’75, or ’76, or ’77.

Bristo: When it existed? It was an organization of one person, who worked for the Rehab Institute. It wasn't an organization, it was a program of RIC. It consisted of Jack Catlin. Jack was not yet an architect. He was a disabled person who was mentored by Helen and helped by some other people from the RIC Women’s Board, including the woman who later became the former mayor's wife, Heather Balandic. The women's board kind of launched a lot of these efforts, I think. And I'm not sure on that stuff because I wasn't around yet. But I can tell you what it did. Well, it did what Jack did for me. It was supposed to be there as a resource for housing, and it did advocacy on architecture, transportation, and curb cuts. Now, I don't know what was going on elsewhere, but my recollection of transportation in Chicago was that Jack was one of the early people talking about multi-modal transportation and that the system needed to be looked at as a whole rather than just its individual parts. So he did a lot of state lobbying, and public speaking, work with the city in the very early days before there was much that required it.

Breslin: Was Helen Goodkin a person with a disability?

Bristo: No.

Breslin: She was the women's board representative who was interested for whatever reasons—

Bristo: Well, I later discovered, many years later, that Helen had broken her back when she was younger. I think it was in a horseback-riding accident but I'm not sure. It healed and she walked away from it, but it left a lasting impression on her. She's a very smart—I'm trying to describe her—you might have called her a socialite, except that she was very smart and not the kind of woman that was just going to be a socialite. Fairbanks Place here in Chicago was named after her parents. So they were very, very well-to-do Chicagoans, her extended family was. Henry can tell you the details about it. They no longer are here, they moved, and a lot of the family resources have shifted around some. But Helen took an interest in this and I don't know what her early reasons were. I just know that when I first became disabled, after a while I learned that there was this person Helen. She was kind of a behind-the-scenes consultant that was organizing this stuff.

Breslin: It's just interesting that somebody who isn't directly invested in the issues, as a women's board member, that she would understand the interrelationship between access and transit and dealing with being disabled.
Bristo: I can't describe it to you, I don't know. She would be an interesting person for you to do a little mini-interview with. Because here in Chicago—you know, I think of her, more than anybody, as the founder of Access Living.

Breslin: She was the impetus.

Bristo: You know, I get the credit on a lot of levels and others take the credit, but Helen was the one hired by Rehab. So you can't take Rehab's role in this for granted, it was their vision to say, "We've got to do something." But when they first brought Helen in, before Access Living, I'm not sure what the motivation was other than I think her life had been impacted by her accident. Later her son was born with serious hearing impairments, so later on in life there were personal issues in the communication arena. But at this point in time, she had kind of backed off her role. Jack was hired, Jack was doing his thing when I broke my neck. Then the Institute had decided that they needed to do something about all the young people who were being sent to nursing homes. So they named it an independent living committee, and their task was to go understand this better and come back and tell RIC what they ought to do. And Helen was the lynchpin of the committee, and she had drawn professionals on staff—doctors, therapists, and a handful of community representatives—Margaret, Augie, Rose, Barbara.

Breslin: Barb Black?

Bristo: Black. I don't know if Barbara was actually in the committee meetings, I'm not recalling that, at the very, very early phases. But there were a small number of disabled people who had been going to these meetings, and I kept saying no. My reasons, as I said, were twofold. I thought they knew everything, but I had already summed up that I didn't really want to be in this club, thank you very much. My way of not being in this club was to try to “pass,” you know, like I could “pass,” right?

Breslin: [laughs] Right.

Bristo: I really thought I could! And all of rehab had kind of promoted, you know, go back to life as usual. But I really didn't want to be friends with other disabled people, except that small little group, because it smacked of institutional stuff.

Breslin: Why was that group exempted?
Bristo: I got to know them as people. We were contemporaries. We were going through the pain at the same moment in time. I recognized them as people who weren't disabled but who had just become so. And I had gotten to know them. They were my friends. But I will be honest, even in that early, early period, if there were four of us that went out in a bar, I would be self conscious about it because we took up so much space and I felt a little like everybody was gaping at us. On another level, I got a sense of power from it. It didn't matter if people weren't dealing with me anymore, because we were dealing with each other. So I was beginning to feel some of the power that came from that, but not on any deep level yet.

So I'm now at the hospital working in this job that I'm pretty bored with, trying to make work for myself so I could do something more interesting. And it must have been during the same period that I started to apply to graduate school, because I left the job to go to graduate school, that's the order that I was unclear about. But I'm still working at the job, and they had been inviting me to these meetings, and I said, "No, no, no." One day in the midst of one of those absolute boring days that I had, for reasons I don't understand, I started to write on my desk blotter the names of the disabled women that were coming through my office. At first I had no awareness of why I was doing it. A woman would come in with cerebral palsy, and I'd just write her name on my blotter. I didn't know why I did that. The next thing you know, another one came in. Then it became sort of an intellectual thing for me as a nurse, that maybe sexuality and disability or something could be a specialty of mine, that I could learn more about it. So I kept a list of all their names until I had twenty-six names down there.

One day, when I was in one of those bored moods, I asked the guy that pulled the charts to bring me all of their charts. He went and brought all twenty-six of them there and dumped them on my desk and closed the door. And I sat down to read all their charts. I had no idea what I was looking for. When all twenty-six of them came to me, all at once, and they were in a stack, I remember thinking, "God, that's interesting! There're a lot of disabled people that just came through here." Then as I started reading, the first thing that hit me was some of the women that I had seen had been referred to me, but they didn't need what I had to offer. They needed a different thing, in a different place. So that was puzzling. Why did they think they needed me? You know, like an eighty-two-year-old post-hysterectomy woman, who was in a wheelchair was referred to me.

Breslin: Family planning services would not be needed—

Bristo: And my note would say, "This person is here for X, refer to such and such." So obviously I had understood it as a wrong referral at the
moment. But this happened over months, so I hadn't pieced it together. Well, then what I understood, which was the most startling thing of all, was that this was a women's health center at a major health institution—the medical histories that we take for women include things like, "When was your last menstrual period? Are you sexually active? What kind of birth control are you using? Have you ever had a venereal disease?" We got through "When was your last menstrual period" and every question after that on almost all twenty six of them are blank.

Breslin: Were they sending these women to me because I had a disability too?

Bristo: Of course, that's what I came to conclude. But then you had to stop and say, "Why did they do that?"

Breslin: Because they don't know anything about what to do with them.

Bristo: And they thought maybe I did.

Breslin: And somehow you suddenly would, six, eight months into your disability.

Bristo: Now, on the one hand a good thing about that is maybe—and here I'm giving them a lot of credit—some of them honestly thought that another disabled person might be a better person to talk to these people, even if they didn't come in here for that reason. But there was no reference to that in the file. No one ever came up to me and said, "Marca, I'd like to have you talk to this person because maybe they'll open up to you." Nothing like that. Then what I saw on file was all these people who had been there, they had been signed in, and then nothing happened. It was as if they hadn't been seen. So I called them up—two of them, only two of them. It happened to more than two. I said, "My records show that you were here on such and such a date, but then I don't see any follow-up—this is a documentation program, could you tell me who you saw and when." "I wasn't seen that day." "Why?" "My Medivan came."

Breslin: And I had to leave.

Bristo: "And I had to leave." Then I would say, "How long were you here?"
"Well, I got there—"

[Audiofile 4, Side B]

Bristo: So then I went back through my memory bank, as I started to kind of reflect through reading the charts, and I remembered seeing people who had been sent home early. I remembered then being there late and
seeing people and going and saying, "What are you doing?" And they're saying, "Well, my ride came, but I was in the room and it left, and I don't have any way home." I'd say, "Well, what are you going to do?" "I don't know." So I'd scurry around and go make arrangements. But up to this point I just thought that was a random occurrence. Well, now I had it all in front of me that either the doctors weren't asking the questions, and who knows why, they were embarrassed, they didn't think we had sex, you name it, I didn't care. Or they got sent home, and when I figured out, when I started asking around, "Why did we send these people home?" "It's because we didn't have any staff to lift them on the inaccessible tables," or they were waiting for somebody to free up—we had one culposcopy table that came down lower, but not all the way, but that one was easier, and the culposcopy room was booked all day. So they made no effort to coordinate, well, if you know you're having a person come in, wait until the culposcopy is available to schedule her. They just brought her in, made her sit there, and sent her home when the van came. And I got pissed off.

I also remembered—and it's almost startling to me that this isn't what triggered me to do all this, but I don't remember that it was—a woman, whose name I don't remember, who was in her late thirties, who had very significant cerebral palsy, who used a Ouija board to talk with. She came into my office, and I was struggling to figure out how do you communicate with her. I had never seen someone talk like this. She got out her Ouija board, and she started to cry. I said, "What's wrong?" And very slowly, and letter by letter, she told me they had just done a hysterectomy on her and she hadn't wanted it.

Breslin: And she is thirty-seven, six.

Bristo: Well, maybe thirty-four, thirty-five. She didn't want it. I said, "Did you tell anybody?" And she lettered back, "I tried to. They didn't understand me." And why she signed the consent, which she had signed, I don't know. But maybe that's what triggered me on that boring day, subconsciously, to go pull all the files. Maybe that's why. I don't know where it happened in the sequence. But I so remember it.

Then, as I'm sort of saying, "Well, what do I do, what do I do?" Remember we are talking about the nurse in me here and the disabled person still hasn't entered the equation yet. Then I had this flashback to when I was a nurse over at the other hospital, and I was ambulatory. And the doctor on duty had just had larynx surgery, so he couldn't talk. He was writing notes, and he couldn't talk during that period. And I got a gravida five, a woman who had been pregnant and had had four babies previously, who was deaf and was assigned to me.
Of course I knew nothing about interpreters, never even knew the concept of an interpreter, I was that ignorant. Remember, I was from New York where we didn't have such things. [laughs] So she came in and she was assigned to me, and everybody said, "You take her, now be careful, because she has had four kids, so she's likely to go quick," because you have quick labors after four babies. I said, "Okay, well, what do I do?" I said, "Well, I'll figure it out." So I went in and we wrote notes to each other and we developed a system. But now remember the doctor couldn't talk and the patient couldn't hear.

Breslin: This was '78, '79?

Bristo: No, let's see. I graduated in '76, so this was '77 or '76.

Breslin: And did this woman use an interpreter or had she requested one of them be made available, or—?

Bristo: She didn't ask for one—

Breslin: She didn't ask for one.

Bristo: To my knowledge she didn't ask for one. She came in and she was ready to have her fifth baby, and this is the way she had managed other times. So we had this system of writing notes, and I had gotten all the notes that I knew I would need—"push," "don't push," "breathe,"—and they were all in my scrub suit pocket. Then the doctor, who couldn't talk, right, puts some notes in his pocket. It was kind of funny but extremely unsafe. Think about this situation—.

So one of our little systems was that she would clap [claps hands] when she thought she was ready to push—when the baby was coming and she knew it, because I knew she would know it. She would just clap in case nobody was in the room and nobody responded to the call. Dumb little old me went on my lunch break and forgot to tell the relief nurse about the clapping. I did everything else, but I forgot the clapping. So I come back from lunch and I hear this clapping [clapping noise], I went, "Oh, my God," I ran into the room, and the baby's coming right then. And it's just me in the room. And the doctor comes in, and he can't talk. I mean, this was extremely unsafe.

Now, I'm sitting in the office with all these charts, going through this memory lane of the people we sent home, the buses that picked these people up, the tables, and all of a sudden this deaf woman comes—

Breslin: Comes back into memory.
Bristo: And there was something about that, the differentness of that disability coming into my memory that just [snaps fingers] snapped me into consciousness, and I thought, "This could be me." Isn't that weird, that it was this memory of a deaf woman, in the face of all these physically disabled people. There was something about that cross-disability common experience of bad medical care just because you're different that all of a sudden hit home. That was the first time that I really felt real injustice—*injustice*—because I was disabled. And I was pissed off. I took the charts and I went up to the nursing supervisor, to Judy and this Angela, other person, Angela Jacoby, and said to both of them, "This is wrong." I showed it to them, and Judy, who had proven herself to me already by then by recasting a job so I could come back to work—she is the one that I pulled in subsequently when I decided to go back to graduate school to tell them I could do the job—Judy took one look at it and she goes, "This is really terrible."

Breslin: Wow, that's terrific.

Bristo: She said, "We have absolutely got to do something about this—this should not go on in this institution." Then she looked me straight in the eye and said, "Will you help me fix this?" My nurse self, of course, said, "Yes, I will." About a week later, I don't know if it was me or she, but one of us came up with a brochure on a conference in California on family planning, sexuality, and disabilities. Either I went to her or she came to me and we agreed I would go. They would send me out to this conference.

So I went to California, I think it was my first airplane ride, the first one that I can remember taking.

Breslin: As a person with a disability.

Bristo: Yes. So, of course, that was quite the ordeal, you know, how do you do this? I knew nothing about what I was doing, and it didn't go real well, my first trip. The wheelchair went to the baggage claim department, and they took me through the airport on one of those big electric cars, and it was kind of awful. But I did it. And it didn't occur to me that it was awful. Just, I thought this is the way people fly if you're disabled.

I showed up, however, at the meeting. I don't really remember how I got from the airport to the hotel. It was in Berkeley, I don't remember the ride there. But I remember being in Berkeley, and you guys were already hard at work. I remember getting into that city and going, "Whoa! This is different." Now, this would have been in '78.

Breslin: Do you remember the time of year?
Bristo: It was warm weather, it was a summer or a fall conference. It was at, I think, the University of California, Berkeley. Simi Linton was one of the main speakers. And, oh, wow! It was like, oh, I found my home! [laughs] We sat up all night talking about sex. [laughs]

Breslin: You actually hadn't talked to any disabled women before, had you?

Bristo: No. No. I mean, I don't think I had. If I had, I don't even remember them. Susan. But see, I was supposed to be—I was there as a nurse.

Breslin: But that's the nurse-patient relationship.

Bristo: Right. But no. I talked to my roommate, I talked to Sharon. So people who understood, I had talked to them. Sheri Tucker came into my life, but I don't think yet. She came later. And Sheri was in her own struggle at this point

Breslin: Well, you hadn't talked to a group of empowered disabled women.

Bristo: No.

Breslin: Ever.

Bristo: No. Well, empowered disabled people.

Breslin: People.

Bristo: Except for the Margaret Pfrommers, and they had their own way of doing it. But it still wasn't where we are now, do you know what I mean?

Breslin: Right, yes.

Bristo: I give them all the credit in the world for what they did when they did it, but it was still not quite the full paradigm shift; it was a part of it, the beginning of it.

So out there, what struck me at the conference was many things. First off, several speakers were people with disabilities. As I remember, when I looked at the program and they showed you who the faculty were, at the end of the day I went, "Oh, the disabled women were also on the committee that planned this." So all of a sudden these light bulbs are going off, and I'm understanding these invitations from RIC to come on the committee. "Maybe I do have something to offer. And they're doing it out here. They're doing the training."
But it really was that evening in the hotel room, as we sat up all night talking about—not just sex and disability, but about how they didn't get it—all that stuff started to sink into me, that I had something that they didn't have. And that is what I now look at as the beginning of weaving my old self and my new self together. Like, there was the old one and the new one, but they hadn't connected. It was Simi and the people at that conference that, like, put the first stitch in, and I started to see this estranged person, me, who didn't feel estranged.

Now I look back and say that I was trying to be my old self in my new body, and there really had been a change in self. I was still all that I had been, but I had gone through a change, and now I was different. Not just that I couldn't walk, but there were new things that had happened to me and I had had no way of integrating them. And it was other disabled people that gave me this—it wasn't some book I read about independent living. It was living that experience that taught me the power we had in ourselves. It wasn't just that we were powerful and had something to give each other; it was so much more than that. It was that these other people couldn't do this even if they tried. There was a point past which empathy didn't matter. Sharon and Dina were the absolute most empathetic people I've ever met, who understood the disability experience as close as a non-disabled person ever could come to it, and they couldn't give it to me. You know, they couldn't give me what these people gave me.

So it was that experiential-personal part. Then it was going out to eat at night in restaurants and having curb cuts everywhere. But I was still not altogether with it. It wasn't until the airplane ride coming home that it all pulled together. In that sky, in that little space between California and Chicago, the whole thing pulled together for me. And when I landed I was complete. [in tears] It was like I came home. What was so wonderful about it was all the things, like the curbs at the grocery store in that story, I never thought that you could get rid of them. It never dawned on me.

Breslin: [laughs] Why would it? You know?

Bristo: It never dawned on me.

Breslin: It never dawned on anybody.

Bristo: We even had curb cuts in downtown Chicago at the time. But I had never been to downtown Chicago. Why would I go there? I didn't have a job, I couldn't get there.

Breslin: Well, you had been, as a non-disabled person, but you never noticed.
Bristo: But hardly ever. I was a young—I mean, I never went into the Loop, much if ever, for anything. Not even shopping, I didn't have that much money. It wasn't a place where people of my age ever much ended up. So I didn't really even know that we had curb cuts in any meaningful number here. And the few that we had were so inconsistent that they had made no impression on me at all.

Then the big thing, of course, was going out to dinner and being in a restaurant, and all those little things that now seem like, mostly they seem like fragments of history because they don't happen as much. These memories came to me on the airplane—that same little movie that I've talked about started playing, but with different frames. This one was about going out to dinner and everybody uncomfortably looking at you and pretending they aren't. And you ignoring them while they're all gawking at you. And you're pretending that you're not seeing them stare at you, but you know they're staring. And sometimes when you were in a humorous mood, you might just go like this, and catch them. [laughs] And do it on purpose.

Breslin: [laughter] Yes, of course.

Bristo: I did have a sense of humor in all of this. I haven't talked about it, but I would do goofy things like that to people, you know.

Then the experience of people, the waiters saying, "What would she like?" That happened all the time in Chicago. I wouldn't say every time I went out, but every other time I went out, I would go out and they'd say—unless you were right near RIC where restaurants were frequented because of the hospital—anywhere else that would happen. Or the times I would have to go to the bathroom while I was out and I couldn't; that came into my mind. All the nightclubs that my friends went to, that I had to stay home on that night.

Breslin: Because they were inaccessible?

Bristo: Yes. God, all these different experiences. And one that I haven't talked about. It happened right after I was out of the hospital. There was a bar on Lincoln Avenue. I went in with two friends. I don't even remember exactly whether we went in to buy a bottle of wine or what. But we started in to the bar. And the bartender jumped from out behind the bar, stopped, kind of met us at the door, looked at the two people with me and said, just like this, "You and you can come in, you, you've got to go." I said, "Huh?" I mean, I thought he was joking or something. I said, "What do you mean?" He goes, "I don't have insurance for people like you. If something happens here, it's on my butt," or something like that.
That day when I went out of the bar, I was so mad that I burst into tears. I don't cry too often, which you wouldn't know after today, because I've been crying all day. [laughs] But I really don't cry very often over stuff like this. But I burst into tears. I came out of the bar, I was so raging mad I just burst into tears. And I happened to come out of the door right at the moment that one of Chicago's finest, a Chicago cop, was walking right there. He looked at me and he says, "Is there something wrong, honey?" You know, he used some little word like that. And I said, "Actually, there is." I, in a kind of raging kind of way said to him, told him what happened. He says, "Come on with me." We walk back in the bar. The cop goes up to the bar, the bartender, he goes, "What would you like here?" I told him I wanted white wine. He said, "Give the young lady two white wines." And the guy reluctantly pulls two glasses up. He goes, "Nah-ah. Give her two bottles of white wine." And the bartender looked at him, comes over and puts two bottles of white wine on the bar. He goes, "Thank you very much. Do you want to drink them here, or do you want to take them with you." I said, "I'd like to take them with me." We walked out with these bottles of white wine.

You know, I looked at that as wrong, but not as unjust.

Breslin: Well, there's no context in which to place the experience, it's very hard to analyze it out of some bigger context.

Bristo: And when I said that I didn't get depressed too much, I was too angry to be depressed. So for me there wasn't a big leap eventually from all my background into seeing this, but somebody had to put it there for me. But the real trigger, and this is so comical—I wish I had kept it and I never did—there was a pamphlet at this family planning—a pamphlet at this conference, called "Towards Intimacy." It was put out by the Planned Parenthood of Snohomish County. It was all about birth control and disability. It was a pamphlet that was this—you know, fold that sheet over, half the size of an 8 1/2 by 11. At the very end of the book, I flipped through it, at the very end of the book there was an appendix. And in the appendix was a paragraph describing Section 504 of the Rehab Act.

Breslin: [laughs]

Bristo: I found my civil rights in the back of a family planning book.

Breslin: That's a story you've told a lot, isn't it? I mean, it's one of those amazing—

Bristo: It is, but—
Breslin: —unexpected coming together.

Bristo: But imagine, that I had to go across the country to a health care professional conference far away from the world's greatest rehabilitation hospital to learn that I had a civil rights law that protected me. So when I came back here, all this came into focus. You know, that curb and everything. I landed on the ground ready to go. The next day, by coincidence, Mary Keenan called me back again and said, "There's a committee, are you sure you won't come?" And I said, "Yep, I'm coming." I went, it was actually on this floor.

Breslin: Of this very building.

Bristo: Of this very building, at the end of the corridor down there. I came late. There was a group of people in there and they didn't know me, except for Mary and a couple of the therapists. There were a few disabled people there, I don't remember which ones that were in the room on that day. And they were pretty far along in this process. They had just completed a needs assessment. They had decided what they were going to do was replicate the—I don't know that they had ever researched this yet, come to think of it, they hadn't gotten this far—gosh, I'm not sure—but they were going to build a transitional living facility. They had the blueprints, they had the building identified. It was the Lawson YMCA on Chicago Avenue. They were going to take several floors of it and convert it into a transitional living facility for disabled people.

Now, at the time the Lawson Y was in a really yucky neighborhood. It was occupied mostly by winos. So just on that basis, it wasn't the kind of place most people would probably want to live in if they had a choice. But I sat there in the back of the room and just listened to the whole thing. Finally, I don't know what prompted me, but I raised my hand kind of timidly and they called on me, and I told them who I was. I still had on my white jacket, you know, a little defense, a little credibility or something, I just raised my hand, I said, "I wouldn't want to live there." And the room went really silent. You know, kind of, "Who is this person? Where'd she come from? What, we've done all this work—." And Helen turned to me and said, "Say more, why?" I said, "Well, for one, I don't want to live with just other disabled people. Two, I wouldn't feel very safe living there, and therefore I wouldn't want to go out very much if I did live there." And number three, my problem was I didn't need a place to go to practice how to be disabled, I needed a place to go period, a place to live. So I hadn't gotten as far as understanding what I later understood, which is it would just become another nursing home, because there was no place for those people to transition to.
Breslin: It's just an extension of the hospital.

Bristo: Right. And I didn't apply 504. But what I had gotten in California was the guts to speak up, the belief in myself that I had something to offer. And when I saw something that looked bad, I felt like my view mattered enough to say it. I never expected what happened to happen though. Never, ever. They all sat down in the room, and then a long kind of silence, and Helen turned and said, "Well, what do some of the rest of you think?" And I don't remember who the people were, I wish I could. I think they might have been patients, or outpatients, they weren't activists. They said, "We wouldn't want to live there either. We agree with her." That's how I got thrust into being a leader, kind of. It really just happened—I didn't go in the room thinking anything about that. They scrapped it. Helen said, "Well, we need to go back to the drawing board." Right then.

Breslin: In that meeting, not six months later—

Bristo: At least that's my recollection. I would love to go back and find the minutes and find out if that's really accurate. But I know that the next thing that happened was Helen decided, "We need to start seeing what other people are doing." So at that point she started expanding her circle of research, and learned about Gerben DeJong, Don Galvin, Fred Fay, Lex [Frieden], and Ed [Roberts] and Judy [Heumann]. Those are the people that I can—and Irv [Zola]. Irv and Fred together. So Helen set about, I think, the process of going around the country. I'm not sure if she physically went there, or just telecommuted, or what. But she gathered all this information about what these guys were all up to. At that point the Rehab Act—

Breslin: The '78 amendments were happening.

Bristo: They hadn't happened yet.

Breslin: They hadn't happened? This was before the '78 amendments?

Bristo: Yes. CIL Berkeley existed. The New Options program in Texas existed. Whatever Boston was doing existed. The Ann Arbor, or wherever it was in Michigan, had something happening. I don't know whether all of them were funded this way, but remember the model programs that preceded the '78 amendments? That was what was going on at the time. So the sort of conceptual predecessors to the Title VII programs were happening. And Berkeley was up and going full swing.

Breslin: I don't remember there being any federal money for any predecessor, but I don't have good memory about this either, so—.
Bristo: Yes, there were some. I don't remember if they were called "Innovation and Expansion," or some concept that wasn't statutory, but there was this experimentation period going on in this field. Out of that came these different models ultimately. When they crafted the Rehab Act the first time, the Title VII stuff, there was a whole bunch of flexibility in how you could do independent living. It wasn't what we have come later to understand. So it allowed for a lot of different concepts. Through that process, I do remember Judy coming to the Rehab Institute. I don't remember whether I met Lex here. I didn't meet Fred, I didn't meet Don. I did hear of DeJong, but the only one I really remember was Judy, who came here probably in this room.

Breslin: Right here—

Bristo: Probably right in this room, and gave a presentation about the Center for Independent Living. It was Judy who then made me see what I had begun to see, but not completely. At that time there was all this tension going on between the ILRU model and the Berkeley model. And I don't know that they were arguing or anything, but Lex thought that this was the way to go [transitional model]. Judy and Ed and others thought that this [CIL model] was the way to go. And I remember Judy talking about the Band-aid approach, "Transitional living centers are good in concept, but they don't get to the heart of the real problem. And in and of themselves they're not bad things, but don't for a minute think that they're going to solve what your real problem is. The real problem is the lack of accessible, affordable housing. That's why we need a community-based organization that's going to take on both the peer support and also the advocacy problems, the community problems that—."

So, basically, after she left here it was a no-brainer. The people here said, "That's what we need to do." I'm still working as a nurse and, by now, I have somewhere made the leap into graduate school and hating it.

Breslin: Are you still working or did you just stop working and go to school?

Bristo: I went part time. I went to part-time work, and now I'm in school about ready to go to full-time student. I might have gotten to full-time student, I guess I did, but I started first part time and then went to full time. That's where I really started to see the need for 504, that was my first experience with 504. I went to Loyola—they admitted me—and then I said, "Okay, where's the campus?" They showed me and it wasn't accessible. I said, "I need a ramp," and they said, "Well, we can't give you a ramp." I went and got that little pamphlet—that's all I had—I knew nothing else. I just went into the office, some big person's office, and said, "You have to do this. I need a ramp, when I
park my car in this parking lot there's no way for me to get to the door. Because it's this huge campus, and I'd have to go way in the street— I'm not doing that. You build this ramp." They built the ramp. That was awesome to me, that I got this ramp built. We hadn't done anything with what became Access Living. We were still in all this discussion.

So then I decided I hated school.

Breslin: Ramps not withstanding. [laughs]

Bristo: I'm still trudging through it, it's just not what I want to be, and I know it's not what I want to be. But I hated my job also, because it wasn't enough. The Rehab Institute approached the State of Illinois for what were called Innovation and Expansion dollars at the time. They had encouraged them to submit it and they did. It was a CIL proposal. The state came back and said, "Bad news, our budget request just got shrunk, we don't have any money." So everybody here went, "Ugh." So there was a little period of time where nothing happened. And before you know it, the state called Rehab and said, "There's just been this new federal thing passed called Title VII of the Rehab Act How would you feel if we took your proposal and submitted it?"

[Audiofile 5, Side A]

Breslin: Marca, you were talking about the very early days of conceptualizing Access Living.

Bristo: Right. It wasn't called Access Living at this time, but when the state came back to Rehab and said, "Can we do this together?" the Rehab Institute said, "Sure, sure, we'll do that." So they applied, and Access Living was ultimately formed. The State of Illinois got one of the first ten grants.

I think of Access Living—even though we were one of the first federally funded—I think of us as the second generation of CIL types. Because the first generation was all those pioneers that preceded us. There was not so much difference between the first ten and those pioneers. But there was a really big difference between Access Living and all the others, and that was, we were started by the big old bad medical model. When I eventually came here, I took a lot of grief, because no one could possibly imagine for a minute that a hospital had any business being involved with this—

Breslin: When you say nobody, who are you talking about?
Bristo: Judy, Lex, Ed, all those folks at that period of time were really critical and skeptical, and really didn't believe for a minute that what we were going to do here was the same as what they did. On the one hand they were right—and I really always need to pay respect to this—because the people who did the first stuff did it out of that personal experience, and then they went through that, you know, being told, "No, you can't do this." That experience converted them into saying, "Hell yes, I can." And they found other people, and they, if I understand it, became a group and started working together.

It didn't happen like that here. Even though I was having those experiences, I was still too newly disabled to really even see it until right at that very moment in time. So I was ripe, it was a teachable moment in my life, coming back from this. But I didn't go through what they went through, and in many respects— I always try to show this difference—we here had it so much easier at the beginning than those early pioneers who were scraping together whatever they could to make it work, to survive. We had the backing of this big institution. With all its potential downside, we had a lot of advantages that they didn't have.

Helen wrote the grant, the state accepted it. Somewhere in my old junk, I still, somewhere, I think I probably still have the original grant application. But it was fifty-six pages. I personally, up to that point in my life, had never seen a budget, had never hired or fired a person, had never imagined myself in the role of hiring and firing. I knew absolutely nothing about management. Zero. So when they got the grant, the very first thing Helen had to do was find an executive director.

Breslin: Had they proposed someone in the original grant?

Bristo: Yes. They had proposed Margaret Pfrommer. I'm glad you asked me this question. And the budget had a salary of like $40,000 for the executive director. So when it came in, Margaret basically looked at it and said, "I can't do this. I just—it's too big for me. I just don't have the skills—I can't do this." So Margaret took herself out, and I knew that. I knew that little bit of history.

I was now on sort of a committee that was really involved, really invested. The disabled people became more invested in this, and we started to pull some other disabled people in. So at the moment that the concept was shaping, more disabled people came in. At the moment that the concept got funded, we even reached and got more. So now we have a nucleus of about ten of us who are actively helping in this.

Breslin: And you had never done this before.
Bristo: I will have to do some thinking—Rose Wilson, Margaret Pfrommer, Jim Charlton, Barbara Black, Karen Meyer, and Augie Christman, a blind person who I am spacing out on—that's as many as I can remember right now.

Breslin: That's a lot.

Bristo: Not all of them are right at the very beginning. They phased in over probably a six-month period. The ones I remember at the very beginning were Augie Christman, Margaret Pfrommer, Rose Wilson, and me. Then the others we pulled in. I got Jim in, because he was my buddy. Catlin, Jack Catlin came in, because he had been hanging around, but he was now back deciding that he wanted to go to school. So he was, I think, in architecture school and had moved on with his life. At that time he didn't want anything to do with disability, he would be quite candid about that. He wanted to be an architect, a mainstream architect, and it was many years later that Jack converted his interest back to disability. He first had to prove to the world and himself, I think, he was really an architect, not just a disabled person pretending to be.

So then it came to the point where they had to find somebody as the director. Remember, there's no real board of directors. Even though it was set up on paper so it sounded like an organization, in its first year's goals and objectives one of the goals was, become a free-standing, nonprofit organization within six months. So that was the goal that was set by Helen when she wrote it. Little did Helen know all of what would go into becoming a free-standing organization.

Breslin: Making that happen.

Bristo: So they went through the process of start up and everybody started scurrying, a big flurry of activity. Helen was working well more than full time. She had a three- or four-year-old little girl and a four- or five-year-old little boy. So this was like the worst time in her life for this to have happened because she was being pulled in twenty directions. So she reached out to me and said, "Why don't you apply for this?" I said, of course, "No." [laughs]

This was so interesting because I did think this was still in the movement on some level. First, I wasn't convinced that Margaret didn't want it, and I thought she deserved it. The second thing was, I had been out to California and I didn't think I knew enough to do it movement-wise. I knew this thing was out there. I didn't think I had enough background in—well, I knew I had no management. So I just didn't feel qualified on a whole bunch of levels.
And I didn't feel disabled enough. Because Margaret had been kind of the leading voice internally. And, by now, I had heard about Ed Roberts and Judy Heumann and Lex Frieden, and their disabilities were all more significant than mine. So I sort of felt like an impostor still. I thought, "God, they're the really disabled ones. They're the ones—." Because I had heard Ed's story about being called too severely disabled to go to work. And I beat the system, I wasn't too severely disabled. But it was, you know how there's a pecking order sometimes?

Breslin: Right.

Bristo: It was a reverse pecking order.

Breslin: Stop a second and think about it. How were you yourself defining severely disabled in the context of this moment? What were the qualities?

Bristo: Oh, very similar. For example, Margaret and Ed couldn't move their arms. I could. I mean, that's simple. They had to use a power wheelchair, so their life was harder and they had more barriers, after all, I was out living independently, doing pretty much okay. I didn't use a personal assistant. They needed one. They had all these things that were harder for them than for me. Therefore, I couldn't be a qualified spokesperson. It took me a year after I got there, at least a year to let go of that, or to begin to let go of it. I mean, truth be told, when NCIL [National Council on Independent Living] was being formed later, even though I wanted to step up to be the president at the beginning, I didn't, because this is part of what held me back.

Breslin: Have you thought about that—I mean, this is an analysis that you've done a lot and talked about a lot.

Bristo: I haven't talked about it much, but I've thought about it.

Breslin: You've thought about it, because it's clear that it's lingering in your mind. But did you think about the sort of medical model implications of your own analysis? Okay. Have you thought about it subsequently?

Bristo: Yes, of course I have. And of course, the other thing that you obviously think about and we all talk about and you hear about in reverse is that there is an elitism within the movement. You hear it a lot from people who've been in special ed, segregated classrooms, when they were kids, that the pecking order there really plays out. I don't quite know this, but I think it's part of what keeps people who have manual chairs from going into a power chair. Myself, it's way
gone. At least I hope it's way gone. But it took a long time for me to get to that point. Remembering that this is all kind of an enlightening.

Breslin: Yes.

Bristo: Even though I say I totally changed, you're still being challenged to understand things about other people's disabilities and the way it affects them. To me, I'm constantly learning, changing my views, and growing up. But yes, I definitely now see it that way, but no, I never thought of it then. I never thought of it then.

I really just plain thought that the issues that an independent living center was going to deal with would be issues that I wasn't experiencing as thoroughly as they were. They had more of them. They had more problems, therefore they would be more valid spokespersons than me. It was, "Who is the more credible spokesperson?" So on some level there was a certain authenticity to my hesitation, that I didn't want to speak for somebody else's issue that I didn't understand. And I, of course, didn't understand it yet, because I was brand new to it. So it was that—my understanding of independent living at that time was largely formed, by then, out of some of that history, that it was a rejection of the medical model, but it was also a rejection of the concept of being too severely disabled to work.

Breslin: But as perceived by whom?

Bristo: The state VR system.

Breslin: So that perception was an external perception.

Bristo: Right. But, that's what I'm saying. At the time I was going through it, I didn't even know there was a medical model. I learned that later, okay? What I was learning was that there was this new thing called independent living. Nobody had contrasted it to a medical model intellectually for me. I had not read anything about that. But what I had heard was that there's this new thing called independent living and it's different. It sounded like a rejection to me—I hadn't heard of the medical model—but what I heard sounded like a rejection of the definition that some people are too severely disabled to do some things.

Breslin: At the same time though, you had been told that you could no longer practice as a nurse, initially.

Bristo: But I was working, and I was getting a higher degree.
Breslin: Well, I understand, but the VR establishment was questioning whether you could actually work with a higher degree.

Bristo: Yes, but they hadn't closed me out as too severely disabled to work. That label had not been applied to me.

Breslin: I see the distinction.

Bristo: And it had been applied to Ed.

Breslin: Yes.

Bristo: And Ed was the person who originated this in the early writing, and he talked about how the independent living model was a reaction against, to a great extent, the vocational rehabilitation model. So the medical model concept for me, as I learned it, came later. To me, the early training I had was a rejection of the vocational model. And it was borne out of Ed's being told he was too severely disabled to work and all those disabled people who were shut out of everything. I've revised my thinking on this, but then this is what I believed.

Breslin: Right, it's interesting to sort of look at the elements that went into the thinking at the time.

Bristo: Yes, at the time I could work, he couldn't. The independent living model was born out of Ed and other people's rejection of that kind of label. Therefore, how can I lead this movement which is premised on some people not being able to work, when all along I could work. You see, I didn't feel authentic.

Breslin: Okay, pause for just a second. Tell me, among the cast of characters that were influential in shaping the direction that RIC ultimately went, in terms of that first independent living application, how many of them did you actually meet or know at the point when the application was submitted?

Bristo: The only one that I really remember, of course other than Helen, was Judy. I didn't meet the people at CIL until after we got the money. I didn't meet Lex until after we got the money. I talked to Fred on the telephone, but not until after we got the money. So really, Judy is the only one that I really remember. And Simi, as I told you, but not in this context.

Breslin: Did you meet Judy here, or—

Bristo: Here.
Breslin: When she came here, not when you went to Berkeley.

Bristo: Here. I'm sure I met other people from Berkeley at this meeting. But the only one I'm sure I met was Simi. She's the one that I hung out with, she left an impression.

Breslin: Do you have early recollections of Judy from that first visit here?

Bristo: Yes. I do.

Breslin: Do you want to talk about it a little bit?

Bristo: A very articulate, mouthy New York person who was single minded in her view, and when people challenged her, she squished them. I say that all in a good way. People in this room were just like you got yesterday, right? Except then it was more raw. And, okay, you know, "What do you mean?"

Breslin: [laughs] A whole different world.

Bristo: And she had eloquent, firm, don't-get-in-my-face responses for each of the things that they raised. She had to have been effective at it because, as I said, I recall her presence being the turning point. Because there was a point where we were evaluating, "Do we go with the New Options model or the CIL model?" We were actually in dialogue over that.

Breslin: Say just a little bit about what you remember about the New Options model.

Bristo: Well, first I remember manuals that were sent here, you know, the difference between CIL and IRLU is ever present even to this day.

Breslin: To the moment that we speak.

Bristo: Yes. Neatly, little packaged in a three-ring binder. I don't know if I still have it, but it was called the "New Options Program." You flipped it over, and you saw people happily living in their apartments, and it showed people hard at work learning.

They both had the concepts of peer support, they both had the concepts of independent living skills training. And some generic advocacy. But what I really remember later after I went and visited them both was that the difference between the two was that IRLU was focused on the person, and Berkeley was focused on the community. Both did the peer support and ILS work. But you could tell that the Berkeley
model's heart and soul was in community change. I mean, that was my impression, after I saw it.

Breslin: Do you have a sense of retrospect now informed by all of what you know now, why that difference was true then, in light of the fact that they knew each other?

Bristo: Well, I didn't know they knew each other.

Breslin: I know, but you now know—now you know they did, so do you have any observations about why you think there were the differences at that time?

Bristo: Well, yes. Berkeley, Texas, for starters, they are really different places. The human beings are really different human beings. I mean, Judy and Ed are activist types who are active, and Lex is an academic type. So what they brought to the table as people was a little bit different. They were rabble rousers ready to break down the doors, while Lex was a-go-within-the-system and work from within.

Breslin: So these are style differences primarily.

Bristo: Yes, and the milieu that they operated in. One milieu was all about activism, change, and having rallies and marches. And in those days you didn't see too many marches and rallies in Texas. Right? So there was a whole different context in which they were both operating. And New Options was affiliated with a big medical hospital complex. I don't remember how, but it was. And CIL money emerged out of people. So I don't know what the early origin of New Options was, I really don't know that, but I would bet it was not the same as what these guys went through

Breslin: I think it's not the same, but it is interesting—

Bristo: I think a more interesting question is, why did Access Living, which on many levels is much more alike ILRU in its structural origins end up being much more like Berkeley?

Breslin: Well, is that a generational issue, you think?

Bristo: No, it was a decision.

Breslin: Yes, but it was informed by the alternatives that were presently available. So you had a couple of options to look at.
Bristo: But still, you've got to say, how is it that this hospital went for this model that they knew was going to be getting in the face of their major donors—?

Breslin: Did Lex come here and say you need to attach it here and it should be person-centered and—?

Bristo: No, no, he never said—there was none of that, no. He focused on what went on within the walls, not with what the relationship between us and them should be. He did, I think he did come here, but I think I wasn't here the day he came. My recollection was I missed several of the other presenters, which might have been fate right there, because I heard Judy and she hooked me.

Breslin: She's pretty persuasive.

Bristo: And therefore, I was probably pretty more persuasive afterwards. I don't remember whether I lobbied the group for this, I don't remember any of that. All I remember is the general series of events, and then we decided to go this route, and then we put the proposal together. And then it was time to hire. But I do remember that we weighed it heavily, and the two things that we were leaning towards was either the Texas model or the Berkeley model.

I remember continuing to say to people, "Well, what the Texas people are doing is very much like what we just decided not to do." And everybody remembered Judy's comments about putting the band-aid on the problem. And those were her literal words that I recall, that transitional living serves a purpose, but it just puts a band-aid on the real problem.

Breslin: I know you have to end soon, but just an observation. The Berkeley program in essence began in a hospital, because Ed was admitted to [UC Berkeley’s] Cowell Hospital.

Bristo: I didn't know all that at the time.

Breslin: I'm not trying to make a point, I'm trying to ask the question by illustrating a couple of examples of what has become clear to me only recently [laughs], similarities between all these programs. Cowell Hospital first put Ed in for a variety of reasons, we don't know, we hope we will learn what those are through this process. ILRU was based out of Baylor originally. RIC went through the process that you're describing, again, a rehab facility, and the Boston group began in a medical facility also.
Bristo: See, what I never knew—I knew that Ed had the experience of being on the campus and living in that place, I knew all that. But the way it was retold to me by other people over the years was that he ultimately didn't want to live there. And it was the struggle to change, to leave, and to create options for himself on the campus that was more the spark to what became the organization.

Breslin: Oh, I think that's true.

Bristo: It was just that he happened to live there, and they let him in. And that I didn't know.

Breslin: Well, they let him in, and there were a dozen other people that were let in. And those dozen people then conceptualized how the campus and the world needed to be modified. So there was a—and that process was supported by the institution where they lived.

Bristo: And that part of history didn't get told.

Breslin: Well, it has been told.

Bristo: Well, but in the movement here, it has not been told. For example, Ed, when he was alive, never told me. All the conversations, you know, I used to pick his brain and grill him all the time. He never bothered to correct that misunderstanding.

Breslin: I don't think it's a misunderstanding, I think it's a function of perception of what the—

Bristo: What the triggers were, maybe, too.

Breslin: Or what the value of the contribution of the medical side was.

Bristo: Yes.

Breslin: Because it's not that valuable. They opened the door, that's really all they did. Then they started supporting issues as people brought them up. They didn't create them, they didn't bring them up, the students did.

Bristo: Yes.

Breslin: To that extent it was completely self-driven. It's just that there's an interesting kind of medical-model nexus between all of these programs.

Bristo: All of them, that's really interesting.
Breslin: Which I didn't understand either. I'm not supposed to do this, but I'll take this off the tape, but it just is interesting to me.

Bristo: Me too.

Breslin: —very interesting to hear you talk about the process here. Because it's part of trying to figure out how the pieces of the puzzle fit together all over the country, almost at the same time, not exactly, but within a decade basically.

Bristo: Yes, yes. Then when we come back the next time—I need to go—when we come back the next time, I haven't really talked about my kind of decision to throw my hat into the ring. And Henry's role, and the early, early, early phases of the support we got here, which is kind of interesting.
Interview 2: June 28, 2002

[Audiofile 6, Side A]

Breslin: Marca, we ended yesterday at a point where you were just about to make a decision to join Access officially as director, I believe, so do you want to pick it up from there?

Bristo: Yes. Helen Goodkin, as I mentioned, once they got the money Helen Goodkin approached me and said, "Why don't you apply for this?" And I explained the reasons why I basically said no. A few weeks passed and they were starting to gather resumes. I went out with one of my old nursing friends for a drink, actually, and I was telling her all about what was going on. This was a woman who went back to get her Bachelor's degree when she was probably thirty-five or forty. So she was a little different, herself. Michelle Roumelle and I were out, and I was telling her how they had asked me. I had said I didn't want to because I didn't think I could. Michelle looked at me and said, "Well, who could do it better?" And if you know her, she was like deadpan, you know, she just cut right to the chase, "Who could do it better?" And she kind of threw me, so I kind of tried to go off on a tangent. She said, "No, I want you to think about the people that you know they're thinking of. Do you think that they could do it better than you?" I said, "Well, I'm not exactly sure who they're thinking of, but if I hypothesize about it, I guess I don't think they've had any more experience than me." She said, "So what you're saying is you're just chicken." [laughter] And I said, "Well, when you put it that way, I guess you're right."

Breslin: As if to say, "Surely that's not it!"

Bristo: Then, we didn't talk for much longer. She just reminded me that I was kind of miserable on the career path that I was on, and what did I have to lose? So I called Helen back and I said, "Helen, I'm willing to put my name in." Then they did, they gathered, I think there were maybe seven people whose resumes came in. They did a series of interviews. I think I remember Barbara Black was one of the interviewers. The only one I remember. There was a group of people we sat before. Then they identified me as the one that they wanted to offer it to, but I had to go before the president of the Rehab Institute first.

Breslin: Who was that then?

Bristo: His name was Hunt Hamill. He was a former sugar manufacturer and had been brought in, I don't know how many years before, as this corporate type to come run the Rehab. Henry was chief medical officer
or chief whatever you call that. He was the head of all the doctors. Hunt was the president.

So I went in to see Hunt and he asked me a few questions. He was an older gentleman. I don't remember anything about the interview at all. I came out and the next day Helen called me up and said, "Well, you've got the job." And I was like completely freaked out, like, "Oh, my God." She said, "Don't worry, it's going to be okay, I'm going to help you." You know, there are only a few people that affect me the way she did. She really is one of the unsung heroes of the movement, because she did a lot of this incredible groundwork. She really understood the issue of consumer control. She got it before a lot of us got it, and she steered us on that path and then encouraged me to do this. Like I said, so many times when I've had those leadership moments where you could either go to the next level or hang back, it has been somebody else's confidence in me that pushed me forward. I didn't have it in me, and it was theirs that gave me the fortitude to say, "Okay, I'll try," to take the risk. Gerben talks about that dignity of risk, and for me it didn't just happen magically. I didn't just sort of start taking risks. There were really people who nudged me and supported me.

So once I got there she said, "Okay, you've got to come to work." I could even show you the offices on the ninth floor; it's about ten by ten. I mean, the two of us could not really fit in the room with a desk at the same time, so my chair sort of sat in the doorway. And for the first few weeks she kind of ran things, you know, she sat at the desk and I watched her. I just plain watched her. I didn't really have a clue what we were going to do. We had this grant proposal, she handed it to me and said, "Okay, here's what we're doing. Read it."

You know, the first thing I looked at, because we hadn't talked about salary or anything, was the budget. The budget had an executive director at $40,000, and an assistant director at $20,000. I said, "That's not fair." [laughs] "I can't really take a job and then hire somebody who—and I'm making twice as much as them?" Then she talked to me, well, part of the reason the salary was that way was because we thought it was going to be Margaret, and we knew she had a higher cost. I said, "Well, I'm not comfortable with that." So, you know, in hindsight it does seem a little naive, but we cut the salary down to like twenty-four and eighteen or something like that. It came back quite low. But that was still a big increase from what I had been making as a nurse, so I was quite fine.

And, really, those first weeks I just observed what Helen was doing. What my greatest lesson in that period was—the greatest skill I needed to learn—was mastery of the telephone. She was one of these people
that could make twenty-five phone calls in an hour. She had her list and she knew what she was to do. She sat there with that list and she [makes phone noise] took care of her business, then went on right to the next one. You know what, that is one of the greatest gifts she gave me; I am a whiz on the phone in that same way. If you're an organizer and you're supposed to do the kind of work we do, that's half of it, being out there, asking, exposing, being present, acting.

It has been very interesting, on my worst days now when I'm feeling down in the dumps or I don't have the energy, and I sit there at my desk and I don't want to pick up the phone. You know those days where you just feel, "Oh, my God, I can't ask another person to help us." Or, "I can't deal with this problem," or whatever. I really get this visual image of Helen coming back to me on the telephone doing all this, and you know, it lifts me out of it and kind of pushes me forward.

Breslin: Let me just ask you, just stop a second there and back up just a little bit. Can you remember anything about the questions that Hunt Hamill asked you?

Bristo: No. I really can't.

Breslin: No, you have no recollection of them being—

Bristo: Probing?

Breslin: —like off the mark, on the mark—?

Bristo: No. What I remember is that they were surface-y. They weren't very deep. I mean, basically, I think it was a pro forma interview. He was a corporate type, he had hired these people, they had gone through a group process and presented the best candidate. His style was to say, "Okay, the people I trust said this is the person, so I'm going to go with the person."

Breslin: Yes. He really isn't making ultimately an executive decision.

Bristo: No, I didn't get that impression.

Breslin: Okay, think about, maybe you were going to come to this next, but do you recall the three or four specific things that this first grant was intended to do? What were the tasks?

Bristo: Yes. Organizationally, create a board of directors, hire the staff. Do you mean programmatically or the mechanics?
Breslin: I'd like you to talk about both of those, but presumably the grant was a programmatic grant, and this business of whether or not RIC encouraged the incorporation of a separate entity was sort of a separate process.

Bristo: No, it was in the grant proposal.

Breslin: It was specified in the grant?

Bristo: Yes.

Breslin: I see.

Bristo: Yes, from the day that we conceptualized this, at the very, very beginning, because of Helen, we knew that Access Living would be a free-standing, consumer-controlled organization.

Breslin: That was spelled out in the grant rather than being understood internally.

Bristo: Yes. It was in the grant. In fact, it was a goal in the grant. It was one of the deliverables. And you know, when I talk to groups now who are helping other groups get going, I really hearken back to that. I say, "Sit down at the very beginning and think where your end is and write it down." If you do that it can be a great way to move forward. But if you don't do that, my sense is that people get into a lot of trouble along the way because people change when recollections are different—so I think it was very, very wise. I think it was, again, a reflection of the way in which the mission was embraced, more by Helen in the small group, more than the institution as a whole. I think as time went forward, the institution as a whole, while they understood it and supported it, they also struggled with it.

I didn't relate to it this way in the moment, but in hindsight it was very much a parent-child relationship at the beginning. And do you know what, I'm not saying that in a negative way. At the moment I didn't experience it that way. But at the point that the child reached adolescence I did, you know? At the beginning everything they gave me I needed, and I wanted, and I took. But at the point that I started to feel really ready to make the break, things were a little bit more challenging, but not a lot more.

Programmatic—so let me just say that we had to do everything from hire the staff, find a location—you know, I remember my first weeks were driving around the city looking at buildings. Then we found somebody, an agent, and the person started showing us property. So the most really basic stuff.
Breslin: Let me just ask about the funding source, this is all Title VII money at this point?

Bristo: Well, remember, the funding went to the state, it was $200,000. The $200,000, all of it, went to the Rehab Institute. They managed all the finances, so I never truly saw the real income and expense report for the organization. We were like a cost center for the Institute. Therefore, I knew I had this much to spend on my grant-related cost, but all the other stuff was in-kind and I to this day don't know how much it was.

Breslin: So your space, your phones, your utilities, your—

Bristo: Space, phones—

Breslin: Some support, parking, all—

Bristo: Those were Title VII, yes. They were.

Breslin: So that you paid rent—

Bristo: We moved.

Breslin: Right. But you paid, there must have been a deduction for rent from—

Bristo: The grant.

Breslin: —the original grant for the space at the Rehab Institute.

Bristo: No, no. That was donated.

Breslin: That was in kind.

Bristo: Yes. Let me give you a sense of the in-kind things. Personnel, human resource management, all the recruitment, all the paperwork associated with hiring and firing, health benefits—

Breslin: That's great.

Bristo: —accounting, finance, administrative support, fundraising. So to the extent that we went over the budget, which for a long time I never had any awareness of, until we wanted to grow, until we programmatically wanted to add some staff or do something different— Then they told me how much they spent on overhead, and we couldn’t grow.

One of the triggers was when the DREDF [Disability Rights Education and Defense Fund] came to us and said, "We're doing this ADA
training, and we want a presence in Chicago. And you guys [DREDF] funded Susan Nussbaum.

Breslin: It was probably the 504 [Section 504 of the 1973 Rehabilitation Act] training, actually.

Bristo: Your 504 [grant] gave us half of her time. We wanted the other half of her time for public affairs, PR. So when that money came to us and money coming in started to become an issue, then I became a little bit more aware of the fundraising stuff.

And let me tell you, just so you get the chronology in a big sense, we were supposed to separate in the first six months. That was completely unrealistic, completely. We didn't even have our staff in place completely. Well, we just about did. Almost completely fully staffed by the six-month point. But we were so far away from being ready to incorporate. We were still finding board members—you know.

So what we did in our reports, we just said, "We need an extension," to the government. RIC was totally comfortable with it. And the people at RSA [Rehabilitation Services Administration], the person was Ted Witham at RSA, he was totally relaxed about it. "Whatever you guys need, just kind of keep us informed." And the state didn't care. So we basically were given a pass on that first goal, which was a good thing. So our original goal of six months just kind of started to drift.

At about the year-and-a-half point, I started to feel, "Okay, we need to get more serious about this." There were early signs of not friction but funding tension, and we wanted more funding. And the way the process would work is after that first year, every year, I would develop my budget, my board would approve it, and then the approved board budget would come over to the Rehab Institute through one of a few different entry points at different points in time. For a while we were just part of this department's grant.

Breslin: Overall?

Bristo: —Education and Training.

Breslin: Grant management money.

Bristo: So we would bring our budget here, and they would say yes or no. At the beginning we weren't very demanding, so they would just say yes, because the government grant paid for it. As we started asking for more, "We want to do this," or, "We want to bring in a new staff member," or, "We need more money," then they internally decided
that we should report to the president. So they relocated us from one department to the president.

During that period I would go through this process and the budget would report to the president, who was Hunt Hamill, and during that period we got whatever we asked for, which was the little-known part of history.

I have to tell you a really funny story. One year when we were asking for extra budget, I can't remember what it was for, but we wanted like a $50,000 increase. This was a $50,000 increase, and on a $210,000 grant that was a fair amount to just go in and surprise them with. So the board had approved it, and it just turned out that day was—I can't believe we did this [laughs]—Halloween that I had my meeting with Hunt Hamill. So I came into his meeting, and Nancy, his assistant, kind of let me in. I said, "Nancy, what kind of a mood is he in?" She goes, "Oh, he's in a really great mood. It's Halloween," you know. I said, "Do you think he could take a good joke?" She goes, "Oh, yes."

So I rolled in, and I had an old girlfriend from years and years ago who had been a Playboy Bunny. She gave me her Playboy Bunny ears, so I went in with my Playboy Bunny [laughs] ears on and said, "Trick or Treat!" And I so threw him!

**Breslin:** "Here's my budget!"

**Bristo:** He just started cracking up, and I said, "Well, I just figured, you know, if you're going to ask, at least you ought to have a sense of humor about it." Then we got serious, and I laid out the budget. You know, I don't think that that had a thing to do with it, because he was already such a genteel, kind person. Thoughtful, but kind. He asked all, lots of questions, it wasn't a shoe-in by any sense of the word. And then he said, "Okay."

**Breslin:** Did this represent an increase in RIC's contribution—

**Bristo:** Yes.

**Breslin:** —of the total amount?

**Bristo:** Oh—yes. So little by little, every year, our budget was growing. I wasn't expected to bring in money. So then we started having more serious discussions about, "Okay, it's time for us to get serious about putting a plan in place about becoming more independent." I would bet that this was at about the two-year point or so, maybe two-and-a-half-year point. So I started meeting with people internally here about, "How do we go through that process of separation? What are all the
things we need to do?" And—I'm trying to remember if there's anything I'm forgetting here—just to give you the big picture. At the four-year point we became a subsidiary corporation, and at the seven-year point we spun off. So six months turned into four years and ultimately seven years.

And what happened was that the first three years were developmental. We weren't ready to go and I wasn't asking to go. Then somewhere at that point the funding issues started to become real and some of our positions started to become real.

This is so funny. We had a newsletter called Independent Life. Susan did a cover story on the newsletter about sexuality and disability, and it was pretty—you know Susan—it was kind of to the point. And it might have been an interview but it basically put sex out there—and not just in a conference for healthcare professionals. We sent it to our whole mailing list. Well, our whole mailing list included the Women's Board and the RIC Board. Several of the women on the Women's Board got really irate about this, one in particular, and went to the Institute and said, "Tone them down. This is inappropriate."

The Women's Board had been part of the operation helping to fund us during this period. They came back and gave me some heat on this, and I did the diplomatic thing of sitting with them and saying, "Well, but this is a really important issue. If it offended people, it certainly didn’t intend to. But, it's important that we open this door." And we kind of mended things a little bit. Ultimately, the person who was the complainer, now is 100 percent on board. I mean, one of our strongest allies now.

Breslin: Yes.

Bristo: But that was a long-term thing. So there were those kinds of things that were going on during that period.

Also, I forgot to mention some of the staffing. Let me finish this thought and then I'll come back. But I was also starting to have some problems with a couple of my staff, and those personnel problems were starting to become a bit of a challenge at the Institute. I had to turn to them when I had sticky personnel problems, and I didn't like the advice they were giving me in some instances. Maybe they were right, but I still didn't like it. And some of the things they were telling me I had to do I was rebelling against. I didn't want to have to do those things.

Twice, I still don't believe the advice I got was the right advice. It might have been the technically legal advice, but I still believe if they
had counseled me to handle it within that legal framework in a different way, the outcome would have been different. But remember, I'm learning all this stuff, I knew nothing about this. Then one of the straws that kind of broke the camel's back was that I wanted to hire a particular person. This is not public—nobody knows this, really, except the people that were involved. I wanted to hire a person, can I remember who it was? Yes, I can. Now I can remember who it was, and I'm not going to say her name. She's no longer alive. But she had a disability that was progressive and terminal. We knew that. And she was really good, and I wanted to hire her. And the HR people said, "No, you can't hire her. Our health benefits are going to go up"—You know, all this stuff. I said, "I'm not listening to you, I'm going to hire her." And we went to war on this issue.

Breslin: I bet.

Bristo: We went to war on this. I didn't listen to them and I hired her. And you know what? This person, just so you know, I'm trying to think—I would say, this was back in probably what '82, '83?—this person died in the year 2000. I mean—

Breslin: Seventeen years later.

Bristo: Yes. She was a great employee, and when she couldn't work anymore she left on her own. Not because we made her—you know what I mean? It was her choice. She had a lot of good years with us, and I was right. I made the right decision, but I pissed a lot of people off. Now, that never percolated everywhere. It pretty much stayed between the legal people—not even them, the HR people and me. Then the HR people went through change, and they got some new HR people who were better to deal with. So it kind of became a big part of our history, and it didn't carry forward with us.

It didn't remain an issue, but I learned something then. I learned that in order to run the show the way I wanted to and knew I needed to, we had a conflict on some things. And therefore—these were not big issues, they weren't public issues. If you were to look back through all of this on every other level, the Institute continued to give us everything we needed.

I should mention that in 1983 we started getting serious about the severance stuff. And, by coincidence, the Institute was going through a corporate reorganization. They were getting ready to create a for-profit subsidiary and a foundation. So their attorney, who had been talking with me over all these years about bylaws—who has become a very good friend—came to me and said, "Look, we're doing this corporate reorganization, why don't we create you as a subsidiary while we're
doing this. That will give you more autonomy, it will give you
technical control over a lot more stuff. You're going to have to assume
more responsibility and you will still report in, but not in the same way
with the same strings. The only decision that the Institute had over us
after we went into that was approval of the budget, and that went to the
board of directors.

Breslin: And that arrangement continued the fiscal support that you had been
receiving previously.

Bristo: Yes.

Breslin: But facilitated more autonomy.

Bristo: What it also did was to create a seriousness around our separation and
what I now would call a business plan. We didn't call it that, but we
had created a transition plan.

Helen had already started to work with us on reaching out to some of
the foundations in the city, so she had started to do the groundwork.
But at this point in time we went to the Chicago Community Trust and
we asked for $75,000 for a person to do fundraising, a development
person. We made the case that, "If we're going to take on human
resources, accounting, and all these other things, we need X more
money. They won't give it to us, so we're in this catch-22. We need to
raise money so that we can be independent." And the Community
Trust gave it to us, the $75,000 that enabled us to hire a fundraising
person, our first one, and a few other things that I'm not remembering.
It might have been some of the accounting kinds of stuff.

The man who was the Rehab Institute's master fundraiser, Charles
Feldstein, was someone I had met over the years. I went to Charlie, on
my own, and said, "Charlie, will you be my mentor? I don't know what
I'm doing. I need some help." So Charlie said, "Sure, I'll do that." And
just on his own he started meeting with our board, helped teach us
what fundraising is—you know, conceptually, how you do it, where
we should start. He advised us to start with a corporate foundation
program, and that we start to think about the board a little bit, not in a
big way, he didn't push us to change the board, but just start thinking
about some added talent that will both strengthen the organization by
bringing in skills that we needed, and to think of people who might
help us reach out to their friends to raise some money.

So we had a little bit of a plan, nothing terribly formal. Then Helen
helped us write, with this new person, the conceptual work of which
foundations should we go to. There were five that we went to then and
said, "Okay, the trust has given us this money for this person. Now we
need administrative funds to help support these programs." The foundation said, "Okay, we'll help you, but we don't give general operating expenses." Well, a couple of them did. A couple of them said, "Yes, we'll just do that." And a couple of them said, "Just talk to us about your programs and we'll give you money. But if you ask us for general operating, we can't quite do it that way." So we were then able to talk to the state about starting to move our funding around to take some of the administrative costs that weren't in the grant, and put them on the grant, and free up fundable opportunities to these private sector people. In other words, we swapped the two funding objectives, and the state was very willing to do that.

In hindsight, this was so important for the State of Illinois' independent living centers. Because what we eventually did at that moment in time was to get the state to rethink itself. And in Illinois, although we asked for programmatic-related stuff, I really think our state is one of the few states that really sees its money as general operating support. They're not nearly as nit-picky as I hear other states are. They really just think—you know, the law says "For the conduct of independent living programs," and that's how they do it. So they are totally flexible with us as long as we do it right, and we tell them what we're doing, you know, don't surprise them. They've always been that way, which enabled Access Living, once we got a new grant, to go after funders that we could otherwise never get. We knew as we were doing it that we could go back and amend our government grant in order to free up those things [budget items] this funder was willing to fund. That enabled us to wide-open, strategically, a whole group of funders that we wouldn't have been able to get to unless we grew. And we didn't want to grow, we just needed to transition into an independent entity.

Breslin: Let me stop you there for just a second and ask you to back up and say what your core program elements were.

Bristo: Yes. Okay, we pretty much lifted the stuff right out of what the Rehab Act said at that time: peer counseling, information and referral, advocacy, and then independent living skills stuff. What I remember, though, is that it didn't categorize into those four groupings. We had a personal assistance program and an education program, which was independent-living-skills training. We had a housing component, benefits counseling, which we never really did terribly well. In the early years we kind of did, but it was a real time-sucker, so we didn't really do much. Those were the basics. So peer counseling, information referral, advocacy, housing, personal assistant services, benefits counseling. And then some more generic areas, you know, like public education and disability awareness.
Now, how did we do that? Okay, we started out with a coordinator assigned to pretty much each of those areas. So we had one human being who was kind of a personal assistance coordinator, an independent living services coordinator, a benefits specialist, and an information referral coordinator. So our initial staff included that person, a housing coordinator, and an assistant director. The assistant director was one of the people who had come into the process, if you remember—

[Audiofile 6, Side B]

Bristo: Okay. If you remember, Jim DeJong was the guy that rolled in the room, and Sharon Green and he were dating at the time. What I did at the very beginning was reach out to those friends, the people who I had become friends with, and say, "Come on, get involved." So Jim Charlton, I had recruited onto the board, Jack Catlin I had recruited on the board, Margaret Pfrommer was the first chair of the board. So all this board development activity was going on at the same time. You asked me a question and I lost it.

Breslin: Well, you were talking about the programs, and you were talking about the staffing pattern with respect to the programs.

Bristo: Okay. Jim DeJong was brought in as the assistant director. You know, I had my biggest lesson there. I brought in a friend. And while we were great friends, and great drinking buddies, and we partied a lot together, we were not the right team to work together. Our working relationship deteriorated which was really painful because he had been one of my best friends.

Right around this time—gosh, this would have been right around the time we were doing staff in-services—I had recruited somebody to do an in-service on alcoholism. I don't know why I did that. But I recruited somebody, and it seemed like the responsible thing for a boss to do for our clients. And the person came in from Grant Hospital and did their in-service, and there are these ten questions that they ask, and if you say yes to more than a certain number then you're an alcoholic. I'm sitting in the back of the room, my staff is here, and the chart is up on the wall. I left the room, I came back in the room, and now the questions are up on the wall. I had missed the asking of the questions. But she was now at the point of saying, "And if you answer yes to more than X of these, then you probably are an alcoholic. So this is a tool you can use with your client." I looked up on the board and I went, "Oh, my God." And I rolled back out of the room, because I had answered yes to way more than you were supposed to.
Actually, this was a little bit earlier. Because I know I went back into denial for a good year, a good long year. Right around the same time that Jim left AL is when I got sober. Everything started coming down on me, I just couldn't cope anymore. I was having all this conflict with Jim, we were starting to separate, and it was starting to feel overwhelming.

For example, we were needing now to get our first computer system. I was totally technologically phobic, which really was my alcoholism speaking, more than anything. And I started having panic attacks, full-blown panic attacks, at the concept of thinking about a computer system. It just put me over the deep end. Finally I was living with a man named Tom Frillman, who I really loved. We had been together for quite a long time. I missed a lot of the sort of intermittent short-term relationships that I had been in. But Tom and I—you know, he really loved me, he was a very good person, and I was very bad to him. And, you know, your self esteem plummets as you progress through alcoholism, and I was at my worst bottom during this point. I was cheating on him, he didn't know it, you know, I was just sort of ignoring him emotionally. Basically just kind of using him—even though I really loved him on some really basic level, I just couldn't help it. I finally just broke up with him. I went to a conference, in Lansing Michigan, where I met Bob Funk.

Breslin: Do you remember what year that was?

Bristo: We all could find that out, because it was the big summit on independent living.

Breslin: '82, '83, yes.

Bristo: '82, '83.

Breslin: Let's get—let me just make sure I've got the dates clear in my mind.

Bristo: Well, I know I don't all the time.

Breslin: Well, not just in respect to that, but in general. The first Title VII grant came through the state in '79, is that right?

Bristo: October, '79, I was hired.

Breslin: Okay. And it remained here [at Rehab Institute of Chicago, RIC] as a—

Bristo: Until '84.
Breslin: —funding unit until '84.

Bristo: No. It remained here as a funding unit until '87.

Breslin: But in '84 you transitioned to—

Bristo: We became a subsidiary corporation of the Rehab—called Access Living of Metropolitan Chicago.

Breslin: So '84 to '87 was the subsidiary unit period.

Bristo: Yes. '87.

Breslin: And you were executive director from '79 to '84. And then you yourself transitioned in '84, is that right?

Bristo: Yes, because—

Breslin: I know we're not there yet, but—

Bristo: Yes, in '84 I became president and CEO.

Breslin: Okay.

Bristo: Because the Rehab Institute went to a new corporate model. So we just lifted their corporate model with us. The only major difference is, as a president and CEO I have a little greater authority than an executive director. No one has to sign over me on big contracts. I have a seat on the board. I don't vote. I could have, if I had wanted it. It originally was in there, and I just thought, "You know what, I don't want that. I want to be an equal player, but I don't really want to be in the position fully."

Breslin: You might not want to be a tie-breaker either in situations that are very close?

Bristo: Exactly, exactly. I just didn't feel comfortable with it. So, it was in the draft that I should have had a vote, and I said I'd rather be ex officio. But I am a member of the board. And the good thing about that for me is, for example, if the board goes into executive session, I'm there, always, unless it's about me. And that, I think, is one of the reasons Access Living has had such a great relationship between the CEO and the board. Because there's a trust. There just has to be, because we're open.

Breslin: You know, it's also a corporate model that isn't adopted by most nonprofits, that I think is really a good one. Okay, I interrupted you—
Bristo: Yes. So I think you're right, it was probably in '82 that I met Bob at this conference. We fell madly in love. [laughs] You know all this stuff. Both of us.

Breslin: You were in the right place at the right time.

Bristo: Well, I shouldn't have been there. I was hitting a bottom with my drinking. It was a wonderful and yet exceptionally dysfunctional relationship. Of course, I'm living with this guy, he's living with someone else, we're commuting all across the country, we're writing love notes to each other practically everyday.

Breslin: Why don't you say who Bob is, just for the record.

Bristo: Bob was the executive director, at the time, of DREDF and is a disability rights leader who is now at Paraquad as the president and CEO. In many respects it was a very good thing for me, and actually in every respect. Even though we weren't right for one another, we were exactly what we needed for each other at the time. As our relationship evolved, in all the kind of craziness that was in it, it was totally passionate, which meant it had those really highs and really lows. One day he finally said to me, "You're a drunk. And you'd better get treatment or I'm leaving." [laughs] You know what, I loved him so much. And everybody tells you in AA that ultimatums don't work, but it worked for me. I owe my life to him in so many respects, because I would never have gotten to that point on my own. At least then. It was his ultimatum that got me sober and into AA. I didn't know or believe I was an alcoholic, and at the very beginning I really did it for him, I really didn't do it for me. But I said, "Okay, I'm going to do this. This is important." And then I also told my boyfriend—I didn't tell him about Bob, but I said, "I can't live with you anymore. You need to move out." And he did. He was brokenhearted, he moved out. Obviously I'm feeling horrible about myself on every level now. I'm a drunk and a horrible person, you know? And now I'm living alone. For the first time in my life, I had no housemate.

Breslin: Not just the first time as a disabled person?

Bristo: No. Except for in college when I had a room by myself. But my entire life I had never lived alone. And I wasn't ready for it. Now we're in '84, and now we're at the point where Access Living is really ready to leave. All this new responsibility is on me. I have all this stuff to do. I have to get a computer system. And the computer system was the thing that really sent me over the top. And I checked myself into treatment, in a total anal, Type-A way. I made an appointment to check myself into treatment. Nobody makes an appointment—[laughs]
Breslin: You just didn't go to an AA meeting, you just thought—

Bristo: Well, I did do that. I called the local AA office and I said, "I need help," and they sent a person over to my house that night. She took me to my first meeting that same night. I went to a meeting at Grant Hospital and sat in the meeting. On the one hand I thought, "Oh, my God, this is the corniest, most horrible thing—" I mean, I couldn't stand it—and yet when they read the opening, the reading from the "Big Book" and everything, I knew, I knew I was where I needed to be. There was absolutely no question. I hated the meeting, but I absolutely knew I needed to be there. And for some reason I trusted the people. That woman from AA came every—not right away—but after a while, every day to visit me.

Then, it was Thanksgiving, and I'm freaking out being alone. I'm having daily panic attacks. I'm not in treatment yet. I had gone to my first meeting, Bob's in California. It's Thanksgiving, and I'm freaking out, and Bob says, "Well, come out here for Thanksgiving." So I got on an airplane, I don't know if you remember this, but I was—oh, my God, I was the worst I've ever been then. Let's see, I got the dates wrong, hold on here, Thanksgiving is a little bit later. This is in July of '84 when I'm kind of coming undone and Bob says, "Come out here," and I told him, "I'm going into treatment on Tuesday." He said, "Come out for the weekend." I hadn't had a drink since the AA meeting, which was about a week. I flew out to see him. We stayed at the French Hotel in Berkeley. We went out and drank a bottle of wine after. I guess I must have been there about four days, I stopped drinking again, and then I went into—it wasn't quite the DTs—but I detoxed in the French Hotel, and I didn't know I was doing it. I just thought I was violently sick. I was shaking and sweating. It was just horrible.

Bob was wonderful, he really took care of me, kind of patched me up, and got me on the airplane. Then I got home and I started to freak out. So I called Tom, my old boyfriend and said, "I need help." So he came and took me and checked me in, took me to my appointment at Grant Hospital. I went into treatment. It was a twenty-one day no-visitor-allowed kind of treatment.

Breslin: Where was it?

Bristo: Grant Hospital. Ironically, the head doctor there was a musician performing with the musicians I was with when I broke my neck.

Breslin: Oh, my God. Is that ironic, or what? Did you figure that out right away, or—?
Bristo: Oh, yes. Well, I didn't know he was until I got there and I went in to see the doctor, and—

Breslin: There he is.

Bristo: "Oh, hello!" [laughs] So that was interesting because he knew me in another way.

You know, I dealt with all the accessibility issues of being in treatment, which were really challenging because they have all these rules, and they didn't fit if you used a wheelchair. I had to push through the hallway to go to the only shower, and I'd have to be naked going through the hallway because I couldn't change there, there was no place to change, you know. I had to get up way before anybody woke up to take my shower so the guys on the floor wouldn't see me naked, so I lost a lot of sleep.

And that's when I recognized, after I got into treatment, that I had a Valium addiction. What I had tried to do during those months after that in-service was stop drinking. It was not uncommon during those years to go out for lunch and have a drink or two or three everyday. And I'm not talking about beer. Like a vodka gimlet or two or three.

But I had recognized, "Well, this isn't helping." Or going out right after work with everyone to drink. I had started to say, "This isn't good, I shouldn't do this." So for a long time I controlled my drinking, or I thought I did. When I checked out of the hospital at rehab, I was still on Medicaid, and they had given me Valium for spasms. I didn't want to take the Valium. I said, "I don't want the Valium." The doctor said, "You need the Valium, you're having all these spasms." I said, "I don't want the Valium," they said, "You need the Valium." So I said, "Okay," and I just gave in. And every single month these bottles of Valium would be sent to me in the mail, to the point that I couldn't any longer fit them in my medicine cabinet. Because remember, my accident was in '77. We're now in '83, '84. I had—

Breslin: [laughs] Nine years' worth of—

Bristo: I had bottles of Valium. You can't imagine. I kept a bottle of Valium in my backpack. This is where disability and addiction are really connected.

Breslin: Yes, this is a pretty common story.

Bristo: It's a whole different story, but, anyway, I would be in the middle of a stressful meeting, and no one would think twice! You would just reach in your backpack—
Breslin: Pop some pills, yes.

Bristo: —take a pill, they would just think that you're taking your pill, you're taking your medicine, right? You're a disabled person. So I didn't even have to hide it, on any level at all, with anybody. I didn't need the Valium for my spasms. I was taking the Valium for my nerves. But I had no connection at all that I was even taking it until the day we checked in and they go through all of your stuff, and they took my Valium. I said, "You can't take my Valium, I need that." "No, I'm sorry, you'll have to do without it here." I said, "I'm disabled, I need it for my—" "Sorry, they'll have to figure out something else. I'm sure there's some other—" And then they went and called Rehab, and Rehab said, "Sure, you can take Baclofen" or some other drug, "and that will handle it, and it's non-addictive."

And in group therapy is when I really recognized it, because in the middle of group therapy I found myself impulsively going like this—

Breslin: Reaching back for your backpack.

Bristo: And it was, all of a sudden, "Oh, my God." I then went through eighteen months of living hell.

Breslin: Afterward?

Bristo: Yes. I went into a profound clinical depression. They called it an agitated depression with an anxiety reaction. I had panic attacks for eighteen months. No one knew this, I hid it so well. You know, I really took treatment very, very seriously. I would like to end this little segment by saying it has been eighteen years since I've had a drink. I did have a relapse about four years ago on prescription drugs, and have been clean and sober now for two years altogether from everything. But initially I needed them, and then I abused them.

When I came out of the hospital and got back to Access Living and was faced with the real issue of really separating from the Institute, I knew enough when I went in there that I couldn't hide it anymore. And I am so proud of myself for taking the lessons I had learned by then in disability, "Don't be ashamed of your disability. You don't have to hide it. There is power in declaring it."

Breslin: Were you identifying, among your disabilities, your alcoholism at that time?

Bristo: Yes. Sure I was, of course. From the minute I recognized and accepted I was an alcoholic, I automatically saw it as my second disability. There wasn't an instant where that didn't occur. There was a struggle—
and this was really an intense struggle—but, let me finish my thought. When I recognized that I was an alcoholic—I'm so proud of myself—I went to my board, the whole board, and said, "I'm an alcoholic, I'm checking myself into a treatment center and I need your support." And they were great, they were great.

In treatment, there was a priest on my board, Father Joe Mulcrone and when I hit my spiritual bottom in treatment—I'm not Catholic, I'm pretty much an agnostic, or was at that time—I remember calling Joe and saying, "Joe, I'm having a spiritual crisis, I need you." And he came immediately and stayed with me, and just talked to me about God. I had never talked to anybody about God. And I, you know, didn't particularly buy the kind of God that was his God, but having that person there to be able to do that with, and just having his support was important, it was really, really important. I don't know if I've ever told him that.

What I discovered in treatment that was really hard for me when I got out was—and this is true to this day—the tools that the independent living movement gives you are almost exactly the tools you can't use to get sober. They are almost exactly the opposite tools. And for a long time it felt like I was going to have to give up everything I had learned in the disability movement, if I was going to recover from alcoholism.

Breslin: Like, what are examples of that?

Bristo: Well, what are the core principles of independent living to you? Self determination, taking control over your life—in Alcoholics Anonymous it's giving up control. That's it. So here is this one part of my life, "Take control for yourself and your life," and this other one is, "Turn it over, let go. You're not in control. You don't run the show." And these, for the longest time, these two things were in direct contradiction, and I felt hopeless. And there was no one to turn to at all who knew anything about these two things to help me figure it out. I was in another identity crisis, where I was again a new person, but I was also the old one, and I couldn't figure out how to weave them together.

You know what? It isn't necessary to weave them together. I'm just lucky that I finally figured out that [laughs] they are both great tools. And when you have both, what you do is you carry them with you. Like my backpack, instead of having Valium in it, now I have these two different tools in there, and I just have to be smart enough to know when I use which one. But I need them both and they can coexist. They are not a contradiction. They are a part of the symmetry now that make up my coping skills, and also who I am. And that was such a
revelation when I finally got to that point, which was eighteen months later.

During those eighteen months I wanted to kill myself. I was suicidal, but I showed up at work everyday. I was also having alcoholism side effects. I was having short-term memory loss—profound short-term memory loss. The day I went in for one of the final meetings on the separation from RIC with a woman named Ruth Ann Watkins, who was now the person I was reporting into the Institute through, she was a vice president there, a wonderful person—I went into a meeting in her office, and we worked up the final details on how we were going to seal the subsidiary corporate final arrangements in 1984. I left her office and got to the elevator, and her office was on the fifteenth floor, so it was from here to there. By the time I got to the elevator, I couldn't remember who I had met with. I had forgotten my briefcase and I had no idea where my briefcase was. And I had a panic attack, I just came apart. I was like, "I'm losing my mind." And somebody came running out, "Marca, you forgot your briefcase." And I was like, "Thank God."

That's the point at which I said, "You know, I need other help." I was doing everything you're supposed to in AA exactly right. I had a sponsor, I was going to a meeting, at least one everyday. I talked to my sponsor every morning. I couldn't sleep at night at all. I'd be up until four in the morning every night, so I was seriously sleep deprived. I couldn't be alone and I couldn't leave my apartment, so I was starting to get agoraphobic. I didn't want to leave my apartment because I was so terrified of being alone. So it was like, the thought of leaving, being with people, and then having to come back and be alone again was terrifying. I was already alone and I could sort of handle that. But the idea of leaving and coming back and being alone—you know, many years of therapy later, I figured out that this deep, desperate sense of fear of aloneness goes back to all of those times that my mom was at the hospital, and I didn't know if she would ever come back. That's what I've kind of pieced together about that. And that was a good thing for me to finally understand.

I still sometimes have challenges with it. Not in the social sense, but over the years in relationship issues, that has been still kind of a challenge for me. But I'm much, much better with it, much more whole—I'm pretty healthy now, more than not. I have continued to struggle with depression a little bit. It's not like it defines me, but it's there, it pops up now and then. I had a therapist in the early years who had me on the sister to Valium.

Breslin: Which is what?
Bristo: I don't remember its trade name, but Diazepam is Valium, she had me on Triazepan. And I could tell I was getting addicted to this again, after I had just kicked the Valium. And the other thing that was happening, which I didn't know, because no one told me until I was all the way through it and finally got a good therapist, the half-life of Valium is really long. So I was still going through the equivalent of withdrawal of Valium about a month after I got out of the hospital. Twenty-one days isn't enough to hit the withdrawal point. The withdrawal is prolonged. So a lot of what I was also going through was physical withdrawal from Valium, but nobody told me that. In treatment they take you through all of this biochemical stuff about alcohol, but not any other drugs. I think, as a nurse, if I had understood that that was part of what was going on, I would have been able to cope better.

Breslin: I'm surprised to hear that, because there was so much known about Valium addiction in the eighties.

Bristo: Not with crips. You know, somehow there's a switch that goes off, and they just figured, "Well, she needed it."

Breslin: They didn't even figure out that there was a Valium addiction?

Bristo: Yes, they did. But they didn't go further and talk to me about how it was going to affect me. The treatment program I was in was ill-equipped to deal with it. Then the doctor they referred me to for aftercare put me on this other drug. Well, I fired her.

Breslin: Wow, that's unbelievable.

Bristo: And called Bob Funk, who was my source of strength at this time. I said, "I have no idea what to do." And he could hear over the phone that I was about to have a complete breakdown. He put me on hold, and he came back on the phone, he says, "Here, call this person." I later found out was, he had called a professional colleague he knew and said, "Do you know any therapists in Chicago?" This person said, "The only one I know is the head of child psychiatry at Pres[byterian] St. Luke." You know, "Here, call—" So I called [laughs] the head of child psychiatry, and my therapist for ten years became this child psychiatrist. [laughs] It was me and all the kids that came in. And do you know, I just hit it off with her the day we got in there. I could care less that she was a child psychiatrist. She took me off that drug. She put me on another one, it didn't work, and she kept moving me until she found the one that worked. Then she made me increase my sessions—I started out once a week, she increased me at that time to three times a week.
Breslin: Therapy two times a week?

Bristo: Three times a week. I was in pretty bad shape. In a profound search for the computer system, we had to go to South Bend, Indiana, to look at this database for client tracking. Myself, my secretary, and my administrative assistant drove to South Bend. [laughter] They're having a hoot going on this trip, and I'm having panic attacks the whole time, right?

Breslin: This computer system is responsible for all of this. [laughs]

Bristo: So we went to this computer—and on the way back we're at a truck stop, and we ordered this food, and I looked at this food, and I thought I was going to vomit. I was totally bewildered. I wasn't talking; they didn't have a clue what was going on. I was pretending I was okay, but I was about to lose it. I went to the payphone, called up my psychiatrist, and said, "I think you need to check me into a psychiatric hospital. I can't do this anymore. I'm afraid." And she talked, she said, "Okay, I want you to go home, when you get home I want you to call any friend you can to come over to spend the night with you. Then once you've made that call and they're there with you, I want you to call me back." Well, I called like four people, and nobody was there. I finally called Tom. And God love him, after all I put him through, he came over and he just stayed there with me. And she got on the phone and said, "I could put you back in treatment, but you're going to go backwards. It always happens. You'll regress. It's bad to be in an institution."

[Audiofile 7, Side A]

Bristo: Well, Tom came over and sat there with me. I called my doctor, she said, "I'm willing to admit you, but I want to talk you all the way through this. This is what's going to happen." And you know, God love her, she talked me through what it was like to be in an institution. You know, you want to say this is the person that we should have involved with Olmstead stuff [laughs], because she said, "Okay, you're going to go in, you're going to get lost. You're going to feel like a condition. You might get the right people, you might not. And I promise you you're going to get worse before you get better. It might be what you need, but I want you to think about it really seriously. And I think if we increase your therapy—you know me, we've developed some trust, I think we can get through this together." Oh, my God, I thank her for that, you know? Who knows what would have happened? Who knows?

Now, on the other hand, maybe I would have come out, in a way, better equipped to advocate on mental health issues with people like
Ray Unzicker and all those folks, you know what I mean? Most people don't know about me. I don't hide it, but because I didn't go through the institutionalization process, most people in the disability rights community today don't know I have three disabilities, that I equally acknowledge and recognize. I have my spinal cord injury, I have drug and alcohol addiction, and I have serious mental health issues with this depressive episode, which continues a little bit now. I continue to take medicine for it. I'm not an anti-medicine person. It has worked for me, but I also respect the people who were institutionalized and their choice about it was taken away from them.

And then I started to get better. That was the turning point, that day. Her having that conversation and pushing me that day. She basically said, "You have a choice here, to live or die, and it's your choice."

Breslin: So the time period again is '83, '84—

Bristo: Okay. I went into treatment in July of '84.

Breslin: So this is in '85.

Bristo: It was eighteen months later, so what is it?

Breslin: '86.

Bristo: It was July to July, so until January—

Breslin: Of '86.

Bristo: —of '86. In '86 I started to feel whole again. It was slow. The depression lifted, the panic attacks went away. My finances were coming undone, I forgot to add. My finances were in the tubes. I ended up having to get my sister to come out to help me, because I couldn't manage them. Intellectually, the cognitive parts of me were depleted. My memory was bad, I couldn't remember what bills I paid. I would sit there every month going, "I'm bouncing checks, it doesn't make sense to me." My sister, who is in banking, came out, sat down with me, and went through my checkbook. And she said, "Okay, this is pretty simple. You're spending more than you're making."

Breslin: [laughs] Yes, that's the bottom line—

Bristo: "You have to change your lifestyle." Of course, then, I can't—because I'm living alone. She said, "Well, you have to; it's not a choice. You just have to do this." Thankfully, for her, she talked me through what the choices were. I went back out and found a roommate. I didn't really
even like that roommate, but I guess on some level, she filled up a room and I wasn't alone again. And I helped her—

Breslin: Well, there's a financial advantage to it, which was the basic reason for doing it.

Bristo: Yes. Then after that, the personal stuff becomes less prominent. It was as if I had to go through all this stuff to get to who I am, and then I started to just become okay again. And put the pieces back together, got back into—oh, we missed a huge piece of my history there, and I need to at least acknowledge it. Oh, because this is where the movement stuff begins—I just missed it.

Okay. Throughout all of what I was just describing to you, 1981, '82, '83, '84, I was creating NCIL.

Breslin: Before you talk about that—because you have a whole, you're running a whole parallel sort of series of political activities as well as dealing with your personal life in that period—I want you to try to back up and focus on some of the movement issues that affected you.

Bristo: Yes, that's where I’ll go.

Breslin: NCIL will be part of that, but let's talk about some of the other movement issues.

Bristo: What was going on in Illinois?

Breslin: Well, wait, hang on a second, let me just ask you a couple of questions, because I think there are people and events that probably intersected in this time period for you. When Access Living began, in its early incarnation, what was Dr. Betts's role, let’s go there first.

Bristo: Okay. Early on, Henry was the medical director. I didn't deal with him. When I became a patient here, well before Access Living, I remember running into him in the snack bar downstairs—and going up to him and saying, "Thank you, I think you're the doctor that helped get me into Rehab." And he sort of dismissed me and said, "Okay." And just went on about his business. So my first interaction with him wasn't very positive; I thought he was kind of arrogant. As time went on what I recall was, during the period that I was working under Hunt Hamill and he was giving us more money, I just didn't have any sense during that early period that Henry was on our side. But it didn't feel at all personal. What was going on was a power battle between him and Hunt. And I think Hunt was kind of using us as a pawn in that power battle. You know what I mean? I think we became a little bit of a football play of some sort. But my impression was that Hunt was our
advocate and our ally, and Henry was kind of out of the picture—I don't think he was against us, but he certainly wasn't doing anything actively to support us. I think it was their power struggle.

So it wasn't until Hunt left—he ultimately was asked to leave, and they went and hired a new president by the name of Ed Stein. Ed was another corporate guy, I don't know where he came from. Nice guy, he lasted here not very long. But this would have been in, like 1986, '87, during that period. Am I answering your question? You want me to go in this direction?

Breslin: That's fine, I just was—at some point you and Henry developed some relationship, I think.

Bristo: Later. It came—

Breslin: It's significantly later?

Bristo: Yes. I mean, he became aware of our stuff. He would invite us in to do sessions with doctors. So we started to form a relationship somewhere in there, but it didn't become a closer relationship until Ed Stein left.

Breslin: After '87.

Bristo: Yes. '87 was kind of a watershed period when we became more independent. I was working with Henry during that in his role as medical director because he and Don Olsen would invite us in for a lot of their education and training sessions here, and Henry would start to ask us to come talk to the medical residents and stuff. My recollection in those early days is when we would be at a function or something, Henry would boast about Access Living as if he created it, and it really irritated me during those years, because he didn't. I felt like he was kind of exploiting us for all our hard work. And I was wrong, too, I have to say, because now I've looked back on all they really did do, and they really did deserve a lot more credit. But what I was feeling was like they weren't valuing what we had done; it was sort of like, "Look, we gave birth to them, aren't we great?" Not, "Aren't they great?"—"Aren't we great?"

Breslin: It wasn't a partnership acknowledged by both sides really, until now probably.

Bristo: Yes, yes. And of course, that happened really when we matured, when we went from childhood to adulthood—the childhood is the first four years, then from '84 to '87 is the adolescence, and '87 on is the adulthood. That's how I think of it.
In '87 when Stein was there it was now time to become really separate from the Rehab Institute. John Kemp had moved to Chicago before that. And my friends in Kansas had told me this was a really good guy, I ought to get to know him. So I invited him over and asked him if he'd come on the board, and he had been on the board for a while. And he was in line to be the board chair. The president of the foundation was Larry Fuller from Amoco, the CEO of Amoco.

Breslin: The RIC Foundation.

Bristo: Yes. And our corporate separation had to go through the foundation board. I don't remember why, but it was that board, not the big board, but the foundation board had to make the vote to separate us all together. So Ed Stein was the president, and we were gearing up to go forward to the foundation board for the presentation. And somehow or another Ed Stein starts asking all these questions, and it becomes really clear to me that Ed Stein does not want us to go. I wish I had a better recollection of what the specifics were. It wasn't just my feeling. We had a serious difference of opinion, and he didn't think we were ready. Maybe it was that he didn't think we were ready or something.

But I remember—oh, my God, John Kemp would remember this, all this painful handholding that the two of us did with each other. I remember going home and having to write up this intense document about why the independent living philosophy was created, why independence is the most essential thing—and this is seven years later—to bring into this board meeting. Now, this must have been—isn't this funny, I never thought about this, because now my husband is in my life, we're dating. I don't think we're married yet. Because I remember Bob critiquing my paper.

Breslin: Bob Funk.

Bristo: No, my husband.

Breslin: Oh, your husband Bob.

Bristo: My husband Bob Kettlewell, whom I married in October of '87. So it was earlier in '87 that I'm going through all this angst, and Bob is a really good strategist and writer and political person. I hate writing. He was my coach. And I really, really remember him spending a lot of time critiquing it and strengthening it and repositioning it. And John Kemp went over it with me, and then John and I went to the RIC Foundation board meeting with Larry Fuller. Both of us were really anxious that they weren't going to approve it. And it was their power, that was their second power. One was approval of the budget, and two was approval of the severance, and so they could have said no. And I
never thought, ever, ever, that they could say no, because we had always agreed on this. And it was this guy Ed Stein that was making this conflict. I don't remember Henry being anywhere in this at all.

We went into the meeting, and I remember Joanne Crown was there on the foundation board, who is now on my—well, has been on my board for most of the time since then. We made our presentation, John did his part, I did my part. Larry Fuller listened to it, asked a few questions, and rammed it through, just called for the vote. Ed started to say a few things, and Larry just commanded the meeting, as a true big corporate executive would. You know, allowed the amount of time he had on his agenda for it, and pushed the damn thing through.

Later Larry Fuller figures back into Access Living. He came on board many years down the road to be the corporate CEO that took Access Living's fundraiser from sort of a rinky-dink little thing and moved it up.

Breslin: To like a citywide big deal—

Bristo: Yes, he chaired it, and donated a bunch of money. And when we were done he went to the head of Sears personally, called them and said, "I'd like you to do this for my friend Marca." And then later when we started our endowment program, it was just a small thing—he had subsequently retired, I just picked up the phone and said, "Larry, I'd like to come see you," I went out and I said, "Would you give me $50,000, personally?" He said, "Sure."

Breslin: [laughs] That's the way to do it.

Bristo: So he became a really important person to me later on, and I never ever would have known it. And I really do believe it was all that stuff that contributed to it.

Breslin: Well, yes, I want to ask you to reflect a little bit on this. You're getting Access Living going at a point when the movement is fomenting all kinds of things nationally and internationally. This is the '80 to, say, '85, '86, '87 period—

Bristo: Yes.

Breslin: When, you know, there is a lot of stuff going on. Can you—I mean, I actually just want you to sort of think about your meeting Bob [Funk] and your relationship with Bob. What relationships were you developing with other national leaders, what were your influences outside of the local situation?
Bristo: Yes, okay. Well, I'm going to back up now again to the very beginning in 1980. Now I took you kind of on a personal tangent, now we have a parallel organizational and movement tangent. The first thing I did after Helen and I sat by the phone was go to Berkeley and Houston. I went to Berkeley first. In Berkeley, I did not meet Ed Roberts, I met Michael Winter and Phil Draper.

Breslin: Where was he [Ed Roberts] in 1980? He was at Rehab [director of California Department of Rehabilitation] in 1980, probably.

Bristo: Yes, I don't know where he was.

Breslin: I don't know where he was, actually.

Bristo: I met Phil Draper and Michael Winter and visited CIL, Berkeley. I had a chance to see it, just to see what it looked like. Up to this point I just had this paper, and it didn't make sense to me.

Breslin: You hadn't physically visited independent living centers before?

Bristo: No, this was the first time. First time. Well, remember, there weren't any, except—well, tell me what there were.

Breslin: Boston.

Bristo: Boston.

Breslin: Houston.

Bristo: Houston—

Breslin: Denver had something going at that point, but small.

Bristo: Didn't know about Denver.

Breslin: Yes, there wasn't much happening. I mean, there were beginnings in lots of places.

Bristo: Right. So I went to Berkeley and I saw Berkeley. But what happened is, the same time I was in Berkeley—and at first I was a little irritated—Max Starkloff, the director of another one of the first federally funded centers, was there too, with Colleen. So Max and I met, and that was pivotal. I really liked him, his story was really overwhelming to me, personally, that he had just written this grant from a nursing home and then had built this housing thing. At the time, he was doing this thing like I was and was right where I was, and we knew nothing. Well, we were exchanging information, "Blah blah
blah, what are you doing, blah blah blah blah blah blah." And then we had to leave. And I just about got home and then went to Texas, saw the New Options program, met Lex [Frieden]. Was not impressed with that program.

Breslin: What did you see when you were there?

Bristo: A place where people lived. I met some of the community leaders in a different location, and talked about what some of their advocacy priorities were.

Breslin: Do you remember who you met?

Bristo: The only people I remember were Lex and Joyce. I really don't remember the other people. But they gathered a group of people. I was very impressed with Lex, so let me clarify. I was extremely impressed with Lex. In the same way that Max had made a mark on me, Lex had. It was clear he had really thought about this thing. It was he who introduced me to the writings of Gerben DeJong, which I had not up to that point seen. It was he who started to give me a conceptual framework outside of the grant proposal. I didn't get that at Berkeley. I saw it at Berkeley, but it was Lex who gave me the conceptual framework.

It was also Lex that planted a seed in my head. I told him how I had met Max, had really hit it off, wanted to be able to learn more from him, and that, you know, we really needed a communication mechanism. He and I talked about a newsletter or something, but we didn't do anything. We both said goodbye and left. Shortly thereafter, still very much like in the first three to six months of us having the money we were called to Washington by RSA [Rehabilitation Services Administration], all the first ten centers. Still there weren't anymore, it was just ten of us. They hadn't funded the second round yet. The first ten of us were called to DC. We didn't know what for. They got us in the room, and the bureaucrats started talking to us about outcome evaluation. They were borrowing concepts from vocational rehabilitation, talking about how they were going to measure what we did, about case closure concepts, and all this. And we were all like—first off, we had no idea what they were talking about. Second off, it was clear to us within our ignorance that they had the cart before the horse. How are you going to measure what we are doing before we know what we're doing?

So we naively, during lunch, ten of us talked together and said, "Are you finding this as boring as we are?" And, "Well, what should we do?" So we had our first little organizing meeting.
Breslin: Who were the ten?

Bristo: I can only give you the ones I can remember. Max, myself, and there was—

Breslin: Somebody from Berkeley CIL.

Bristo: No.

Breslin: Oh, because they didn't have any Title VII money.

Bristo: Berkeley didn't have Title VII. St. Louis, Chicago, Kansas. A person by the name of Paula McElwey or something like that.

Breslin: Where was she from?

Bristo: Kansas. I don't know where in Kansas, somewhere in the country. Bob Williams from Boston. Somebody from New Hampshire—no, Maine. Steve Tremblay maybe from Maine. I don't remember after that. It would be easy enough for you to check.

Breslin: This is '80—

Bristo: '80.

Breslin: '80, so there were ten centers that were federally funded in '80.

Bristo: Ten centers for Title VII, Part B, centers for independent living.

Breslin: Right, but in terms of what they actually were in the committees evolving there?

Bristo: Oh, yes, okay, what were the ones that had their center within the vocational rehabilitation agency?

Breslin: Right.

Bristo: There was somebody that had their center in a vocational rehabilitation agency from maybe somewhere in the South. But I'm sorry, that's as best I'm going to get.

Breslin: It's okay, that's good, that's very good.

Bristo: You guys could easily get that, though.

Breslin: I was just curious about it, just for my own interest right this minute. We can absolutely go back and look it up.
Bristo: Charlie Carr might have been there.

Breslin: Somebody from Boston probably was, other than Bob, but anyway, go ahead.

Bristo: I wish I could remember who they were. So anyway, the ten of us got together. Most of the people who were there are no longer in the movement, and that's why I'm having a hard time remembering them. They were short-termers. The first ten CIL directors, most of them are long gone. Several of them were non-disabled people, or a couple of them anyway.

The nucleus was really me and Max, and Bob Williams. So we came back after lunch, and when they got us all in the room, we reasonably diplomatically said, "You know, this isn't working for us. We understand you guys need to do this, but would it be okay with you if we got a different room? There's so much stuff; we're not going to be here long; we'd really like to talk to each other." And you know, that was the first meeting of NCIL, in its own kind of way.

What happened was that magic of peer support at an organizational level happened. Oh, it was incredible, we spent the whole day talking about, "Well, how do you do peer support? Where do you—?" I mean, it was really just that really basic Q & A. And at the end of the day we said, "You know, this is not enough, we've got to get back together." So when we went back into the room, and they're still talking about their data collection system [laughs], then is when we said to them, "We respectfully need to say to you we think you're approaching this wrong. You're ready to start evaluating us, and we just spent the day realizing we don't really yet know what we're doing. What would really be helpful would be if you could bring us back together again." So they agreed to. They said they would pay to bring us back together again. They must have done that two more times. So, the feds paid for those first ten to come back together.

I think that the second meeting was in St. Louis. What I remember about the St. Louis meeting was, after the first meeting we had agreed we didn't know enough, and we needed some of the old-timers to come. So we brought Judy [Heumann] and Gini Laurie, because she was right in St. Louis. It may even have been the second meeting that Bob Williams showed up, because I kind of remember his presence there and not in the first one.

Breslin: Right, more likely the second than the first. But I'm guessing.

Bristo: But we still only had ten centers. We weren't yet at the point of the second batch being funded. But by the third meeting, the next group
joined us. So it was the first ten that started, and then they must have hunted a few more, not a lot more, in the second go around, and they came to one of the next meetings. The leaders in this, I don't know that anybody else would agree, but it was really me and Jim DeJong. Because Jim DeJong really had high political aspirations. Jim and I would come back to our office and spend a real lot of time, like, afterwards kind of—

Breslin: Analyzing and talking.

Bristo: Analyzing and organizing. We were the infrastructure behind it. We created all the phone calls, we organized what the agenda would be—

Breslin: Now, did he come to the first meeting of ten with you?

Bristo: No.

Breslin: He came to the second.

Bristo: Yes. And the one I really will give credit to is Jim; it was largely Jim's thinking that put together the NCIL structure. We kind of did it together, but it was more him than me. We came to a meeting in Kansas. Now we're after St. Louis, and now we're in Kansas, and all the while we're making little developmental leaps. On the one hand, part of our agenda was that we would have an hour-long session on personal assistance programs, and someone would take the lead on giving a presentation on how it's being done in their state. Then we would have pre-identified who seemed to be the farthest along. So we had an agenda where people were giving presentations, so we were learning. We were starting to get just a little more formal.

But then the other part of the agenda was on organization. Okay, we need bylaws, we decided, okay, we're going to be an organization.

Breslin: When was that decided?

Bristo: The organizational first meeting was in '82, but the groundwork, crafting the first bylaws, thinking through the membership criteria, all that groundwork was happening in-between meetings from late '80 until '82.

Breslin: Do you remember when it was decided that an organization should be formed? It was obviously at one of these meetings or was ratified at one of these meetings.

Bristo: Yes, I think the strategy session where we came to look at organizational structure was in St. Louis. Now there were a larger
group of people, and gosh, I think I'm remembering that Kansas University got that training grant to do the conferences, and that was when we made the presentation to the broader group of CILs who were brand new and who hadn't been in the planning. And that's the meeting at which I have a really clear visual memory of being in an auditorium with Jim DeJong and me in the front of the room with a flip chart and the organizational chart that we had come up with. It got tinkered with a little bit there. We didn't have at-large members. Jim and I had the board and the regional representatives. And at the meeting, for some reason, I'm not sure I remember why, the concept of at-large members came up, and so we added them. It was at that meeting that we left with the structure in mind and that we started to write the bylaws.

Breslin: Do you have any memory of which organizations came in in addition to the first ten? I mean, obviously that's written down someplace.

Bristo: Yes, it would have been people like Bobby Simpson in Arkansas, it would have been Charlie Carr, John Chappel, Eric Griffin—those are the people I remember. It was more than that, but those were the folks I remember. Let’s see, were there any California people yet?

Breslin: There may have been somebody from southern California at that point.

Bristo: June [Kailes] maybe?

Breslin: Maybe June, yes.

Bristo: I'm not sure.

Breslin: Maybe Brenda.

Bristo: No. Brenda came to the first big meeting. My first recollection of Brenda was when we had a really, honest-to-God first meeting. But what happened, I missed one meeting in New Hampshire, I got sick—no, in Maine. Steve Tremblay hosted the meeting in Maine where I think they hammered out more details on membership. Then I was made the bylaws committee chair. So I got the task which I eventually gave to Charlie Carr at a certain point in time. So between Charlie and me, we wrote the bylaws. Then they came to Chicago. So the places that I can remember being in were Washington DC, St. Louis, Maine, Kansas, and Chicago. And I don't remember whether Kansas or Maine came first or second.

Breslin: RSA funded the first three meetings, how did the next three or four come about?
The R&T [Research and Training] Center grant brought us together for the Kansas meeting, and by Chicago we were using our own money, and people were actually paying their own way, their organizations weren't, I don't think. People were using their own bucks to come.

Oh, Gordon Anthony was at the Chicago meeting, because I remember partying with him and his personal assistant. They sang, there was this song, and they sang this song together, whenever it came on the radio they burst into song, and it was so funny! [laughs]

In Chicago we incorporated, we approved the bylaws. It happened in the Americana Congress Hotel.

And that's 1982?

Yes.

Marca, you were continuing on the NCIL incorporation.

Yes. We were now incorporated, and we elected officers. The first officers, I don't remember all of them, but the best I can remember was that Max Starkloff was the president, I was the internal vice president, John Chappell, I think, was the external vice president. I might have this wrong. I'm now remembering Charlie Carr was there somewhere. Well, I remember John Chappell, Max, me, Charlie Carr, and Eric Griffin, I think, were the five officers. Who was in which role, I'm not positive of. I was the internal vice president, [laughs] which meant I did all the work. Max was kind of the titular leader.

It's like the COO [chief operating officer] position.

Yes. And I was pretty good at that. I kept Max focused. You know, "Max, we've got to do this; Max, we've got to do that; Max, we've got to do this." I also remember, when we were deciding who was going to be the president, I wanted to be. But I also really deferred to Max.

Why did you do that?

I don't know. I really don't think I fully know. I think I wasn't quite ready to take it on. Remember that whole thing about not always stepping forward, but needing to be pushed? Nobody was pushing me, and Max was older, Max was a guy, Max was more disabled than me, and I can't explain what it was that made me do that. I don't know. But I was too timid, that's what I guess I would say. I wanted to do it, but I was too timid, and so I kind of let him do it. I didn't put myself
forward. A lack of confidence maybe. I don't really know. It wasn't a confidence of my ability, it was a confidence of my leadership. Would they accept me as a leader? Not, could I be an effective leader? So, I'm not sure.

Breslin: Okay. This was '82?

Bristo: '82. Then NCIL—do you want me to continue on this?

Breslin: I want you to stop a minute and I want you to say whether or not you, at this point, had met Ed [Roberts]?

Bristo: Ed was an elusive figure to me at this point. I had met him, but at a conference with a million people. Judy [Heumann] I had met briefly, but she was still a little bit more remote, and I had her way up on a pedestal still. It was only after I got to know Judy a little more that some of my own self-confidence came out. Judy really helped me—you know how Judy is. On the one hand, she is the queen, and on another hand she is right there with you, and you're just as important as she is to you in this moment. You know, everybody is Judy's friend. So she really breathed confidence in me by, you know, by taking herself off the pedestal and making me see her as another disabled woman. And she did that, I didn't. I mean, she, you know, when I would act sort of in awe of her in the early days she would go, "Oh, come on!" I mean, she would almost self-deprecate in order to bring me to her level.

Breslin: To put you at ease.

Bristo: Yes, yes. And eventually it stuck. Eventually it stuck.

Breslin: Was she involved in the formation of NCIL?

Bristo: Remember she was at the St. Louis meeting. I seem to remember her, but I'm not positive when we started really having the battle around membership, because after we organized, then we had to recruit members. We had the first meeting in Washington at the same time as another one of those conferences, so that probably would have been in '83, where after we were done then we sent out stuff to whoever existed and said, "Come join."

The bylaws established a certain level of understanding about membership, but then the membership application did more. So we tackled the issue of consumer control in that first membership meeting. And it was a raucous meeting. I mean people shouting at each other, getting angry with each other.
Breslin: What were the issues, as you remember?

Bristo: Well, I think there were two. Well, the main issue was whether or not a center for independent living who was a member of NCIL had to be consumer-governed, and what did that mean? The law only said "substantial consumer involvement" when it was written. And NCIL, through all these meetings we had had, they had allowed this flexibility in the law, particularly in the South. A lot of the states were funding things that looked nothing like a center for independent living. They were run by non-disabled people, many of them were in the state vocational rehab offices, and all they had was a little sign up that said "Independent Living Center." They had state employees running them. They weren't cross-disability. If they had disabled people, they weren't cross-disability. There was no meaningful involvement. There were often token boards that you could tell were token.

Breslin: There were advisory boards.

Bristo: There were hospitals that were doing them, unlike we did them, with no real commitment. It was total tokenism. And these were being funded. There were centers starting to develop housing—residential facilities for people with disabilities. I'm not positive whether this was the same meeting where we also fought over whether a center could operate housing or not. That could have come later, but that was another watershed moment where centers were starting to build housing. And NCIL said no, you can't build segregated housing and be an independent living center. It might have been in this meeting, or it might have been later; somebody else will have to tell you that.

Then there were organizations like us who weren't yet independent, but who were on the path to it. So there was also that. The leadership had come from us, and we were setting and agreeing with a value system that excluded us. So there was also a need to find a way to take the well-intentioned entities and let them in. So we built a transition plan. We voted on a concept that if you weren't consumer-controlled right now but you submitted a reasonable transition plan, the membership committee would review it and you could be admitted based upon that. And that's what everybody was fighting over. It was really raucous. I wish I could remember the people who were yelling.

Breslin: [laughs] It's always good to know who the yellers are.

Bristo: I do remember Brenda Premo yelling, but on our side. And I remember—and this is when also there was tension emerging with John Chappell—John Chappell, Eric Griffin and Charlie Carr had all this fighting going on between them in their own state. And Jim DeJong and John Chappell had become very good friends. And Jim
DeJong was now trying to control everything. So there was this just little clique of these guys that was really running the show and pissing everybody off. This came a little bit later over personal assistant services—the state of Massachusetts ran their PA money through their centers, and there was a strong feeling that that was a conflict of interest. How could you be an advocate if you're the one administering the PA program? So there was a lot of battle going on over that. John Chappell then went to work for the state and still remained on the board, and was incrementally becoming a bureaucrat, and bringing those ideas in, and people were clashing with him left and right.

Also, somewhere in this period, during the time Max was president, the independent living centers were supposed to have three years of funding under Part B [Title VII of the Rehabilitation Act], and then end. Let me clarify something, now they've changed the A, B, and C, so I'm talking about during this era. There only was—

Breslin: Pre- the '85 amendments.

Bristo: Right. There was only A and B. B was for the conducting of independent living centers' services, so it was to fund centers. A was to fund services. The concept was, "We'll get these centers going, and then we're going to fund Part A to the states. They'll have a pot of funds like vocational rehabilitation dollars that they will, on behalf of their clients, purchase independent living services from the independent living centers." So the original concept was the Part B dollars were intended to be startup seed funds, at which, at the end of three years, we would segue over into fee for service, the state would buy our services for the clients, and the funding that had funded us would be free to fund other ones. That was how it was supposed to run.

Breslin: Yes. Theoretically.

Bristo: They never funded Part A.

Breslin: Right.

Bristo: And so two things happened. The three-year point came. We all reapplied, they allowed us to reapply. At the three-year point they defunded Max, somebody else also. During that period we had been working to build momentum to change the law. What years was the law amended?

Breslin: '85—

Bristo: '78.
Breslin: '78, and then again in '85, or '87, I think, and that's when the 51 percent was—

Bristo: '87—'82. There were '82 amendments, I think. That's right. '82 would have been the year. Between '80 and '81, NCIL had had the battle on membership and consumer control. We made our criteria clear, we voted some people out of the room. The first year we let anybody be a member that wanted to, just to get them there. Then once they were there we had these things adopted. And in that meeting is when everything blew up, and a lot of the people just left. They weren't members, they were really furious with us. Then NCIL went to the Hill as a group to make the change in the law, to change it from substantial consumer involvement to consumer control.

Breslin: To fifty-one percent. So that was '82 you think?

Bristo: Yes. And interestingly at Access Living's grand opening here in 1980, we had Senator [Paul] Simon coming to do the ribbon cutting. Because Senator Simon was coming, this political organization called, at the time, Illinois Public Action Council. Do you know the Citizen Action—?

Breslin: Yes, sure.

Bristo: Okay, it was the Illinois Citizen Action. And Bob Creamer was one of the founders of National Citizen Action. Bob Creamer was the executive director of Citizen Action, and he came to our ribbon cutting. I had never heard of him, I didn't know who he was, but he came to our ribbon cutting. He invited me to come to his annual meeting, to his dinner. I went to his dinner, it must have been in 1981, and at his dinner I was awestruck. He had every politician in the State of Illinois on the dais, on the Democratic side, all of them. The mayor, the senators—all these congress people, the secretary—you know, you name them. It was at the Conrad Hilton, probably fifty people up on the dais, and I was, "Whoa!" It was my first introduction to real politics, and I said, "I want to know these people." And I developed a relationship with him. He ultimately invited me to come on the board, I was the first disabled person. Later I became the board chair.

But during this period I knew nothing about electoral politics. So Bob took me under his wing and started to really kind of teach me. He had a lot to gain because he had no disability presence in there, and he was starting to see us grow. Paul Simon came to our thing, so he thought we were hot. So I was having a hard time on this consumer control thing on the hill. Max was the president; we were lobbying on the hill. We didn't know what we were really doing. I called Creamer, and I said, "Bob, what should I do, I need your help." He put me on hold, he
came back and he said, "This is what I've done." He had called his colleagues in Iowa who ran the Iowa equivalent of Citizen Action. Later on I discovered it was Mike Lux, who was later in the White House, but I didn't know that at the time. It was just some guy in Iowa.

Without me knowing any of this because I hadn't even been smart enough yet really to focus on who are the people we should focus on—it was right at the beginning—Creamer called me back and he said, "I called my friend, he's on the other line. I want you to tell him the issue." I told him the issue, the guy on the other line said, "Okay, I got it. I'll get a meeting for you with Tom Harkin." So I said, "Great, who's Tom Harkin?" [laughter] And he told me who Tom Harkin was [Senator from Iowa]. And somebody had happened to tell me Tom Harkin's brother was deaf, so I brought Tom Benziger from my staff at Access Living to the NCIL conference. He's deaf. Tom Benziger and I went into this meeting, I think maybe Eric Griffin was there also. There was one other NCIL person with me, just the three of us, and Tom Harkin. And we had been working on some other stuff on the House side, the same issue on the House side earlier with, is it Steve Bartlett. No, he was a Republican. Who did Bobby [Silverstein] work for on the Hill, before—?

Breslin: Harkin.

Bristo: No, before Harkin.

Breslin: Before Harkin, I don't know.

Bristo: He worked on the House side.

Breslin: Yes, I don't remember.

Bristo: I forget who, but he worked on the House side, and we had been lobbying that member on consumer control, and Bobby was the staffer over there and Bobby totally resisted us. We had no access to his boss, and he was winning, completely. You know, where he was saying, "You can't do this," and he cited all this affirmative action crap, you know, "You can't do it. You can't put this in the law." So Tom Benziger and I and this other person walked in, and here's Bobby Silverstein, and I'm like, "Oh, my God, I just fought with this guy." He had just transferred over to Harkin, I didn't know that.

So here's this guy in the room, Tom introduces him as his new staff director on these issues, and we start into the discussion. And I'm making this argument, and Tom Harkin strikes up this conversation with Tom Benziger in sign language, and the two of them are, in Tom's rusty way, talking, and he's telling him about his brother, and
we're talking about cross-disability and why this is so important, first. Then we got into the consumer control thing, and we laid out all of our arguments. Tom Harkin looks at me and Tom; he goes, "Sounds good to me, Bobby, let's do this." And Bobby, you should have seen Bobby's face. [laughter] He was pissed! I wonder if he even would admit to this. It was one of those moments in time that I'm sure it shaped my relationship with Bobby forever, because I had gotten to his boss. And you know, if I had known I was doing it, I don't even know if I would have done it. But—

Breslin: It's one of those wonderful serendipity moments—

Bristo: Isn't it? And it also taught me the power of coalition politics. I've had so many remarkable opportunities that shaped the way I do my work, and one of it is being born in Chicago, where we're a really political city. And you're either in politics or you're not, and if you're not you give up. You're not a player.

Breslin: [laughs] If you're not, you're not getting anything done.

Bristo: Yes. So I really had a great lesson in the power of coalition politics, how much other people can help us. And it really shaped everything after that for me. I've really used that over and over and over and over and over and over, that there are things other people have that we haven't developed yet, and if we're working with them, and there's an advantage to what we have there, they're likely to help us with that stuff, and that will make us all stronger. So we won on the consumer control thing.

Then the competition for the grants came up, and they de-funded Max, and we were pissed. We were really pissed off. So we all went back to Tom Harkin, and to Tom Eagleton?

Breslin: Could be. I don’t—

Bristo: Yes, from Missouri, I think so. And we turned it into a cause célèbre. We made it into this big deal that because NCIL was using the political process and speaking up as advocates, our president was being punished. And he ran a competent organization. I remember taking his application and mine and saying, "His is just as strong as mine, why did mine get funded and not his?" Everybody rallied around Max. Up to this point we had been more on the membership side of things, you know, helping each other with technical assistance. Then it was these two back-to-back battles of consumer control and then fighting for funding. We were able to get a band-aid solution. They found a way to give him funding. Then we went back to the act, and I don't remember if that was in the next round of amendments, or
what—maybe they did a technical amendment or something. But what they did was, they changed it the next time into—you could continue to be funded. And Part A never got funded for years, and then when they rewrote it in '87 Part A, B, and C changed.

And then a significant thing happened in Illinois politics. Sue Suter moved from being the head of the Illinois Planning Council on Developmental Disabilities to being the head of the Department of Rehabilitation Services. And the department was created—no, it already had been a department under Jim Jeffords, before. Jim Jeffords was a disabled man who worked to get the Illinois office of rehab made into a cabinet-level department. It stayed at cabinet-level department here for a really long time. Jim Jeffords supported the application of a few more centers to get federal funding, so shortly after Access Living was funded there were four more centers.

Breslin: In Illinois.

Bristo: In Illinois. I can't exactly tell you what year that would have been, but a few years down the road. Not the next year, but maybe two or three years out. So now there were five of us. While NCIL is being formed, I'm now simultaneously back in Illinois, at the same time, doing the same thing there. With a little different level of energy, but basically saying to these guys, "If we get organized, we can grow, we can do more," and serendipitously Sue Suter became the director of Illinois Department of Vocational Rehabilitation. She was watching what we were doing and was starting to get really intrigued by it, and hired Jim DeJong away from me, which was a blessing, but it really pissed me off. I felt she was promoting this guy with whom I had been having difficulties, and I was anxious about what that was going to mean.

Now, I don't know if you've ever followed Jim DeJong's history, but this is one that I'm not uncomfortable talking about. He was a divisive force in the Illinois movement, even though he's a nice guy on some other level. He did many divisive things here. But he also went inside state government and decided, because he wanted to expand independent living and also have a little fiefdom, both—they were both going on, the good motive and the not-good motive were, at the same moment—he pushed Sue to start expanding the independent living centers. So they went to the state and got general revenue dollars to create new independent living centers. He did, over time, start pitting the old ones against the new ones and all this weird stuff went on. But through his tenure, I would bet by the time he actually left there were probably about twelve of us. And the new ones were all state centers.

Breslin: With no Title VII money.
Bristo: Right. So Sue and Jim brought the number of independent living centers in Illinois from, well, from one, really, to probably twelve or fifteen in a pretty short period of time.

Breslin: About how long was that? Five years?

Bristo: Two. I mean, they did this quickly. They earmarked dollars and moved it rapidly. So we had, overnight, rapid state expansion. We then formed the Illinois Network of Centers for Independent Living. Ann Ford, myself, Beth Langen — after that I'm forgetting. It's the three of them, there were five of us. Springfield — gosh, I don't remember where they all were. Peoria, Springfield — Oak Park was in the second generation. So that was going on at the same time that we were developing new centers. I was kind of nurturing them to take the lead, because I was so invested with NCIL. In 1985, now, I took a leave during '84 to '85 from NCIL. I was in recovery, and I just said I need a break, and I stopped going to everything at NCIL, for a year. That would have been probably '84 to '85. In '85 I was feeling better, not altogether better, but I went through this period in therapy of, "Do I want to be a professional crip? Is this what my life calling is? I don't know what I don't want to be when I grow up." And in therapy, finally, I came through and said, "Yes, I do." But I went through that, "Do I want to do something else?" mode, came out the other side of it and decided, with my therapist kind of urging, to go back into NCIL. It had meant a lot to me.

When I got back in, I had been gone for a bit, the election was coming up, and the people slated to run for Max's seat — Max was now gone — were Eric Griffin and Charlie Carr, I think. I don't think John Chappell was running, I think it was the two of them.

Sue Suter happened to come to the NCIL meeting, and all of a sudden Sharon Mistler started attending — so her center was now there, June Kailes' center was there, Judy was there, who else do I remember? Denise McQuaid from New York. I don't know, or I'm not positive about Denise Figueroa. Gina — this is funny, I can't remember the people. Sharon Mistler was the leading force on this. The two guys were lobbying and Sharon got pissed off by it, didn't like either of them, and decided to hold a caucus in her suite, a woman's caucus. None of the men were invited. So up in that suite there was sort of this women's movement takeover of NCIL. The women in the room decided that they didn't like the choices, we needed to draft our own candidate. Not only that, we needed to have our own slate. Somehow or another Duane French found out about this meeting and came to the meeting.

Breslin: Well, his hair is long enough.
Bristo: Yes. And at that time he was so young.

Breslin: Was he in Kansas then?

Bristo: Probably. Nebraska.

Breslin: Nebraska, that's right.

Bristo: He was brand new, he was young, he knew nothing. He was—

Breslin: He had probably just gotten out of the nursing home at that time.

Bristo: And he was like wide-eyed. He would sort of just listen to everything we told him. And everybody liked him, because he was kind of a nice guy and had a good sense of humor, and he was sucking up everything that was going on around him. And he didn't like these guys, this was clear, he did not like these guys. And I don't remember if Duane was in the room, I don't remember that—so anyway, the women started saying, "Okay, so who is going to run for president?" And I probably was thinking, well, maybe I should, but I was really not volunteering, and not feeling at all confident in doing this, especially under these circumstances.

All of a sudden people just kind of looked at me. I had been the vice president, so I guess I was the logical person, and I remember everybody's eyes kind of came to me, "Well, Marca?" I started saying, "I can't do it, I've got my center, we're just becoming independent. I mean, I just can't." Like I always have said in the past. Sue Suter happened to be sitting next to me, and she, as the conversation moved on she leaned over to me and she whispered, "What would it take to have you run?" I said, "What do you mean?" She goes, "Well, if I could help you in some way, what would it take?" I said, "I need somebody to help." She goes, "Like an assistant?" I said, "Yes." She goes, "Would $10,000 do it?" And that seemed like an enormous amount to NCIL. I said, "Well, yes." She goes, "I'll get you $10,000." This was all whispered. So I raised my hand and I said, "I guess I'll do it." And everybody clapped, it was really one of those really cool moments where your women friends were there for you. And they kind of launched me into this. They drafted me, it was almost like a pep rally, you know.

Breslin: When was it, what was the year?

[Audiofile 8, Side A]

Breslin: I'm sorry Marca, go ahead and finish your answer to the question, when you served?
Bristo: Yes. Let me ask you a question, we passed the ADA in—it was written, signed, in July of '90. When did the Hill process end, how much time was there—?

Breslin: Two years.

Bristo: So it took two years to get it, from '88, '89, and '90.

Breslin: Yes.

Bristo: Okay. I think I ended my tenure in May of '89, that's what I think. I think it was May of '89—but you know, I am not positive.

Breslin: Your vitae says, "President, '86 to '89, immediate Past President '89 to '90."

Bristo: That would have been right.

Breslin: Does that sound right?

Bristo: Probably.

Breslin: All right. So this women's meeting and being drafted occurred in '86.

Bristo: Yes.

Breslin: Okay.

Bristo: Yes, I think that's right. Anyway, so on the slate with me were, I remember June Kailes, I don't remember anybody else, isn't that terrible? But it was all women. It was June, it was me, who was my vice president? Gina might have been there, or might not have yet. Denise McQuaid, maybe Denise Figueroa. I don't know, Sharon might have been like a secretary.

Breslin: Sharon Mistler?

Bristo: Yes. And then there was Duane. It was a women's slate, plus Duane. Duane was the treasurer.

Breslin: That's great, that's terrific. So what was the process of rolling over the originally composed slate?

Bristo: Oh, so then somebody went and made fliers and then everybody went leafletting the whole hotel. And there was like, I had a campaign committee!
Breslin: Got a campaign going overnight!

Bristo: It was the first time NCIL ever had a campaign concept in it. These women just became my campaign committee, and they started leafleting everybody, and this literally happened the night before the election, so nobody expected it. We came in and the next day they introduced us from the floor, and we swept it. I mean, it wasn't even close.

Breslin: Was it a voice vote, was it a hand vote, was it a written secret vote?

Bristo: No, it has always been a hand vote, and I don't remember the numbers but it was a landslide.

Breslin: How many members were there at that point, roughly?

Bristo: Forty?

Breslin: That sounds about right, but—

Bristo: It wasn't over one hundred. I think when I left maybe there were eighty, so—. Then that was a very interesting period, because that was when a lot of my visions started to come alive, my national vision. Up to this point I had been the structuralist, you know? We need an organization; I do claim that as my vision, others were part of it, it wasn't solely mine, but I was really a big driving force behind NCIL, and getting it started. But I was more looking at the structural stuff and some of the operational stuff. It wasn't until I got in NCIL that I started being more focused on broader vision issues. What I really felt like I brought was—well, for one, I recognized that having just won as a women’s slate, that we really needed to do more to promote women and bring women in. And coming from Chicago as I do, I recognized that NCIL was all white, and that wasn't okay with me. So the very first two things that I started was to add a multicultural dimension to NCIL. I appointed Don Galloway as chair of a minority taskforce or a minority committee or something, and put him in charge of starting to recruit people in.

Then at our first annual meeting—also, remember the coalition back here, Citizen Action, that I was part of? I had continued my involvement with them, and Jesse Jackson had come to give a speech at one of their meetings, and I had asked for a few minutes of Jesse's time. I wanted to talk to him, I don't even remember what the subject was initially. Bob Creamer said sure, he'd set it up. So I showed up to go to the meeting, and the room they had Jesse in was up a half flight of stairs, and so I was pissed off. Jesse came down the stairs, and I'm sitting at the bottom of the stairs, and I told him, "I was supposed to
meet with you today, but you were up there and I'm down here and I'm not a happy camper." And I got his attention. [laughs] He went into the room right after that and gave a speech about broadening the movement to include disabled people, and, "When we do things like what just happened here today and have meetings like this—" He converted his speech to a disability speech—and I'm sure this was probably the first time it had entered his consciousness. He came out of the room afterwards and then I went up to him and said, "Now, I have a favor. I'm the president of this organization. I would like you to be the keynote speaker."

So how I did the other part I'm not sure. But the other thing I did was I got Ellie [Eleanor] Smeal, who was the head of NOW at the time. So at my first annual conference of NCIL—oh, and that's the other thing. We threw Kansas out. Kansas had been running all the conferences. We went and said we want to run the conference.

Breslin: You're talking about the University of Kansas.

Bristo: Yes. We said we want to run these conferences. So we took over the running of the conferences. I hired Maggie Shreve, who had been the director of The Whole Person as my assistant. She moved to Chicago, and we set up the first mini-office here at Access Living, where she had a desk and used that infrastructure.

Breslin: You still, at this point, hadn't moved. You were still in your affiliated stage, hadn't actually become independent yet?

Bristo: Yes, we were right—

Breslin: —you were right in the middle of the transition.

Bristo: Yes.

Breslin: Okay. Let me stop you just for a second there, because I just have a series of little questions I want to ask. We haven't talked about any kind of substantive issues that in the early eighties, the early to mid-eighties, you were participating in or aware of—

Bristo: Yes.

Breslin: You know, what kinds of substantive issues were on the table for you?

Bristo: Well, most of our work at this point—and I think this was true amongst most of the centers—was local and state issues. So the first issue we took on was on my very first day. We wrote a letter to the governor about the absence of a personal assistance program, and that
there had just been a new waiver program, and Illinois should be in it. I remember this letter because it was my first advocacy letter, and I ended it—well, in not the way that most people end letters. It was kind of a demanding, obnoxious ending. "And if you don't do this, then—" da da da. I don't remember. But it was like perceived as completely inappropriate. Well, maybe it was completely inappropriate, but I got the governor's staff to call me to yell at me for writing this letter in this totally inappropriate way. Well, that started the engagement process. Then, Margaret Pfrommer, who was the one that had planted the seed that this was the issue, it was her idea, but it was my letter. You see there? So she was more of a thinker than me on this issue, she was more experienced, and it was more important to her, because I didn't use a PA [personal assistant]. So it was her issue, my letter, and then my leadership that caused the state to start—and Access Living's leadership—to start to develop its first PA program. It's not the greatest one in the world, but it was the first one, and one of the first in the country.

Transportation became a huge issue here. There had been an old lawsuit here that hadn't gone well under 504. But the issue was still a hot issue. So we—what year was this, this was a little bit later. So that was a hot issue, which eventually, I'll explain to you our role in the lawsuit that occurred. Forming ADAPT in Chicago, Wade Blank came to town and wanted to meet with me. This is where Jim DeJong and I started to have our huge falling out. Wade called and wanted to meet with me.

Breslin: Just say who Wade is.

Bristo: Wade Blank was the founder of Atlantis and ADAPT. Wade had already started to do his stuff with protests for lifts on buses in Denver, and had had success, and was now starting to go national. He had worked with Shel Trapp from the National Training Information Center, which started out as part of the same organization with Bob Creamer. And Heather Booth and Shel Trapp, and some other people. They ultimately split earlier, in the sixties. They were organizing around a Saul Alinsky model. And the people in that group who were older than us split in half, and Shel Trapp's group pursued a Saul Alinsky non-violent organizing model, and Citizen Action followed a more electoral reform political model.

So I got a call from Shel Trapp saying this guy, Wade Blank—I didn't know Shel Trapp, but he called me up and said, "This guy, Wade Blank, has come to Chicago; he'd like to meet with you." I said, "Sure, have him call." The phone call came in and it was for me, but Jim DeJong was working the phones that day, and he took the call. And he didn't tell me it had come in. So he told Wade to come. Then he
managed to royally piss Wade off. "Who the hell do you think you are coming into our city?" You know, really—they went head to head. Well, I didn't even know this was happening up to this point, until Wade started reaming me out for what was going on here. I immediately shifted gears and said, "That's not our position," you know, "We should be the ones talking." Wade ended up helping him connect up with this guy, Kent Jones, our Kent Jones, and Kent ended up hosting Wade at St. Joseph's Hospital for the first organizing meeting of ADAPT.

Kent was on the Access Living board of directors, and Kent and I had good rapport. So from the very beginning, after that thing with Jim DeJong, Access Living started to develop ADAPT. We gave them our meeting space, we let them use our Xerox machine and telephones and things. So it's an interesting little piece of history, because I think later it colored some of my tension with Wade, who I always—well, I had a problem with a non-disabled person in such a leadership role, but I respected what he was doing a lot. And he pissed me off to no end the way he always made us the enemy. You know, his way of getting you moving was to attack you. If you weren't 100 percent where they were, then you were evil. He did that with me so many times. But I have to say, to my credit, I really didn't let it blur my respect for what they did, and during my tenure as NCIL president I really forced NCIL to start to work through its conflict. I went to all the ADAPT actions, I really invested myself in trying to prove to them that I did believe in what they were doing, and I wasn't the evil person that Wade was making me out to be. All of which made me stronger as a leader—having to go head to head with him for a long time.

Breslin: I would imagine so. Okay, transit, ADAPT—

Bristo: So transit, ADAPT, housing—

Breslin: PAS [personal assistance services], yes.

Bristo: But we were making no progress on housing. Curb cuts were big in Chicago at the time, and, also, I now know we were being given a line of bull, because all the things that I was told by the people from the city which turned out to be just wrong. They were giving me all these technological reasons, structural reasons why you couldn't put curb cuts in the Loop because of the vaulted sidewalks, thus it would weaken the structure—well, we've now done it. So really, it was just bull, but it all sounded good at the time. So we were mostly doing advocacy of the persuasion mode, we were building ADAPT. I think those were the early eighties kind of core things there. We were developing the other centers for independent living.
Then DREDF came to us for 504 training. We hosted you guys, we had a subcontract from you. Susan Nussbaum came on board, we started doing 504 technical assistance with you. You came to Chicago and did that wonderful training. That's when I first met Pat [Wright]. I don't think I met you.

Breslin: I wasn't at that training.

Bristo: No, I don't think I met you.

Breslin: I mean, at least I have no memory of it. That doesn't mean I wasn't there. [laughs]

Bristo: I remember Pat. I don't know who else I remember, but I remember Pat.

Breslin: I wonder who was here?

Bristo: Women!

Breslin: Oh, yes, most of them.

Bristo: That's all I remember. Women, and was Marilyn [Golden] there that early? No.

Breslin: It might have been Corbett [O'Toole].

Bristo: Corbett, yes.

Breslin: Shelley Bergum, possibly.

Bristo: Yes. That's it.

Breslin: At least those two, yes, possibly Pat. Okay, and then, remind me about—

Bristo: Oh, and there was a state Governor's Committee on Employment in Illinois going on, and that was garbage. I mean, really, it was like this whole “do-nothing” kind of thing. So that became another issue that we all rallied around to get rid of it. So we eliminated it, we just shut it down. We just said, "This isn't doing anything, it's taking time and money." So it was those kind of issues. When you guys [DREDF] came along, one of the first national things that I really remember getting really involved with was the Bush regulatory task force.

Breslin: It was my very next question, actually.
Bristo: Yes.

Breslin: What is your memory of that?

Bristo: Well, that you guys led a campaign. First, you put out all the information, you told us what was going on with Bush's efforts to kind of deregulate 504. This was after that huge battle to get 504 regs. I wasn't part of that. I was not even disabled yet, I don't think.

Breslin: Same year actually.

Bristo: Same year. So that was history that I later learned, and probably learned through your 504 trainings. I think that's the first time I heard that piece of history. So you guys had just been here doing your trainings when this thing ignited. Therefore we all knew you, and [laughs] we wanted to perform well for you, you know. So I remember we were the hub here of getting that out. I think we did a really good job. We generated a million letters, and that was one of our first sort of national letter writing campaigns. I think Susan was the person that was the point person on it, that's what I remember.

During my NCIL presidency, the biggest issue there—and I don't remember my meetings with Pat before this—was the Fair Housing Amendments Act. I would love to hear Pat's biography or whatever you call this, her oral history on this, because I'm sure she'll have a different take than I do.

Breslin: She won't do it.

Bristo: She won't do it? Why?

Breslin: She's just obstinate. [laughs] I don't know. Anyway, go ahead.

Bristo: Gosh, that's not right! Somebody should get in her face. She's really important.

Breslin: Before the Fair Housing Act, just back up a little bit. Did you guys become involved at all in any of the other legislative—?

Bristo: Name some.

Breslin: Civil Rights Restoration Act?

Bristo: What year was that—no, that came right after Fair Housing, didn't it?

Breslin: No, it was before, it was '85.
Bristo: Yes, yes, we definitely did. So that would have been where I first met Ralph [Neas] and Pat [Wright].

Breslin: Right.

Bristo: Yes, yes, I did. And NCIL did, and that was during my presidency, '85—no, that was not during my presidency. That was not during my presidency. But yes, we did get involved in it. This is something that others have challenged my memory on, so I have to say right up front, I'm blurry on what filibuster this was. I thought it was an '88 filibuster, and it was definitely during my tenure as NCIL president. One of the years I was in, and I thought this was at a point when the Senate was holding up the ADA, no?

Breslin: I don't remember, it went through the Senate so quickly, and so little fanfare that it probably wasn't.

Bristo: Okay, then it had to have been the Civil Rights Restoration Act.

Breslin: Which was extremely contentious and went on for five years, but it was broad-based in terms of its application.

Bristo: Well, this is so interesting because my own memory of this, and I've told this story before, and I think it was [Jonathan Young?] who first started saying, "That can't be right, your dates are wrong, it just can't be right." And I'm like, "Yes it is, yes it is." So I still don't remember then what it is. But my first real, real meaningful work with Pat was on this particular bill, whatever it was. NCIL was at an annual conference, and Orrin Hatch was holding up a bill, and it was really late into the night.

Breslin: And this would have been, probably would have been this—

Bristo: Civil Rights Restoration Act.

Breslin: The Restoration Act, yes.

Bristo: And Ralph and Pat were working together. Ralph and Pat were over there—you're right—because there were some women's rights leaders there too, I don't remember who.

Breslin: The issue had to do with a Supreme Court case that had said all of the federal laws that are tied to federal dollars go into recipient agency—

Bristo: Right, right, oh, yes.
Breslin: Yes. Just so you—remember that it affected women, minorities, anybody who was covered by any of the civil rights laws, including Title VI.

Bristo: Yes, it was the program versus the whole institution issue, right?

Breslin: Right.

Bristo: Grove City stuff [Grove City v. Bell].

Breslin: Exactly.

Bristo: Yes, I absolutely remember being very involved in that. So that must have been the issue. Isn't that interesting, for so many years as I've kind of retold my thinking, it was an ADA issue, but this was even before that, so that's interesting to me.

Anyway, Pat and I are over in the hotel and we're down, I think, in the bar, and I got a phone call from Pat Wright saying, "We need help. We need the troops." I said, "Well, what do you need?" She said, "This filibuster is going on, we can't break it, you guys are over there at NCIL, any way you can get some people over here?" I said, "Let me see what I can do." Whoever I was with, I don't remember who, and it was probably already ten or eleven at night, people were already in bed.

Breslin: Oh, this is why it stands out in your memory.

Bristo: Yes. So we just did what at that moment in time NCIL did well. We just sort of spontaneously, with no rules—

Breslin: Rose up. [laughs]

Bristo: Just rose up! So we went around and knocked on people's doors, where we knew people were, and said, "Come on, we need you." So people came out. Some of them didn't get all the way fully dressed even, they came out with like their pants, but their pajama top on, that kind of stuff.

Breslin: [laughs]

Bristo: And lots, you'd have to ask Pat how many, but we filled the room. There were lots of people in wheelchairs. I remember watching Pat and Ralph and being awestruck at the way in which they were orchestrating all of this. It felt almost like a musical performance where—you know, the two of them and another woman, and I don't remember who it was, would caucus for a minute, and then they'd split
up. One of them would go over to this person, that person, and then people would flurry. What I also remember was we had to leave there. I remember all of a sudden being given orders that we had to take this group of people and go over to the actual—

Breslin: The chamber.

Bristo: The chamber, and do something there. I don't remember what we had to do, but we were given orders by Pat and Ralph, and I took a group, and we all went, finding our way in the middle of the night, over there. Then we came back, and when we got back I remember Hatch sitting there, and now it's probably around one or two in the morning. I might be exaggerating, but it's pretty darn late. I remember his sort of finally looking up, and whether he said this or I just remember it, I'm not sure, but the impact it left was, "You guys just aren't going to leave, are you?" And we kind of warmed down, and something happened, and he ended it, and there was this big applause, and everybody is hugging each other, and then we went, you know, all went our way.

Breslin: Yes. We need to both check our facts to verify that it was the Restoration Act. I think it probably was, because that was the first big coalition.

Bristo: What year?

Breslin: It was '85 or '86.

Bristo: If it was '86, that would have made sense, because it could have even have been right after I was elected, the same year.

Breslin: Yes, it might very well have been, I can't remember, I should be able to remember the dates, but I always have to refer back and check my facts, but it was the first big coalition effort that included disability into the broader civil rights community, which is why Ralph was involved.

Bristo: Yes.

Breslin: So I think that's what it was, yes.

Bristo: That might have been it. Well, one thing I wanted to say, and then I probably have to start to get ready to go. During all this time, while I know I had been demonstrating leadership skills, I felt absolutely nothing like a leader. Now, I don't know what a leader feels like, Mary Lou, I mean, if there is a feeling. All I can say is that I didn't feel like a leader. Even though throughout this whole period of time that I've been talking to you I know I had been demonstrating leadership skills,
inside me it didn't feel deserved. Little by little this little stint with NCIL started to make me feel it a little bit. But I didn't really, really feel it until the day I left office.

Breslin: When you left NCIL?

Bristo: Yes. The second leadership challenge, I mean, there were a lot of them, you know, just dealing with the unruly crowds there was hard, the budgetary issues consumed me. But the next thing that I remember was the Fair Housing Amendments Act. My recollection is that the civil rights community had been trying to work on it for quite a while, hadn't been getting too far, and maybe on the heels of this other thing they kind of thought, "Well, let's get together with the disability community." In any case, I came in after all that early stuff was done. The negotiations had already been going on between Bonnie Milstein, Pat, maybe Paul Marchand, I'm not sure about him, and whoever it was working on Fair Housing.

I got a call in the spring, maybe in April, something like that, asking if I would testify at a Senate hearing on behalf of NCIL on this. I said, "Well, yes." I did know what was going on, but I didn't know the details, and I said to them I had never testified before a Senate—well, before Congress before. So I was understandably really nervous, and I didn't really know what the testimony should look like, even. So I said, "Yes, I will do it, but I'm going to need help." Of course, the CCD [Coalition of Citizens with Disabilities] types said, "No problem, no problem." And at this moment in time—whether she is or isn't anymore, she was then— Pat was working with the inside-the-Beltway people pretty much. She may have been leading it, but she was still there.

So they said, "No problem, we'll write it for you." I said, "Great" So they wrote this testimony and they sent me a copy, and all this is happening really quick, right? Not a lot of time to think. I read the testimony, I had by then read the bill, and they called me up to ask for my input, and I said, "Well, I'm fine with everything except two things." No, except one thing. The only thing I brought up to them—. One part of this I'm hazy on. There were two things I had problems with. One was the definition of disability, where they left out people who were recovering from alcoholism, and I was [laughs] recovering from alcoholism. And I don't remember how the definition came across to me.

Breslin: That was in the 504 definition. I believe that was—but anyway, go ahead.
Bristo: Well, it wasn't there, and maybe it was implicit, but it wasn't there. Then the second thing was, at the time that they brought it to me there was nothing in there that said building new housing inaccessibly was discriminatory. So they were getting at all the behavioral practices, but not the architectural stuff. I said, "Why not?" They said, "Well, that's accessibility code stuff, that's not discrimination." You know, and I said, "Come on. At the point at which a person thinks about building a building, when they're drawing the plans, that's the discriminatory moment. So if you don't tell me that when you think about building something and you build it inaccessibly—" and they argued me out of my position. "You will never get it passed."

Breslin: Who was the “they” in this context?

Bristo: Pat and Bonnie. Pat and Bonnie on the phone, on a teleconference. "We'll never get it passed, and the civil rights community will never go for it, you're a newcomer, blah blah blah," and they talked me out of it. You know, the two of them up against little old me at that time. They were way more experienced than me, I had never fought with them, and they overwhelmed me and intimidated me, and made me go against my better judgment. So I went with their testimony, I flew into Washington, I testified. Then maybe either the next week or a few days later was the NCIL annual meeting.

So I came into the NCIL annual meeting, and I gave my president's report. In my president's report I handed out my testimony. And the NCIL membership, somebody raised their hand and said, "Wait a minute! Why isn't this in there?" And I gave them the well-reasoned arguments that had been given to me. And they all went nuts, and they reversed me. And I was like humiliated that here I am at maybe my one-year leadership point, and the membership has just overthrown my decision.

Breslin: [laughs] Oh, God.

Bristo: They voted on it, and they basically overthrew my decision, because I had in essence signed us on the bill. I hadn't gotten their approval, because there really wasn't time. We didn't have any process, I was just making it up as I went. I felt I had the authority, and they basically said, "We disagree with you, and you've got to go back and tell them we're off the bill." Well, Pat was there, and I don't know if she watched the whole thing or if she was in the hall and she heard about it.

By then I saw the writing on the wall and I realized, "Okay, you know, if the troops aren't following, you're not a leader." So this was a big lesson for me, a good lesson, that leaders aren't leaders without troops.
[Audiofile 8, Side B]

Bristo: If you don't have your troops you're not leading, and sometimes leading is really following your troops. Later on as I got to learn, really know Justin, that lesson became differently profound. I don't know how well you know Justin, but he uses a lot of eastern mysticism, eastern thought in his leadership. How many times he would say to me, "Marca, you've got to do the Zen thing." At first I thought he was teasing me, but basically, do the opposite of what you think you should do. Take your opponent off guard. And this is a little bit like that. It was counter-intuitive that the leadership thing was not to convince them that I was right and get them with me, but to let go and follow them. So I came down off the podium, I exited the ballroom, and Pat was at the door. And you know Pat so well, she lit into me, and she started really screaming at me, screaming at me. I said, "Pat, you know, the grassroots don't agree with you." And I will never forget her. She said to me, [shouting], "The grassroots!? I am the grassroots!"

Breslin: [laughs] I can hear her saying it.

Bristo: And I said, "Pat, you're wrong. They are. I have nothing more to say to you. Goodbye." And we parted, really pissed off at each other. That was the turning point in our relationship, a great turning point, because you know, I believe that with Pat, you have to have your showdown with her at some point. Then you're on a new level, because she sees you as a player. And we had our showdown, I fought with her, and I submitted—you know, I said, "I was wrong by going along with you. I was right the first time, I should have trusted my instincts, you're wrong, these people are right. And if you don't see that, I'm sorry. They're going to bowl you over." So I left really pissed off.

By the time I had got back to my room, really literally, I got back to my room that night, this was all happening in the late afternoon or evening, when I got up to my room there was a voicemail on my telephone from—I want to say his name was Jeff Blatner, is that a name you remember from Kennedy's staff?

Breslin: Could be.

Bristo: Whoever it was on Kennedy's staff that was working on this issue, the voicemail said, "I just learned that NCIL has come off the Fair Housing Act. What's it going to take to get NCIL back on. And here's my number, call me." So when I called him back I said two things, and one thing I honestly don't really remember how it ended in the law. But I remember the conversation, so maybe I'm wrong, but at least it would be—I should check this out myself. The first thing was, "We've
got to make building housing inaccessibly an act of discrimination."
The second thing was this recovering person issue. I do remember
having this conversation with Bonnie, not Pat, because Bonnie was
going on, and I said, "Bonnie, for God's sake, I didn't fight all these
years to be not discriminated against in this part of myself only to find
out that this other part of myself is now discriminated against. This is a
disability just like this is a disability, and it has got to be recognized.
How can I possibly give you my support for this bill if I know I'm
signing away my rights, just because you guys don't happen to think of
this as a disability." So I've always thought that the law somehow
addressed this, because I remember not long ago when this whole issue
of current users—is this in the regs, where is it?

Breslin: I don't have enough memory about the regulations to actually be able
to answer, and I remember the many long conversations about
substance abuse, but I think the issue was that the housing people
wanted alcoholics and drug abusers with histories of current use to be
excluded from protection.

Bristo: Right, right. They did. And I think we did win a little there. What
ended up happening was current users were excluded.

Breslin: It became a good standard because the current users were not
protected, but it was articulated, it was tacitly understood prior to that,
but was articulated in the Fair Housing Act.

Bristo: Yes, but people with a past history who were in recovery—

Breslin: Covered—record of, and regarded as—

Bristo: And you know what, maybe no one else will look at it this way, but I
remember being a solo voice on this issue, and it was really—solo on
my side. Maybe other people were fighting it elsewhere, but amongst
the little group I was the only one.

Breslin: Yes, it was a big issue.

Bristo: I remember really, really, really being in the center of that because it
was so personal. I was right in the middle of it. So anyway, I felt like
those were two huge accomplishments. That foiled leadership
experience, it turned out to be a grand leadership experience. It just
goes to show, you never know.

Breslin: Well, hindsight is really good too in terms of being able to assess the
benefit that comes with those kinds of trials by fire.
Then I remember it, when the bill got signed and NCIL had a reception, I remember Senator Kennedy coming over to me at the reception, and I knew him through Henry Betts a little bit more. So I wasn't just a face, even, by then to him. Teddy knew me a little bit, and I remember him coming over because I was pregnant, very pregnant at the time, and he pulled me off to the side before he made his formal remarks, and he goes, "Marca, I'm told you had a lot to do with this one part of the law. That was good." Something to that effect. Then he got up and in his formal speech to NCIL he said something like, "History will show that what we've done here," he talked about how this is the first time these civil rights laws like this had been moved to the private sector, "And history will show that we've opened a door that can't be shut." Something like that.

That's an interesting remark since the Fair Housing Act always applied to private sector, from the beginning.

No, but I'm talking about the architectural aspects.

I know, but, it's interesting that he chose to say that since the act was always intended to cover private housing.

No, no, no, I'm not saying it right then. What he was referring to was that the bringing of building inaccessibility into a civil rights law applied to the private sector was a first. And later on, if you look at some of his stuff, he has often said that the Fair Housing Act was the precursor for the ADA [Americans with Disabilities Act]. I've heard him say that in speeches more than one time. That's probably where I need to stop, but the one thing I want to say that I didn't say about NCIL that you should remind me, or whoever interviews me next, I didn't talk about my role with the ADA, which was extremely significant even though I wasn't president when the law was finally passed.

Yes, we haven't even begun that part of the story. I mean, that, we need to do at least that next time.

Then the other stuff I didn't really cover with you are the other leaders and the evolution during this period of time of my relationship with some of these other people.

Who specifically do you want to include?

Lex, Ed, Judy, Justin.

Good place to stop.
Interview #3: May 10, 2005

Bonney: This is the Marca Bristol interview. It is May 10th, 2005. This is interview three, tape nine. [pause] Marca, when you and Mary Lou last talked, you were about to talk about NCIL. It was in about 1980, about that timeframe. Can you tell me what NCIL is, and how you got involved?

Bristo: Okay. NCIL is the National Council on Independent Living. I need to back up just a tiny bit. In 1980, ’81, right after the first ten independent living centers were funded by the Rehabilitation Act, Access Living was one of those first ten federally funded independent living centers. RSA [Rehabilitation Services Administration] brought all of the directors to a meeting in Washington. That probably was sometime in 1980. Maybe ’81, but during that period. Their goal was to try to come up with a means by which they could evaluate our work. Well, we hadn’t even started to do our work. We had just gotten our grants, and here they were ready to lay down some evaluation criteria.

They were so far ahead of where we were that, part way through day one, we all got together over lunch. We were thirsty for what each other had to share. Do you have a personal assistant program in your state? Yes? No? How’s it funded? How did you get it? What did you do? How are you guys doing peer counseling? What is peer counseling where you live? This is well before any of the core services for independent living were developed. So we, during that lunch, decided we really needed to talk some more. So when we went back into the meeting we said to the feds, you know, “With all due respect for what you need to do, we really need some time with each other.” So we kicked the feds out of the room, with their permission, actually, and they tabled the whole process of this data collection meeting, and gave us the opportunity to talk together. Then at the end of that meeting, we asked if they could reconvene us. So they agreed to do that, and they brought us back together, maybe six months later.

Through that process, we began to realize that we really had a need to stay connected. I had remembered from my very early days at Access Living—I went to Berkeley and the New Options program in Texas, to see what an independent living center looked like. At the time, there were those two different models going on. I remember Lex Frieden at that time talking about how there was a need for some sort of a newsletter or something. So when we got together the second time, we agreed that we needed to stay connected. So we started talking about maybe putting a newsletter or doing something. RSA agreed to have us
come back together a third time. By then, there was a next wave of independent living centers that were funded.

So through that couple of year period, either through our own resources or through talking the feds into paying for us to come together, we were able to meet two or three different times. Through that process, we all realized that we really had a need for an organization. So it really was a small number of us. Some of the people that I can remember, of course, were Max Starkloff, myself; there was someone from the Vermont program; there was somebody from Kansas. Just a handful of us that started to get this process going. Then the second generation group came in. So we had a little more raw material [chuckles] to work with.

In 1982, after a series of these meetings, we convened in Chicago to really approve some bylaws and really establish an organization. The first organizational meeting of NCIL was at the American Congress Hotel, the Congress Hotel here in Chicago. We set about establishing a regional network that—Max Starkloff was elected the first president; I was elected the first vice president and chair of the bylaws committee. We began the process of putting in place the structure that would eventually become NCIL. It was understood that there were independent living centers that were going to be developed. So I think we had a vision of being the membership association for those organizations, with both an advocacy and a membership service role.

Bonney: Mm-hm.

Bristo: Then something interesting happened. The original Title VII program had a couple of components to it then, Part A and Part B. Part A was established for the federal government to give funds to the states, for the states to purchase services from the independent living centers. Part B was to establish independent living centers. The original concept of Congress was, there would be some seed funding for three years, and then Part A money would be available to purchase services from independent living centers. The problem is, they never funded Part A. They never funded it.

So as the three-year cycle started to come up, there was nothing there to purchase—to buy our services. We were all starting to get a little anxious about what are we going to do when we hit this three-year point? At about that time, the independent living centers that the federal—let’s see, the—I’m trying to remember exactly the mechanics of it, I’m probably not going to be able to, but—we had to reapply for funds. Max Starkloff, the president of NCIL, his funds got cut. They basically just funded most of the rest of us, but not Max. We took it as fighting words, because we had been out there advocating
strengthening Title VII, trying to add language in there that would concretize the consumer control language. They cut Max’s funding, and the rest of us got really upset.

So we launched NCIL’s first real national advocacy strategy, which was to secure continued funding for independent living centers, and go in and change the language in the act. When the act was first passed, it spoke about the organizations funded under this needed to have substantial consumer involvement. Those were the terms. What we were witnessing, as more centers were funded, we already could see how hollow that phrase was. Organizations were being funded that had virtually no disabled people in any authority or decision making positions. Executive directors were being hired who were not disabled people. Boards were being formed that had limited voice, they didn’t have an advisory committee. And then more of the traditional organizations, hospitals and others, were seeking the funding. And the centers that were out there saw this as a real threat. So we went to create language for consumer control. The first language was changed to consumer control; and then later, we had to clarify that even further, to say 51 percent of the boards are people with disabilities. That—

Bonney: Let me stop you. [audio file stops, re-starts]

Bristo: —that Max got his funding reinstated. So we all felt pretty powerful after that.

Bonney: I was going to ask you, why did they cut just Max’s funding?

Bristo: Our view was, he was the president of our organization. We didn’t believe there was any good basis for it. But we were able—I’m forgetting the name of the senator that was in Missouri at the time. Senator Danforth. And he was very good friends with Max. We were able to go in and get Max’s funding reinstated. So it was a real boost to our collective ego. We realized that we could be powerful in that way.

So around the same time, DREDF [Disability Rights Education and Defense Fund] had been funded to do Section 504 trainings throughout the United States. The independent living center network was now kind of coming up and running. Therefore we, including Access Living, were the recipient of this really powerful training on Section 504. The early independent living centers, while we were driven by the new paradigm of independent living versus the old paradigm of the medical model—I’m sure somewhere along the way, somebody’s talked about the paradigm shift that was going on—in the early days of independent living, we didn’t use the word discrimination. I can even remember giving public education seminars, and we would talk about
attitudinal barriers. You know, it took us a while to go through the transformation of being able to call it what it was, discrimination.

I really think DREDF did an enormous public service for the field, when they got the 504 training grant and went around the country and started training us on what our rights were, what 504 was. During that period, DREDF, therefore, was linking up with the independent living centers. They were really the only show in town, in terms of sort of a broad civil rights oriented organization. Around that time, Reagan appointed Vice President Bush to head up this deregulatory taskforce, where they were going to deregulate our rights. This was after there had been this long effort, before my time, to get the Section 504 Regs out.

That preceded my involvement with the disability community. But now, having been through that battle to get the regs out, and we still had several agencies that hadn’t completed them, now we had Bush Senior come along as Vice President, and Boyden Gray [Counsel to the Presidential Task Force on Regulatory Relief] working for him to propose deregulating 504. DREDF saw this as a call to action, and started this sort of call to action around the country, through the independent living centers, to fight back. I think this was the first time, from my perspective, that the infrastructure which had been created by the national network of independent living centers had been tested outside our own little effort around independent living related issues.

It, I think, informed all of us that, hey, we now had something we didn’t have before. We had a cross-disability network of organizations that were sprinkled around the country, each of whom had a telephone, fax machines—well, we didn’t have fax machines yet—telephones—an ability to connect with each other. And we had a common vision. With this seeping in of a civil rights orientation, we now had even a stronger framework from which to build, than the one previously. It was in that context that we launched, that DREDF launched, letters written in on a regulation, ever. We were all doubly empowered by that process.

By then—we’re probably now in about ’83 or so, somewhere in that ’84, ’85 period—NCIL was starting to grow. In the early days of NCIL, there were some drag-down, drag-out battles over who is NCIL? After creating the bylaws and now sending out requests for people to join the organization, we had to come up with some sort of membership process that we would vet people through. I can remember one of the early NCIL meetings where, on the floor of the assembly, was real, real divisive debate. The issues were over should the boards of NCIL be 51 percent consumer controlled? And what
happens to those groups that weren’t? They were strong in number, and very loud.

I was amongst the group that pushed really hard to create 51 percent of the boards of members of NCIL had to be disabled people. At the time, the federal law still didn’t require that. So when NCIL did that, what we were doing is essentially cutting out a whole bunch of these federally funded programs. And those agencies were really pissed off, and felt that we should use the same language that the law did. Well, we had already begun to see the results of that mushy language. We felt, it’s our organization. We believe that you fundamentally get a different product when you have disabled people at the helm, versus if you don’t.

So I was very proud to see that when the vote actually came, after very heated debate, those who believed in 51 percent prevailed. And when I look back historically on this, it’s quite significant. Because if we had not done that, I absolutely am convinced that the federal law would never have changed, because we didn’t have a crystal clear vision of unified voices that were willing to fight for it. And who the heck would have known what the independent living field would look like today? Now, I know there’s a lot of controversy in the field as to, “Are all the centers staying true to what the founders’ mission was?” You’re always going to get some of that. But I do think that those early battles for identity were disability identity politics struggles.

Bonney: Mm-hm.

Bristo: I’m very pleased as to how they ended. So shortly after this, Reagan appointed the National Council on Disability [NCD] members. When he first came in, he fired the existing council. This was a Carter council. Judy Heumann was amongst the people who were on the National Council at the time. It’s my understanding that Reagan either asked for their resignations, I think several of them refused to resign, and then he terminated them and put in a fairly right-wing conservative council.

Little did they know that in that council, they also put in two people, Justin Dart and Sandra [S.] Parrino, who were avid advocates on behalf of people with disabilities. I’m not going to go into the history of NCD in detail, but I will mention that for its early years—I’m going to say that would be from ’78 or thereabouts up ’til maybe—[pause] You can check the history on this. It was not a freestanding, independent agency. It was an advisory agency to RSA and the Department of Education, basically. It was established to give guidance to those programs.
It’s my understanding that because it was supposed to be given advice, the agency never listened to its advice. And so somewhere in that period of time, people went back to Congress and said, “We need a really strong independent federal agency.” Senator [Lowell] Weicker was the one who carried that forward, and had Congress make NCD a freestanding, independent federal agency, appointed by the president and confirmed by the Senate. That was a bit of a battle. When Reagan then appointed the conservative council, it didn’t have terribly great visibility at the time. I do remember that it had some visibility, but not a great deal. Lex Frieden was then recruited by Mrs. Parrino and Justin, to come in to be its executive director.

Then, in about 1985, Justin Dart and the National Council, Sandy Parrino, started to make efforts to look at formulating some sort of national policy directives around disability policy. Up to this point, there had been nobody at the federal level that had ever tried to look at it.

In 1986, the National Council came up with something called *Toward Independence*, which you’re probably familiar with. It was the first snapshot at how federal policy impacted the lives of people with disabilities. It was quite significant, in that it identified that no matter what area—it looked at ten areas of life—things like housing, education, health care, work, et cetera—it discovered that the common thread that ran through all of those areas was discrimination. Therefore, the solution that was needed was a comprehensive civil rights approach.

Now, that report came out in 1986. During the period leading up to the issues of the report and the period right after, Justin Dart started going around the country and holding town meetings in all fifty states. During that same period, the national inside-the-Beltway groups were beginning to talk more around some of these large issues. There wasn’t a lot of connectivity, however, between those of us in the grass roots and the inside the Beltway groups. ACCD [American Coalition of Citizens with Disabilities] had come and had begun—I think by then it had already dissolved. When I first came on the scene, it was in its kind of dying breath. And as I understand it, it was just really hard to hold together that coalition, because the funding—

Bonney: Was ACCD a Beltway organization? Is that what you mean when you—

Bristo: [Over Bonney] No, it was the American Coalition of Citizens with Disabilities.

Bonney: Yeah, but what were the Beltway organizations you referred to?
Bristo: Oh, no. Because ACCD was dying out at this point. But I’m talking about the ARC, the MS [Multiple Sclerosis] Society, the Epilepsy Foundation. Somewhere in this period, DREDF decided it needed a DC presence. And so DREDF started up its DC presence. So all these things were kind of going on. The centers for independent living were growing. I’m never remembering exactly what year I became the president of NCIL. I think it was, like, 1986. ’86, ’87, ’88. Or maybe ’87. I served three years. My last year would’ve been in May of ’89. So that would’ve been the period I was NCIL’s president. So what was happening during that period, also, within NCIL, was we were growing members.

We wanted to play a more active role around advocacy issues. We seemed kind of sluggish. The leadership had been all male. I think I might have been the only female on the executive board. And at the annual meeting, when Max was stepping down as the president—and again, I’m forgetting the years, but—there was an election, and there were two men running against each other, in a kind of heated and not very friendly debate. You know, there was a lot of attacking and a lot of grumbling. People were not really happy with the direction NCIL was going. There was a lot of backbiting and things going on.

That evening, the evening before the election, Sharon Mistler, who at the time, was with the Arlington, Virginia Center for Independent Living, decided to hold a caucus in her room, for women, around the election. I don’t know if she had this in mind when she got everybody there, but the goal was—people were irate. And so the women, a whole bunch of women, met in a kind of clandestine room, and decided that we were going to run a women’s slate. They looked around the room, and everybody kind of looked and, well, who’s going to head it? And eventually—I don’t think I was first—but eventually, they looked at me and said, “Marca, will you do it”? Because I’d been the vice president. I was terrified. I didn’t feel ready. I knew how hard I’d been working, with rural support, and felt like I wanted to say yes, but I needed help.

So that’s what I said. I said, “You know, I can’t—I would need help.” And they said, “Well, what kind of help?” I said, “I’d need some staff.” You know, and that was a non-starter, because we didn’t have any money to buy staff. At the time, the Illinois Department of Rehabilitation Services was headed up by a woman, disabled woman, by the name of Sue Suter. Sue was sitting next to me. And she leaned over to me and said, “How much would you need?” I said, “Well, I don’t know, a half-time person.” She said, “I’ll get it for you.”

You know, I don’t know if I’ve ever properly thanked Sue, because it was one of those—she took away my final defense of my fear of
leadership. It was those women that really carried me forward. I really look at that as a turning point in my life, because up to that point, and not even for years later, did I really feel like a leader. It really took my last day as NCIL president. The last day is when I felt I was a leader. So we went in, we pulled together a slate of all women, except for one; we had an honorary guy. Duane French was our treasurer. And we won. We just took the election, and it was kind of a real triumph for women.

Bonney: Are you willing to say who the men were who were fighting each other?

Bristo: I think it was—The two men who were running against each other. Gosh, I’m not positive, but I know there were four guys involved in this, I can’t remember who the candidates were. Eric Griffin and John Chappell, I think. But the people were Eric Griffin, John Chappell, Charlie Carr, and Jim DeJong. Those were the people who were—and they were split. You know, they were split against each other. John Chappell and Jim DeJong kind of versus Charlie Carr and Eric Griffin.

Bonney: Hm. Okay.

Bristo: It’s what I recall. Okay. So I got elected, and then I was, Oh, my God, what am I going to do? So I hired Maggie Shreve, who was at the time, the executive director of The Whole Person in Kansas. She moved to Chicago. We started up a little, tiny office in my old office at Access Living. It was the first staff that NCIL had. We began a process of trying to both increase the budget a little bit [and] professionalize the organization, really focus more on membership. In my own way, I wanted to kind of elevate NCIL.

So at my first conference—I ran on sort of a feminism-slash-diversity slate. So one of the first things I did was create NCIL’s first minority committee, to really start reaching out to people of color, because there were none in NCIL. Zero. So we created a mechanism both for a committee and a board slot, so that we could start to develop leadership opportunities for people of color within the field of independent living.

At our first conference, I had a great lineup. I had Ellie Smeal, from the National Organization for Women, and Jessie Jackson spoke, from Rainbow/PUSH. We got Ebony magazine to come in and do a feature on independent living and people of color. So it was a real, I think, just—it helped advance the organization at this time. During this period—now we’re about in ’87-ish now, ’86, ’87—Toward Independence has come out. It is talking about, discrimination. NCD is beginning to think about what they ought to do about it.
At the same time that all that was going on, the Fair Housing Act was up for reconsideration. I’m leaving out a lot of stuff. There were some struggles going on at the time. There were a fair number of things happening that had our attention. But one of the big ones was the Fair Housing Act. So you had NCD over here doing its thing; and DREDF was kind of working with the inside the Beltway organizations and key members on the Hill, on the Fair Housing Act. To my knowledge, this was the first time that the disability rights and the civil rights communities really came together. It was not without some controversy.

The fair housing community had been trying to strengthen the Fair Housing Act because it lacked teeth, for several congresses preceding, and they didn’t have the steam. They came to the disability community, I think, at the same time the disability community was poised to go to them and say, “We should be in there.” There was an understanding that if we worked together, everybody could gain. So we began the effort to bring people with disabilities into coverage under the Fair Housing Act.

What was interesting about the process was I was a brand new president. I didn’t know the Hill. I was just learning the Hill. My only experience up to this point was—and maybe concurrent with this—was getting the language in the Rehab Act changed to 51 percent. That was done through Senator [Tom] Harkin. Bobby Silverstein had previously been working on the House side, I want to say with Congressman Steve Bartlett of Texas, but I’m actually forgetting who he worked for. But we had been over to the House side and had tried to get the 51 percent thing through over there. We were getting a lot of resistance.

What we were hearing was, quotas are out, and this is going to be seen as just another quota. We weren’t getting the kind of support we needed on it. And lo and behold—I have been part of a political coalition here in Illinois. At the time, it was called the Illinois Public Action Council [IPAC]. Subsequently, it became called Citizen Action/Illinois. You may have heard of that national organization. But IPAC had been—is a coalition of labor, farm workers, senior citizens, minority; and access living had just become a part of that organization, in Illinois. Their counterpart in Iowa had just run the ground operation to get Senator Harkin elected to his first position. When we were hammering away on this consumer control thing, I turned to my friend in Illinois, a guy named Bob Creamer, who had worked closely with the Iowa people. I told him what we were trying to do, and he said, “Well, let me make a call to the Iowa Citizen Action people.”
Bristo: So he said, “Let me reach out to the Iowa equivalent and see if they can help.” So he called the Iowa organizers and said, “We’ve got this good friend. She’s on our board. She needs some help getting to this guy, do you know him?” And they said, “Not only do we know him, he’s given us a lot of credit for his elections. So sure, we’d be happy.” So the Iowa [Citizen Action people] called Harkins’ office and said, “There’s this young woman from Illinois that would like to meet with you.” And just like that, I got in to see Tom Harkin.

He was pretty brand new. Bobby Silverstein had just come over and joined his staff, and I knew from my Illinois friends that Tom Harkin’s brother was deaf. So I brought one of my staff, Tom Benziger, who was also deaf, to the meeting, and we went in to make the case on consumer control, 51 percent. And Tom and Tom, the two Toms, were signing with each other at the beginning of the meeting. We explained why this was so important. I thought I was going to have to make a hard sell. He just looked over at Bobby, he said, “Makes sense to me, Bobby. Take care of that.” And that’s where 51 percent came from.

We still had to go sell others on it, but it just goes to show you, all politics are local, you know. I would not have gotten in the door. And then the fact that I was able to connect with him and express to him why this was so important, in a way that he could relate to himself, I think really made all the difference. That really had been the extent of my Hill exposure. So I was pretty green.

I got a phone call from Bonnie Milstein and Pat Wright, asking me to come and testify on behalf of NCIL, before a Senate committee on the Fair Housing Act. It might’ve been a joint meeting, I’m not sure. I don’t remember. So I said, “Well, ok, I’ll do it, but I’m going to need some help.” So I rapidly studied up on the Fair Housing Act. They said, “Don’t worry, we’ll help you.” So they crafted my remarks for me. They took the first stab at it. I looked at the remarks and I said, “You know, I’m all for this, but I know in reading the law that there’s nothing in there about accessibility. That’s the biggest problem that we see in housing, it’s not accessible.” What came back from the Beltway folks was, “You know, this is a nondiscrimination law. That’s got to be taken up [with] architecture, or the access board, or— I forgot. The Architectural and Transportation Barriers Compliance Board. Somewhere else. I said, “I don’t agree with that, because it seems to me when an architect sits down and designs a building that’s not accessible, it’s that moment in time that the discrimination occurs. He is not thinking about us.” They said, “Well, we’re not going to get it here. We can’t do it.”
So I went in and testified without it being in there, and when—I don’t remember how much time, but shortly thereafter, NCIL had its big conference, where everybody comes to town. I think this might’ve been my second year as president. It probably was ’88. 1988, that would make sense. I, in the president’s report, before the whole roomful of people, I shared that I had testified on the bill. And somebody in the audience raised their hand and said the same thing, “How come there’s nothing in here on accessibility?” I told him how the Beltway people told me that it wasn’t appropriate. Well, NCIL overrode me. This was, like, both a leadership crisis for me, but an incredible leadership development opportunity. My members, basically, took a vote that day; a resolution came forward that NCIL should sign off the bill. Like, oppose it. I was, like, up in front of the room dying, [Bonney laughs] you know? Oh, my God. I felt like, you know— Well, I just felt like a bad leader, because I hadn’t followed my instincts. My members—But they validated my instincts.

So I left the room and was out in the corridor—I’ll never forget this—and Pat Wright came up to me, having just heard what had occurred, and she said, “You can’t let this happen. You can’t let this happen. We’ve already voted. I said, “Pat, it’s happened, you know. The disability community didn’t agree with me.” Pat didn’t want to hear that. This was a second test of my leadership, because I don’t know if you know Pat, but to go up against Pat in those days, when I was feeling so—oh, what’s the word? Like a leader in development—was one of the hardest things I ever had to do. But an important thing. I learned so much from this.

So I went and left a message for Senator Kennedy—I think this was going through the Judiciary Committee, I’m not sure. But I left a message for his staff person that NCIL had opposed the bill. Then I went back in and ran the rest of the meeting. That evening when I got back to my hotel room, there was a voicemail message from that person saying, “What do we have to do to get NCIL back on the bill?” And so I called ’em back and I said, “Just one—Well, two things, actually. You need to add this.” The definition of disability, at that time did not mention anything to do with people who were in recovery—alcoholics, addicts. And I was. I was. In 1984, I had admitted myself to drug and alcohol treatment. I was now coming through the other side of that. As we were working on this bill, I don’t remember whether the initial bill said it excluded us, or whether the definition of disability didn’t include it. I think it must’ve been excluded. In any case, I wanted to be sure that all the parts of my disabled self were covered. So through the rest of that process, through the amendatory process, the bill was changed to include those things. Once we got to that point, all the other groups came around it and were in support.
Now, I subsequently think that part of the reason that my friends were not as comfortable with those provisions early on was because of the fear that the broader civil rights community would maybe not go along with these changes, because it was essentially kind of changing the character of the civil rights law. In any case, we got it. And that was sort of another big thing.

Why I think that’s so important—Up here you can see a photo of a really skinny Senator Kennedy. And the inscription is gone. But this was right after the Fair Housing Amendments Act had been passed, and NCIL was giving Senator Kennedy an award for having included people with disabilities, and working with us to get the Fair Housing accessibility provisions put into the bill. And at that speech—I’ll never forget this—Senator Kennedy said that this was the first time that a civil rights law of this nature at the federal level was applicable into the private sector. Later, after the ADA was passed, when he spoke again at a NCIL function, he referred back to how NCIL had led the way to get the Fair Housing Amendments Act changed, and that that was an absolutely important stepping stone to winning support for the ADA, because we had already been through it. Okay. Am I giving you too much detail?

Bonney: That’s okay. But let’s move into the ADA.

Bristo: That’s where we are.

Bonney: What was NCIL’s and your role in the ADA?

Bristo: Okay, Justin had gone around the country, and had brought people together. NCD, through the leadership of Lex Frieden and Bob Burgdorf and Sandy Parrino, were now beginning to float different concepts. I remember two things in particular. One was a meeting that was convened by Lex Frieden at NCD, with maybe about six or eight of us. I was there on behalf of NCIL; Bob Funk was there from DREDF; Evan Kemp, from the Disability Rights Center; the NCD staff; probably Pat, and that’s about all I can remember.

In that first meeting, the discussion was whether we should amend the Civil Rights Act [of 1964] or go for our own. I remember I was in the minority. I felt we should amend the Civil Rights Act, because it seemed to me the ultimate act of discrimination that we weren’t covered in the nation’s major nondiscrimination act. It felt to me, in and of itself, if the law which protects the people who are most discriminated against discriminates against us, that that’s a double whammy. So I was of the strong opinion—but then I was still learning. And what I heard in that meeting was there were two reasons not to do that. Or three. First was opening up the Civil Rights Act to
amendment would surely bring opposition from the civil rights community, because they were afraid it would impact them. Second, there were elements of disability discrimination that were more than behavioral—all the architectural things—and that there were processes needed; and therefore, the remedy for some of our forms of discrimination took something other than saying, “You will cease and desist.” It took proactive measures. And that would be hard to just attach to the existing legislation.

Finally, we had the history of 504 upon which to build a framework for a law. The concepts of reasonable accommodation, the definition of disability, and certain other ideas, undue hardships—those concepts had been tested. If we could use those things in the legislative process, it would help us get the congress over the fear of the newness, that it’s been untested and it’s uncharted territory. So I ultimately went along with them and agreed with that.

After that, Bob Burgdorf crafted a first stab at the legislation. I can remember being in town for a NCIL event, and him coming over with Sandy Parrino, to the lobby of the hotel we were in, with a rough draft. I thought I remembered it in handwritten form, but Bob has reminded me he never did things by hand, so it must’ve been just a—you know. It was all marked up, let’s put it that way. And seeking feedback. Candidly, I didn’t know enough about the structure of the law at that time. But my general feedback to him was I believed that this was something NCIL would get behind in a really big way, and that he could count on our support, not withstanding whatever some of the details might be.

Then you probably are getting the history of how that came about afterwards, so I’m not going to go into the history of the ADA. Now there was a first draft out. That was in ’88; I think ’88, the first draft. And that’s been lovingly referred to as the “flatten-the-earth bill” because it basically said all barriers had to be removed within XYZ date. Also, that first bill, the first draft, included nondiscrimination—Or at least the first concept that was taken by NCD to Lowell Weicker, who was the original cosponsor, also included health insurance. Weicker, from a state where there’s lots of insurance companies, came back and said, “Look, it’s a killer. If we keep the health insurance industry in here—that’s an industry I know something about. They’re very powerful. They will not let this go through. But I promise you—So it’s your choice. If you want it in there, we can leave it in there, but I think it will kill the bill. So I want you to think through what you might gain and lose by making that decision.” So the decision was made to lop out the health insurance stuff. Weicker agreed that he would come back in after the ADA was passed, and have a stand-alone bill to tack—Well, and then of course, he lost his next election.
So when I was the NCIL president, after passing the Fair Housing Act, and the ADA was now starting to gear up for real, we wrestled a lot with the challenge that NCIL was the best thing that we had at the time of a grassroots-connected network. And as we had fought for this, we had fought at the rehab act level, for 51 percent. We had fought for participation of membership. So we went into a challenging period, because our members believed they wanted to have a say in everything; but this legislative process was moving so quick that there—it took us a period of time to try to figure out how do we stay true to our grassroots wanting to have a say, versus, how do we stay responsive enough to have a voice in what was going on? Because it was moving so quickly.

So we put together an ADA task force. As I recall Sharon Mistler was one of the leads on it. Eventually—Gosh, I can’t remember. I think Eric Griffin was involved. But we had a team of people whose job it was to work the bill, and attend regular conference calls. By then, the inside-the-Beltway group had developed the means by which they would staff the bill. So Liz Savage was the person that kind of was the liaison to the grassroots. She and Marilyn Golden. Pat Wright was kind of the Hill strategist. There were regular meetings that occurred in the church. I think they were on Monday afternoons. And NCIL attempted—we did reasonably well—to have somebody attend those meetings. And we rotated that. Then during that period, we attempted to have somebody in Washington from NCIL throughout the whole process. We kind of rotated whoever could get to town. Then whenever there was a big event or a hearing, where we needed a lot of people, we would specifically get those people in.

We were connected through both Liz and Pat, through a regional network. So for example, my staff person here, Rene Luna, was in charge of the Midwest. So if Liz or Marilyn needed to put pressure on a congressman from Michigan, then Rene would reach out to the independent living centers in that part of Michigan and say, “We’re having a problem with this. We need letters to go to these three congressmen.” And that was how it worked. There was a group of people that I would call the sort of “brain trust” strategy group in Washington. They would tap into NCIL; and NCIL would tap into its network of people around the country, who could then put more focused pressure on the particular areas. We also participated in Justin’s effort to do the discrimination diaries, where we were, all around the country, writing in our discrimination stories.

We got to a point where the bill had been moving along, and then we were now getting White House resistance. We needed the White House to give some signal, or it was going to get bogged down in the Senate. Up to this point, the White House was sort of there or not
there. Remember, we now have Sandy Parrino, Justin Dart, Lex Frieden and Evan Kemp, all kind of working behind the scenes. Evan was now the chair of the EEOC, Sandy was the chair of NCD, Justin was the vice-chair of NCD, and Lex worked for the two of them. They were all working to try to get the Bush administration in the right place.

Evan was bridge partners with Boyden Gray, and had remained very good friends, old family friends for a very long period of time. So I understand that there was a lot of tension or turf wars or something between Evan and NCD. I know there was-- I don’t know enough about it, but one of their researchers-- they weren’t working as much in unison as they might have, during that period. They were working towards the same goal, but from what I’m understanding, there were some bugs in that set of relationships. So NCIL came to town for my last meeting as president. I think this was May somewhere-- it must’ve been of ’89. There was a filibuster going on in the committee that was [Senator] Oren Hatch’s committee. It was in the middle of the night. These meetings blur together to me, but what I remember, this must’ve occurred over two different meetings; maybe a board meeting with—It’s not clear to me.

But two important things I want to share. One was this filibuster, where NCIL was in town for something. Pat Wright and Ralph Neas were over working the Hill. We’d been over there all day. It was tied up in a filibuster; it wasn’t going anywhere. Pat Wright calls me at NCIL and says, “We need people.” It’s, like, eleven o’clock at night. So we start calling up anybody whose room number we had, at eleven-thirty at night, saying, “We need people over in room such-and-such.” Well, I’m not kidding, some of the people ending up going over in their pajamas. You know, their night clothes. We packed the room. Just all these people came. They weren’t expecting it, because they were doing it in the wee hours of the night. I remember Ralph and Pat running shuttle diplomacy, because they were communicating with people over in the capitol on something else. So anyway, throughout this whole process, all these people with disabilities came in. Finally, Hatch gave in on the filibuster. And that was a big hurray. You know, everybody was pretty excited, and we thought, Yay, we did it.

Well, but keep in mind that the White House was still obstructing things. We couldn’t get the White House onboard on a few provisions. I think they were the transit provisions, but I’m not 100 percent sure. So we had a march. This was an impromptu march. NCIL had never, up to this point, done anything like civil disobedience or rallies or anything. We were supposed to be in town for a big conference. After that occurred, we decided, we need to do more. So we pretty much canceled the conference, and went in and said, “We need to have a
rally and a march.” So we all worked into the wee hours of the night making posters, all sorts of stuff, to have a march the next day from the Capitol to the White House. It was completely impromptu. The inside-the-Beltway groups worked really well with NCIL. They got all the DC area people to come in and join us.

So the next day, we ended up having this huge march, starting at the Capitol and moving—walking over to the White House. It was raining. And we weren’t expecting the rain. I still have some of my fondest memories—Justin joined me at the front, because it was a NCIL march, and we all had trash bags that we took from the hotel, because it was—it was supposed to be a candlelight vigil; it was raining like you wouldn’t believe. And the pictures I remember have me, Justin, at the front of this huge march, with garbage bags over our heads, and candles that we were trying to keep lit. So it was really spirited and we got over to the White House. Now we’re there. And up to this point, I’d been feeling, oh, this is really cool. We get over there, and I’m like, okay, now what do we do? Now they’re here. It felt so anticlimactic, you know. You just go home?

So not knowing-- I mean, just in a gesture of street theater, I went up to the phone booth where the security desk was and picked up the security telephone there and said, “Hello, I’d like to speak to the president.” And somebody said, “Please hold.” I went, [Bonney laughs] Well, that’s wild. I said to the crowd, “They told me to hold.” And everybody starts yelling, you know? So now I’m on hold. A couple minutes later, a different voice comes on to the phone and says, “May I help you?” I said, “May I speak to the president?” And they put me on hold. I’m like, what the heck’s going on here? Yet another voice comes on and said, “Who is this?” I told him, you know, “It’s Marca Bristo. I’m out here with members of the National Council on Independent Living. We want to talk to the president about the ADA.” And he put me on hold. So I’m now on hold three times in a row.

Bonney: Now they’re looking out the window to see what you--

Bristo: Well, whatever. I subsequently figured this out. But what had happened, somehow, was Evan Kemp, who is the chairman of the EEOC, he’s in the march with us, which is relatively radical, for a member of the government to be doing a protest against their own administration. Somehow or another, Evan had gotten a message in to the man who was the head of the Domestic Policy Council at the time. I’m going to draw a blank on his name. I can’t believe I’m drawing a blank on his name. You can look it up. Anyway, he told him that, you know, these people were angry. They got a message to Boyden Gray. Boyden Gray called over to the White House and said, apparently, “You ought to meet with these people.” I didn’t know any of that. All I
know is when the voice came back on the phone, they said, “You can bring in a small delegation at nine-thirty tomorrow, in the Roosevelt Room.” I hung up the phone and told the crowd, “We got a meeting.” The crowd went crazy.

So then we designated who the people would be that went in, and we went in the next morning. This is the meeting that Justin always called the “bullshit” meeting, because it was one of my first times—I’d been in the White House a lot, but I’d never been in this kind of a real sit-down meeting, that I can think of. The other meetings were more ceremonial. This was a meeting. It was in the Roosevelt Room. So decorum, I was not that familiar with. We were all sitting there talking about why it was so important to pass the law, and why we needed to have the provisions. And no, it wasn’t going to break the bank, et cetera. And this man who’s-- You’ve got to find out his name. He kept giving us all the reasons why we couldn’t quite do it, and how they were going to have to look at this a little bit more.

Boyden Gray and Evan Kemp were at one end of the table. I was here, Pat Wright was over here, Justin was right next to me. And the night before this, my husband had called me from Chicago. My son, who I was pregnant with in that picture [pointing], was maybe—let’s see, this was in 1989—a year old, a little over a year old. Bob, my husband, called to tell me, “You’re not going to believe this. They just ripped up the play lot and they’ve made it completely inaccessible. You’re not going to be able to take Sammy to the play lot anymore.” This was the night before this meeting. When I heard him one more time say why we can’t do this, I lost it. And I went, “This is bullshit!” Just like that. Everybody looked up at me, and I told that story about the play lot and how that’s just plain wrong, you know?

You know, it wasn’t the greatest play lot, but I was able to take my kid there, and now I’m not going to be able to. It had the impact. This guy, whose name I’m forgetting, got up and walked out of the room. Just walked out. Left. He was really pissed off. I guess that’s the time Justin later leaned over and said, “Bet they don’t hear bullshit said in the Roosevelt Room too often,” [Bonney laughs] and why he always called it the “bullshit” meeting.

However, the effect that it had was Boyden Gray leaned over to Evan and they had a little side discussion. And then Boyden said, “Let me—I’m going to need to take the results of this meeting, and we will get back to you.” We left not really knowing what was going to happen. Very shortly thereafter—and I don’t remember if it was the same day, the next day or the next week, but shortly thereafter—we got word that Dick Thornburgh was going to be allowed to testify before the Senate, and would be coming out in support of the bill. You know, there were
a lot of different things that contributed to this. All the work that they’d all been doing leading up to this—most notably, I think, Evan’s efforts there within the Bush White House, but shortly thereafter, they came out in support.

Then the only other thing I want to share about my role with NCIL, that must’ve preceded this, or it may have been the next day, ADAPT was having an action in Atlanta. I don’t remember, again, chronologically; they all blur together. But their goal was to get lifts on buses. In Chicago, my center and a local ADAPT had paired up to sue the Chicago Transit Authority [CTA] in the mid-eighties, under a state law. The CTA fought us with all they had. And we won. A wonderful decision from the state entity. One of the only good ones before the ADA that basically said, in a going forward way, all new buses would need to be lift equipped.

[Audiofile 10A]

Bonney: This is the Marca Bristo interview, May 10th, 2005, tape ten, interview three.

Bristo: Okay. So as I was saying, the Chicago lawsuit had resulted in a state decision that people with disabilities had a right to ride the bus, and that in a scheduled way, new buses would begin to be purchased, with lifts on them. Our congressman, Bill Lapinski, had an important post with the Surface Transportation Committee. He was very knowledgeable about the CTA [Chicago Transit Authority] case. While he didn’t like it, he understood how much money the CTA had spent defending its case. Back in the mid-eighties, they had spent over a million dollars in legal fees, just fighting us.

ADAPT had as its primary goal in the ADA to get lifts on buses. Therefore, I was passionate about this. At the same time, ADAPT and NCIL—Wade Blank was the head of ADAPT at the time. Or the non-head head [chuckles] of ADAPT. He had been, ever since I came into NCIL as the president, he’d been sparring with us. If you knew Wade, if you didn’t go one hundred percent the ADAPT way, then you were part of the enemy. Even though he knew that I was in support of the same thing, his approach to get NCIL to do what he wanted was to keep attacking us, or keep on nudging us. My goal during that period was to build a relationship between NCIL and ADAPT, and to get NCIL members more supportive of ADAPT. So to that end, we had started coordinating some of NCIL’s meetings around the same time as ADAPT’s meetings.

Also, as NCIL president, I started encouraging NCIL members to go to ADAPT actions. And of course, that meant me. So I had already
participated in a few ADAPT actions, and when this one was coming up in Atlanta, I really felt passionately about it because of where we were with the ADA, and we were getting resistance on this. So I went to the ADAPT action. Several NCIL people also went.

What happened at that action was quite significant. They were in a federal building. The feds came in, the police came in and were throwing everybody out of the Federal Building. They were really rough. So rough that one guy got thrown out of his chair, cut his head. There was, you know, blood there. They were pulling people out of their chairs and taking them off in the paddy wagon, leaving wheelchairs behind. They had taken Wade. They picked off who the leader was, and got him immediately, and took him away. So things were a bit rough.

Well, having been through all of what we’d been through, I called Evan Kemp and said, “Evan, you know, does the Bush administration want this on their face? This is no way—” You know, because it was the feds that had called in the cops. So Evan said, “Call Boyden.” He said, “He’s probably at home. Call him at home.” So he gave me his number. I called him. I don’t know where I really reached him, but I called Boyden and left him a message. No, I actually got through to him, and told him what was going on. I was really animated. I said, you know, “Boyden, whatever, you got—you know, do something.”

So now they’re evacuating the building. I’m on a pay phone, talking to Boyden Gray. This police officer comes up and he says, “Ma’am, you got to get out of here.” I was one of the few people still in the building. I said, “Well, I’m on the phone. Can’t you see?” He says, “I don’t care. There’s been an order to evacuate this building. You get out or I’m going to arrest you.” I said, “I’m on the phone with the White House.” He goes, “Yeah, right.” I said, “Here. You talk to him.” So I handed Boyden to the police officer. He goes, “Oh, oh, oh, Okay. Okay.” And he let me finish the conversation. So I told Boyden what going on, I hung up. A few minutes—Now we’re out. A few minutes later, this guy—some guy from GSA says, “We’ve just received word from Washington that we’re to let you all back in the building.” [Bonney laughs]

It was another [makes roaring sound]. So everybody got to go back in the building. I remember them ordering Chinese food for a hundred, and laid it all over the floor, and everybody eating Chinese food and roarin’ it up a little bit. And shortly thereafter, the lift on bus provisions got through. Those were my two—And then, of course, this would’ve been in May of ’89 or so. It couldn’t have been ’90. I’m not exactly sure. But the law passed in June, right? It was signed in July. May or June. So I think could’ve been ’90. I’m not exactly sure. That’s
my NCIL stuff, and the ’88 stuff. Now I would like a break; if I can just—[audio file stops, re-starts]

Bonney: Marca, during this time, I think he was in the House, Major Owens—
Bristo: Yes.
Bonney: —developed a taskforce.
Bristo: Yeah. Well, let me back up a little bit, because—just a slight thing. When I was NCIL’s president, Major Owens had just been elected, or just been appointed to chair the Subcommittee on Select Education, which is where disability stuff was. Maria Cuprill, who subsequently became his wife, but at this point was his AA, his administrative assistant—administrative director, the woman in charge of his staff—they were moving into their committee office in the House Annex Building. I stopped in and paid them a visit. We were working on the consumer control stuff at this time.

I dropped in to say, “Hi, I’m the president of NCIL.” Well, Maria was there in her work clothes, unpacking boxes. They were literally just moving in. I’ll never forget, because she said, “You’re my first visitor in our new role. Wow, aren’t you on top of things?”

Bonney: Wow. [laughs]
Bristo: Truly, I was the first person who’d been in their office, I was in there to talk about how important disability was. I always felt a special bond to the two of them, as a result of that. So they had worked with us on this stuff. Therefore, I think they were already starting to get primed. Also, Major Owens, if you know something about his upbringing and background, he’s from the inner city of New York, I think from Harlem. He was a librarian. You know, grew up himself in the midst of racism in this country and had an activist core to who he was. And therefore, grasped the significance of civil rights on a personal level.

So we were really lucky. You know, when you look back at ’88, we were so lucky to have the planets align the way they did, or the people align. I mean, we had Tony Coelho there, who had epilepsy; we had Lowell Weicker there, who had a disabled kid; we had Bob Dole, who was the minority leader; we had Ted Kennedy; we had Tom Harkin, whose brother was deaf. You know, the Kennedy family’s history with disability, and Teddy Junior was an amputee. Now we had Major Owens who, at least to my knowledge, didn’t have disability experience, but he had very strong civil rights experience. It was, like, all these things that aligned to work in our direction.
Then those people made it their business to then start to find where were the other people in the Congress who had disabilities, and how do we get to them? It was definitely a community organizing campaign that occurred outside, by us. But to be very honest with you, there was a little community organizing going on within the Congress, by Tony Coelho, by Tom Harkin, when Tom came in. All of this stuff worked to our advantage.

Justin, through this whole process, had become acquainted with Major Owens. Major really adored Justin. Though he was a Republican, Justin had been part of the civil rights movement in the South, way back when he organized the first NAACP [National Association for the Advancement of Colored People] chapter on his campus. Therefore, when the ADA process was kicked in, Major Owens and Justin collaborated to create this Congressional Taskforce on the Rights and Empowerment of People with Disabilities.

Several people—it was a fairly large—I don’t know, maybe twenty or thirty people who represented the full array of disability organizations, were asked to serve on this taskforce. So NCIL had a seat on it. Lex and Justin and Elizabeth Boggs, I remember, were the sort of people who kind of guided it. I looked at is at a sort of promotional arm. It held some hearings, one of which was in Boston, that NCIL helped coordinate. It lined up speakers, it orchestrated things—it was the vehicle through which things like all those testimonies, the discrimination diaries—it gave Justin the ability to reach out and do that kind of unorthodox stuff, and then pop it back into Major Owens. It enabled Justin to get an additional level of validity to the town meetings he’d done. It enabled him to have sort of an additional, not only bully pulpit, but stamp—that he could issue the findings through. So it added stature to what was otherwise a community organizing voice, matched up with the imprimatur of Congress. So Major Owens could convene the town meetings; but it would enable us to do what we did best, which was to find the speakers, develop the momentum around it, the turn-out to show up.

Therefore, that’s—it was not a strategy body. It was not the entity that looked at the amendments except in the broadest sense of the word. So I know it convened teleconferences every so often. I think some people who didn’t [coughs] have a role to play in the legislative process, who were on the committee, wanted it to be that, and it wasn’t. I think there was some frustration amongst some that they weren’t more hands on. Those of us with a foot in both places understood the difference.

Keep in mind, none of this was—there was no cookbook that said, “You should do this, this, and this.” It was all a work in motion, a work in progress. But I think it really enabled us to have more unity. It
brought all those people who Justin connected with in with much greater bang than they would’ve been brought in otherwise.

Bonney: Mm-hm. What was the outcome of the taskforce? Did it make recommendations? Did it publish—

Bristo: It issued a report, yeah. You should ask Yoshiko for a copy of it. It spoke about the discrimination that people felt. It did things like provided a vehicle through the full-page ad that Justin took out in the *Wall Street Journal* or the *Washington Post*, it gave a tag to that. So it was more—this is what I’m trying to say—it was more the promotional arm of this whole thing.

But it had the hearings, the findings of the hearings got reported back in through Congress. So it helped build the case for the need for the law. Therefore, I think it helped offset some of the opposition. This group also talked about things like public relations strategy. And this was something I didn’t know until years later. You know, I’m not even sure—we, in this taskforce, were talking about how we needed to get some op-eds placed here and there. Every so often, there would be opposition that popped up.

We’d have to have sort of a focused strategy to that opposition. So for example, the over-the-road bus companies were the big ones. What you’ll see there is they got a whole different grace period than everybody else. You can always tell where there was opposition to the law by how long the sections of the law are. Those sections where there was minimal opposition to the law were less detailed. Where there was a lot of opposition, there was a lot more detail, because the negotiations were more protracted, with more give and take.

But what I was going to say is, I didn’t—That group that was sort of the innermost strategy circle, which was Ralph Neas, Pat Wright, Lex, they had a different—What am I going to say here? We were working on trying to get press around those kinds of things, because they put out fliers. Somewhere along the line—I learned this in hindsight, that there had been a prior discussion that we didn’t want to have a massive press strategy, because the fear was, the more press, the more people that were going to get involved; the more people that got involved, the more we could safely bet they didn’t understand disability. They would be worried about how it was going to affect them, and generate more resistance.

So I heard after the law was passed, that there was an active decision made to low key the PR strategy for the bill. I can’t say that that got out to those of us in the hinterlands, because I know we were actively working, and we were one of the communities that was successful in
getting the *Chicago Tribune* to write a positive op ed—or editorial, rather—on the ADA.

**Bonney:** This is interesting, because some of the criticism you’ve heard—I don’t know if you hear it anymore, but early after its 1988 passage—was that when it was trying to get implemented, the general population didn’t know enough about it—

**Bristo:** [Over Bonney] Well, this is—

**Bonney:** —and they didn’t understand it—

**Bristo:** Yeah.

**Bonney:** —that they didn’t do enough background stuff on people.

**Bristo:** If you talk to, like, Pat Wright and that group, I think their view was, the more visibility this gets, the more we create resistance to passing it. But I do think that one of the downsides was, after the law was passed, there was a lot of misinformation, or no information.

**Bonney:** Yeah.

**Bristo:** I don’t think any of us were well enough prepared in the post ’88 period to help sell it properly. But I’ll speak more about that when we get to the next section. I’m trying to think if there’s anything else to add. I think where this leads us—somewhere here, I feel I want to weave in more about what was going on here at Access Living. My perspective on the whole is definitely that of a person who lives in the real world and who does real live community based work, with a great appreciation for how the grassroots and the grassroots are kind of connected. What I see here influences what we do there, at the national level. What happens there has a ripple or trickle down effect on what’s happening here. During the whole period that this was going on, all of what was happening there was influencing the evolution of what happened here. Also influencing—what was going on here also influenced my future decisions. For example, to become more involved with NCD.

I think when we come back, what I need to do is pick up the—After I stopped being NCIL president, that’s when the ADA passed; that’s when I missed the signing ceremony because my daughter was born on July 16th. Actually, Justin’s was the first phone call I got after Maddy was born, calling me to tell me that he was going to invite me to the signing ceremony. And this was just a few hours post-baby.

**Bonney:** Oh, God. [chuckles]
Bristo: So here I am in the hospital, calling my office to arrange my airplane ticket to go to Washington sixteen days later. I was not ready to do that. So I ended up celebrating it here, with our mayor, who hosted a big event. And brought my newborn baby down to celebrate the ADA, here with my new baby, instead of being with everybody. I missed not having been there, after all that.

But on the other hand, this is what I’m saying to you about local/national. I bet there weren’t very many mayors in the country that did anything about this, so—

Bonney: Yeah, so you were very unique. And you had a unique celebration.

Bristo: [Over Bonney] Yeah. And then, you know, how the ADA and how all this has influenced us in what we do here.

I think that’s a very important part of my perspective on the national movement. And also, the role that I think the independent living centers must play. Because it gets this whole circle back to where we started. The beginning of the IL [Independent Living] movement. This whole process then takes us to what’s the next chapter for the IL movement.

Bonney: Okay. Well, let’s do that after lunch.

Bristo: [Over Bonney] Okay. Yeah, it’s time for a break. [audio file stops, re-starts]

Bonney: Marca, when we broke, we were about to start talking about how these national events were going to be impacting on the local centers for independent living. So could you talk about that?

Bristo: Yeah. Well, remember when—Well, I didn’t tell you this, but when Access Living started, we started with a staff of six. That was in 1980. We’re now at about 1990, so in that ten years, we had really gone from a staff of six to probably a staff of about thirty or thirty-five. We’d really grown a lot. And our growth came, in part—at least at our organization—paralleling the track of what was going on at the national level. We always knew that an independent living center’s four core services were what the law set out: independent-living skill counseling, peer support, advocacy, information and referral.

I might add—Well, see? I knew there was a reason I was doing this. NCD was given the charge to sort of put the teeth on the bones—what am I trying to say—put the meat on the bones [Bonney laughs] for the new standards that were out for independent living. When the Congress started to look at continuing independent living centers, they
said, “Okay, we will continue funding centers, but we have to have some means of accountability.” So they turned to NCD, and asked NCD to craft standards for independent living.

At that time, my center had grown some. I had become involved with NCIL, as NCIL’s president. When NCD convened a group of people to think about what the standards for independent living should have within them, I was one of the people who was picked to go in and give some advice to NCD. And actually, I remember very critically working on this, because here again, this preceded the 51 percent [requirement] in Congress, I think—my chronologies are a little—we went from substantial consumer involvement, to consumer control, and eventually to 51 percent [control by persons with disabilities]. But during this period, NCD had to go along with 51 percent, also. They had to articulate what the standards for a good center should be. So myself, June Kailes, and just a few other CIL directors met with the members of the NCD board and Lex’s staff to articulate what makes a center better. It’s actually through that process that the four core services were laid out, so—Independent living skill counseling, peer support, information and referral, and advocacy. NCD then basically embraced those things, and also looked at what are the other things you should look at, which are cross-disabilities, that you’re community based and you have a connection to your community, that you’re doing both service and advocacy. The kind of core principles that Ed Roberts set out at the very beginning.

That became the standards for independent living, from which RSA has now developed the monitoring tools for independent living centers, called the 704 Report. The 704 Report derived from the standards that NCD passed and served as the indicators or the means by which we would demonstrate that we’re adhering to those standards. So I guess that there are many ways in which the locals and the national connect up. The National Council on Disability, I think, unique amongst these federal agencies, understood that connection between the grassroots and national policies. I’ve already talked about how they did that within the ADA, but here was another case with the independent living standards.

They reached out into the field to have us help them define what should be best practice. To this day, that is what is used to evaluate whether we should continue receiving funding. Excuse me. I might point out that the Bush administration right now is going through a sort of government-wide accountability upgrade, and looking at some very scary goals for evaluating independent living centers, which would narrow down everything we do into four kinds of things. You can’t do that with independent living.
You can’t just look at how many people we taught to ride buses, or how many people got assisted technology, or how many places we opened up access to health care. Those are the kind of very specific things that they’re going to try to lay upon the independent living centers to determine whether we’re doing a good job and whether we should have our funding continued. Very frightening. Okay. So that is one example.

But the other thing that was going on while all this federal stuff was happening, the independent living centers themselves were kind of changing, growing, and becoming ourselves—growing up, so to speak. My center, for example, understood from the beginning, but I think really had it reinforced through this national policy work, that to be a good independent living center, we have to have a very solid advocacy program. Our advocacy has to be both systemic and individual. We have to be working both with individual people to teach them their rights and help them become their own best self-advocate; and we also have to tackle the big problems.

Now, why my center has done that is largely acknowledging that there’s five-hundred-thousand potential clients of Access Living here in the city of Chicago. There’s absolutely no way in the world you’re going to, through individual direct service, affect all the people we might be able to affect through one-on-one advocacy. However, we have a responsibility to pay attention to those repetitive issues that come through the door over and over and over and over and over, and have that inform what our advocacy agenda is going to be; and then look for ways to empower and bring along those people who come here first as clients or looking for something to make their lives better. When we do our job right, as they become more skilled at it, bring them into the process of collective advocacy, so that they can join the chorus of trying to change things for the larger group of people who share their common problems.

Bonney: Mm-hm.

Bristo: That has had a significant impact on the direction our organization took, causing us to look at advocacy as a really big part of who we are as an organization. Similarly, as these laws passed—the Fair Housing Act and the ADA—it had an impact on our programmatic priorities. When the Fair Housing Act [Title VIII of the Civil Rights Act of 1968] came out, for example, including people with disabilities, there’s a big stream of funding that funds the fair housing organizations around the country. We sought funding through that, and were the first disability organization to get funded to do fair housing work in the country. Therefore, we kind of wrote the book on it.
We actually paired up with the local organization that was the first fair housing organization, started by Dr. [Martin Luther] King in the 1960s, and learned how they did it, based on race. Then they helped us put together a winning proposal through HUD [Housing and Urban Development]. We got it funded. They worked with us during that first year, to teach us how to do it.

Then after they did that, we realized quickly that the new construction part of the Fair Housing Act couldn’t get tested in the traditional way. We had to come up with a whole new paradigm for that. So we have developed that, and have consequently become sort of one of the nation’s leaders in this. It’s definitely by working on the Fair Housing Act, that we saw how important nondiscrimination law was. By being part of that coalition, locally and nationally, we developed the networks that enabled us to have partners here that would help us then be able to go learn how to do this. And that has strengthened our local relationships with other grassroots organizations that are working on broad civil rights issues. And, you know, that, to me, is where it’s at. You know, taking the connection between what’s happening here in Chicago on the ground, how that percolates up to federal policy; and then once the federal policy is there, how that trickles back down to the local grassroots, and how you use that to your advantage as an organization. [audio file stops, re-starts after a pause]

We were started as an affiliate of the Rehab Institute of Chicago, [as I said] in my prior interview. In 1987, we finally separated from the Rehab Institute of Chicago. It took us seven years to go from complete dependence to complete independence. And we did it, our board, a consumer-governed board; visited this issue every year to determine, from our own perspective, when we were ready to make the move. And the main sticking point for us was the inability to give health insurance for our employees, once we were freestanding. So it took us quite a while, but we finally were able to negotiate that. In 1987, we became freestanding. When that occurred, we had learned enough about organizational development and fundraising by being part of an organization that had sound organization and sound fundraising.

Then we turned our attention to the philanthropic world, helped pay for some of the advocacy work that we didn’t have enough resources for through our governmental grants. I’m, therefore, looking at this whole process of “becoming” by having our mission—particularly our strong advocacy flavor—kind of guide our vision of organizational development. I also really viewed fundraising as a form of advocacy—my view on it has always been. Okay, there’s all this money out there in Chicago’s philanthropic sector. Right now, the little bit of it that does go to disability is funding stuff we don’t like anymore, a lot of it.
Not all of it, but much of it. They need to go through the paradigm shift.

You know, away from dependence to independence, away from exclusion to inclusion, away from paternalism to empowerment, just like government, just like business. If I can, we can, get them to think about disability in a different way, then not only will we reap the benefit of their money, but they have the ability to leverage, to use their carrot—i.e., money—to influence all the other nonprofits who should be serving disabled people, and who aren’t. If they start asking questions as they’re giving out money. So for me, the notion of going beyond what the governmental funding would allow us to do, seeing fundraising and philanthropy as a vehicle to help us do it, enabled us to grow our advocacy component, which strengthened our organization and made us a greater force to be reckoned with; so that now, this many years later, as we’re now into the ADA side of implementation, we’re taken more seriously.

I know there were peers early on who thought, you know, by me spending a lot of my own time in fundraising, that I was sort of abdicating my responsibility to the issues. I have felt quite the opposite. I have felt like by turning my attention to fundraising, it has enabled me to grow the organization, which has therefore enabled us to turn our collective attention to many more issues, with more depth, and more forcefully. And finally, when the ADA got passed, at first, we, like everybody else, hung out a technical assistance [TA] shingle. But it took us a little while to get our shingle up. We were a little insecure about it. We’d never really sold our services in that way. So we probably spent a little more time kind of trying to get our act together. We were a little less confident of our ability to do so in an accurate way.

Well, what I subsequently learned was, half the consultants who were out there selling the ADA didn’t know what they were talking about. We missed the curve a little. We did get some technical assistance contracts for a period. And then soon, we realized that—I mean, we felt we were in a compromised position; that if we gave advice to somebody and they didn’t follow it, our hands were a little bit tied, we felt, because we couldn’t really then go back and beat them over the head. We felt there might be some ethical issues there. In terms of filing litigation or something, you know, if you’re the one that had provided the TA, it just—so we eventually decided, through lots of discussion with our board of directors, that it was time for Access Living to move into another role. That is the impact litigation role.

So we, probably unlike almost all of our peers around the country, we built a legal team that focuses on broad impact litigation. Some of the
emphasis is housing, because we have the HUD grant. But then we have used unrestricted and private dollars to broaden our reach to ADA more generally. And that has probably done more for us, in terms of being able to affect change. Not so much because we’re filing lots of lawsuits—we pick carefully those that we focus on, and do so with an eye towards broad impact.

I think that there still is a role for the independent living center movement to play in this area. It has concerned me, although I have respect for the P&A [Protection and Advocacy] system, the P&A system emerged after all this. I often think to myself, Gosh, if the independent living centers had been positioned to get the P&A system, how much stronger we would be as a movement, to have had this capacity in every center for independent living. We have a very good rapport with our P&A. I really believe it’s because we have some lawyers on staff who can speak their language. It levels the power dynamics between disabled people and the organizations that are mostly run by lawyers.

Bonney: Mm-hm.

Bristo: It has certainly given us greater stature in our own community, at the level of press; in terms of the kind of meetings we’re—the ones you heard me setting up over here; being able to either speak to the head of a city agency or other very high level, influential people. Not all the time, but—

Bonney: How do you reconcile your budget with that kind of legal advocacy? Do you get, like, federal funds still to run your programs?

Bristo: [Over Bonney] We still get some—yes. Sure. What are you—I’m not sure—

Bonney: [Over Bristo] And you’re not supposed to use those monies, I thought, for lobbying or for political reasons, or for—

Bristo: No.

Bonney: —certain kinds of things. But is—

Bristo: No, that’s not true.

Bonney: Oh.

Bristo: You can lobby as a nonprofit, as long as you do it within the bounds of the IRS [Internal Revenue Service] rules. And we do. And number two, litigation is not lobbying. So you can—I mean, any nonprofit
could open up a legal shop, if they wanted to do that. If you can find the money to do it. We’ve had to turn to our private sector unrestricted dollars, to help support that, or go after specific legal funding for it. It’s hard to get that money, the specific funding, because a lot of it’s been picked over. But what we were able to do, given that we are—we have sort of the—what’s the word?—moral authority on our side, because we are an organization of disabled people. So when we decided to get involved in this, one of the things that we were facing was outsiders saying, “Isn’t that redundant to what this other organization is doing?” Well, what we knew on our own was, if you went to any of them—legal assistance, foundations, the P&A—all of them were overwhelmed with volume. So we would all say, “That’s ridiculous. You know, there’s a need to coordinate, but there’s such a shortage of legal resources for disabled people, who are mostly poor, that the more the merrier.”

Bonney: Mm-hm.

Bristo: The issue then became coordination. So when we came on the team, we created a network of all the legal providers who focus on disability, simply because we were coming on the scene. That group has continued to meet over all these years and share strategies, refer cases, sometimes collaborate on litigation. It’s really been an added value to, I think, the movement. I think it took an organization of disabled people to bring everybody together to do that kind of thing. And so what I’m trying to say is, while all that was happening, we were growing. The shape we were taking was to try to balance our advocacy and service. In the early, early years, we did more service than advocacy; and then we built our advocacy, and we’re right now, you know, in this kind of always looking to find the right balance between the two—especially since funders often take it out of your hands. You know, they make some decisions for you about what they’re willing to support.

Bonney: Right. Where do you get your major funding in this period of time?

Bristo: We probably have about twenty different governmental grants. Then we probably submit another hundred, hundred-and-fifty private sector grants every year. And a very large gala that we do once a year that brings in a lot of unrestricted and then—it’s a big part, and we have a good number of people working on just fundraising.

Bonney: So you must have a development department.

Bristo: [Over Bonney] Yes, we do. We do have a development department. As I mentioned, you know, as we begin to look at what’s next, we also have kept our eye on what’s next nationally. Like, what’s the trend?
Where’s the emphasis? And try to connect those two things up, so that we’re moving in the same direction as the curve. I think that’s an important thing to do, because you look for critical mass of interest around the nation. Sometimes if you’re the only one yelling about something, it can be great, and you can really make a difference. In the early years of Access Living, just by a fluke, we hired a lawyer to come over here, who previously had been doing domestic law, domestic violence work. A big group of her clients were deaf, so she signed.

Bonney: Oh.

Bristo: When she took the job here, which was not a domestic violence job, she said, “I’ll come, but I want to bring my deaf domestic violence clients with me.” We said, “Sure, why not?” You know? And so that started Access Living on its course to have the first real domestic violence program that we know of anywhere in the country. This was back in, like, ’84 or—I mean, well before it was a popular thing. So sometimes when you’re the only one, you can really make an impact. Other times, it’s by aligning yourself with—a little bit ahead of the trend, but where it’s going, so that you can be there, positioned to be part of something that is already about to occur.

Bonney: What do you think is in the future? What are the issues of the future that you can see now?

Bristo: Oh, boy. There’s so many. But I think I would be wrong to not say finishing up the stuff we haven’t finished, by way of continued implementation of the laws that we worked so hard to pass. I think that has got to be a central priority for all of us, because they don’t self-enforce. And there’s still so much that we can do with the law that we haven’t tried to yet. So that’s one.

Two is economic empowerment. You know, really getting serious about figuring out why everything is failing to tackle the unemployment rate, and getting at the sources of the problem—which I think takes us back to elementary school education. You know, it starts in the pipeline. The first pipeline, I think, is the academic pipeline. We’ve been working locally on a lot of initiatives to get to the employer community, and the government employer community. Ironically, they’re now kind of ready and poised and a little bit—much more receptive to go. But even with all these years and money into the whole rehab system and TWWIA [Ticket to Work and Work Incentives Act of 1998] and everything else, we keep hearing the same thing: Okay, now we’re ready; we’ve got these jobs; where are the people? You know. There’s still something wrong.
You know, my view has—and this is unpopular—but I feel like one of the things that’s wrong is the middlemen and women, the middle people that we have to go through to get to the jobs. But I think we have to be starting to say, “The heck with all them, we’re going to go get that job ourselves.” How can the independent living movement facilitate that, without becoming a job placement organization that has all the same systemic barriers that everybody else has? That’s where I feel like we haven’t done it yet. We can do it. I mean, look, we’ve done it in the field. We’ve done it here.

I don’t know that we ever have. Maybe once. We have an apprentice kind of program, and we do there. But generally speaking, we find people because they’re out beating the streets looking for jobs, and we’re out interviewing. I think somehow, we’ve got to come up with ideas that—we’ve got to empower people that they can do that. You know, that they don’t have to go through VR [Vocational Rehabilitation]. They don’t have to. I mean, they can get the benefit of VR, or the programs that VR funds, but they—somehow, that’s where I feel like some of our problem is. As long as other people translate us to people, then we don’t get to translate ourselves to them, and we don’t get to tackle the number one issue, which is their discomfort and fear and wonderment about can you really do the job?

Bonney: Right.

Bristo: So. But ok, that’s one. Two, well, I think this one’s coming along pretty good. I had worries about this for a while, the technology revolution, and how it does or doesn’t open doors or close doors for us. I actually think that one is—while it’s far from perfect, I can see evidence that it’s beginning to catch up.

But again, that’s a place where our legal tools and our strong advocacy has to play a part. That’s not an area we’re expert on. So for us, that would be the biggest stretch of all. And then the two final things—[pause; cough in background] Giving voice to the people without voice, in the movement, because that’s a really big issue; the under-represented voices, whether they are people of color—and by giving voice, I don’t mean me giving voice; I mean—

Bonney: Right.

Bristo: —nothing about us, without us, and looking for ways for serious leadership development of both youth, minorities, and people with very unrepresented disabilities. My last, and probably the one I think is the most important, political empowerment. True, honest-to-God, and get as smart as everybody else on it. You know, get serious about real
voter turnout, get serious about beginning a process to surface people who we can run for office and win. That kind of stuff.

There’s a million other things, but those are the big national ones. I think around the margins, are all the really, really big ethic issues. Right to die, right to life, and all that goes with it, you know—physician assisted suicide, genetic discrimination, you know, the brave new world kind of things.

Bonney: Right.

Bristo: Okay.

Bonney: All right, should we go onto NCD?

Bristo: Yeah.

Bonney: Okay.

Bristo: Right when I left—well, that’s a perfect segue.

Bonney: Yeah.

Bristo: Because throughout my tenure at NCIL, I had come to be exposed to the Republican presidents—a little bit of Reagan and Bush. I had been able to see that the handful of people who knew them well were being able to be influential. I also understood through the local political work I was involved with, with the group I mentioned earlier, that disabled people were not at all politically engaged in the electoral process. My good buddy Fred Fay had worked to bring the disability community into the DNC’s [Democratic National Committee] apparatus. Some of us had been involved in that, to some extent, but not in a really vocal and loud way.

When I stepped down as NCIL president, and we were gearing up for the elections, during the primaries out of which came the Clinton nomination, Harkin’s people came to me and asked if I would be a delegate for Senator Harkin in Illinois. It was a little unorthodox, because usually that happens a little bit more at the state level. But I said, “Absolutely.” Shortly thereafter, Becky Ogle was hired on in the Harkin camp to kind of work on the disability constituency work for Harkin. Well, as you know, Harkin lost the nomination, and then he shifted his support to Clinton.

I knew the people who were running the Clinton campaign, because they were Chicagoans. They had been friends of mine through the political organization that I’d been part of. And when I came back
from NCD—I’m sorry, from NCIL—that organization said, “Okay, you’re not so busy any more; will you be the chair of our board?” So I became the chair of this statewide—the state’s largest public interest organization called, at the time, Illinois Public Action Council; now it’s called Citizen Action.

In that role, I was beginning to learn more about party politics, and how campaigns are worked, how door-to-door grassroots campaigns—how you influence a candidate’s position, how you do candidate surveys of their positions, how to get disability issues into those generic legislative surveys, and the data that’s being tracked on it. It became a much more important thing for me, through that political experience here. So towards the latter part of that campaign—I would say in only the last nine months, really—I went back to NCIL as the past president and said, “You know, you guys, you need to get more involved in this campaign.” So NCIL reached out to both the Bush and the Clinton campaigns, and asked for opportunities to meet with them and talk to them.

Well, the Bush people were out in California, and they had this—I don’t know, they closed the door on us. There were all these demonstrations and everybody was really ticked off. The Clinton people, of course, heard that, and then the people at NCIL similarly put forth a request, and had a much more open door. Bobby Simpson was the director for the state of Arkansas [State Vocational Rehabilitation Agency] at the time. Bobby and I were kind of working behind the scenes on the Clinton campaign. I’m quick to point out that I was late coming into this, having been a Harkin supporter. But because I had connections here in Chicago with the campaign, and Bobby had connections there in Arkansas with the Arkansas people, the two of us were doing a lot of work behind the scenes.

I was in Rome when the—Well, the election had happened and Clinton won. I was in Rome for the big Vatican conference on disability. My husband and I were there. My phone rang in Rome. It was Bobby Simpson saying, “You need to come back. They want you on the transition team.” I said, “Are you crazy? I’m in Rome. [laughs] I’m not coming back.” He said, “Okay. Well, call me as soon as you get back. They want you to come to Washington.” So I did come back, and then for about, I don’t know, I guess it was four or five weeks, it wasn’t the whole duration of the transition, but I moved into the Vista Hotel in Washington, and became one of the three people who were staffing—Actually, it started out with two of us, and grew to one, two, three, four, five of us, who were staffing the disability desk, essentially, for the Clinton transition effort. Myself, and Michela Alioto, whose—you probably know, was it her father or grandfather was the mayor—I forgot which—of San Francisco.
Bristo: I think you’re right. She was there, I was there, and then Michael Winter, because Michael knew her very well. Then shortly thereafter—Oh, there was a guy from [American Federation of State, County and Municipal Employees], who was a good guy—at the time, I didn’t realize what an enemy AFSCME would eventually be. But we started our first discussions with AFSCME during that period. Then also, eventually, Paul Miller came in, sort of right when I was winding down. We were doing the policy stuff, Paul was doing personnel. Then we finished our work, and then Paul stayed kind of full-time.

Our work was to do an assessment of all the different agencies that had anything to do with disability, write up reports. We went to daily briefings; we would feed in what we were learning, but ultimately, we each had a sort of a high level person that our report would go to. That would influence decisions regarding budget, consolidation, staffing, appointments. In theory, it would. You know, I’ve come to—it was very heady when you were there, but at the end of the day, the thing that we did the best, that I really believe, it was our work, collective work, was we got people with disabilities into important jobs.

We set our sights too wide, I think, early on, and tried—we wanted to get people on all the different boards and commissions, into all these key posts throughout government. Finally, we learned that a different approach, where we had a specific person for a specific job, would have been better. We got thousands of resumes that came in. Most of them were in a filing cabinet drawer, because it was just too many to vet. But through that process, I think we were able to get somewhere around twenty people with disabilities—which, you know, sounds little, but it’s more than we’ve had, and more than we’ve had since—into policy positions throughout government. Our goal was not to just have them in the disability places, like at OSERS or the President’s Committee, or NCD, but to get them in the State Department, to get them in HHS [the Department of Health and Human Services], to get them in, you know, OAS and various places.

NCD was one of the agency reports that I wrote. So we interviewed all the agency people and put it together. About part way through the whole process, when they started then asking us for recommendations of people, all of a sudden people I’d been working with were saying, “You should go for it. You should go for it.” Once again, I went through the same leadership fear that I did with NCIL. “No, not me. I’m not—there’s never been a disabled person in this post before.”

Bonney: Mm-hm.
Bristo: So eventually, after thinking about it and realizing, you know what, I think I can do it as well as the next guy could, I went back to the transition team and said I would be interested. Well, because I had dilly-dallied a little bit in thinking about this when it was first asked of me if I wanted to do it—

Bonney: Yeah.

Bristo: —a little campaign started. There were several other people who were interested. So as it turned out, Max Starkloff, Ed Roberts and me were all kind of being pushed by different people for the chair of NCD. And eventually, Max withdrew. I believe Max withdrew. In the end, it was my political ties to the people who ran the Clinton campaign—most notably, a guy named David Wilhelm, who by then had been appointed by Clinton to be the chair of the Democratic National Committee. David kind of helped put the final touches on it. So that got me nominated. It took a very long time to go from nomination to confirmed. This was during the Zoe Baird investigation. You remember? Nannygate and all those things?

Then there was also somebody, I forgot who, there had been some allegations of drug use within the White House during that period. So anyway, my nomination was pending during all of that. I had had a personal assistant childcare worker who, you know, frankly, I never even thought about, I had just paid cash for. I had not done all of what you were supposed to. Then the FBI commences their check on you. Also—I don’t know that I told you, but I definitely told Mary Lou—I’m a recovering drug and alcohol addict. I had a lot of history, and that was hard. When I went in to my FBI interviews, you have to fill out mountains of paper about this stuff. I basically told them, both of those. “This is the deal. Yes, I did this, and yes, I did this.” I think it’s fortunate that I did, because I know of another person who was in the running for an appointment, who had said no to a drug use question. It was contradicted by the other people that they interviewed. The person didn’t get the position. So I think that what they were looking for at that point was your honesty, more than anything.

But it did take fourteen months to go through the process of being nominated. More than once, I was told by—by now, I was sort of the shadow chair, even though I couldn’t be the real chair. Mrs. Parrino had been asked for her resignation by President Clinton, which was rare. He let most of these independent agency’s tenures, incumbent tenures, wind down and run out the clock. But apparently, she had gone to an international meeting and was making commitments on the part of NCD and things that got back into the White House, that didn’t have the seal of approval from the Clinton White House. So that, coupled with the fact that NCD had just decided to give an award to
MDA [Muscular Dystrophy Association] and Jerry Lewis, right at the time that Jerry Lewis was a very controversial figure, with Jerry’s Orphans, and Evan Kemp, who had been in the Republican administration, had been very outspoken against—

[Audiofile 11]


Bristo: Okay, so those two things got back to the White House, vis-à-vis Paul Miller, and the president decided to ask for her resignation. As a result, the vice chair, who was a labor union official from the fire fighters union, a guy by the name of Jack Gannon, was appointed to be the acting chair person. Jack and I hit it off great. I couldn’t officially do anything during that period, but Jack sought my counsel significantly during that period, and made a very smooth transition for me.

When I first got to NCD, my first order of business was to fill out the remaining vacancies. We had worked already, Paul and I, on putting forth several names into the pipeline. So several of them came up at the same time I did. But then there was the next batch of people who were about to cycle up, and we, therefore, had a whole bunch more. So that was one of the first things I worked on, trying to make sure we had some good names who represented America. You know, people with a cross-disability perspective, that brought different areas of expertise.

I was very pleased by the end, with the kind of council we got. We did not get a clout council; we got a movement council. And you know, there are a lot of tradeoffs. The prior council had had a lot of clout. They weren’t movement people, but they were able to get into the highest corridors of power. Ours, because it was more of a movement council, didn’t have the ability to do that in quite the same way. For the first several years at NCD, I spent a lot of my own time nurturing relationships at the highest level in the White House, the Domestic Policy Office, the Office of Public Liaison, the DNC—anyplace where I felt that establishing a strong relationship would position us to be able to move our issues forward.

Bonney: Now, let me ask, did you move to Washington to live?

Bristo: No. No. The NCD members are not full-time, they’re per diem, meaning you’re paid for the portion of time that you’re working. So I split my time here and there. During the early years, the council was in disarray. It had a bunch of problems internally. Staff problems, legal problems, you know, different contract disputes or discrimination complaints. It didn’t have much of a program left. It had been sort of
in limbo for a while. It had fallen from—I don’t want to say fallen from grace, that’s too harsh. But after having done the ADA, it had shot its wad. I think some of the power dynamics that I spoke around earlier left it with a lot of credibility issues. So it was there, but it didn’t have the same pizzazz or bang that it did. I don’t mean to be offering any value judgments; I’m just telling you by the time I got there, there were a lot of problems. So I knew what I was inheriting when I went in.

One of the things that we inherited was the prior executive director had been terminated by the prior chair. That person had sued, in a very complicated discrimination complaint. I found myself defending that litigation, which was very complicated. I don’t want to spend more time on it, but it took a lot of time and energy. So I did spend a lot of time trying to meet different cabinet heads, high level people in government. I’d make one step forward and three steps back. It really took me a while, first off, to realize that the White House has a revolving door of people; that just as soon as you get close to one, they leave. At one point, for example, one of my best friend’s dad became the White House counsel. So for a short period, we had a really good rapport there. Then he left. The guy that was in charge of disability at the Office of Public Liaison was the same guy that had gotten the phone call in Iowa about—

Bonney: Oh.

Bristo: Remember? From the people here—saying—I didn’t know it at the time, but it was the same person, from Iowa, that had been brought in to be the assistant head of Public Liaisons. When he left and new people came in—and then our people, the disability community that were now in government, were there. There also became, for a little while, some turf within us, the political appointees. We mostly got over that, but in any government there is—you know, power is the thing that makes people tick. So it finally took—I’m trying to remember what the issues were. I don’t remember. But I finally realized that I was barking up the wrong tree; that the word “independent” in our charter, an “independent” federal agency, meant we were never going to be one of the club. Because we didn’t have to listen to them in the same way. We could take legislation to Congress. It did not have to get through the White House. We could issue a report, independent of OMB [Office of Budget and Management] clearance. So they could not control us, technically, by definition. Therefore, technically, by definition, you’re not the same part of the president’s team. I was trying to make myself into something that was impossible to be. Once I grasped that, it was—I’m not saying I didn’t continue to work those relationships; but I found where the true power of NCD came from, and that is, again, from the people, in the voice of
the people, disabled people. So it shifted our course. I don’t know how much detail to give you. What do you want to know about it? What were some of the priorities?

Bonney: [Over Bristo] Well, I know that one of the things that you did while you were there is, you had the “Unequal Protection under the Law” series printed, published.

Bristo: But—

Bonney: So I guess what I need to know is, sort of what was your vision for it, I mean, for NCD. What were your accomplishments?

Bristo: Yeah.

Bonney: I know that the unequal protection series was one of them.

Bristo: Okay. Well, I’ll tell you, once I ended up there, I had this, Oh, my God, now I’m here. Now what? And all of a sudden, the weight of it hit me, that this is the agency that crafted the ADA. How am I going to top that? I quickly learned, in my own gut, you’re not going to. Don’t try. That’s a once in a lifetime thing.

Bonney: \{inaudible\}

Bristo: [Over Bonney] It’s a once-in-a-lifetime thing. Okay. Having taken that off my back, I then said to myself, Okay, what do you really think needs to happen? I had my own set of goals. But what I wanted to do was validate them. So I did a few things. The first thing I did was set up a series of informal meetings with all the people who I most trusted, and who I thought were most influential. I went to each one of them and talked a little bit. What I realized, without knowing I was doing it, was, NCD had kind of lost its community credibility. Just by reaching out to people, it started to bring people back.

The second thing that I discovered was that all of our discretionary money had been obligated by the prior Council at their last meeting. They took all the money that we had, and voted to give it to CDC. What’s CDC stand for?

Bonney: The Communicative Disease Center? [The Center for Disease Control]

Bristo: They were going to give all our money there, to do a research project on prevention of disability.

Bonney: Oh.
Bristo: I said, “I don’t think so.” So we were able to kind of call back in that—the contract hadn’t been signed yet. The board had voted it, but we were able to re-vote it. In a fairly controversial way, we rescinded that agreement, in order to reclaim the resources for that year, and to put it on something that I felt the community would be more supportive of. That turned out to have a good impact on CDC, because we were able to say to CDC, “Look, if you want to be looking at prevention issues, look at secondary disability prevention issues. The community does not want you to put all this money in how to get rid of us. We’d rather see all your money go into how to help us live a better quality of life.” And for a while, they really made that shift. I think they’ve shifted back again, but there was a period of time where most of what they were working on, including down the road, changing the international classification system; they worked really hard on changing the definition of disability at the international level, to make it more consistent with the independent living sort of functional definition, rather than a diagnostic medical label.

So there I was, having won that and needing to, therefore, come in pretty quickly, as the chair, with some recommendations of what we were going to do. So the first year, I just did it by my gut. I wanted to bring the voice of people of color more strongly into the council’s work, and looked for a way to do that. I wanted to look at the area of international, and have some ability to determine why it is that the money we spent overseas appeared not to be held to the same standard for accessibility as what we did in the US. There were two or three other issues that we put our resources in, in that first year. They were done kind of quickly. But they did start to set a tone.

I also knew that I really wanted to consult with disabled people, to hear from them, “What do you think the next big policy agendas should be”? So we organized a summit, which took place in 1996, ten years after the 1986 Toward Independence report. So we situated it as the next Toward Independence, and following the ADA. So we created certain assumptions for the group.

We brought about between two and three hundred leaders from the grassroots, to Dallas, Texas. We spent three days in a working meeting, looking at ten predetermined areas, all juxtaposed against what’s going on with the demographic shifts in the world; what’s going on with the devolution of policy, from the federal to the state levels; what’s going on, and how do we, in the backdrop of all that, change the post-ADA era towards pushing the principles of the ADA into the rest of public policy? That was the challenge of the group. What do we need to do to take the values that were in the ADA into health care, into housing, into the other areas? That ended up being a report called Achieving Independence.
It was done in a different way. The *Toward Independence* [approach] was sort of what I would call an ivory-tower kind of process—analysts, and a think tank, and a big compendium of data was put out. Ours was, I think, consistent with what had happened in the intervening ten years, the movement grew. So I wanted our report to, in part, flow from all that new data; but equally importantly, lift the voice of disabled people. That report then crafted the direction for the rest of the work that the council did.

From that, we focused on several areas. One was leadership development. We recognized—somewhere around this period, Ed Roberts had just died, Paul Hearne had died, Evan Kemp had died, Elizabeth Boggs had died. Any number of our leaders who helped us get the ADA through were gone. I really felt that that meant we were going to lose the movement, if we didn’t do something about it. So I started at NCD, the first national youth organizing summit, a youth leadership summit, which gathered steam. I think it’s one of the biggest impacts we’ve had. My understanding is after we left government, the concept left—first it was at NCD, then we passed it over to the presidential task force, through the president’s committee for a while.

Then when we left government, Judy Heumann put it in OSERS [Office of Special Education and Rehabilitative Services], in order to lock in the funding for five years, as a subcontract out the door. So somebody couldn’t get rid of it. As a result of all that, I think we really created a consciousness around the country that youth programming, youth development, is really important. I think that’s one of the things that I feel really proud of, that there’s no concrete law that’s changed, but I can look around the country and see evidence of it all over the place.

The second thing we did was organize—I forgot something. We were going to do the summit in year one. You know, towards the end of year one. Then Newt Gingrich and friends got elected. The Unfunded Mandates Reform Act came up. All the right-wing people started calling the ADA an unfunded mandate, and saying that it wasn’t helping the people. There was a huge backlash campaign.

So NCD stopped the planning for the summit, and decided we were going to go out, in Justin Dart style, and go around to all fifty states and gather stories from people. This is five years after the law was passed. And we did so, rapidly. We went to all fifty states in three months, and came up with a very good report, if I do say so myself. I mean, it wasn’t scientific, it was just intended as a PR tactic. But it really had a strong effect. We were able to get [United States Attorney General] Janet Reno and [former United States Attorney General]
Dick Thornburgh on the same stage, when we released the report. We were able, for that period of time, to shut down a lot of that bad backlash.

It came back again later, through the courts. But it taught me, even before we did the summit, that enforcement of the law was the community’s obligation. Even though other people had to implement the law, it wasn’t going to happen if we weren’t vigilant and paid careful attention to it.

I had read an article by Tim Cook, who was an attorney, did a lot of work with ADAPT, a disabled guy who had died. Before he died, he wrote this incredible article in the *Temple Law Review*. Basically, it was his reflections, right after the ADA was passed, reminiscing about how the same feeling was shared by advocates right after 504; that there was, amongst a smaller group of people, there was a sense of jubilance and hopefulness; and that if you track the legal history after that, the law didn’t materialize. It didn’t get implemented root and branch, is what he said. It compared ADA to other civil rights laws, and basically called us all on that, and said that we can’t rest on our laurels.

If the ADA is not going to go the way of 504, it’s up to us to make sure that the enforcement is moved forward in an aggressive way. NCD had a summit at about this point. We had the summit, and then we convened our own board in a two-day working session and decided that we would focus our efforts, nearly all of our money for the rest of our time there, on ADA and civil rights implementation. And the way we decided to do it was by doing a study on how well the federal government was implementing the different civil rights laws, called *The Equal Protection under the Law Series*.

Bonney: And which civil rights laws did you look at?

Bristo: The Air Carrier Access Act, the Fair Housing Amendments Act, the ADA, IDEA [Individuals with Disabilities Education Act], and CRIPA [Civil Rights of Institutionalized Persons Act]. Each one came out in its own report, over, like a two- to three-year period. In the final one, we started, but we left before it was finished. It was Olmstead

Bonney: Oh, yeah, mm-hm.

Bristo: It was a specific one on the Olmstead case. The reports stand today as very compelling evidence of what more needs to be done. There’s been several things that—[interruption, audio file stops, re-starts]
Bristo: Reports aren’t really worth the paper they’re written on, if things don’t happen for them. There’s a variety of things that happened as a result of this. With each one of the reports, we organized press conferences and got constituents involved. Some of them kind of took on a life of their own. So for example, in the IDEA report, we found that no state has really fully implemented IDEA, and we were able to point out really egregious lack of enforcement. So we worked a lot on trying to tighten the enforcement procedures. I’m remiss in saying that I don’t know where the Olmstead report ended up completely. But I know that up to that point, there had been no enforcement, really. And what we started to do was try to get measurable goals. That if somebody was found out of compliance, that there’d be consequences, and that it be done in a foregone way that they would know about. The election occurred right before the final touches were put on this. I’ve heard through the grapevine that they’ve enhanced their enforcement monitoring, but I haven’t followed it to see how specific their recommendations track with what we were doing.

Then, of course, No Child Left Behind came in. I’ve always had a regret about this, because we were really poised to have a senate hearing on this legislation. Then some other things were happening that made Senator Kennedy’s people feel like then was not the right moment. I really wish that we had pushed harder, because I think there was that window of opportunity, where the Democrats were in power; the Republicans were pushing for full funding of IDEA. We had the argument in our hands as to why they needed more funding. The hearing didn’t happen, and then the Congress switched power, and the whole idea of full funding of IDEA, you know, dissipated. So that’s one regret I have.

Bonney: Let me back up for just a minute. When you started the studies, how were they funded?

Bristo: Through us.

Bonney: And who actually did the studies?

Bristo: Different organizations did different studies. DREDF did the first two. Or they did the first—[pause] Let me see. Hang on just a sec here. They did the Air Carrier Act with that, and the ADA. Somebody else did Fair Housing; I don’t remember who. We had multiple different contractors. But DREDF did the early one. So it kind of got us on the track. One of the things that happened when we came out with the ADA report—With the Air Carrier report, a lot of positives came out of that. First off, DOT [Department of Transportation] joined us in the press conference, and said they agreed with us that this was a terrible
track record, and they were going to be putting in place changes to improve it. A lot of things have come out of that.

They’ve changed the consumer reporting mechanism. It’s now mandatory for airlines to report things that they weren’t reporting before. They’ve done a revision of the consumer complaint forms. They’ve staffed up the complaint division, so that it’s got adequate people to handle it. There are penalties to the airlines. They’ve increased the amount of monetary damage if they break your wheelchair, they’ve increased that. They’ve intervened on the nondiscrimination aspects, where there’s a code sharing agreement. Different airlines from different countries fly together; so Lufthansa and United are in a code share. It used to be that, if you flew halfway on your journey on United, and then switched to Lufthansa, Lufthansa wasn’t required to non-discriminate because it was from a different country. Now, when they redid the code sharing agreement, they changed that so that our nondiscrimination rights extend more broadly. They started on this whole thing of changing the process you go through to get onto an airplane, the screening procedures, the training, just a lot of stuff. Even to this—and then September 11 [2001] happened, while NCD was convened with all the airlines. On the day.

Bonney: Oh, goodness.

Bristo: We were in our second day of bigwig meetings with all the VPs from the different airlines, when their cell phones went off. I wasn’t there, because I was sick. But my staff reported to me that all their cell phones started ringing at the same time, and they all went pale, and said, “There’s been a tragedy, we have to leave.” But the work we had been doing with boarding and deplaning assistance and screening, et cetera, ended up—the moment in time we were working on this, right when the entire system was being regrouped.

Bonney: Mm-hm.

Bristo: So for a change, instead of being the P.S. [Post Script] after they’re done, we were already cued up. So we were able to be involved in the revamping of things right at the beginning, when they redid the system. I think that that has had a, generally speaking, positive impact. Not a hundred percent of the time, at all. So different reports generated different kind of recommendations.

The administration, especially some of our friends, really took critically our complaints about the Justice Department and its failure to properly resource and have a set of policy goals for their ADA implementation. We were quite critical. We basically said the EEOC [Equal Employment Opportunity Commission] had done a better job at
issuing sub-regulatory guidance than Justice had. Therefore, even within the ADA, we had disparity over how well it was being implemented, according to who had jurisdiction; and that there should be more lessons shared.

That was taken very critically by our peers in government. I can’t say that we saw a significant impact out of our study, even though the work was really strong, the findings were really strong. But one of the byproducts of that was, we had become very knowledgeable on this. We had also started to reach out to the legal community. When the first Supreme Court decisions started to come down, another thing we did under my tenure was fight to have the right to file an amicus from NCD at the Supreme Court level. The first time we tried to do that was in the very first ADA case. It was an AIDS [Auto Immune Deficiency Syndrome] case.

The solicitor general, who is the gatekeeper of amicus briefs, has to give you permission to file. And they came back and said NCD did not have jurisdiction to file, only the EEOC and the federal government can—they have to speak with one voice. So we couldn’t file. So we went back, when we rewrote the Rehab Act, the Rehabilitation Act amendments in ’96—we amended it, just in slight little ways, with the help of Senator Harkin, to broaden our mandate. So it now says that we were to give policy guidance to the president, the Congress, and other federal entities.

So we then interpreted “other federal entities” to mean the Supreme Court. The Sutton Case and the Garrett, and—gosh. Olmstead. When all those cases came up, we decided to file in Olmstead. That was our first opportunity to file. When we filed, because we were trying to get our brief together, we pulled a lot of the lawyers together to help us. One of the byproducts was, afterwards, those lawyers have stayed connected. And therefore, there’s been a collegial strategy; each time the Supreme Court hears something, we’re ahead of the ball. We’ve got a strategy. They know each other, they know who’s going to write which piece. I can’t say that it’s had the greatest effect in the world, but I think it was a really important thing.

Our international work was of significance, in that we maintained the presence, that NCD had begun to chart, for keeping some focus on international. We had done a study—with WID [World Institute on Disability], actually—on embassy accessibility. It was a self-report study, and we learned early on, in the very beginning, that very few embassies reported that they were accessible. So we were able, then, to write a report. Again, a report. I learned so much over the years about—
Bonney: Report writing. [laughs]

Bristo: Yeah. That report opened the door at the State Department, to start doing some work there. We were successful in getting disabled people seated into US delegations as officials. Not as NGOs [Non-Governmental Organizations], but as government agencies. So I was slated to go to all the world summits. But I had worked with Tony Coelho and Judy Heumann to try to get the advocacy done to make this happen. I went to two, and Judy went to one. But there, our voice was very important in working on those documents, and also beginning to understand how the UN worked, on both sides, the NGO side and the government side. So that put us in the position of an understanding of how the treaty process would go.

That’s when Lex was elected the president of RI [Rehabilitation International], and came to us and said one of the things he was looking at was trying to promote the establishment of a convention on the rights of people with disabilities. So to that end, NCD did a lot of work to convene people. Before this happened—I’m sorry, I forgot. After the study on embassy access, we organized a formal advisory committee at NCD called International Watch, which brought a critical mass of people together who could talk together in a consistent way, with phone calls paid for and planned for by NCD on these issues.

That helped germinate what became the DPI [Disabled Peoples International], DPI/RI affiliate called USICD [United States International Council on Disabilities]. We were able, I think, to stimulate and give some small contracts through to USICD to get the ball rolling. The work that we did there was twofold. One was to look at rights. Well, threefold. One was to look at rights. The second was to look at internal operations at the State Department, its obligations under 504, and why it had pretty much taken a pass entirely on seeing itself covered under 504. Three was to look at foreign assistance programs to make them more responsive to disabled people. So accessibility of our properties overseas, internal inclusion of people with disabilities in everything the State Department does, and foreign assistance, sensitivity to disability development issues were our priorities. We convened a big meeting of all the federal agencies who worked on international issues. [audio file stops, re-starts].

We worked with the man who was the assistant secretary for the Bureau of Management, Budget and Policy at the State Department. We’d met with him, he was all geared up. He had money set aside, the positions organized to create a disability section at the State Department. Then he left government. He left it before it got through the General Counsel Office of State, and the whole thing died. So that shifted our attention more, since we weren’t seeing the kind of support
we wanted from the administration. We started, then, to look more outside to the Hill. And the UN convention, Lex had come and said that RI was looking at that. He wanted NCD’s backing. So we had an international meeting on the convention, where we brought all the US entities together, and came out with a strong position in support of the convention; continued to try to work the government from the inside, on a convention. And then we lost the election.

It was really a shame, because [Senator] John Kerry’s sister, Peggy Kerry, is the NGO liaison for US/UN. So she is the liaison to the international NGO committee from the United States, at the UN level. She was all cued up and ready to help us take this to Kerry and get the US onboard. That’s what I was saying earlier. There are 191 or 192 countries that are working on this. The United States has essentially taken a pass. They took the public position that there’s no need for a convention; that the US would be happy to provide one-on-one sort of unilateral—or bilateral, rather—consultation, but they didn’t believe that a convention was necessary; they could not be in support of it.

They sat silent at the first four convention meetings, where the whole world—you know, three hundred diplomats from around the world debating text, and our country just sat there. At the last two meetings, they spoke up. They ended their silence, to speak up on behalf of the right-to-life community, who had an effective lobby and got to them. So that’s where it stands right now, that there are some people who want to see the US come onboard. But suffice it to say, the world community doesn’t want to see the Bush administration come onboard, because they’re afraid of the negative that could come from it.

Bonney: Now, what is the UN convention focusing on? What are they trying to do?

Bristo: Well, it will do at least two things. The biggest is, have a general statement on nondiscrimination on the basis of people with disabilities. Then there’s multiple articles, and multiple different areas of life, where they—Countries that decide to ratify the convention, to sign it and ratify it, voluntarily agree to come under the force of these {inaudible}. So just the same way that the Human Rights Declaration works. Countries that ratified it are open to international sanctions and international law, countries that voluntarily agreed to be part of this would similarly come under the sweep of that authority. So there’s a rights component.

The second component of it has to do with development. You know, that there’s a service component. Many countries have nothing like rehabilitation, special education, Social Security. There’s just zero. So this would essentially say that people with disabilities have a right to
these programs and countries should take proactive measures to create
them. We don’t yet have a convention. We have the Standard Rules on
Equalization of Opportunities for People with Disabilities, which are
not at all binding. There are interesting cases where, for example,
existing human rights laws have been used, for example, to end
government policies on forced sterilization or forced
institutionalization in subhuman ways, in countries where the law—
And a lot of it becomes the law of world opinion.

Because if you’re brought up before one of these bodies, then the
world spotlight shines on you, and countries are often kind of
embarrassed into ending a bad policy. I won’t go into all the reasons
why the US government feels that—they have what’s called treaty
fatigue—that they think these things are not useful, we’ve gone too
crazy with treaties, that only the countries that know they’re not going
to adhere to them agree with them, and then they use them as a vehicle
to try to get money. Then if they can’t adhere to them, then they say,
“Well, you have to give us more foreign assistance, so we can.”
There’s all this circuitous logic. But our community has always felt
that the ADA is one of the best exports of democracy, and therefore,
we should proudly be there trying to urge it. Anyway.

Bonney: Let me ask you another thing, just for people hearing this in years to
come. Could you identify what an NGO is?

Bristo: Non-governmental organization. It’s like the word for nonprofit
organization, except at the international level.

Bonney: Okay. So it would be like what kinds of institutions, or what kinds
of—

Bristo: In disability, it would be the World Federation for the Deaf—

Bonney: Okay.

Bristo: —the World Blind Union, Disabled Persons International. There’re
seven right now, I think seven, international NGOs in disability.
Others you might know, Human Rights Watch, Amnesty International,
Greenpeace. You know, these big, large issue or constituent based
nonprofits that are global in nature.

Bonney: Okay.

Bristo: To be recognized, the UN has to acknowledge you. So you have to
apply and be acknowledged by the UN to have standing, and be able to
participate in anything that the UN does.
Bristo: Let me think for a second. There were some other things that we did of significance. We did a lot of stuff to raise profile. So for example, on the issues of minorities, we did some reports on the status of minorities with disabilities. We hosted the first White House meeting on race and disability, in the White House, with high level people. We did a whole series on youth and education; a series of papers on not just the Back to School on Civil Rights, which was the IDEA one, but we did a whole series of things leading up to the IDEA reauthorization. We held town meetings all over the country, and we wrote recommendations that worked their way into the IDEA reauthorization.

We did a series of stuff on technology, well before anybody else—other than WID—was looking at technology. In part because of Debbie Kaplan, and a guy here in Chicago by the name of Newton Minow, who had started to look at communication access as the wave of the future. My very first meeting as NCD chair occurred in Seattle. About a month before we were to go out to Seattle, the blindness community national organizations came to me and said they’d been trying to get in to see Microsoft, and they couldn’t get a meeting. Would we help? Because Microsoft had taken over the world, and their screen readers couldn’t read it.

Bristo: So we got the meeting with Bill Gates’s people. Not with him, but the high-level folk. It became apparent to us that we were getting lip service in the meeting, that we weren’t being taken serious. I ended the meeting halfway through it and kind of walked out. We then went on and found Section 508, that nobody I knew knew about until then.

Bonney: Right.

Bristo: Through work on the part of an advisory committee we created Tech Watch, the first, you know, real national info public policy technology body. We gave that group the charge of helping us figure out what should we do in this area? That group helped us get GSA [General Services Administration] to start looking at rescinding Microsoft’s contract, because it was violating Section 508. When GSA decided that they weren’t going to play with us anymore because the big antitrust litigation kicked in and everything else cleared off the government’s plate with Microsoft, the Boston and Massachusetts community passed legislation similar to 508 at the state level, and did get their state to withhold, or threaten to withhold, the contracts from Microsoft. At that point, Microsoft then called us to say, “Okay. what do we have to do?” So I like to think that it was NCD’s work that,
through the connection with the disability community—we gave voice
to them to carry their issue, and then they helped us have the technical
expertise we didn’t have to be able to use our bully pulpit and insignia
to move it further than they could have.

That led to a whole series of things that we started to do on
technology, including pushing that the Access Board be given more
rule making—or, you know, authority over this. So then as the Access
Board built a technology component, we kind of pared ours back. I
think those are—it’s hard for me to know. I think when I think of what
were the big things, focusing on implementing our civil rights and
drawing attention to everybody’s responsibility, our need to be
vigilant, our need to watch the Supreme Court, I think our work
indirectly led to ADA Watch being formed, and some of the other
groups that are now out there marshalling things. Oh, I forgot a biggie.
I forgot this. Early on, after I got confirmed, a couple of the other
political appointees said to me, “You should get NCD to convene us.
You’re the right group.” So I took their advice {inaudible} And
convened all the political appointees {inaudible}

Bonney: We might wait until you get back, for the microphone, ok? We don’t
want to miss what you’re saying. [audio file stops, re-starts]

Bristo: This is very important. I convened the political appointees with
disabilities that were all sprinkled in government, together for a
summit on a weekend. And my charge to them was, “What can we do
together, that none of us can do alone? We’re all in different agencies,
we all have our own bureaucracies to deal with. Here are the NCD
Achieving Independence reports. Here’s the executive summary.
Here’s everything that the community wants to see. Surely, in this
document, there’s something in here that we can work on together.”

Bonney: Yeah, mm-hm.

Bristo: The two things that we selected primarily to work on were in getting
the country to see unemployment as the national disgrace that it is, and
look into the report for some solution. That was one. The second was
the enforcement work, the ADA enforcement work. We did that, and
they were aware we were doing it, but we didn’t do that so much as a
group. Then the third thing was getting people with disabilities more
voice in government. So we all collectively were looking for ways to
plug more disabled people wherever we could. But the biggie was—
buried in the report was an observation that the Labor Department
didn’t even know we existed. They don’t track us, except for this one
little report in the Bureau of Labor Statistics. But it’s an inadequate
report.
Bonney: You mean, they don’t track disabled employees.

Bristo: Or unemployed. They don’t have programs. The programs that they do do, they had just come out with the one-stop concept. The first concept of one-stop was for able-bodied people. I mean, they actually said it, in the first draft, that—and so we weren’t even intended to be part of it. So that led us all into a series of meetings on, what could we collectively do? And that resulted in two things. We decided to write an executive order, which is the one that’s up on the wall there—

Bonney: Oh, mm-hm.

Bristo: —for creating the Presidential Taskforce on the Employment of People with Disabilities. It had a three-year sunsetting provision. The purpose of the taskforce was to fan the flames, to really get the president behind declaring this a crisis and charging the government to look for ways to solve it. Now, we didn’t do all of it. But what we did get out of it was quite a few things. One, it gave the platform for the TWWIA legislation to go. I forgot this. As a follow-up to the summit, in this whole economic independence track, there were lots of comments about the work disincentives in Social Security. So one of our members helped us organize town meetings all over the country, to go more into that. We came up with recommendations to Congress on how to get rid of some of those disincentives. That was happening at the same time that the summit of the appointees was happening. The executive order created the taskforce. And through those two processes, Susan Daniels [deputy commissioner for disability and income, in the Social Security Administration] came forward, then, with the outline for the TWWIA legislation. I can remember her drawing it on a piece of paper in the room.

Unfortunately, there were major elements of her original concept that didn’t get included. I mean, for example, the original concept had buying into Medicare and Medicaid for people who went back to work. Automatic. Given. Entitlement. When it cleared through OMB, it came back that the states had the option to do it. So if the states wanted to do it, great. Then they could pick what their, you know, sort of what percentage of poverty—you know, who gets it and who doesn’t, and how much you can earn before you can’t get it anymore. So that was an unfortunate thing.

The report that we came up with at NCD called for even more radical changes than TWWIA did. So, you know, ultimately, I think there was a lot of really good stuff that came out of that, some of which made it into law. The other big thing was the Department of Labor’s Office on Disability Policy was established. That was a byproduct of this whole thing. So, to the extent that we have begun to focus attention on
employment—I think there has been some looking outside the box, thinking of it differently.

We also did things like—we called for radical changes to DR [Department of Rehabilitation]. That got squished like a bug. I mean, people don’t want to hear that. We thought—There’s, like, the blindness programs have their own stream. You know, they have sort of special standing in the Rehab Act. We called for the elimination of that. And we created quite a controversy there.

Bonney: I want you to talk about TWWIA. Can you explain what that is?

Bristo: The Ticket to Work—I forgot the name of it. Ticket to Work—Hm. Work Incentives Act, or—

[Audiofile 11B]

Bristo: Ticket to Work and Work Incentives Act or something like that. It was the legislation that came out in 1999 that does a few things, one of which, it creates competition for the--disabled people can have a ticket that they can take to any provider that they want to, or to an employer, anybody they want, to give them a chance to go to work. If they're successful, after a period of time, that entity gets paid. Therefore, it was an attempt to cut the monopoly that Voc Rehab had had, and allow disabled people more control, by essentially having sort of a voucher that they could use to go to whoever they wanted, to get assistance to become employed. It got all convoluted down the road, but that was the first part.

The second part was the healthcare. It was originally supposed to allow people with disabilities to have access to health insurance by paying into—you know, sort of sharing the expense by continuing the Medicare, Medicaid. The actual law ended up by, once again, making it a state option. But still, like in my state, we had it. So if somebody takes a ticket, gets a job, they are able to get health insurance by paying for their Medicare or Medicaid, rather than losing healthcare coverage because of pre-existing conditions.

Okay, now I would wrap up by saying—Okay, my tenure with NCD ended after Clinton finished his second term. I served until my successor was named, which was Lex Frieden. I served for about a year in the [George W.] Bush Administration. One thing I’ll say is, initially, I actually was having some—not high hopes, because, you know, I’m a Democrat, and I voted for Clinton. But the rhetoric that he [Bush] ran on had some positives to it. I will give credit where credit’s due. At first, they came out with more money and commitment to Olmstead implementation than we had seen under the Clinton
Administration. All that has been a flash in the pan, though. I think that subsequently they have cut back that money. A lot of what they’re doing now in this budget is of serious concern.

But what I’m bringing up right now is, when I was at NCD, we issued reports that were critical of the government. That’s the job of NCD, to both say what’s working well and what’s not working, and to try to get it to the president or to Congress, so that change can occur. We had invited President Bush to the release of our technology report. We had a report coming out talking about technology accessibility. Bush was president, and we had invited him to come. There was actually some chance he was maybe going to come. The people in the White House asked for a copy of our report. It became clear to us that they wanted to send it through OMB [Office of Management and Budget] clearance.

Now, NCD, we had readied ourselves for this, because we had expected that at some point in time, somebody would try to say, “You can’t issue these reports without OMB first running their analysis.” So they tried to tell us we could not issue that report. In fact, they told us we couldn’t issue the report. We sent back our legal analysis saying all the reasons why we felt we could issue the report, and we issued the report. It gives me great concern to see that that occurred. I feel very glad that we were there to be able to react the way we did. And you know, I’m hopeful that NCD, as it goes forward, continues to understand that their most important mandate is to bring the voice of people with disabilities into government, and to recognize that as such, it takes boldness, it takes being willing to tell people what’s wrong, what’s right, and what people with disabilities want to see different.

Sometimes I look back at my tenure and I think, Okay, when you--you know, what are the concrete laws and things? And there’s quite a few. None that equal the ADA, in my book. But I’ve always believed that the ADA was the easy part. Even though it was hard, it was one of those once-in-a-lifetime things. The harder part is for us to stay united. As you go into the more complex phase of, you know, deciding when things happen, who gets what—you know, how we stay united. Pat Wright used to say that it was easy for us to unite before the ADA, because we were all in the same shitty position. None of us had rights. So we were able to kind of unify over that.

Now, you know, as we look at—the courts have hacked away at the law, narrowed the definition of disability, narrowed its reach, narrowed its scope, narrowed who it applies to, under certain settings, found it unconstitutional, in certain components. Staying united becomes way more difficult, because—we can’t be afraid to take the bold steps that we need to take. But I think we also have to look for
ways to keep our dialogues open with each other, and look for ways to find reasonable compromises within the movement, so that we can be prepared to go back out and battle the bigger forces that are out there. You know, whether that is trying to come up with an amendment, or a series of amendments, to fix all the things that have—to right the ADA, which that whole series that NCD has done since we left, called *Righting the ADA*, they flowed out of—

When I was there, I was organizing us to try to start moving towards amending the law. By the time I left, it was clear to me that there still wasn’t enough consensus built to do it. I know subsequently, NCD did come out with a report saying that it needed to be done. And the fact that there wasn’t a loud chorus of voices behind it saying, “Yeah, right on, NCD,” it sort of came out they were kind of the only voice. To me, it’s something we need to figure out what to do with, because I felt, you know, when I was there, I was ready to issue that report, too, because I believed deeply we’ve got to fix it. If you have epilepsy now, and under most circumstances, not all, you’re no longer protected under the ADA, because the mitigating measure of taking your medicine takes away your seizures, and therefore, you’re not disabled anymore. That sucks.

**Bonney:** It’s ridiculous.

**Bristo:** When you know that you’re still being discriminated against because somebody thinks you might have seizures. You know? Yet by the same token, you can see that the people who think this is not the time to open the ADA up are equally right when, you know, we’re learning that the US Conference of Mayors right now is organizing to come behind an unfunded mandates act again to try to push back on laws like—I don’t know for sure that they’re including the ADA, but—it was a battle. That’s another accomplishment of NCD, by the way.

When the Unfunded Mandates Reform Act came out in 1995, after [Speaker of the House] Newt Gingrich came in and they were trying to say, “All these laws are unfunded mandates. And unless there’s money there, they can’t pass it.” We, NCD, started the effort to push back against that and have the civil rights laws amended. I mean, exempted. We were successful with that. Well, we’re now gearing up to come back at it again. You know, there are so many things like that, it’s hard for us to know where to turn our attention. There’s so many things to yet get done; and yet there’s so many things that the resistance has grown. The right wing reactionaries, who don’t support some of our goals, have gotten stronger. I think we need to be looking for ways to deal with some of the arguments head on because some of them, I think we can win. But you know, it’s a tall order.
The place where I get my hope—and then I think I’ll finish. You know, when we said early on, you know, the local and the national are all connected, another way—what was his name? [Speaker of the House Thomas P. J] Tip O’Neill used to say, “All politics are local.” You know? What really keeps my eye on the prize and keeps me optimistic is watching the growth of the international disability rights movement. Seeing the ideas take hold; seeing, in everybody’s own cultural way, the same ideas that we fought for here, being fought for all around the world.

You know, we talk about the concept of universal design in the US. What that flows from is a more important universal, and that’s the universality of a disability experience. It doesn’t know culture, it doesn’t know race, it doesn’t know religion, it doesn’t know ethnicity. It does, of course. I’m not saying that Latinos with disabilities don’t have a slightly different cultural spin on things. For sure, they do. But at the most fundamental level, you know, you can look at a person who either uses a wheelchair or wished they used a wheelchair, from a country where they don’t even have them, and they know what it feels like, like we know what it feels like to be laughed at, to be devalued, to be not even in the loop, to be so far on the margins that people don’t even know you’re there. While in some respects, we’re a little further in the circle than we used to be, we’re still so close to those margins that it’s easier for us to relate to and bond with people who haven’t even gotten in there.

When I see this movement growing internationally, and I remember my friend Ed, and think about—he’s got to have such a big smile on his face that never in his lifetime did he imagine, I think, that this thing would really explode the way it has. We have really started something; it’s like a revolution. It’ll take us awhile, but the more and more of us that ignite this, that’s why I come back to the “All politics are local.”

So, you know, look at this worldwide thing we started. And yet, if it’s the person sitting out in my waiting room here who still hasn’t caught it, you know, still hasn’t got it, then we’ve got a lot of work to do right here in our own backyard. Ultimately, it’s by building that political base, spreading the message of disability pride, culture, rights, shedding off the oppression and the systems that exclude us—You can only do it by getting in there. You know, getting in there. That’s where I feel the work is and the hope is, both, because there are huge numbers of people that we haven’t tapped yet. And when and if they get ignited, there’s just so many of us. We’ve got a lot more we can get done than what we can’t.

Bonney: All right, thank you, Marca. This has been wonderful.
Bristo: Well, I’m not sure if I covered everything.


[Audiofile 12A]

Bonney: We’re continuing the Marca Bristo interview. It is May 10th, 2005. Interview three, tape twelve.

Bristo: I think the last thing I want to talk about is the people of the movement. I don’t mean in specific, each person. But by now, whoever is archiving this has talked to a lot of people. I think that’s the real story of this whole movement, the people.

You know, I learned a long time ago, as a kid, that one person can really change things. I saw that again in all the people who were my pioneers and heroes. I saw it in Ed [Roberts], I saw it in Judy [Heumann], I saw it in Pat [Wright], I saw it in Evan [Kemp], I saw it in Justin [DART], I saw it in Max [Starkloff]. You know, I’ve seen it. And none of us think we can. Because the problems seem so big.

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You know, I’m looking, in my office here, at a photo of Jesse Jackson giving me a kiss. [chuckles] I mean, those messages from people like him, from Dr. King, of “I have a dream,” or Jesse Jackson, “You are somebody,” you know, they’re telling us the same thing, that change happens one person at a time; and that when you get a whole bunch of people who individually believe that, yes, they can make a difference, and who see beyond their own ego to work together—and sometimes that’s a hard thing, in any movement. You know, getting people to keep their eyes on the prize. But you really can make a huge difference.

Without being schmaltzy, I think that the disability rights movement is a story of the pieces of the quilt, with each piece being a different person who has given their heart and soul, their wisdom, their vision, their creativity, their skills. It’s pretty remarkable. You know? I remember when Justin died. He left that open letter to all of us, where he said he dies the luckiest person in the world, because he’s shared in the struggle with us.

Because of us, he died free. He really believed those things. I think each one of us pass that kind of belief on to the next generation, the next person. I know that this is a little bit rambling, but you’ve been sitting here, you and Mary Lou, interviewing me; I spent a whole lot of time just talking about me and what I did, and my view, and my perspective. It’s a little intimidating, because by the end of it, you’ve kind of pumped your ego up. You know what I’m saying?
Bonney: Yes.

Bristo: Truthfully, I think all of us have a need to feel appreciated and respected; but I think it’s when you can see beyond yourself to what the big calling is, and then you find a way to get outside of yourself, that you can really make a big difference. I don’t want to call it my final chapter; I’m too young for that, but—what I feel right now is, the important thing for some of us who’ve been around for a while is to be passing that on to other people. That requires us to step aside. It requires us to put other people out front. Help them, be there when they have questions, but back up a little. I think—that doesn’t mean we disappear. Doesn’t mean that we’re still not part of it. It just means that the way in which we do it is a little bit different.

I think that for all the people who—I don’t even know if they believed it, but the impact they had on my life was to realize that you get power by giving it away. You know, that each time Judy Heumann or Pat or somebody kind of pushed me on to something, or shared their power, they were giving some to me. Then there was more, because our circle of influence has grown. I think that that remains one of the big things that we have to do. I was really blessed to be able to look at the people who really shaped American policy, and think of them, first and foremost, as my friends. And gosh! Who gets that? Who gets that, you know?

I think truly, we are really, really lucky people to have been given that opportunity, and to continue being able to give to it. It’s something that I think makes me, even on the hard days, when you’re dealing with all the mundane aspects of running an organization, I still can see it happening around me. It’s what keeps me engaged, is being able to realize that what others have done for me, I can do for others. And then they get to do it with others. And ergo, we pass this on. To me, that’s what I wanted to end with. Thanks.

Bonney: Okay. Thank you.

[End of interview]
**Sharon Bonney**  
Research Interviewer/Editor  
Regional Oral History Office  
Disability Rights and Independent Living Movement Oral History Series

Sharon Bonney received a BS in Communication and Journalism from the University of Illinois and an MA in Public Affairs from the University of Iowa. After working as a reporter and freelance writer, she established the Services for Handicapped Students Office at Iowa before working in the Department of Rehabilitation as a client advocate in Tennessee.

In 1979, Ms. Bonney became director of the Physically Disabled Students' Program at UC Berkeley for nine years. She later was the assistant director for the World Institute on Disability. Since 1996, she has been an interviewer/editor for the Regional Oral History Office at UC Berkeley for the Disability Rights and Independent Living Movement Project.

Her professional activities include numerous publications on disability issues; founding member, president, treasurer, and conference chair of the Association on Handicapped Student Service Programs in Post Secondary Education (now known as AHEAD); participant in the White House Conference on Handicapped Individuals; and current member of the Society for Disability Studies.

Ms. Bonney has muscular dystrophy and is a wheelchair user.

**Mary Lou Breslin**  
Research Interviewer/Editor  
Regional Oral History Office  
Disability Movement History

Mary Lou Breslin has been a disability rights law and policy advocate for over twenty-five years. In 1979 she co-founded the Disability Rights Education and Defense Fund (DREDF), the preeminent national disability rights law and policy center, and has served variously as DREDF’s deputy and executive director, and president and chair of the board of directors. She is presently a senior policy advisor with DREDF directing the organization’s research, and international law and policy initiatives.

During her career she has served as a policy consultant, trainer and lecturer on diverse disability and related civil rights topics. Ms. Breslin has taught graduate courses at the University of San Francisco, McLaren School of Business, and an undergraduate research seminar at the University of California at Berkeley. She also serves as interviewer and researcher with the Disability Rights and Independent Living Project of the Regional Oral History Office of the Bancroft Library, UC Berkeley. In 2000, she directed *From Principles to Practice*, the first-of-its-kind international disability rights law and policy symposium attended by attorneys and policy advocates from fifty-eight countries.
In 2002 Ms. Breslin received the prestigious Henry B. Betts award for improving the lives of people with disabilities. She also received the Paul A. Hearne Award from the Physical and Mental Disability Rights Committee of the American Bar Association in 2000, and a Mary E. Switzer Merit Fellowship in 1995. Ms. Breslin had polio as a teenager and uses a wheelchair.