Regional Oral History Office
The Bancroft Library
University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Project

William Bronston

Physician-Advocate for People with Cognitive and Developmental Disabilities: Exposing Conditions at Willowbrook State School in New York, Medical Director and Consultant for the State of California

Interviews conducted by
Kathy Cowan,
in 2001-2002

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William Bronston circa 1995

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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. Many in this group, like the Berkeley interviewees, were among those 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.

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.

A series list of project interviews follows the transcripts in each printed volume. The project Web site (http://bancroft.berkeley.edu/collections/drilm/) offers the researcher four points of access to the collection: by geographic location, by organizational affiliation, by research themes addressed, and by name of interviewees. There is no claim to completeness in the collection; further interviews are planned pending additional funding for the project.

Interview Themes and Topics

An overarching research goal for both phases 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 (who also took on myriad project management responsibilities); and Denise Sherer Jacobson, writer and educator on disability issues *(The Question of David*, *A Disabled Mother's Journey through Adoption, Family, and Life*, 1999). David Landes, former coordinator of student affairs for the Computer Technologies Program in Berkeley, took a less active role in Phase II when he was appointed to a full-time faculty position in economics. Susan O'Hara, former director of the Disabled Students' Program at UC Berkeley and the initiator of the original idea for this project, again served as consulting historian, occasional interviewer, and convenor of monthly project meetings.

Conducting interviews in Massachusetts and Washington DC was Fred Pelka, 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, moved from project interviewee to interviewer, conducting one New York oral history and then organizing and moderating a videotaped group discussion with four New York advocates. The Regional Oral History Office production staff, coordinated by Megan Andres, transcribed interviews and carried out other production tasks.

Bancroft Library project personnel in the Technical Services unit collected, arranged, and catalogued personal papers and organizational records and prepared detailed finding aids. They included Jane Rosario, supervising archivist, and project archivists Susan Storch and Lori Hines, all under the supervision of David DeLorenzo, head of Bancroft Technical Services. The staff of the Berkeley Library's Digital Publishing Group, headed by Lynne Grigsby-Standfill, prepared the oral histories and other texts, photographs, and finding aids for digital archiving in the Online Archive of California. Brooke Dykman designed the Disability Rights and Independent Living Movement Web site. Theresa Salazar as curator of the Bancroft Collection, provided curatorial oversight for 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 a indication of personal values and cultural meanings.

The DRILM project team, primarily based in Berkeley, all contributed to the original design of the project and assisted in developing interview protocols. Bay Area interviewers were joined by Fred Pelka from Massachusetts for a two-day orientation session in December 2000 and by telephone during regular monthly meetings, held to plan and evaluate interviews and review progress. Interviewers assigned to document the movement in a particular location conducted research to choose potential interviewees and interview topics. 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. The final stage added subject headings, a table of contents, and an index (for the print versions). Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs. Interviewees were offered the opportunity to seal sensitive portions of their transcripts, or omit them from the Internet versions.

There are nearly one hundred oral histories in the Disability Rights and Independent Living Movement series. Nearly all of them are available via the Internet in the Online Archive of California (http://www.oac.cdlib.org/texts/); they also can be accessed through the project Web site at http://bancroft.berkeley.edu/collections/drilm/. Print volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to other libraries and to organizations and individuals for cost of printing and binding. Many of the oral histories are supplemented by a videotaped interview session. Video and audiotapes are available at the Bancroft Library.

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. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at http://bancroft.berkeley.edu/ROHO/.

The Bancroft Library's Disability Rights and Independent Living Movement Project, of which these oral histories are a part, 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. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agency.

Special 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.

Ann Lage, Project Director
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The Bancroft Library
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April 2004

INTERVIEW HISTORY—William Bronston

Dr. William Bronston was invited to participate in the Disability Rights and Independent Living Movement oral history project because of his extensive activities as an advocate for the rights of people with developmental disabilities, his twenty years as a medical professional in the field of developmental services, and his role in the California Departments of Health, Rehabilitation, Education and the Developmental Services Program.

Dr. Bronston recalls his years of activism, beginning in his college years when he organized fellow medical students to promote the concept of a nonprofit health care system. He graduated from the medical school at the University of Southern California and moved to a residency in psychiatry at the Menninger School and the Topeka State Hospital in Kansas. He describes his efforts to unionize medical workers there. In New York, working at a neighborhood mental health clinic, he again mobilized drives to change medical health care. In 1970 he became a clinical physician at the Willowbrook State School on Staten Island in New York City, where he encountered a place of "towering misery and human humiliation, and violence." Bronston became a principal figure in exposing the shocking conditions at the institution, an action that resulted in the closing of the school and marked a major advance in the campaign for the normalization of community services and deinstitutionalization.

In 1975 Bronston returned to California where he has worked with the state's departments of Health and Developmental Services. In 1981, he launched Project Interdependence, a project to promote the integration of youth with and without disabilities. Bronston recalls the fight when, in 1995, disability rights advocate Sandra Jensen was denied a heart/lung transplant entirely on the basis of her disability. Dr. Bronston coordinated the campaign to successfully protest the decision. In his interview Dr. Bronston offers many insights on the concept and progress of disability and human rights issues.

The interviews were conducted in five sessions, beginning in October 2001 and ending in February 2002, at Dr. Bronston's home in Carmichael, California. The interviews were frequently interrupted by phone calls regarding the many projects he is involved in. Dr. Bronston has an excellent memory and spoke extensively with telling details about the events of his life and career. In addition, Dr. Bronston has donated his large and remarkable collection of papers, photographs, posters, news articles, manuscripts, daily logs, newsletters and other materials to the Bancroft Library. The transcript was edited by the interviewer and returned to Dr. Bronston, who made extensive changes to the transcript, to clarify the recorded interview and provide more information.

Dr. Bronston spoke with great passion in his oral history, conveying the maelstrom of activity and emotion-filled events, particularly in relation to Willowbrook, in which he was a key figure. During his review of the transcript, he suggested that we rearrange the order of a few passages to more accurately reflect the actual chronology of events, but we chose to keep the transcript closer to an actual record of the oral interviews, which convey so well the spirit of his extraordinary achievements. The researcher will be able to confirm dates and exact sequence of events in Mr. Bronston's written records and published accounts. Tapes of the oral history interviews are available for listening in the Bancroft Library.

Kathy Cowan
Interviewer/Editor
Castro Valley, California
March 2003

INTERVIEW WITH WILLIAM BRONSTON

I. FAMILY BACKGROUND; UNDERGRADUATE AND MEDICAL SCHOOL YEARS, UCLA AND USC, 1957-1965

Roots in Jewish-Russian culture

[Interview 1: October 12, 2001] [Tape 1, Side A]

Cowan: This is Kathy Cowan interviewing Dr. Bill Bronston. We are in his home, in Carmichael, which is near Sacramento, California. It is October 12, 2001. Bill, could we get started with some questions about your early childhood? Where were you born, and where were you living?

Bronston: Well, I was raised in Beverly Hills, interestingly enough. My father [Samuel Bronston] was a movie producer aspirant, so we lived in Beverly Hills, naturally. That was where the image of the industry was. I was raised in three or four or five consecutive homes in the Beverly Hills area as my father's career moved forward. We had a very traditional kind of a home life, with a boy and a girl child, and a father and a mother. What was, I guess, different, was that we always had live-in workers. We always had a chauffeur, and a maid and a cook and a nurse. So I was raised in significant part by salaried staff who I adored, and identified with. They were my solace and my nurture and my playmates, because there weren't any kids around where we lived. Because we lived in houses that were either too big or too isolated, or we weren't really part of the neighborhood scene.

My father was never a normal neighborhood guy. My mother was never a normal neighborhood mom. So she serviced my father, as his chauffeur, because he couldn't drive. We lived in these amazing places. My first house, I don't remember, of course. The second house, there are photographs. So I live in my babyhood through all the picture albums that the family has. We finally wound up with a wonderful house where I had a pair of ducks and a raft of chickens in the back yard, and hutches that we collected eggs from. And a big polliwog pond and it was fabulous. A dog and a cat, and there were always critters around in my life, as part of my companionship.

Cowan: That sounds wonderful. Were you born there?

Bronston: I was born in Los Angeles, right.

Cowan: What about your parents' background?

Bronston: My parents were both Russians. My father was raised in Bessarabia for a little while. His father was what one would call a rich peasant. He actually was an ice cream man; his wife was a dessert baker. My grandmother's name was Elizabeth, and my grandfather's name was Abraham. They were real Jews in old Russia, in Bessarabia.

My mother was raised in the Ukraine, in Kiev. Her father was also a kind of upwardly mobile guy. He was a real dandy of a guy who I just adored. He was my favorite member of the family. He really loved me and was tremendous fun and very physical and had a great sense of humor.

Cowan: What was his name?

Bronston: Boris. Boris Bogatchek. And my grandmother on my mother's side was named Rebecca Bogatchek. And Rebecca was a kind of roly-poly typical traditional kind of grandmother in those days. An inelegant woman who was absolutely the love of my life. She came from a very famous family of sisters who were connected to the Ratoff family. Gregory Ratoff, the actor. So they had an enormous history in Russia. But my parents met, I think in France, in Paris, where my mother's father, Boris, was a banker. He owned a couple of movie theaters. My mother was this absolute savant; she was a concert pianist and had her own radio show by the time she was fifteen years old in Paris. She was an only child.

My grandfather, Boris, was a real ladies' man and left my grandmother at home. There were some really unhappy stories about the oppression that my grandmother experienced and humiliation because of my grandfather's disinterest in her. He carried my mother around with him everywhere, out in the community, in order to show off her really prodigious piano-playing abilities.

My dad, on the other hand, grew up, in a whole different kind of unstable way. Leon Trotsky was my great uncle. Trotsky was my grandfather Abraham's brother. Trotsky's name was Leon Lev Davidovich Bronstein. That was my family name, Bronstein. My grandfather, Abraham, really was not into the Bolshevik experience at all, and wanted to get his kids out of its grip. Trotsky wanted to take the kids and put them into an academy in order to train them. What a great opportunity for my grandfather to turn down, at that time. But who knows what the real circumstances were and how controversial and threatening that whole tumult must have been for all the people who lived through it. So my grandfather insinuated the kids out of the country and moved them one by one into France. There was another uncle in Paris who I never met. I think his name was Misha, I'm not sure. There were five boys, my father being the third, and four girls. They came out, one at a time, from Bessarabia, into France.

Cowan: In what year?

Bronston: Oh man, this must have been 1918-1925, something in that area. I was born in 1939. My father had already come here to the US, in 1937, to the United States. He was sent out as a very young kid. His oldest brother, Eli, came to Paris first and became a physician. His second brother, Dick, also became a physician. My father, Sam, came next. He was a very different guy from the other two boys. The fourth boy, Jacques, turned out to be a concert pianist. The fifth boy, Alex, was involved as a business man in buying and selling material, fabric.

Cowan: Still in Europe?

Bronston: In France, yes. So anyway, the boys grew up with maybe one or two pair of pants between the five of them. They could only be out on the street in shifts. They had to earn money by playing music. They were all musicians. They were all trained to be musicians as children in nickelodeons, very early on. Which was very interesting. Somehow my dad got involved with the movie industry as a representative for one of the major US companies. And while his two brothers went to medical school, my dad never did, nor did the fourth or the fifth boys. After the five brothers, the four girls emigrated from Russia. The whole family was assembled in Paris. This was, of course, before the Second World War.

Cowan: The parents too?

Bronston: Yes, the parents finally came out, and they continued to live in Paris, in their home, until they died. They were there forty or fifty years afterward. My father was really unstable, vocationally, and was a different kind of a dreamer. I have a feeling he was somehow—not threatened, but worried about the way life was going to work for himself. He really needed to project himself as an omnipotent kind of presence. He really convinced himself early on of his destiny, of his interest in making movies. He was one of the world's better hustlers. He was an extraordinarily persuasive and charming and extremely handsome man. He was diminutive, but gorgeous. Black, wavy hair, big blue eyes. He could just talk a bird out of a tree. He talked my mother into his life, and talked her father, Boris, out of his fortune. He wound up after a number of incredible struggles and problems, having to leave France, travel to England, and then come to the United States, 1937.

Cowan: With your mother?

Bronston: Right, from New York, he came to Los Angeles within a year of arriving in the United States and had already set his course to be a film actor. He had made friends with Charmaine London, Jack London's wife, in France, and had developed a fantastic relationship with her which he could have developed with the snap of a finger, because he was just incredible that way. And he got her to commit her support to give him the rights to make movies of Jack London's works and life. When he got here, he began working on that agenda. The first movies that he made in 1940 and 1941 and 1942 were movies surrounding Jack London, his life story, a movie called *A City Without Men* which was closely linked to the Jack London story book group. Black and white movies were really very fine, culminating in two movies where he finally lost control and lost his grip on that particular period of his life in the business. A movie called *A Walk in the Sun* which was one of the most compelling and first adult war talk movies with John Ireland and Sterling Holloway. It had an amazing cast, amazing cast of young men. And then finally the movie *And Then There Were None*, Agatha Christie's story, with Barry Fitzgerald and Louis Hayward and Linda Darnell. It was an amazing career.

Cowan: About what year?

Bronston: 1940, 1941, 1942.

European Hollywood home filled with art and music

Cowan: So you were already born and living in Los Angeles when your father got his career launched?

Bronston: Right. I was born in March of 1939 and I was raised in a Hollywood home.

Cowan: Any siblings?

Bronston: Yes, I had one sister, Irene, who is six years younger than I am. She was born in 1945. We were living in the Hollywood Hills, above the Sunset Strip, at that time. We lived there all the way through my elementary school years. Irene now is working for the Office of the President of the University of California. She has a masters degree in public health, and two sons. There's four more of us that are half-sibs and step-sibs, as a result of my father's remarriage--Andrea, Phillip, Kim and Michael.

Cowan: I don't think you've mentioned your mother's name.

Bronston: My mother was known as Dony. Her full name was Sara Bogatchek Bronston, but she called herself "Dony." She was an incredible pianist.

Cowan: Did she ever play here?

Bronston: She never concertized here. But my mother lived among a number of girlfriends that were around us, families that were all Russians. They lived in West LA. There were maybe fifty or sixty families that socialized together. They were all upper middle class, some of them extremely wealthy, living in Westwood and the beach areas. We lived more in Hollywood because of my dad's career. My mother hung with these women, with these families, till her death. There were relatively few American families in the mix. All of her girlfriends had kids, so I had a peer group of fifteen or eighteen kids that I was associated with, not necessarily close with, but saw regularly, growing up. There were constant dinner parties and gatherings and card games and every conceivable kind of social and cultural activity which was really very powerful for me. Because I grew up really thinking that when you went to somebody's house, there were great mountains of food laid on the table, musical instruments always came out, people recited poetry, sang opera, lived in houses covered in Persian rugs and stuffed furniture and art and flowers and servants. I didn't know any better until I got to junior high school when I had this rude awakening that that's not how America normally is. The world isn't music and art and expression and energy and passion and loud voices and tradition.

Cowan: Did your grandparents come to this country?

Bronston: Yes. Well, not my father's parents. My father's parents stayed in France, and I didn't meet them until I was eighteen.

My mother's parents were already here when I was born, and I grew up with them intimately involved in my life. They lived in Ocean Park, at the beach. They lived a block away from the water. So, we would go every weekend in the summertime and sometimes live as much as a month in the summer in a cottage right on the water, in Ocean Park, by the pier. And that was my boyhood, my childhood, it was totally wrapped up in swimming and surfing and volleyball playing and really a happy, albeit lonely, childhood.

Cowan: Was your father around much?

Bronston: No. He was never around. He was always off on business and when he was home he was on the telephone. He had a phone plug in the dining room and he had his phone on the beautiful mahogany dining room table so that when calls came in at dinner time, he would take the call. Or he would walk out. I never really had any kind of substantial relationship with him, ever, my entire life. He was always remote. He was always absorbed in his own odyssey, in his own dreams. Though, I really adored him, and was really amazed at his beauty and his grace, he was a rotten dad. He provided money instead of time, and kind of carte blanche support instead of teaching. And that was very painful. It's more painful now, when I look back and see that we never played a game together; he never took me anywhere. He never intentionally taught me anything. I don't have quotes of what my dad told me. I mean, obviously, he talked to me, and he loved me. He loved me hugely, but he didn't know how to be a dad.

Cowan: You mentioned earlier the caretakers in your family and how attached you were to them. Do you recall that any were particular role models for you. Were you aware of the financial differences between them and you?

Bronston: No, that was totally never an issue. I had a nurse, Daisy, that was a Caucasian woman who just took care of me, and who was just a part of the blob of my well-being. I remember her vividly, but this was before I woke up to words and to concepts. There were always black people working in the house, and they raised me. There were two major couples that lived in my home; one was the chauffeur, one was the maid, and they raised me. I hung out with them. There was nothing for me to hang out with of my family, you know. They were off to the office or my mother was practicing piano for five hours a day. So I'd lay under the piano when she was playing for hours on end, and just daydream. There was no television in those days, so there was radio, my mother's piano, my dog. I didn't read. I may have, but I don't remember reading as being a critical piece of this thing. It was much more action oriented and sensory oriented.

We also had a cook, an incredible Japanese woman named Kiko Hayishida, and another wonderful woman whose name was Rachel who was an African American woman. They just took me to their heart. The cook, Rachel, who worked for us for many years, was really a handsome woman. She had a big gold tooth in the front. She was a gorgeous dame, that I remember, and I just adored her. She would take me downtown with her to her church. So I was the little white kid, little four-year-old, five-year-old, six-year-old kid that was with her. And she was like, she was my blood, we were one person, I was one person with all these people. I loved them; they were joyous and physical, and clear. There was an incredible sensuousness; I mean, they were the source of food and the source of affection, and the source of playtime for me. And my major teachers. I learned to eat ketchup on everything from that world, which I treasure. I treasure that taste because I know right where it came from.

Cowan: When did the real world start to appear to you? Was it junior high? Was this all through grammar school, but you got more aware of the world around you after eighth grade or junior high?

Bronston: No, I would say that I didn't really become aware of the world around me until I was in the middle of my college years. I just kind of lived on automatic.

Those early years, I sang. I had a lot of music in me, I mean, my whole family had a lot of music in them. And so I spent a tremendous amount of time singing, and being happy about singing. My mother picked up on that because the one thing she really really loved about me was my voice. I had a very high soprano voice and it lasted, literally until college. I had a huge range of singing capability. I could operate with the highest sopranos, girls, and then had kind of a lower voice as well. I wound up spending all my time in junior high school and high school in choir. I never learned to read music, but I could sight-read rapidly, and I had a great voice. I could hear pitch, really well.

Cowan: Where did you go to elementary and junior high school?

Bronston: Well, my elementary school was right by my house in the Hollywood Hills, it was a public school. It was at West Hollywood Elementary School. It was really interesting, I remember all of my teachers very vividly. I was in a small class. I was a mid-termer and there was about thirteen or fourteen kids in my class all the way through school. Then I went to Bancroft Junior High School in Hollywood, and then Hollywood High School after that, and then UCLA [University of California, Los Angeles] after that for five years. And then medical school at USC [University of Southern California].

Cowan: What kind of student were you?

Bronston: Oh, maybe a little bit above average. I was never very locked into school very hard. I was always kind of a dreamer, always an outsider. I never really felt like I belonged. I was pretty sick when I was a kid. I had a bad case of mumps and somehow or another, it rolled into a bad case of Glomerulo Nephritis and I wound up in bed for a semester with an itinerant teacher. I was "a vulnerable child." My mother really thought I was going to die. I didn't know, I was just whoever I was, but she really made me very fragile, made me feel very fragile, very uncompetitive. So when I got back into school, I was on "special gym." So I never really competed with or was involved in any athletics or sports, because I didn't lock in when I should have locked in. Then I became kind of fearful. I just didn't like it. It was very aversive for me to be in a more combative, more physical, kind of a male, competitive environment. I didn't like competitive sports at all. So I was always in the special gym program and always got excuse notes from home, and even when I didn't need it any longer, I continued to get notes to be in special gym just to have that waiver. It resulted in my being very isolated, and very much not part of the American scene on a day-to-day basis, culturally, and emotionally, and language-wise. My parents spoke French and Russian constantly in the house, which was not my language to speak, it was their language. But then to add to that the physical and school marginalization, was a whole other way of taking me out of the mainstream.

Cowan: And did you feel that then, or is it more in looking back?

Bronston: Oh no, I was really self-conscious. And I was a year or a year-and-a-half younger than all the kids in my class because as a mid-termer, I started half a year early. Then at a certain point when I was thirteen, and my parents were struggling about getting divorced, I wound up going to New York for a year. And the New York grade system is just upside down, their B is the high grade and A is the low grade. I went in grade seven B, anyway. I came back to California, and because I was in the B or the A, they jumped me ahead another six months here. So I was a year younger than everybody. I wasn't sixteen until my last three months of high school. I couldn't drive. In order to go on a date, my mother had to drive me, which was absolutely a humiliation for me.

University of California, Los Angeles, 1957-1961, influence of high-energy character-filled family

Cowan: Well, you were sixteen and finishing up high school. Was college your idea or just automatic?

Bronston: Automatic.

Cowan: Graduating from Hollywood High and going to UCLA?

Bronston: Yes, automatically. I didn't even think to apply to UCLA. I thought that you just went from A to B, and school to school, and I thought you just went from Hollywood High straight to UCLA as soon as school starts. You just go back in and enter classes. There was a major hassle, because I guess my mother did apply for me. UCLA cashed her check and then didn't accept me into the school for some reason or another. My mother went to war with the dean's office, and because they cashed the check, she was able to get me admitted into the college. So I began college amidst this hullabaloo. She really got me in. [Tape stops for phone call.]

[Tape 1, Side B]

Cowan: Was your mother involved in your career?

Bronston: No, no. My mother was one of the highest energy people imaginable, which I just took for granted. I just operated along side her and didn't realize, almost till the year that she died, what an atomic level of energy she had normally. I mean, she was a from-the-hip thinker, and a from-the-hip talker. And was just as energetic, as indefatigable as a human being can possibly be.

Cowan: Do you have an example of something that—

Bronston: Well, she just practiced piano, three to four hours daily. She was just a storm all the time. She was a card player. She was always doing something. She moved fast. And I just took her for granted. I didn't realize, not until real late, like in my forties, what a role model it was that I was coping with and being raised by. People talk to me about, where do you get all this energy from? I can't tell you, it happens to me all the time. I mean, everybody says to me, in every conversation, "Where do you get all this energy from?" I don't get it from anywhere, it's in me. I was raised at this level of energy, attention, and stamina. My father and mother were high-wired people. They were high-wired. They were dynamos. That was just my normal context. But I really do think I was wired in with more juice than I should have been. My life is not the norm.

Cowan: Was your mother political at all?

Bronston: No, neither of my parents were political. My mother was hugely judgmental, very sentimental, and a kind of reactionary woman. She and I had stormy battles. Not substantive battles, because, you know, a prizefighter doesn't hit an amateur. By the time I got political and I began to see how ordinary her views were, and how often racist they were, despite the fact that we were surrounded by people of color, in our lives, all our lives, they were "the servants." Though my mother was not an aristocrat, she was an elite upper class European woman. She had enormously deep relationships with people of color all the time, her students, and people she worked with. But on the street, she was really frightened of black men walking on the street, and had a very real contempt, at some level, of certain kinds of behaviors in certain kinds of people. And a fear. And a growing isolation. As a person gets older, they lose the fluidity of association and contact and so forth. She never really did understand what I stood for, why I risked what I risked, why I had the positions I had.

Cowan: You had no examples of political activism in your family?

Bronston: Zero. On the contrary. My father was a monarchist. My dad defined himself as a Democrat, but he was a chameleon. Whoever was in power, that was who my dad lauded. So when Reagan was in power, you know "Ronnie" was his friend, and worked for him, and there was that whole thing. Even my dad's Jewishness was a source of continuous pain for him and so he distanced himself from being Jewish, from my childhood. He never came to synagogue with my grandparents and my mother and me.

Then he had this incredible relationship with [Pope] John the XXIII, and the papacy directly, as a result of the work he did in Italy and in the Vatican during one of the periods of his productive life when he was doing this gigantic documentary piece of work of the entire Vatican treasure. It was one of the earliest narrative formulations of the entire Vatican. So he began seeing himself as a Catholic. He was constantly crossing himself. He began the myth that his mother, Elizabeth, was a Catholic. And I didn't believe him, but it didn't matter to me because it was just part of his take, as he got older.

This was a very interesting phenomenon. Because my family is extremely turbulent and character-filled. Not necessarily in the best way, but they're characters. They're very definite people, very articulate, very forceful, very combative, Russian-Jewish, intellectuals. They're all doctors and musicians and they battle against each other and they came out of a battling world. They came out of the Nazi occupation of France, in which they were at risk, as Jews. My father got out of there before the shoe really fell, and he was somewhat cognizant of what was going on. Most of my family were trapped there and they had to partly live underground.

My eldest aunt, Dora, who is the sixth child of the nine, was held by the Nazis in a hospital and had this terrible infection of the bone of her forehead, which she kept picking at to keep infected, because she knew that if this thing ever healed, she'd be carted off to the concentration camp. So for a couple of years of the war, she maintained. I don't know why the Germans would make that kind of dispensation or consideration. You would think if they were going to kill her, they would just knock her off. She somehow saved herself that way. Two of the girls, two of my aunts, Frieda and Joan were married to Spaniards who were part of the underground, who came out of the Spanish civil war, and were liquidated in that whole world. In that time, my youngest uncle carried a gun and was part of the underground and was constantly working to save whoever, and to deal with the Nazi situation, occupation of the Vichy government in Southern France.

Cowan: Did you know these stories as a young man?

Bronston: No! Totally oblivious! I lived in the comfort culture of America in my Beverly Hills home, in my Hollywood Hills home, with my dog and the people that raised me and my father with his chauffeur-driven cars and his movie industry. I didn't know if he was successful or unsuccessful. All I knew was that my household was a war zone between my mother and my father. They were constantly battling, because my father never had the money to pay the druggist, or the market, or anybody for that matter. He lived in debt constantly. My mother had to face the bill collectors. She had to answer the door and answer the phone. My mother was very concrete. She was the antithesis of my father. They were ill-matched. Ill, ill, ill-matched couple. My mother was meat and potatoes, right now, pragmatic, very practical woman, and my father was just out in space. He lived in the dreams of grandeur and fame and being a major movie producer. My father was like one of the original movie moguls. My father was a movie mogul, heart and soul, even though he didn't succeed, in longevity, the way the big boys did, he was one of them. Ten years later, he was one of them. He was there shortly after the industry had just been established, and he was a Russian Jew, and he had all of the characteristics, all of the features, all of the grit, all of the imagination, all of the chutzpah. He had it all. He was a gorgeous, gorgeous, compelling, powerful man. The problem was that he had this huge personality flaw. He had this huge, ego-maniacal, hypo-maniacal kind of consciousness. So he could not make good judgments about people. He lived in a world of wish and a world of possibilities, not in a world where he could assess people's reality. He could get anybody to do anything, but they could get him to give up anything. So he never was able to generate any holdings for himself. He'd give money away. He wasn't interested in money. What he was interested in was the power and the capacity to spend money. But he never saved a dollar.

Cowan: Were you becoming more aware of what the world was about during the first year at UCLA?

Bronston: I was a pre-med major. I was still asleep. I was still going to the beach to surf and play volleyball, and spending time with my grandparents, and singing. I sang professionally, almost all the way through college. I had a musical group that developed once I hit UCLA. I found a partner, Warren Garfield, who was a guitarist and we sang folk music.

Cowan: Professionally? Where did you sing?

Bronston: In all the coffee shops on Sunset Strip and Santa Monica and Beverly Boulevard. The old coffee-house circuit.

Cowan: What year was this?

Bronston: This was 1957, 1958, 1959. Artists like Theo Bikel, Harry Belafonte, Odetta, Bud and Trav, Leon Bibb, The Weavers were all our role models. They were the big-timers and we were just kids growing up in the genre. Like kids sing now in the genre of the current movie scene. We were on stage and we got paid, and I had a bass player, I had a guitarist or two, and a percussionist, and I sang. So we just did shows at night and I went to college in the days.

Cowan: So your life then was probably more about the shows, probably, than about school.

Bronston: It was always around music, and it was always around performance, and it was all having fun and discovering a social life and women. Very apolitical.

European trip changes life-direction

Cowan: Was there a precipitating event at UCLA that suddenly changed your direction?

Bronston: In college, what happened was that I wound up going to Europe in 1960, at the end of my sophomore year with one of my friends, Danny Stewart. He became a very significant lawyer in LA and is retired now. My dad had begun making *John Paul Jones* at the time, and this was the first movie he made in Spain. We spent two-and-a-half months in Madrid and the south coast of Spain and in Europe. I was a pre-med major when I went there and kind of brittle and unhappy about that.

Cowan: Did you choose pre-med because your uncles were doctors?

Bronston: No, I just wanted to be a doctor. I wanted to be a healer since I could walk. I've always wanted to be a healer. I started wanting to be a veterinarian, and then that translated into people medicine early on. But I lost my way in college because by that time, I understood that being a doctor meant being a "plumber" and being a "business man," and I wanted to be neither of those two things. I was into romance. I wanted to care for people, with all the poetry that was in my heart.

Cowan: What made you aware that it meant being a plumber and a business man?

Bronston: Well, I could see it. I understood early on the venal politics of the AMA [American Medical Association], and all the harsh realities of making money and tinkering with people with no vision, no tenderness, no ideals, no dreams connected with doing medicine.

Cowan: That's amazing that that came to you so early on.

Bronston: Well, I'm not exactly sure what it was, but I was clearly aware of that. So that my trip to Europe that summer—

Cowan: You brought that awareness with you on your trip to Europe?

Bronston: Yes, and I wound up, for the first time, meeting people that were so interesting, so unusual. I was involved in a night life in Madrid, as a strange kid, as an American eighteen-year-old kid. I met my father's side of the family for the very first time, in Paris, which was one of the most moving experiences of my life. I was so moved that I had this whole mature, fabulous family that was my blood-uncles, aunts, first cousins that I had never met before!

I was really like an only child because my sister left my home and went to live with my father when she was five. When my parents got divorced, my mother had to go to work, for the first time in her life. So she just carted my sister off to my dad in New York, where my dad had gotten remarried. My father's wife new, Dorothea, raised my sister there in White Plains, New York. I stayed with my mother in LA and by that time I was already about getting into high school.

Cowan: Do you remember how old you were when they divorced?

Bronston: I was thirteen. So this was 1952 to 1953, in there.

Cowan: I didn't realize that about your mother having to go to work. Did that affect you?

Bronston: Terrifically. The next thing I knew, there was a divorce, my dad was with this other woman, and I ended up living with my mother in Hollywood, in a small bungalow house. My mother was at work, and I was moving from junior high school to high school and my sister was exiled.

Cowan: Were you still having significant relationships with your grandparents in Santa Monica?

Bronston: Yes, that was always the constant.

Cowan: To resume. You were talking about your mother, your move back to LA, and your mother was divorced and working.

Bronston: Well, what happened was that after she finally got her feet under her, she finally came to grips with who she was and who she had always been, which was this marvelous musician and pianist. She had really devoted in a very begrudging and bitter way to my father's career and to raising the two of us, my sister and I, which she always complained about. It was always a bone of contention that she had to give up her piano to have kids that were unplanned. So she began teaching piano. She developed that capacity until she died. She was really a great piano player.

My mother was an extremely rare pianist in the sense that she was a child of a stream of passage of direct knowledge from the original nineteenth century romantic composers through a set of selected students in the world that happened to connect in a chain to each generation. If you're in music, especially in Europe, in those days, there was a school that came straight from Bach, and school that came straight from Beethoven, a school that came straight from Chopin, from Liszt. My mother was one of the chosen students because of her enormous talent as a child, to be trained by this group of teachers in the early part of the twentieth century that had a direct linkage back to the composers, and knew things that ordinary teachers don't know because secrets were passed on about innuendo, about nuance, about the substance of performance.

My mother had that kind of musical origin. She knew things about how romantic music was supposed to be played; that was unique. She found half a dozen kids in the period of her whole remaining life as a piano teacher, thirty years, forty years, to pass that knowledge and those skills onto. And when she died, there was this incredibly moving memorial service in her living room, at her home, for about forty or fifty people, and her major students who came, in order to commemorate her passing. My sister and I put that together and half a dozen of her students played pieces at the memorial, and it just knocked the roof off. I was moved to tears at the recognition of what it was she possessed and passed through.

They had her touch. It was like, I could close my eyes and hear her practicing when I was five. Hear the power, and the confidence, and the musicality, just the richness of tone, and the incredible passion that came straight from the source. It's a strange thing to be aware of. There's a tradition in passing the message of music on, across decades and centuries that is amazing. It gave me a whole new view of her, a whole new understanding of the mission that she had been, architected, to carry out in her life. It wasn't to raise me, or my sister, or be somebody's wife. She was a carrier of this classical musical tradition.

Cowan: Did she support the family?

Bronston: Yes. My dad would send money from time to time, to me. I moved out of the house at eighteen years old. I had my first car at UCLA, and moved into Westwood, closer to college, to go to school and to have my own digs and live with roommates.

Cowan: How old were you when she died?

Bronston: She died eight years ago. So I was fifty-five, fifty-six.

Pre-med program At UCLA

Cowan: Let's return then to UCLA. You had your first year there as a freshman, and to the sophomore summer, you were a pre-med major.

Bronston: I was a pre-med major. That was my agenda, and I kind of stayed in that area of science and wound up beginning to take some art courses, some art history courses. Then I spent this amazing working and travel summer in Europe, around my dad's movie *John Paul Jones*. We were living in the south of Spain, in a little coastal town called Benidorm and nearby Alicante, a larger city. Both were fishing towns. My dad had floated three galleons, three sail boats, John Paul Jones boats, the *BonHomme Richard* and a couple of others, from Italy, in order to shoot this film in the Mediterranean. It was the location for the shooting of this film. Stars like Bob Stack and Charles Coburn, MacDonald Corey, Bette Davis and Marissa Pavon were in the movie. It was just magical, even though it was an awful movie. It was filled with pomp and splendor and was amazing. It was his first production in Spain, when he kind of set his roots down. I spent a month in the south of Spain going out on these tall-mast sailing boats every day as a still photographer for the company. Then my friend and I left and traveled. We went to Paris to meet my family for the first time, and Sweden and Denmark and England. It was really quite wonderful.

Cowan: What was going on politically in Europe and Spain while you were there?

Bronston: Nothing, nothing that I was aware of. I was totally oblivious. What I became sensitized to was something of human thought, something of philosophy, of values, of conviction, of being. The trip really woke me up so sharply to my own feelings and to my own interests. We would spend hours in the nightclubs, listening to Flamenco music. It was a totally profound experience for me. We wound up meeting intriguing people and talking about everything. I can't even remember what the everything was, except that it completely recruited ideas, experiences, and a validation of who we were as young men in the middle of college, and the role we could play in consuming and embracing people, community, the arts, values. It was totally philosophical, hugely eccentric. We would get back to our hotel at five and six in the morning. My dad would call me at six in the morning to see how I was, and I'd have to fake that I was waking up instead of just going to sleep. Dan and I were living in this very, very sumptuous hotel in Madrid, that my dad was paying for.

It was like we were these two teens on this sentimental discovery of who we were. It was like out of Flaubert, you know. It was like nineteenth century, sentimental, romantic kind of a journey. It was just this total transformation of a young boy into a young man. I came back to UCLA, I came back to the United States a whole new person. I was nowhere where I was when I left. I had this dream in me. I was just laden with a sense of romance and excitement and love and hunger for more. I wanted more of this discovery. It was almost like I'd discovered my mind, I discovered my head for the first time. All of a sudden it was a renaissance, like a rebirth. I dug into school. I changed my major to twentieth century history. And connected with another very beloved friend in school. A guy named Bill Golant, who was a year ahead of me at that time, and was just a genius. He literally taught me how to take tests, how to think, how to analyze.

Art and philosophy become foundation of political growth and identity

Bronston: We had these great European-born professors in common that we pursued, incredibly powerful, existential, contemporary philosophy, very progressive, humanistic. They really understood the struggle for integrity and authenticity in everyday life, and the sense of being a historical human being, what it meant to be historical. Not in the sense of elite, corporate-oriented philosophy, but from the standpoint of soulful, artistic, creative, set-breaking, relevant, thinkers that had to do with what it meant to be alive and influential. What was one's obligation as a world citizen. This was intro to politics at a certain level. It had to do with laying the social and philosophical grounds for intellectual meaning, for social substance. And I loved it. I loved it, I was just lost in it.

So I just took art course after art history course because I somehow saw the translation of that value-based phenomenon in art. That is, art was the way in which people finally got to the highest level of saying something about what it meant to be alive in the world. There was art that was recreation and art that was decoration and there was art that was entertainment, but then there was art that was what I would call now, politics. The highest form of human expression, human message, human learning. It was to that stream of art, what I call the "black cartoonists" Michelangelo, Goya. There's the whole stream of entity who comprised the German expressionists in the twentieth century, the twentieth century revolutionary Mexican muralists, the people who had something to say about the drama of life, the extremes of the human condition, the consequences of the mutilation of soul that has been one of the fundamental challenges to rise above. And to battle from imposing on others in life. And it laid a soulful and sentimental and romantic and idealistic foundation that has always been the ground of my more ideological political growth and alliances and identifications.

Cowan: So as you were energized and activated by these new thoughts—

Bronston: It was explosive.

Cowan: Explosive is a good word.

Bronston: It was a discovery, like an epiphany. It was an adolescent epiphany. Like I finally got, at eighteen, what people say people get around sixteen. It had enormous power to it. I was really living the life of, sort of, a young prince. I had no responsibilities: I didn't have to work. My parents supported me. I was in love with this TWA airline hostess that I had met going to Europe. I ultimately married her two year later. Janet was my first wife; I got married when I was twenty. She was from Britain, she was a Brit, who had been in the Second World War, had been evacuated as a nine-year-old child from London, twice, as a result of the German bombing.

Through her experiences, I recognized that there was something so profound about life, crucial about life, so crucial about the world's experience, so much a part of all of us, that most of us are never aware of, most of us never identify with, never have a sense of the possibilities that exist in building a brotherhood in the world. A sense of commonness, a sense of love. That came through her very powerfully in those days, for me.

Cowan: How was this manifested? Did you continue in your art major, your history major?

Bronston: Yes, I finished my pre-med studies, I got my degree, my BA in contemporary history, with a minor in contemporary art history. I wound up sort of a very different, enriched person. I was really in love with a bunch of stuff. I began collecting fine art when I was in that period of time. I would haunt the art galleries in LA and look for these friendships, these relationships. The affinity relationships with Picasso and personal relationships with artists named Leonard Baskin and [Rio LeBrun] and the classic crowd, you know, the Rembrandts and the Goyas and the Mexican muralists, Orozco and Rivera and David Sequieros, I can just read them all off, Kathy Kollwitz. As you see, I have this whole collection of art that I've been gathering since I was twenty, of this "black art." It was not paintings, but etchings and lithographs, wood cuts, drawings, because I couldn't afford color art. I could only afford maybe fifty, sixty, eighty dollars to buy a piece in those days, and it would take me two or three months to pay that off.

Cowan: Were you becoming an activist in any way at this time?

Bronston: No, I was totally caught up in this awesome intellectual and sentimental journey. It was a total private, aesthetic journey, aesthetic exploration. It was like William Perry of the soul. I was going to the north and the south poles and to the unexplored jungles of ideas and people to just discover art and literature. Defining the human condition, the intellectual human condition, and identifying myself with the stream of explorers of that world. I clearly identified myself with a certain value system. A certain image.

Cowan: Humanist.

Bronston: Yes, a hugely humanist oriented kind of pursuit. I was maybe the proverbial baby "liberal." Unideological, undoctrinaire, just emotionally and sentimentally identified with extreme life. It really all of a sudden made returning back to studying medicine make sense for the first time emotionally since I was little. That return to medicine was to psychoanalysis, to psychiatry. I had this course that was taught by my great philosophy professor, a man named Hans Meyerhoff, who was really one of my great teachers at UCLA. He was a philosophy teacher at UCLA at that time.

Meyerhoff taught existentialism. He taught Plato and the Greek philosophers. He taught everything. He was a genius, he was an absolute genius and a man that didn't just teach out of the book, he understood this stuff. He understood it at a level of meaning—he was a German—and carrying the legacy of what Germany did, and being a German Jew, he was really something. He taught a course in "Marx and Freud." They have been my two rails, the rails of my life since then. The teachings of the two greatest philosophers of the twentieth century, bar none. My hunger to serve and heal reignited, and I made up my mind to apply to med school.

University of Southern California Medical School, 1961-1965, preeminent school for clinical medicine

Cowan: Did that [course] spark your interest in psychiatry as you went on to medical school?

Bronston: Yes. I went to USC Medical School, in 1961. I went to USC because I found it to be the preeminent school for clinical medicine and I was interested in serving poor people. I was interested in serving people of color. By that time I spoke fair Spanish, which was pretty unusual in those days. I was the only non-Latino person in medicine around me that spoke Spanish. Because of my stints in Madrid, and I'd also gone to Mexico with my dad on a trip way back, I had really been struck with the frustration of not being able to communicate with non-English speaking people. I was really filled with words. Filled, filled, filled with words and the craving to communicate!

Cowan: You were already sensitized when you went to Mexico with your dad?

Bronston: Yeah, and then the Madrid situation was hundred-fold that, because I would get in discussions and I had to have the command of language. I had to be able to speak ideas at the level that I could understand. That really pressed me hard to find those incisive words. To be able to make my words communicate about ideas and values, which are subtle and moving.

My UCLA experience, in the first two years when I first got there, was very alienating, and then second and third year summer, things really changed. My last two years at UCLA were incredible. Then, I had to spend a fifth year, to get accepted at med school, because I had a beard. I always had a beard, since I was 16. And I wound up not being able to get into medical school that first year. I had applied to the ten top medical schools in the United States: Harvard, Yale, Western Reserve, John Hopkins, Stanford, you know I just picked out the best ones. I thought, okay, that's where I'm going. I had just about as much insight as to what the possibilities were as I had had going from high school to UCLA. It was sort of like, okay, I fling myself out there and I'll end up in the right place. And I was rejected by all of them. I didn't find out until afterwards that four of them rejected me just because I had a beard. Period.

So I had to spend another extra year in college in advanced sciences and reapply, which was really one of the most exciting and interesting intellectual years I've ever spent in school. I came back to science and took these amazing courses in biochemistry and organic chemistry, in nuclear cytology. I mean amazing graduate courses at UCLA which were just profound. And the next year, with the help of one of my dad's business associates, I got into USC. One of the trustees from USC was also the head of United Artists. He told me to cut my beard off to get into medical school. My wife and I were at the barber shop together when they shaved me, and we both were sitting there crying. It was like, why do we have to do this? I went through my first year of medical school clean-shaven, until I got my grades. He said to me, "Get your first year grades, and if you pass, then you're on your own, it's your trip, it's not a reflection of my support." So that's what happened and I grew my beard back. I wound up being excluded from my OB/GYN rotation because I had a beard. I was the only person in medical school who had a beard until I was a senior. Beards just weren't there yet.

Cowan: In your first year in medical school, what was going on?

Bronston: I hated it. It was boorish, it was the antithesis of where I had come from.

Let me tell you, I came from this immense Don Quixote world of dreams and values and so enriched with the culture from my parents. I was just filled with this goodness, this rich fare that I had been fed and nurtured on, from friends, from art, from reading, from movies, from theater. I had become addicted to this whole explosion of new existential art, Albert Camus, Kafka, Edward Albee and Stephen Beckett. I was submerged in a whole world of amazing twentieth century artists and poets that were just part of my virtual peer group that I had been culturally hobnobbing with every day.

I met T.S. Elliot in Jamaica. Aldous Huxley lived about a mile from my Hollywood house, and I went and knocked on his door one day and spent the day talking with him, just an adoring kid in the neighborhood.

In college, I went after and sought to meet all the people that I was interested in, that were the great artists around, and somehow wound up meeting lots of them. I had no fear, I had no idea there were these barricades, that people didn't or couldn't or might not do these things. So I just came out of my adolescence and out of my college year, with a boundless sense of confidence. I don't know if it's unrealistic. Certainly, it's realistic because it's governed my whole MO, my whole life. If you have to call the pope, you call the pope, that's what you do. That's what my dad did, that's what I do. Whatever you have to do, you do it. If you need help, and if your cause is just, then you recruit whatever help you need right now and expect the help to be delivered. That's where I started when I arrived at med school.

Cowan: What was disillusioning about the first year of medical school?

Bronston: It was coarse. The people in medical school felt like thugs. They weren't there for the right reasons. They were there for money; they were there for prestige. They didn't even know why they wanted to be there, really. There was no romance to the people in my medical school in large part. A clique arm-farted in the back of the class and they cat-called and they played bridge at lunch time. Just a whole lot of stuff that I didn't get. That to me was not what the sacred role of new doctors was, or what the inspiration of medical school was all about. Plus, medical school itself was really callous. The curriculum was cut-and-dried, and we were taking notes, twenty pages a day, five, ten pages in an hour.

My writing degenerated into a straight line, and from articulated penmanship, I wound up scrawling, because of the vast amount of new vocabulary that is the warp and woof of medicine. It's just learning new words. It's learning a whole new language. You learn the language, you learn the ideas, you figure out what you're looking at from the words and that's medicine. That's what it's all about. You've got to write fast, write hard, remember a lot of stuff, and apply it to what you see and try and understand something. So that there's a very profound objectification of life through the looking glass of allopathic medicine. It is not a soul search in any means. It's an inventory operation and an algorithm of enormous magnitude.

Cowan: Were you starting to think you'd gone the wrong way?

Bronston: No, I just knew that I had to go through this gauntlet to get to child psychiatry. I just had to go through the punishment. I mean, I loved histology, and I loved the visual. And when we got from the mechanics to the practical, I loved deeply connecting with people. My medical school was housed at Los Angeles County Hospital. It was way downtown, it wasn't at the USC campus. The medical school was at LA County Hospital which was the largest single-building hospital in the United States, dead in the center of one of the largest Hispanic, black, poor communities in LA. And man, it was home. It was home for me.

I loved the people. The seething mass of people, of ordinary people. And my limited Spanish was vital. I could just handle myself, marginally, with the Spanish-speaking community. These were mostly farmworkers. There was this explosive growth of movement around those days. Little by little, the movement of the Vietnam War, the United Farm Workers, and progressive reform in medicine. Slowly but surely. Because medicine was so cut and dry, so controlled by the AMA, self-agrandizing, so elitist, so mechanistic, so pejorative towards the student and patients. There was this huge power gradient from teacher to student and a huge tradition of compliance, obedience, of rote learning.

Cuban Missile Crisis inspires lifelong activism, creates "wild-eyed radical" reputation

Bronston: I came to medical school with philosophy, fiery philosophy, value systems, sensibility to what was going on in the community around people, a trained humanistic concern. Then in the middle of my first year came the Cuban missile crisis, which was another one of those absolutely incalculably powerful influences on me, because here I was, I didn't know how to do anything. I was just this pampered kid, that had been protected in school, learning these esoteric aesthetic things. I didn't know how to change a tire, I didn't know how to do anything, planning to be a doctor. In my first year, we were faced with the imminent atomic destruction of the country in an all-out war with Russia.

I would be useless on the street. Doesn't matter how much I wanted to help, be helpful, sacrifice myself, I was worthless, and powerless. Because this decision that President Kennedy had forced us into was not a decision of our popular making. The leaders made it. I didn't know what was involved in it. And why we would go to war with Russia over missiles in Cuba didn't compute to me. I didn't even know where Fidel was at that time, in terms of his politics. I just knew that we out-gunned them a million to one and that they could have whatever number of missiles they wanted on their bloody island, that they were not an aggressive, expansionist country. They were just there because we were beating the hell out of them all, the time.

Cowan: Were you knocking this around with other students?

Bronston: Yes.

Cowan: So you found like-minded people.

Bronston: A very few in my medical school. There were two or three people in my medical school. But I went back to UCLA and reconnected with Meyeroff, because Meyeroff had become a major spokesperson for the antiwar movement at UCLA at that time and was speaking powerfully in his incredible special way about the crisis. And all my professors at UCLA were speaking out too. This was a world cataclysm. Overnight everybody was drawn into this crisis. This confronted all of us, like were we going to be destroyed. There was going to be nuclear war tomorrow. When the US interceptor warships got together and the Russian ships carrying their missles to Cuba refused to stop and we refused to let them come—I swore at that moment that I would never again be out of touch with or not be active in the national decision making to advance the body politic of my own country. Or the world's situation. It was an incredible omnipotent-thinking kind of attitude, but that's where I came from. I felt I could do anything, think anything, be anything. I felt I could do anything, I'd just not been tested yet.

From that time on, I began learning, I began reading. For the first time, I discovered working-class history. I read this book called *The Biography of Big Bill Haywood* and William Z. Foster and the founding of the IWW [Industrial Workers of the World], and the founding of the CIO [Congress of Industrial Organizations], and the founding of New York's Leather and Furrier Workers Union. And the real story of America's working class. SDS [Students for a Democratic Society] finally began to billow. The whole black power movement, the Black Panther movement emerged during that time. I was reading the *Guardian* newspaper from New York that I avidly just sucked up. *Ramparts* magazine and the *New Republic* were left magazines, not what they are now. I couldn't wait to get my next issue of these magazines, and with that came exhilarating analysis and communication. No Internet then; it was reading, letter exchange and phone calls.

I had appropriated that into my medical school. The whole struggle was applied where I was and where I lived. It was only a year from the time that this all began to happen. In my junior year there was a med school election. I nominated myself to be president of the medical school because a freshman med student John Bettenhouse had nominated himself to be the president of all USC. This freshman, this wonderful guy, he was running on a platform to "abolish student government." Just to stick it to the university, to show that student government was just a farce, a puppet and a facade, there was no real student power. But he was also kind of a cynical guy. I was just thunderstruck that instead of going to build student power, John would play his nihilistic card. I wanted to go straight to the jugular and make student power a reality, at least in the medical school. I wanted to challenge the whole betrayal and surrender of value and daily mediocritization that was imposed on us as medical students.

The iniquities and the inequities of the experience of going to medical school in those days were astounding. No black kids, three girls in my class, no real commitment to poor people or to service movement people. The going paradigm was money-hungry drug companies sucking dollars out of people, private practice medicine, no commitment to national health care, no social medicine. And yet below the surface, waiting to be evoked again, there's this gigantic trend, this gigantic history, this movement that has been there forever in the United States of progressive, caring medicine. Of social medicine, public health and rightful oriented medicine, completely missing to me, completely missing in my education. And the alienation in school. I didn't know anybody outside of my class. I was in the third year by that time, and already in clinical training, loving the stuff I was learning, but I didn't know anybody in the first year or the second year or the fourth year. We were totally isolated from each other by intent.

We're crossing over a line here in the story that is really profound and I don't know how to articulate it because it happened in such a rush and in such a complex cloud. It's kind of like the story of the *Wizard of Oz*. I was picked up by a tornado and I woke up somewhere else. I was picked up from private aesthetic preoccupations, sentimentalism, chasing girls, surfing, playing volleyball, being just a playboy, to this joyous interest in the structure of clinical medicine and the whole aesthetics of all that. I was still involved in a lot of my cultural activities, theater, movies and art collecting. Aware that my father was out there in Spain, married, having kids, doing his movie-making thing and getting bigger and bigger. So there was another kind of a behind-the-scenes secret life that I had, that nobody shared, with my dad coming out with his spectacle movie openings at the Grauman's Chinese Theater and the Egyptian theater in Hollywood. My wife Jan and I decked out at these openings with major stars, all that going on behind the scenes. It was not part of my identity in medical school. And also being a cultural and political outsider, I always, always, always had like six friends and hated the unconsciousness of the rest of my class. I had nothing in common with them. I felt they were just subhuman.

[Tape 2, Side B]

Cowan: Tell more about your reaction to the missile crisis.

Bronston: Okay, let's go back just a minute, because there are some specific things that I think are key to nail. That whole situation that arose around the Cuban missile crisis was really a shock for America. At the time, people were extraordinarily naive about the words to describe what was really at stake and where the political antagonism was. I had one friend, my closest friend in medical school, who styled himself as a "pacifist" and a "socialist." I knew what neither was. I more or less had an idea what "pacifism" was, I kind of got that, you believe in peace and refuse to resort to war. But I didn't really know that there was a <u>tradition</u> of pacifism of any kind. And I didn't really understand what "socialism" was, despite my UCLA class on Marx, although my friend explained it to me very simply: a cooperative society that was a non-war-making society, where people lived in a whole different way of sharing with one another. That was really moving for me.

That was the beginning, those were the first two words I learned that had to do with establishing a principled basis for living and acting in society, and understanding what even a principled relationship was with the world around you. How you became a defined force based on ideas of a certain way of living. How to make life have a definition, to make it have a meaning, to make it have a contributing role. And that in fact there were competing political paradigms like this, and competing life styles that went to the absolute core of drawing a breath every day, if you're really serious. All of a sudden the idea of what it meant to be a Christian, what it meant to be a Jew, what it meant to be a Democrat or a Republican. What it meant to be a socialist, a pacifist, an atheist, became consistent ideas from which to choose and demonstrate to others life long.

All of a sudden, I thought, wow, there's something to this, I mean, there's something you have to know. You don't just use a word and not understand. There is not only a whole explanation, but there's a whole hundred year, or five thousand year practice that makes authenticity or denies it. Words like "imperialism" came next, "colonialism" and "neocolonialism" dynamic relationships in the world. "Capitalism", "monopoly capitalism", "fascism" all of a sudden, the words I had heard as a child from the second World War began to have substantive definition for me. I wrote an open letter that day, the day of the missile crisis, to President Kennedy, denouncing him for his behavior and misleadership.

Writing to Kennedy wasn't really the important thing. The important thing was that I posted my letter everywhere in the medical school. I made about fifty copies and I just tacked it up everywhere as an expression of my moral outrage. I wrote from the standpoint of being a future doctor. I began to be able to say that I, we, stand for exactly the opposite of what he was doing. We stand for life, we stand for health. We stand for human well-being. And what he was doing was coming against everything for which we had been training and for which we stood, sacredly in opposition. It just created a fire storm in my medical school. Because most of the medical school guys were yahoos. It only further positioned me as kind of a, well in those days, a wild-eyed radical. Even though I hadn't yet become a wild-eyed radical. That was yet to come. They didn't know what a wild-eyed radical was. So it was really quite wonderful. I felt a wonderful sense of accomplishment from that declaration.

That letter really gave me a reputation. It also locked me in to an irrevocable path that has never changed and that was really to be a major battering ram against tradition in my medical school and the whole medical school system in the United States. As I began to gather all these pieces of what it meant to be an actor in the world, the whole value-base, the appreciation of beauty, the appreciation and search for meaning, the whole struggle around what it was that alienated human behavior and people, and how people acted to hurt each other. The real bottom line here was how to get people to stop hurting each other, to not need to pummel or to be cruel or to dominate each other, and that the enormous energy that would be liberated from a non-fearful cultural community. Where people could feel invited and rewarded for their virtue, for their values, whatever. It was pretty vague, pretty mushy, but it really has been a fountain of plutonium energy for me. That simple mushy idea just absolutely nurtures me day in and day out. It gives me a sense of being able to stand up against any odds, any time, and to speak the truth.

That was the first time that I reached for and used my word ability and said something about what I believed in and stood for, what medicine stood for, what I thought we stood for as a democracy. I spoke straight to the President with that letter I wrote to the newspapers and plastered it everywhere. At that point it was like drawing a line in the sand with a sword. I've never, ever, forsaken that line, I've never compromised that line and I continue to feel that that's the only way to be. It's the only way to stand with life, to stand with caring, to stand with friendship, to stand with cooperation, to stand with mankind. Whether it has rigorous origins or ideological definitions, it's a sentimental thing for me. I am always haunted by the fact that maybe the privileges of my life may have thwarted my radicalism or protected me from ever having to experience anything that has hurt me for standing up like that has spoiled the situation. It's not like I'm an Afghani refugee sitting out there watching my wife and child starve, or I've got death squad three bullet holes in me, or I've stepped on a US land mine and I don't have a leg. Or I've been put in jail for an extended period of time, or tortured like so many Chileans or Guatemalans.

Cowan: After the letter about the Cuban Missile Crisis, what other kinds of political things were happening?

Bronston: Well, within the next 18 months, between the Cuban missile crisis and my deciding to run for president in my medical school, a lot of things were developing. One of the things that struck me was that what was missing in my medical school milieu was a sense of comradeship and friendship and a high road mission that would promote us to be better doctors. And the thing that was so prevalent in those days was all this talk about how there was a huge shortage of medical manpower. I thought to myself, Jesus, there's three hundred thousand of us in the United States, medical students, not to mention nursing students and dental students. We all were just sitting there, waiting, waiting to serve the people.

So I ran for president of the medical school to address this reality. I ran hard, but I didn't win the election. It was kind of strange. The whole establishment of the medical school worked assiduously to block my election. The administration didn't want a bearded eccentric who spoke out against the President and who was demanding medical school reform. They had handpicked a dental surgeon, Jack Lytle, who had come back to medical school to get his M.D. degree so he could prescribe drugs. This wonderful, nice man was always a friend of mine, but was not a part of my crowd. He was a straight-shooter. So the election, whether it was straight or not, was very dramatic. I lost the election to this other guy, Jack, and he became the medical school president. A pyrrhic victory!

As it turned out, the senior class voted as they went out, and mostly voted for Jack because they were still part of the conservative, old-guard crowd. My class, the Juniors, was split almost fifty-fifty, so much so that they nominated and elected me to be the Senior class representative that next year, even though I had just lost the presidency. And I don't know quite how that all happened, but they gave me this consolation position, because they thought I had done a good job in articulating a platform. The sophomore class voted almost ninety percent for me, and there was no incoming freshman class at that point, but when the incoming freshmen arrived the next semester, because the election was before the next semester, they came in with beards and social consciousness.

They were part of the new generation of antiwar, progressive, liberal, conscious group of kids that had purposefully been selected by the school trustees for whatever reason, to bring in a more "diverse" class. Because the pressures were on the schools to have more women, more kids of color, more different kids than just the children of the doctors that had been recycled for generation after generation back into medical school, which made a very narrow sliver, ideologically, culturally, intellectually, racially, to serve. So when I walked into the first meeting of the student government, the president who had just been elected, did not have a single vote, and I controlled the student council because I had the platform.

Proposes fundamental changes in medical school program

Bronston: My platform was this: I put together very quickly a set of fundamental programmatic ideas that I felt would make a real difference. One, we had to have a "forum" for those issues that weren't being taught to us in the medical school around social medicine questions and the controversial issues in medicine. That forum needed to be held in the LA County Hospital and open to everybody, patients and other doctors, medical and nursing students. Secondly, we needed to have a program that brought together the natural skill sets and needs of all the four med school class years. In the fourth year we had a surgery rotation which matched up beautifully with the anatomy classes of the first year. So I created a "piggyback" model for linking fourth and first year students together. For first year students to piggyback and see where they were going in terms of surgery, and for the surgery kids to help and apply some of their understanding of concrete anatomy. And between the second and third year, where the second year studied theory in medicine and the third year was beginning practice in all the medical specialty clinics.

It seemed like a natural way of setting it up, and I called it a "piggy-back program" and every kid would have a partner, or there would be groups of three or four that would work together on a voluntary basis. It was never really engineered and particularly made to happen, but it was a great idea, and it would have made a difference to be able to show kids in the first year where they were going in the fourth year so they wouldn't be so alienated and drawn along blindly like sheep.

Cowan: Like your own experience?

Bronston: Yes, exactly. I wanted them to have some power and some knowledge of how to influence and shape what they were all about and to understand this larger picture of our school as a community.

The third thing was to establish a major independent, student-run newspaper, which I named *Borborigmy*. Borborigmy is the word for stomach gas gurgles, stomach gurgles. So over that summer between my third and fourth year, a group of us, kids from the second year, and the first year that came in, put together, out of our own pockets, this eight-page newspaper, two folded eleven by seventeen inch pages. We used the newspaper as a way of uniting all the disparate interests in the medical school, regardless of whether they were reactionary or not. We were interested in social medicine changes, but we invited the kids that were involved in medical history to come and put a column in, and we invited editorials from whoever.

I wanted unity in the school. It didn't matter where their politics were. The important thing was what drew us as students together, was that we were the seed-corn of the new medicine of America and there had to be a ground for us to bring all of our intellectual, scientific, cultural, social, political interests together. I used the art from my personal library. I would take and Xerox and put in the graphic pieces from German Expressionist, Picasso, the Mexicans and from my whole art collection into the newspaper as illustrations, which was really quite wonderful. Issue after issue, the newspaper became more and more interesting and lovely and consolidated. It was really extraordinary and got famous fast.

It was probably one of the first underground medical student newspapers for twenty years that existed. I had become aware of a very powerful legacy called the Association of Interns and Medical Students [AIMS], which had been snuffed out by the AMA about twenty years prior as a result of the students in those days being very progressive and very much connected to world social medicine and social justice issues. The AMA which was a right-wing guild apparatus, saw this tendency among the medical students and interns as extremely threatening, and when the president of the AIMS, which was a nationwide organization, was photographed in a youth festival in Bulgaria, the AMA immediately engineered the withdrawal of all the advertising for the AIMS journal which was called "The Intern," and destroyed the communication basis of that organization almost overnight. They replaced AIMS with an insurance company-funded thing called the Student American Medical Association, SAMA, which was actually run by an insurance salesman, who sold life insurance to us as medical students and subsidized the SAMA Journal, which was a totally irrelevant thing that had nothing to do with the deeper agenda of healing, progressive medicine, or world health.

I had found the remnants of the old AIMS leadership now in leading positions all over the United States in schools of public health and preventive medicine, and infectious disease. These doctors had been idealists in their student time and had drawn their inspiration from an earlier tendency of medical progressives around a group called the "Physicians Committee" that was headed by a very significant physician, John Peters, in the thirties, and just some amazing philosophical people like Siegerist that really were national health care, social medicine giants, giants in their field. Major sociology, writers, anthropologists who were physicians also, that talked about the history of medicine and the tendencies in medicine, between commodity and material-based medicine, capital-based medicine, versus the real thing, which is to guard the public health, in the broadest sense. And to make sure that poor and rich alike had full access and coverage.

The assault from 1902, 1903, 1904, when the Rockefeller-Flexner Commission first articulated their battle cry to command the market totally and completely for capitalist-based medicine, plunged the US in a kind of dark ages. The battle between the left and the right in medicine, between the social, humanist wings, and the money-making, market-control, authoritarian elements of the profession has raged since. I had accidentally discovered this progressive AIMS tendency and wanted to reinstill it and felt absolutely no barrier. There was this vacuum, there was this starvation from my peers to suck meaning, to get a sense and reassert the romance of why they came into medicine. We had come in as servants, we came in below the people, not above them. The people gave us strength, not the other way around, at a certain level. We would provide a full commitment of all our time, all our love, all our care, all our skill, and what we would get back would be acceptance in this society. Which, if you look at it on a certain level is a little bit distorted in terms of my own personal alienation as not really being an American, typical kid, and always looking for family and always looking for company, and always looking for community and acceptance. But it did translate right, it did translate in a way that would make a profound and fundamental difference in terms of how people should relate to one another in a merciful, caring and tender way.

Cowan: How did the school react?

Bronston: Well, it was very interesting, I was just—I don't know quite what to tell you—I had done such a sensitizing job in my school. I had the student body. There was community in my student body around activism, and there was an element in there, ten, twelve, eighteen percent of those kids that were on fire like I was on fire. I could articulate what that struggle was all about. I was able to point the way, express the vision, write the words. All this stuff in me just kind of began to come out and our newspaper, *Borborigmy*, was so incredible. We were so proud of it. We'd come in with this newspaper, it was just absolutely the best thing we'd ever done, and it was beautiful. It really was heartfelt, it really exemplified student power. The whole thing was around student power, a new voice, a new idealistic voice to bring about a better care in America. And it was strictly an American kind of a deal. It wasn't a patriotic thing, we were just looking in front of our nose at our own responsibility here because we knew that what we had to do was to massively multiply the number of doctors in the nation.

New breatkthrough challenges exploded. For example, we knew that if the medical schools, all of them, devoted every seat, the three hundred thousand seats, for more than five consecutive years, to only black students, that the ratio of doctor to ethnically-identified patient would still not reach parity compared to white doctors to white doctors to white population. That is to say, the ratio between white doctors and white American public was a certain number, and if we took the production capacity of the entire American medical school system, five straight years in a row, and generated nothing but new African American doctors, there would still be a disparity between the number of black people and black doctors. So grave, so drastic was the shortage.

Then you want to talk about women in medical school, that's another issue. We knew that half the doctors in Russia were women, or more. I knew that I would much rather have a good woman doctor than a good man doctor. Because men doctors were hurtful, in a lot of ways, from what I could understand and see. It was a pretty crude instinct, but it was, well, moms are nicer to you when you're sick. Moms take care of you, not dads. So it was a very powerful kind of paradigm that had to be addressed.

New ideas lead to creation of a Student Medical Action Conference

Bronston: What we did was, the fourth pillar of my platform. The whole thing was to build a new health student organization. Through our newspaper, the information, the relationships at USC, I built a ten-school alliance. The LA regional coalition, a regional congress of students, consisting of dental, medical, nursing, med-tech, which I brought together as peers to establish an action congress, which we called the Student Medical Action Congress [SMAC]. Since my first wife, Janet, was a TWA airline hostess, I had free tickets to fly everywhere, so I would take cargos of my newspaper, make phone calls ahead (my dad had given me a credit card to make phone calls, four or five hundred dollars a month). I was making telephone calls every month. Organizing all over the country, looking for student activists interested in this new resurgence of social medicine tendency in America in order to help address the country's need for the shortage of doctors, and to provide more justice and to promote social medicine in the land. So I would fly to New York, Detroit, Philadelphia, to Denver, to San Francisco, to Chicago and meet with ten, twenty, forty kids, kids from each of the five or ten or so health science schools in each of those areas, show them the newspaper, show them the program, talk about changing the student government apparatus. Overnight, I mean, overnight, there was this explosion. They got it! They got it!

There was no coordination, it was like everybody did their own thing. Within a year and a half, there were sixty underground newspapers in all the major city medical centers in the United States that were indigenous. I would sit there and look at all these covers, I mean, overnight, underground newspapers made by the kids. The one in Chicago was called *Yes*, and it was done by a very sophisticated crowd. There was one in New York, there was one in Berkeley, there was one in Stanford.

Cowan: And there was no opposition from medical school administrations?

Bronston: None. It was like a dam had broken. There was no way to stop it. Plus there was this entire "War on Poverty" that was going on at the time. The head of the Office of Economic Opportunity was a physician by the name of Joe English and Joe gave us millions of dollars. He gave it to us, we didn't even apply! He said, here, make something important happen, because one of our things was, we wanted to serve, the whole thing was around service. So we set up these fantastic summer-long events that we worked out with a hundred Health Science kids in one place that would come from all over the nation. We had a summer project operating in New York, one operating in Chicago, one operating in Delano, here in California, serving poor people. And we had these fundamental alliances with the United Farm Workers, with the Black Panthers. We were connected everywhere. We became part of a movement. And then what happened was that all the disparate and orphaned interest groups linked up. Like there was a whole batch of kids that were keenly interested in what was going on in Mississippi around the Southern Christian Leadership Conference efforts to promote civil rights, human rights, voting rights.

Cowan: You mean, medical students that were already involved?

Bronston: Right, so there had already been a stream of kids going into the South in conjunction with an organization called the Medical Committee for Human Rights, which was one of the two progressive medical organizations in the country. The other major progressive structure was the Physicians for Social Responsibility who were struggling against the threat of nuclear and the atomic bomb shelter program; fighting against the obfuscation of the implications of nuclear war. In order to bring that to the general public they did this incredible job, ultimately blocking the atomic shelter program in order to say, you can't, dig a hole and be safe from atomic war if the US or Russia decides to wage it. So the Medical Committee for Human Rights was the civil rights side of that two-sided structure that existed, separately in the medical community. We, as medical students, were interested in seeing the unification of all the progressive tendencies in the medical community.

But the doctors were schmucks, they were into their own sectarian stuff and they didn't have the energy. They had one newspaper each. We had sixty, seventy. We just had illimitable power and energy and would move with lightning speed. There were no liberal battles around fine points of left ideology in the student upsurge. We just acted, we made things happen. And we were trying to serve the people the whole time, which the real doctors, the grown-up doctors couldn't do.

There was a major effort among the progressive medical establishment in the med school to put together these social programs. Somehow or another, they got the picture that this was going to mean "market expansion." This whole movement, to open up services and health care to poor people, to union people, to farm workers. There was a kind of a "get on the band-wagon" ethos in the country emerging at that point. We were in the middle of the 1960s. Everything was being redefined. My job was to move this cohort of America, the medical student, the nursing student, dental student, health-science students into the breach. We had a historic role to play. We had a responsibility. We had a hyper-responsibility because we had a special relationship to the Vietnam War, we had a special relationship to Mississippi Summer. Our relationship was to bring an uncompromising commitment to human integrity, human safety, human protection, human dignity, through health care, through caring, into this equation, by the tens of thousands.

[Tape 3, Side A]

Bronston: There was a supportive material ground, and a subjective ground in the country. We had money, we were the darlings of the liberal establishment. Because who had ever heard of medical students coming out and doing this in twenty years? We had access to media and the Stanford and UC Berkeley crowd were particularly advanced and sophisticated. The Stanford guys were absolutely committed to developing this enormous opposition to the war. They invented a button that was a Caduceus with an omega superimposed on it called the "Medical Resistance." We built a pledge—but I'm getting ahead of myself a little bit. What had happened was that I had put this Los Angeles base of schools together and had begun traveling all around the country to seed the idea of student power, student leadership. And, of course, everybody was aware of the NY *Guardian* newspaper and everybody was aware of the *Black Panther News*, and everybody was aware of *Ramparts* magazine. It was like, if you were interested in your own generation, you were learning the vocabulary of how to understand the politics of what the Vietnam War was all about, what the Southern Struggle was all about. SDS student radicals were talking, King was talking, Malcolm was talking, Ho Chi Minh was talking, Mao was talking. It was incredible.

Cowan: The free speech movement was at this time?

Bronston: You bet. All of this was exploding, and here we were, in grad school over the hill. We were over the hill, we weren't in college anymore. I said to myself, let's go! Let's put our act together, and bring our hearts to this struggle. We have a place to play here. It's a little bit refined, but damn, let's do it. So I was just thundering. I was writing polemical stuff in many of our newspapers and writing to *Ramparts*. People were doing articles about the student medical movement, about student power issue in the health science schools. And, interestingly enough, the schools, the deans of Harvard, Yale, Hopkins, my medical school dean, stood by us. He was an incredible guy. His name was Roger Egeberg. He was a public health guy. He was this great big bear of a guy with a big voice. Just this amazing guy. And I would go to him and I would say to him, it's going to cost me this much to do my Student Forum lecture series. We're going to bring these great professional leaders in to speak and we would bring people in, we would have a special three-day lecturer.

We would have a special guest once a year. We brought in Gerard Diel, the publisher of the *Scientific American*. We brought in Paul O'Rourke, who was one of the top farmworker health physicians and Belle Poole, who was a major pediatrician and public health physician in California. We brought in Lou Lavinia, who was this amazing anti-drug company guy in the pharmacy world. We brought in, Michael Harrington, who wrote *The Other America*. We would bring in these fiery, fabulous, socialist, progressive intellectuals to talk to the thousands of people that came to our forums. They were all incredible. At the end of that year, I graduated. My whole senior year was completely, totally submerged in this day in and day out, night in and night out, activity. I just couldn't get enough of it.

Cowan: Did you go to class at all?

Bronston: Barely. Barely, and I fell from being near the top of my class to being under the fiftieth percentile when I graduated. It was so interesting how even though the school was very resistant—I say that there was no opposition—they didn't oppose actively, they opposed passively. When we graduated, there was a huge bunch of awards that were given to many of my classmates for the best student, the most active student, the best scholar, the best this, the best that. Maybe twenty or thirty major awards, but I was not publicly acknowledged. The yearbook from my medical school that year, had, on almost every other page, a picture of me, or what I was doing in the school because I had my hand on everything in the school. Everything. All the clubs, the newspaper, the activities came from our organized innovations.

Okay, so the question is the reaction of the medical school. We had a totally committed dean, who was behind us a hundred percent, behind the program a hundred percent. The administration began to understand that there is market expansion. The medical schools are beginning to get into the business of community-based care because there's lots of money coming from the federal government for the War on Poverty. Health coverage and so and so forth happening, all this stuff happening, very significant.

It's paradoxical in retrospect. We became the shock troops, unknowingly, despite our good faith, for the medical school corporations trying to expand their role and their incomes. So the medical students are sort of like the good guys out there making connections with the activist communities. They are the political organizers that are laying the ground for the medical schools to start moving in an "imperialist" way into the poor communities to set up clinics and hospital programs and so forth. For a short while, the whole black community needs and interests, and Latino community needs and interests, were embodied in the civil rights movement, from the United Farm Workers. These reached a point of maturation fed by the mobilization and the militancy around the antiwar movement. It was just all beginning to come together. The medical school's openness seemed to float without necessarily a craven agenda which had yet to manifest itself as we can see now what's happened with the whole HMO [Health Maintenance Organization] system and so forth. The whole privatization process lay ahead. Then, they were looking for expansion, and my medical school and UCLA particularly, were looking for expansion.

So that's the context the year of my graduation. For my graduation, USC completely ignored the role I had played, almost single-handedly in revolutionizing student affairs in my medical school and in the LA region, and scores of schools in the nation by that time. It hurt, but it was also very funny. I thought, this is the only way they can get me. This is the only way they can count coup against me, is to ignore, to trivialize. It was very interesting, because I thought, where is the balance, here? And how sad that they don't celebrate. The issue wasn't to recognize me, they didn't even recognize the enormity of what had happened in this last year that had changed everything in the medical school, changed everything. There was such an explosion of goodwill, such an explosion of community, such an excitement.

Then of course, in that first year, so much had developed that we knew, I knew, we had to have a national meeting. My hero and confrere, Mick McGarvey, was a sophomore at the time, was my solid alter-ego. Where I was flamboyant, and the big speaker, he was the instrumentalist, he put it all together. Everybody trusted him. He had an even temper. He would chuckle and laugh at my excesses in front of other people. He was the good cop, I was sort of like the wild cop. So we called a first nationwide meeting at the University of Chicago Medical School.

Student Health Organization founded, 1965

Cowan: A national meeting?

Bronston: A national meeting. And founded a thing we called the Student Health Organization, which is predicated upon the tenets of the World Health Organization, by defining "health" as complete physical, mental, and social well-being and not just "the absence of disease". We came to that meeting, sixty-five kids from medical and nursing schools all over the United States. We sat there and we organized and we knew we were making history. We knew it.

Cowan: Do you know what year it was?

Bronston: 1965. Out of that came kind of a Magna Carta, a mission statement, a declaration of purpose for the Student Health Organization. We have all the documents, it's all been printed. And then an independent national newspaper was begun for the national student movement that was pulled together and created out of USC, where we had money from Joe English and the OEO [Office of Economic Opportunity], and their War on Poverty money. So between then, 1965, and the end of the Vietnam War, there was this meteoric rise in organization, in membership, in program. But the interesting part of that was, well, I was gone by that time, I was gone on a day-to-day basis and a whole new generation of student leaders rose up.

Mickey became the CEO of the LA [Los Angeles] office or the SHO [Student Health Organization] at the LA County Hospital. We had staff in that office, and I went off to my pediatric internship and then to my psychiatric residency and continued to go to student meetings every other night, and to work in the LA Childrens Hospital every other night. It was a very grueling and invigorating struggle because we were in constant polemical battles with SAMA and the politics of the situation were heating up. Every day, we would become sharper, understand more, know more, about what was going on. Every day, there would be an escalation in the Vietnam War. Every day, there would be more barbarism in the racist repression in the U.S. South. Our stronghold was in the medical schools.

Cowan: And everyday, was the other side getting more opposed, stronger in opposition?

Bronston: If so, they never came against us. Now that could have been for two reasons. One is that we posed no real threat, which is in large part the more likely—we served a certain agenda of the medical schools, and we didn't attack their base. We never attacked the medical schools directly and said, here's whose on your board. We never did the radical research to look at their complicity with the problems in the world. There was no anti-apartheid movement that would say that the medical school holds stock in apartheid. We weren't at that level yet. We were still in the middle of the black power movement, and of the antiwar movement. Again, it was a very romantic movement where history was really on our side.

We were really involved on the crest of the wave, of the huge wave that we rode with enormous pride and enormous exhilaration and enormous accomplishment. Medical school, all of a sudden, became really exciting. And the difference between learning your ABC's of medicine and being a "citizen doctor" began to have a very interesting dialectical play with one another. So when I graduated medical school, the Student Health Organization was in place, the SMAC council in Los Angeles was in place. There was funding and staff in place. I then went on to do my pediatric internship at Children's Hospital under the tutelage of my beloved mentor who was this wonderful pediatrician that worked in the child development specialty area. His name was Richard Koch.

Cowan: Now let me just interrupt for a moment. Do you have anything further, or a concluding thing to say about the student movement before we go on to your internship?

Bronston: Well, there was a lot of documentation of the thinking in those days. There was a tremendous amount of back and forth writing and stuff and letters to the editor all over the place. And there's a lot of material. What was happening was we were cutting our teeth growing, thinking, learning. But there was no ideological rigor, and no organizational membership requirement to be a member of the Student Health Organization. Kids belonged to it because it was the right thing to do. At the point where it no longer had a day-to-day ardor, a day-to-day adventure, people began to fall away. And they began to fall away for lots of reasons.

Ultimately, the majority of the active students fell back into the fold. They fell back into the fold over time because you had to become a doctor, you had to pay attention to your lessons, you had to get up at four in the morning or five in the morning and do your internship. Training was rigorous and very demanding, and the SHO was extra-curricular. We were adding to an already full plate of activities. That either had to result in pulling back from our studies or less sleep or something.

The relationships, the love that we were sharing—we would have these meetings, we would come to these national meetings, in the hundreds, that would occur year after year, they would just spend the first day hugging each other. We were so happy to see each other. We were so happy to not be alone, in actively caring. To not be alone, at the most profound level of what it means to be a political citizen, to know that there are others that stand—for better, for worse—for what you stand for, that honor, that are joyous in your company. It's really extraordinary, and would come five hundred, eight hundred, a thousand kids to our national meetings in Detroit and Philadelphia. We would have a meeting every year that would bring the whole SHO together. And we would come in, just to be there, just to see each other, just to polemicize, just to talk about what the dream was, to keep the dream alive, to keep hope alive.

Cowan: Did it begin to diminish?

Bronston: Yes, with the end of the war— When the Vietnam War finished, after King was killed, after the civil rights movement changed its character, after the laws were passed to kind of take the harsh edge off that pre-transformational reality. And as a generation moved through the schools—we're talking about a generation from those freshman who came in who didn't vote for me because they weren't there yet, to the point where they graduated and became interns and residents was the main wave. This one generation, this one flamboyant, fabulous generation that was allowed into American medicine, because of the times, because of the dollar incentives to bring a new kind of kid in, because of the challenges against racist, chauvinist practices that had been embedded for so long and because of our work in company with the rest of the country's activism. We were really part of the fabric of a continuous flow of defiant energy. Defining and defiant energy, that changed all our lives. It gave us a new sense of right and wrong.

Cowan: And the coming generation did not have that?

Bronston: No. The schools realized that they had made a great mistake. They began to re-crank-down on who got into medical school again. They went back to the drawing board in order to circumscribe who they let in because there were a tangible number of kids that went through medical school and decided at the end that they didn't want to graduate because they didn't want to become doctors because of what being a doctor meant. Kids that were so sensitive to the arrogance of position, of the privilege and of the obligations to exploit and subjugate people in carrying out that privilege in medicine that they often became other things. They found themselves. And they had the courage and the integrity to say, I want to have a bookstore, I want to be an artist, you know? Given the opportunity to be doctors and the gold chip that that implied, for the rest of your life, many of these people decided to become something else because for them with new eyes, it was the right thing to be. They felt something more profound, more true about what it meant to be in the world, than just to be a doctor. It was really quite moving. We've never summed up that experience. We've never called us all back together to expose our own history. There were hundreds of us, there were thousands of us who were indelibly changed.

Cowan: It would be really interesting to know where they went to. And how their lives worked out.

Bronston: It's a whole area of progressive social history in the United States that has to be researched and written and there's very few people really looking at that area. There are so many pieces of that time. But there were about five or eight thousand of us in the United States at our apex.

Cowan: We could do another oral history on that subject.

Bronston: Yes.

Cowan: Before we leave it though, let me ask you, if you, noticing all the different kinds of movements that there were in the country, did you have any awareness of the movement on the part of people with disabilities?

Bronston: None.

Cowan: And how about with children with developmental disabilities?

Bronston: That was very profound.

Cowan: Before your internship?

Bronston: Oh, yes, I was woven into the fabric of that whole world by my teacher, by Dr. Richard Koch. When I was in my first summer of medical school, I began doing a fellowship with the Child Development Clinic at Children's Hospital, and was adopted by this wonderful, sweet man, this wonderful competent pediatrician. It was the last summer student job that was available and nobody wanted it. People wanted surgical fellowships, people wanted "real medicine" stuff. I wanted something in psychiatry, and I somehow wound up working at the CDC in the basement of Children's Hospital.

Cowan: Children's Hospital, where?

Bronston: Los Angeles.

Cowan: So this was your first year?

Bronston: Yes, first summer of medical school. So Dick offered me the position, I don't know, a hundred dollars a month or two hundred dollars a month for the summer, some little piece of money, and he kept me right with him. He introduced me to this incredible model of multi-disciplinary services to families with kids with suspected developmental delay. Their purpose was to evaluate those kids, find out what the hell was going on, and keep them in the community. It was essentially one of the most sophisticated community-based, comprehensive, diagnostic and service programs in the world in its time. Carved by my teacher, who had gotten the legacy from his teacher, a guy named Arthur Parmalee. And Parmalee had vested in my teacher, Dick Koch, this commission.

This program was carried out in the basement of the Children's Hospital. That was how much it was respected by traditional pediatricians, though it was the dream of social medicine. It was a comprehensive team of the most capable people from social and medical specialties—a public health nurse, social worker, psychologist, speech and hearing therapist, pediatrician were the core of the team. Around him was the entire basilica of American medicine focused in this giant research hospital, Children's Hospital, which is one of the crown jewels of children's services in the world and was the western United States region center for rare and exotic and mortal diseases for children. So we had it all. Genetic labs, neurosurgery, cardiology, specialists, metabolic chemists, we had everything! We could do anything in those days.

And we were at the cutting edge of that technology. A kid would come in, and he would get a comprehensive work-up and then a support system with home-visiting nurses. We had the finest public health nurse system in the United States here in California. It was the crown jewel. The public health system in California under the Pat Brown administration, the old Brown administration, was second to none in the world. This was all part of an enormous capacity, even though it was devalued by the straight-doc types.

What Dick did was put together a comprehensive multi-disciplinary social medicine clinic and practiced there, in the hospital, on a model basis. Plus, he would take the core group of professionals out and travel all over California in order to train other professionals in how to do this diagnostic and family consultation work.

Cowan: Do you know what year he started that program?

Bronston: It must have been in the late 1950s. It was always his thing. He had other residents and interns that he was training.

Cowan: So Parmalee thought of it, and Koch instituted it in the late 1950s.

Bronston: Yes. And to his clinic came the leaders of the world of mental retardation, which at that time, had a tiny group of leaders out there. Nobody was professionally interested in mental retardation or developmental delay. Nobody saw it as feasible for "curing." What was happening to that whole cohort of people was that they were being put into warehouses, all over the United States, all over the world. In thousands. Just put them in warehouses and get rid of themBout of mind, out of sight. There was no science there. There was no medicine there, because it was defined as a chronic, incurable disease. It was not seen as an educational challenge. Or as something in which human beings and sciences had to adapt in order to lead to the success and emancipation, through any means necessary, of those individuals. It was seen as, if you didn't fit the mold, "out," and that was it.

The pioneers gathered around Dick—Dick became one of the first national presidents of the National Association of Retarded Children, at that time, now called Retarded Citizens, NARC. He was a global physician. He did cutting edge research in phenylketonuria and other genetic conditions that lead to delayed development and slow development. He had the most sophisticated genetics and metabolic lab on the planet, right there, next door to the basement, in the basement, with him, down there with these sophisticated docs. Two hundred fifty physicians, 118 beds in the LA Children's Hospital. (Compare that to when I worked at Willowbrook, in 1970 where there was me, alone caring for two hundred of the sickest and most disabled people you could imagine, in this one building. And that was that. With no research, and no hope, and whatever.) He kind of raised me.

Cowan: I'm interested in how he came to you and asked you to join up.

Bronston: Well, I came to him. I went to him just as a medical student.

Cowan: You didn't come to him because you had a particular interest?

Bronston: No, I was just looking for a summer job, to make a little bit of money during the summer. And I met him cold, and here's this lovely man. And I don't know what he saw in me, but he grabbed me, he just grabbed me. This was before I woke up, this was when I had just walked in. I was living in the CHLA neighborhood, more or less. I would work there on weekends and all summer. I worked with him everyday, was his right hand, quietly, meeting scores and scores and hundred and hundreds of people, all the top scientists, all the top educators. People came in from all over the U.S., Scandinavia, from Europe, from everywhere. They came to look at his clinic because it was perfect. It was the best. It couldn't be made better. To this day, it couldn't be made better, on a certain level. Everybody, school teachers, everyone, was sitting around the table, working with these kids. Those families got the best, most humane, most comprehensive assessment and definition of what was cooking with their kids from a social and health science standpoint.

Cowan: And what were your feelings when you began to become aware of what the situation was for developmentally delayed children?

Bronston: I was raised to be ferociously against state hospitalization. The state hospital was the enemy, it was the bad guy.

Cowan: What do you mean you were raised?

Bronston: Well, Dr. Koch essentially said that institutionalization was the wrong thing. To reconstruct, the politics that were going on then, it's hard to put it all together. At that time the NARC was just beginning to get its feet under it, it was only about ten to fifteen years old altogether. The founders of the NARC organized around the early 1950s, when their kids were preschoolers. The whole beginning of the NARC was for preschool children whose families needed something better than what was going on, and who had decided to keep their kids at home, rather than turn them over to the institution, the warehouse. They were a stalwart group of families. And this guy, Gunnar Dybwad was the first executive director of the NARC then. He just died two weeks ago at the age of ninety-two.

I met Gunnar at CHLA. He was always in our clinic. He traveled from New York constantly. Dick and he knew each other really well, because Dick was a really committed and knowledgeable medicine man in this whole area, in which, you know, you could find maybe ten in the country that really knew what they were talking about, that really had seen thousands of kids already, who understood the politics of disablity definition.

Everything was the politics of definition and labeling. How you labeled, how you defined the child that was in front of you, determined the fate of that child, that family, everything. It was the warehouse, or, we don't even know what, was the other side of warehouse.

II. INTERNSHIP AT CHILDREN'S HOSPITAL OF LOS ANGELES; RESIDENCY AT MENNIGER CLINIC, TOPEKA, KANSAS; MOVE TO NEW YORK, 1965-1968

Innovative Child Development Clinic fosters deinsitititutionalization beliefs

[Interview 2: November 9, 2001] [Tape 4, Side A]

Cowan: Was any part of the work that you were doing in the Developmental Center for Children in UCLA influential in your decision to go on to Kansas for your residency?

Bronston: Not really. Just for background clarification purposes, the Child Development Clinic was at Children's Hospital of Los Angeles, and actually it was an affiliate of the University of Southern California. Dick Koch was a USC professor of pediatrics. No, it didn't. It was a strange detour for me. It felt like a strange detour. My trajectory towards child psychiatry really came from a more philosophical place. My college professor, Hans Meyerhoff at UCLA, taught this amazing course in "Marx and Freud," and really presented these two giant thinkers as philosophers. I was trying to find a way to merge my hunger to heal and help and my sense of being a physician, not a "medicine" man, really, a physician. It's kind of a different feeling. My selection to go into child psychiatry, then, was a solution to a dilemma I had about not wanting to be a "plumber" and not wanting to be a "business man." I wanted to become doctor to be able to bring sentiment and romance and the arts and wonder and discovery and synergy and all those soft things that were part of my unspoken internal vocabulary to caring for people.

The thing with Dick, with the Child Development Clinic, was a whole other deal. First of all, I stumbled into it, just as a happenstance job. I thought that the focus was terribly innocent, terribly sweet and terribly kind. I really had no sense of its significance, because it was not a deep intellectual or cultural happening. There wasn't the kind of thoughtful, dialectical, kind of things that we discussed. Things were very much on the surface. A kid comes in, you check to see where that child is in their growth, and how they're doing, and step in and try to level the playing field for that kid and for that family.

Cowan: Compare it to the level of activism you were involved with in the medical student movement.

Bronston: It was tame. This was totally different. In my naivete, this was butterscotch pudding. Whereas the world around the student movement was an extraordinarily complex Persian rug. The stuff that I was doing in the Child Development Clinic, first of all, was very passive, I was observing, I had no power. I was doing a piece of research with Dick. We were studying 134 families that he had been following for over a decade, of children, in order to see what happened with them through this wonderful community-based clinic intervention. It was just sweet, red, white and blue, and did not have the profundity or the complexity of what I was really searching for in the field of psychiatry.

Cowan: Were you thinking at all that it needed to change? The way developmentally disabled children are treated?

Bronston: No, it was really a new thing for me. One doesn't understand or know much about developmental service or developmental disability or mental retardation in the normal course of things. It's not taught in medical school. "Mental Retardation" was a diagnostic label. It's presented as a chronic, incurable condition, and it's linked to I.Q. There's no pedagogical depth to the whole issue, so that the drama of family life, the drama of the delicate and profound fabric of what holds any of us in our place in community, in society, in school, in home life—that stuff is not part of what we learn. As med students, we learn this esoteric litany of illnesses and even more esoteric and changing pharmacological ways of approaching different kinds of conditions, and exquisite diagnostic strategies for which we don't have treatment capabilities. We have infinite ability to describe and define a problem, and had only about six ways of dealing with almost anything in child development. The thing with the CDC, with Dick, was that it really did broaden me, and my perspective matured over the years. It really gave me a sense of tremendous familiarity and connectedness to this remarkable collective strategy of serving people.

The CDC literally was a medical village. We were a medical village. And families came to us, oddly enough, as an external member, as a visitor to that village, to our center. The center being the hospital, which in itself is a contradiction. We then brought every drop of diagnostic and service capacity to put back in to that family, into their home, into that kid's school and keep that kid at home, out of hospitalization, out of warehouse placement, out of the institution, and support that family. The most profound lesson and reality of that experience was that all kids grow. As human beings we all relentlessly grow. We never stop growing. It doesn't matter whether you hit the normalcy mark at two, or you hit the normalcy mark at twenty-two, or you hit the normalcy mark at eighty-two, you're going to keep growing and changing. To sentence a human being, a child, to the ignominy of some kind of low social or status plateau, or to define a young person as an "eternal child," and all of the stereotypes and superficial, dehumanizing, objectifying, stultifying, is really so destructive to that child and family's healing, growing, development. Most typical medical and professional people are taught to see and enhance their own relationship to the public by sterile and one-dimensional judgments.

Dick's clinic was this incredible flower of evidence that growth and development are the same as life. He underscored that if a kid was breathing, they were growing and developing. It didn't matter how clinically trashed they were for the CDC team to value and affirm an optimism for that child's future.

The dramatic outrage was that the system of out-of-home-placement would take a kid that is significantly disabled, with significant growth retardation, developmental delay, and put them in an environment that doesn't expect anything more to happen, and can pretty well make that growing creature stunted. What we saw, across the board, in segregated institutions was children put into death-making, life-taking, hope-extinguishing, expectation-destroying environments, milieus, and professional relationships. From that moment they would become progressively retarded. The thing that was the most impressive to me was that "mental retardation" was an artificially constructed phenomenon. Not only in its definition, but in its management. The system managed people to "manufacture" mental retardation, and made a living at it. Residential facilities and segregated schools made a living at stunting growth and demonstrating that people can be disabled beyond repair as a way to justify professional ignorance and dehumanization that was the norm all around us.

Cowan: When did you reach that point?

Bronston: It just kept coming. It was so amazing. I'll tell you, the point where it exploded in me was many years later after my work at, Willowbrook state school, when I began to learn, through the eyes of Wolf Wolfensberger and Burton Blatt, leaders of that whole movement. They articulated the principle of "Normalization in Human Services." This paradigm became the cutting edge of the civil rights movement for the disabled community in those days. The absolute opposite outcomes of the two cohorts, one cohort of people put into segregated congregate institutional life, left in traditional dead-end, with dead-expectations, medically oppressed, abusing environments, versus those children that were served in extremely integrated and demanding, small group community-based developmental programs, especially where there wasn't more than one in five, or one in ten of the kids in the program with some kind of disability. The difference between the latter children, age-appropriately and culturally managed and served, in an integrated, inclusive setting, where normal expectations existed, for all the kids, and where the paradigm was typical growth and development, showed the utter evil and destructiveness or institutionalizations.

I learned that you get what you expect. Human expectations, conscious and unconscious, are the absolute determinants of behavior and development. If you expect a kid to grow and be something, they will be. If you don't expect them to grow, they won't. What happens in the developmental delay field, the mental retardation, developmental disability institutional reality world is that this whole world has ratcheted down their expectations. It trades on the thesis that people are what they appear though appearance is completely misleading. There is no link between the traditional "helping" approaches and the indomitable spirit of life and possibility and miracle that's inherent in life. It's so dramatic. Dick Koch started this insight and Wolfenberger took it to the highest point.

As a result of the law suits, we saw children in matched partner programs there in high-level, high-intensity, high-challenge, small, fully integrated community programs and the matched kid in a state hospital, back ward. The latter became a knot of desperate flesh, being seen as something that the janitor forgot to sweep out that night and put in the garbage can. The former became a smiling, glowing, energy-yielding child. Regardless of the magnitude of the disability, the kid could be close to coma, but would be properly dressed, properly positioned, properly surrounded with the right development media, the right peer relationships, that child would become an asset in that environment.

Cowan: You saw this early on?

Bronston: Yes.

Cowan: I just want to ask you for a second about your reference about the *Sesame Street* segments for future readers. What did you mean?

Bronston: Well, *Sesame Street*, at least in the old days, I haven't seen it in a very long time. *Sesame Street* began experimenting with putting on segments on their program specially directed to kids with mental retardation. They would reduce the complexity of the segment, and they would minimize and reduce the variety of stimulation on that particular segment, on the assumption that a kid with mental retardation, or with slow development or whatever, couldn't handle that much stimulation and couldn't learn. They had to carve down, reduce down, simplify, slow down everything in order to match up with the capacity of their perception of the child with suspected or presumed mental retardation, their stereotype.

All *Sesame Street* did was succeed in creating "retarded segments," thinking that the retarded child, so-called, labeled, "retarded child" would relate better to the retarded segment. It was almost comical. They did tons of "research"—the way they did research on segments for regular kids to figure out how to get across a piece of information. It's very interesting. And what you saw was this strategic and ludicrous development of the whole education industry that is into "manufacturing" mental retardation for profit. Whether kids fit it or not, they're going to have "retarded" records and "retarded" books, "retarded" toys, "retarded curriculum." And they call it "special." "Special" is the code-name for anything with lowered expectations. With "special" goes this haunting sadness that the user or learner will never be quite normal. They'll never quite "make it." Rather than saying, 'making it is pretty complicated in this life,' it has about two billion variations. Making it is about two to five billion wide, it's not three wide, it's not one wide. Making it is inherent to everybody's life. So the question is, how do you make each of those lives cherished? How do you nurture? How do you ensure respect? How do you make each child effective? How do you level the playing field. How do you invent or discover or acknowledge that exquisite give and take between any two human beings, unjudged, and about the contribution each gives to the other, in terms of making life a marvel for all?

Cowan: How did your path go from the clinic and med school to your internship and residency at Menniger School of Psychiatry? Tell me how that evolved.

Bronston: Oh boy, that's a very complicated period. It's hard to bring all that stuff back in clear focus because I'm not even sure I was in clear focus. I was like a landslide. I was just this gigantic rock and gravel slide coming down this endless hill, with enormous momentum, and all over the damn place. I didn't know what was happening. I was not being managed, it wasn't a career for me. It was like a discovery, day in and day out. The sequence was going from these heady and totally ecstatic experiences around the SHO [Student Health Organization], then of course, my whole sojourn at CHC [Children's Hospital Clinic]—after medical school, I had to go to my pediatric internship at Children's Hospital in LA.

At the end of medical school I was already an active voice in the nation around the medical antiwar movement and the civil rights movement through my relationships with Dr. Quentin Young and the Medical Committee for Human Rights centered in Chicago. I was on the National Governing Board for the MCHR which was a physician, medical student and nurse professional organization devoted to progressive, social medicine and social change, and the doctors as social activists. Also I was very active in an informal way with the Physicians for Social Responsibility, and Dr. Bernard Lown at Harvard who was a very beloved friend. Because of all the organizing work that I was doing with the Student Health Organization, and the anti-poverty money that was coming in, through the work of my colleague, Mick McGarvey and others in the organization from the Office of Economic Opportunity, and Dr. Joe English who was the head of the OEO at that time, the SHO was becoming really famous. It was a big deal. It was well known and very vibrant and very active and there were thousands of us that I had facilitated and put together by my trips throughout the whole United States.

Internship At Children's Hospital, Los Angeles

Cowan: When was this happening?

Bronston: When I was a senior in medical school. At the end of my medical school career, I had to do an internship, and I decided first of all, I had been so politically active, that my normal career path was a little confused. I knew I wanted to be a child psychiatrist, so I knew I had to go to a psychiatry residency. I figured it would do me well, as long as I'm in medicine, to really get an intense grounding in pediatrics. Where better than at Children's Hospital? While I was still a senior, I had met such interesting leaders from around the world, through the CDC [Child Development Clinic], that I decided that I would try and spend a year in Sweden in a post-doctoral year of study. So I went to visit Stockholm, knowing where I was going and who I was going to go meet, and set up a model plan for a three-part fellowship program with the Swedish government leadership in mental retardation, child psychiatry, regular children's public health, and set about making plans to go do that as part of my next adventure.

The problem was that I couldn't legitimately leave the United States. I found out afterwards, because my draft board wouldn't let me leave the country. Because they wanted all us medical students to be drafted into the military. I then applied as a conscientious objector because I was fiercely, self-consciously pitted against this country's war policies and politics in Vietnam. To be a conscientious objector, I had to gather support letters. I spent, god I don't know, I spent months thinking about and writing about and positioning myself because I knew that no matter what the draft board decided and what they did, I was not going to serve in the military even if I had to go to jail, or whatever.

I didn't care. I was a student leader, and I needed to walk the talk. Fortunately, the draft board in West LA, in Westwood, gave me my 1-Y, they gave me the c.o. status. I brought in twelve, fifteen letters from the leading progressive people in the United States in the medical field affirming my stance as a pacifist and to vouch for my integrity. Because I didn't have a Quaker background, or a traditional religion analysis, I had to invent a secular position that legitimized my opposition to war, and to killing of any kind.

Cowan: Did that mean you got to go to Stockholm, then?

Bronston: No, I couldn't leave the country. As a conscientious objector, I had to go to do two years of alternative military service. So all this was happening during the end of my internship year. The point of draft was at the completion of my internship, then to Vietnam. Dick Koch helped me get accepted at Children's Hospital to do my straight pediatrics internship.

So I spent the year at Children's Hospital, really embedded in one of the most demanding, rich, beautiful and complicated experiences one can imagine, taking care of the sickest children in the world. Children's Hospital was a regional medical center where kids were sent from doctors and hospitals in the Southwest region of the United States that didn't have the answers and couldn't deal with the magnitude of their patients' illnesses. So we saw the most esoteric conditions that didn't even have names, many of them. Children's Hospital had these enormous research and lab-based professionals and the most exquisite gamut of specialty physicians in cardiology, neurology, metabolics, whatever. Every medically different kid, every unusual dying kid came to Children's Hospital in Los Angeles. I was on duty every other night and every day, and lived with my wife, Janet, in these ramshackle tenement quarters that were assigned to the house staff, the residents, and the interns,

Cowan: Were you operating as a psychiatric intern?

Bronston: No. This was a pediatric, straight pediatrics. There was no psychiatry, although there was a psychiatric program of course. And, of course, I still had my profound relationship with Dick and the CDC. I was on duty all the time in the hospital. I would go to work at six in the morning, I would work through till four the next day. Then I would go to a meeting that night, because I was still very much an influence in what was going on with SHO, or something. And, of course, I had a wife also. Then I would go back on duty at six the next morning, through four the next day. Day in and day out, it was relentless. The problem was, how to balance my political life, my work as a student leader and a spokesperson, because the war was only getting worse, and the civil rights movement was only getting fiercer.

Cowan: How did you do it?

Bronston: I don't know, I don't quite remember, it was just a blur. I was everywhere. One of the problems I had was that I continually had to shift my on-call schedule, which really upset the administrative leadership of my residency program. I would trade around with the other interns and take two nights in a row as opposed to every other night, depending upon when meetings were. Nobody had ever asked us, day one, word one, about what we were doing for all these months, and now years, in putting together a radical health science, human service, professional movement in the United States, to some how turn this giant battle ship away from the AMA, away from fee-for-service, away from private medicine, towards socialized medicine and public responsibility and full citizenship. As students we knew we had to normalize our relationship in this society from being seen as immortals, the medical priesthood, back to being just folk, which, all of us felt, was critical to healing. We had to be able to relate to people shoulder to shoulder, eye to eye, heart to heart to really have the kind of enduring, comforting impact on healing. Right at the end of my internship, I was invited by the US/Mexico Border Public Health Administration for the first time to give an international presentation about the work we had done in organizing medical and nursing students, progressive medical, and nursing students in the United States. It was an incredible honor. Mick McGarvey and I co-wrote this presentation about our student organizing work and our ideas that had gone on, the events and the showcase service models that we had developed all over the United States, in Chicago and New York and LA. But I couldn't get off work, when I asked for time to make the trip. They wouldn't let me off work. The chief resident, Mark Peterson, was fed up—they were finished with me. There was only about another month of internship left and I could not get one of my peers to take my place while I went to Mexico. The meeting was held in northern Mexico in a town in the state of Coahillo, in Mexico. In order to get there it took an entire day. I had to take a plane, a train, a bus, and then a car to get to where this meeting was being held. This was into the hinterlands of Mexico where this amazing international meeting of U.S. and Mexican public health professionals was being held, the annual meeting.

[Tape 4, Side B]

Cowan: Did you get to attend it at all?

Bronston: Yes, I did. But let me tell you, I was desperate. So finally, I went to Dick. I said to him, "My dear teacher, help me. Can you cover me for two nights?" He was a full professor of pediatrics. Of course he said, certainly, I'll be glad to do that for you, but it really pissed off my chief resident. I mean, to have the professor of pediatrics doing my work. My peers didn't understand what was at stake. I had to take off and go to Mexico in order to deliver this talk, and I thought to myself, goddamn. If they fired me from my internship, I would still go. I was going to go. I was going to go. This was the first recognition of all of our student work, to be able to speak at an international meeting about the significance of what we were doing.

The whole thing was kind of silly because no meeting, no one talk really makes a difference, but it was a poignant time. I was so tired, we had worked to so long and so hard that I just wanted to sum up. I wanted somehow just to get in touch with the big picture and the very effort of pulling it all together and describing it all, what it meant, what it stood for, what had happened. It was like a final culmination, a final realization of all this work. It had been a totally wild, unmanageable, many month kind of struggle and discovery. It was very confounding and confusing in my head about what the hell we were doing, and was what we were doing shareable. Was it transmittable? Would other med students or doctors around the world care?

Part of what I was interested in was that it was clear to me that most medical students in most of the world were progressives. It was only in the U.S. that we had this aberration of egotism, greed, business-orientation, male-chauvinist subjugation of women professionals, white chauvinism as the norm. So I wanted to go to this international meeting, to Mexico and say, "Brethren, we have seen the light, a few of us, and we're trying to regain the high road and the path of service, of humble service, and of organized service and of social consciousness and of militancy, and we're not going to let anything hurt the people if we possibly can organize and oppose it."

Cowan: That must have been a wonderful meeting.

Bronston: It was great! And the trip down there and back was wild. [Laughs] I was just going out, who knows where the hell we were going out into the hinterlands? Public health people in those days were like anthropologists—they were very authentic and low to the ground and authentic professionals. It's not like being an elite doctor where you're behind the mystique of technology. It's like being with the poor on the land. It's a wonderful different professional consciousness. Most of the public health people tend to be very progressive, very socially conscious folk.

Cowan: Was the meeting successful?

Bronston: Oh yes. It was fabulous, I'll give you a copy of the article.

Cowan: I would like that. So when you got back to Children's, was everyone mad?

Bronston: Yes, I was really persona non grata but then it was all over anyway and the internship was finished and they gave me my internship certificate. So I came back, and of course, I was elated. It was a little bit anticlimactic, also. I went down there with Mick McGarvey, my comrade, who was at that time a third year medical student. He's just incredible. Mickey's just been a great brother, comrade, all my life. Even though we don't see each other much, we have this great friendship. Anyway.

I came back, and I just embraced Dick, my mentor, and thanked him and told him about the meeting and gave him the paper that we delivered. Of course, the chief resident, Mack, stayed pissed at me forever. He never forgave me. This was just a transgression. I had breached the fundamental ethic of being a responsible intern and a doctor and my obligation. I understood where he was coming from, but there just had to be more than one of us taking care of business out there. And the business was bigger than just what was right in front of your nose.

Cowan: Before we move on to the residency, do you have any final things to say about your internship?

Bronston: Well, the internship was profoundly complicated as I said at the beginning. The rotation that year took me through the opportunity to see and meet the cutting edge technology and people of children's medicine. What was most interesting at CHLA was an enormous traffic in neonatal problems, in newborn kids that were teensy, born well under five pounds, some only as big as your hand. Less than a pound. A pound in size that were going to be kept alive and helped to thrive in whatever way. The heroic medicine I saw was so awesome. I couldn't really fathom it. I couldn't fully understand it all. But I really was in the water with some of the most toweringly inventive and capable doctors and nurses. They weren't necessarily very social people, but the stuff they did was fabulous. The fact that these rare cases were all collected in one place, embedded in me a sense, over and over again, of the possibilities of what human beings can do, of the miracles they can bring together, especially in collaborative contexts.

There was no limit to what medicine could do to make life better for people. It just hinged upon its philosophy and its practice. I learned a lot, in spite of myself. You couldn't help it, they pounded it into all of us in training. You were on duty all the time, dealing with the most complicated problems. Any given kid would have three doctors. This was the norm. This was what I presumed was business as usual. Here I am in this teaching, research, regional hospital, one of the greatest hospitals, maybe in the world, which I just took for granted. I was like, hey, I'm going to work this morning. I stumbled out of my living quarters, which was like a hundred yards from the hospital, throw on my whites, grab my tools and I somehow slide into the hospital and begin work, often dead tired, learning and watching and dealing with the sick children. I met some magnificent people there. The drama and power of having kids close to dying all over the place every day was really riveting. It's an overwhelming experience, and you can't do it alone. You have to do it in company, and there was company there. It was good, it was a great experience.

And in the meantime, the world situation was boiling over. The Vietnam war is growing. This was 1965, 1966. The civil rights movement is growing, and I'm two years ahead of most of my activist peers, my political peers, who were still in medical school. I had to go on, and I was ready now. Now was the time to make the move that I had been aiming at since Meyerhoff taught his course in Freud at UCLA; all those years to go into child psychiatry. I had to pick a residency. So I looked very intensely at those residencies that were classical residencies in terms of Freudian psychoanalytic theory and the way in which the residency would be taught in a more than straight medicine way. I finally settled amongst a number of programs. I was looking at Albert Einstein in New York and I finally settled on Menningers, in Topeka, Kansas, which was a strange settlement because I had no idea what living in the middle of the country would be like. I didn't have any idea what the culture was going to be like.

On the other hand, it seemed to me like I was going to a sanctuary and monastery. It was out in the middle of nowhere. It was a highly classical orientation with a psychoanalytic ground to the whole thing.

Residency at Menniger School of Psychiatry and Topeka State Hospital, 1965-1968, seeking balance between public health, psychiatry, and child development

Cowan: This is the Menninger School of Psychiatry in Topeka, Kansas?

Bronston: Right. It was the largest physical psychiatry residency, the largest in the country. It had something like three hundred residents, it was huge. It had been shaped to serve the United States during the Second World War. It had been founded by Will and Karl Menninger in order to feed psychiatrists into the Second World War effort in order to support the troops getting back on the front line despite this overwhelming destruction that was going on to people, and social and psychological consequences of that. So when I finally realized that I couldn't get out of the country and I couldn't go do my year in Sweden, which really was a year to try and develop some kind of understanding between public health, psychiatry, child psychiatry, and child development that would really make me a national force, it would make me a national professional, I drug off to Kansas.

My first wife, Janet, who was an airline hostess, for TWA, refused to go with me. She, at some deep level, knew that we were a mismatch, that she was looking to settle down and I was looking to explode out. I was growing at a rate of speed and with a frenzy and a fervor that just depressed her. There was no limits in my life, whereas she had learned that life had to be accommodated and that limits were part of what made life beautiful. I just had no time for that. She resented my parents putting money into our lives to help us, and wanted very much to be the principal provider while I was in school. She was away almost all the time flying anyway. These were the pre-jet days. So she was flying on a constellation, she'd be away for a week flying to New York. We didn't see each other very much. I was not a responsible husband. She must have sensed that.

Cowan: No kids?

Bronston: We didn't have children. At the end I wound up packing up my VW with my belongings. I left my art collection with her. Whatever I could carry in my VW, that's what I went to Kansas with. I drove to Kansas, and I cried for the first day, I almost couldn't stop crying, through Needles and then through Arizona. It was really hard. I arrived in Topeka in the middle of this corn field terrain and drove up to this very extraordinary, mansion-like facility which was the Menninger School of Psychiatry, and near it, this ancient hospital that had been built very early in the 1900s or late 1800s that was the Topeka State Hospital where I was going to do my two years of alternative military service. I was living on the grounds of Topeka State Hospital. It was a very idyllic space. I came soon to understand that this was the style of institutions built in that period during the time when they wanted to exile deviant populations from the general population, initially to protect the devalued people, but then, to also "protect" us from them, during the eugenics period.

I was able to engineer a double dorm room in a sub-basement. So my windows were at ground level, and I was on the corner of this stone building. I had a bathroom in between my two bedrooms. I had kind of a sitting room and my bedroom and my bathroom. As I said, I went there to learn classic psychoanalytic theory. I was in a state hospital psychiatric residency program that was part of a complicated constellation of operations managed by the Menninger Foundation. The Menninger Foundation was this extremely elite organization that was one of the three largest economic industries in the state of Kansas. The way that the program worked was the residents came and paid tuition to the School of Psychiatry where we underwent their didactic program and paid tuition. In the meantime we earned a salary from one of a number of state or federal service programs. One of them being the V.A. hospital where a contingent of my class was in training. The State Hospital where I was working, a mental retardation facility called the Kansas Neurological Institute, and others including a boys' training hospital, a girls' training hospital.

Cowan: What do you mean, a "boys' and a girls' school"?

Bronston: There was a boys' school and a girls' school that were sort of like residential programs for kids that "needed fixing," whether they were adjudicated kids or crazy kids or whatever. They weren't retarded kids. Retarded kids went to Kansas Neurological Institute. Then, of course, there was the private Menninger Hospital. Two residents from my class, out of the hundred or so young men and women in the class, wound up being selected to be residents at the Menninger Institute which was a private hospital for private-paying, extremely wealthy, extremely significant people. Children of significant people were sent there, like going to the Mayo clinic for care. The rich people would send their crazy kids to Menningers for treatment at the private hospital at something like twenty-five thousand or thirty-five thousand dollars a year, which was sort of like two hundred thousand a year in today's dollars.

Cowan: So it was very different from the Neurological Institute.

Bronston: Oh, the Neurological Institute was the other end of the spectrum. Curiously, I never set foot in it. Interestingly enough, in the whole time I was in Kansas, struggling and organizing, I never went to KNI because it was almost like another world in itself and I wasn't sure what it was. I did become acquainted with Bob Perske, who was the chaplain at KNI. Bob later became the leading writer in the most spiritual and poetic way about the lives and experiences of people with special needs in this country. His wife, Martha Perske is the leading artist that has done some of the most poignant imaging of children with severe disabilities, and elders mental retardation.

Bob was in Kansas at the time on management's side, and it's something that we've always pondered after that. There I was, very depressed, in my residency program, somehow from the anticlimax in my life and break-up of my marriage, after two years of what seemed like total chaos. It was almost like coming back from a war, after being at war for two years. You finally come home and you're trying to reorient yourself. It's like, where did I leave off, what was I going to do, how am I going to get back to normal, what's normal anyway?

Priority, still, to bring humanity into American medicine

Cowan: You're referring to coming out of the—

Bronston: The movement, back to my medical academic training. I didn't pay much attention to learning while in med school. Even so, I got to be a fairly good doctor, but that wasn't my priority. My priority was fixing American medicine. My priority was somehow being at the helm of articulating where we, as a new generation of doctors and nurses, needed to put our efforts and needed to make our mark in order to somehow bring some kind of humanity back into this terrible for-profit system. What I thought was terrible then! In retrospect, compared to where we are now, it was heaven.

Cowan: So you wake up, at the Menninger Institute—

Bronston: In classes, right. I would go every day to classes at Menningers, didactic classes, lecture classes, and then I would go back to my state hospital residency to work and to run my ward. I had a ward of twenty-five to thirty very dynamic, very crazy, mostly young people, with a very small professional staff. My ward charge was a guy named Emerson Stamps, who had been a hospital worker forever and was the senior African American psych technician. He was my basic teacher. I don't even know how to begin to talk about some of this stuff, on the ward, you know. It's so ancient. It's like antebellum relationships. First of all, it became clearer and clearer to me that despite the fact that Kansas was a free state, that the black community of Kansas was really the underclass, naturally, as the black community is everywhere in the United States. Not only are they the underclass, they're the "maintenance" class.

It was these black workers, psychiatric aides, there at their barely minimum-wage positions that essentially were the ground of training and of guidance for all of us in the residency program, to teach us the rudiments, of where the rubber hits the road, how do you treat people? How do you interact? Who do you interact with, and when do you interact on the ward? Our psychiatry professors were sitting out there at Menningers Foundation, which was a few miles drive away, in classrooms, completely divorced us from us as trainees, where the misery and the struggle and the suffering existed as we practiced in our various public hospitals. It was the psych aides on our wards that really knew the ropes.

The other interesting thing to me that I began to understand was how central the hub of the Menninger Corporation was and how it essentially had control, literally ownership, of every mental health facility in the state of Kansas, and used the federal, state, and county support dollars as a way of subsidizing us, to in turn subsidize them to run programs which were in fact extremely different from the quality of the program that they ran for their rich patients in their private foundation hospital.

Cowan: How did you come to understand that?

Bronston: Well, it was very obvious. We went to our private school class every day and got state of the art criteria of what the diagnosis and management of mental illness was all about. Then we would go back to a public hospital ward where I'm the only doctor, and there's twenty-five to thirty of really the most disturbed people imaginable. With one or two charge aides and a nurse.

Cowan: You were on these wards with just a few people to help and you were the only doctor?

Bronston: Yes, and there was no way that we could put into practice the theory and the strategies of healing, interrogation and support just by time and by numbers. On the other hand, the situation at the Menninger Hospital was that there were <u>two</u> charge aides assigned to <u>every</u> patient around the clock. Two to one. Not one to twenty-five. It was the beginning of my learning. I was really thunderstruck by the class distinction, but not in an antagonistic or hostile way at that point yet. Part of it was that I was really trying to reduce if not liquidate my activism. I knew from day one that I needed to get back to normal, and I needed to be a student again, and I needed to learn again and to stop talking, my advocacy to stop. I was a "human doing," not a "human being." I needed to pull back. I can't tell you how out there I was for the two years, my senior medical student year and my internship year. I was WAY out there.

I just somehow wanted to be comforted with a normal, repetitive day and no political activism. Even though I was still subscribing to all my at that time radical literature; *Ramparts* magazine, *The Guardian* from New York, the SDS *New Left Notes* and the Panther newspaper would come regularly in the mail which I cherished and was my contact with the real world, the outside world. Because Kansas was really parochial. I just tried to settle down and learn and work. I didn't really take full note of the discrepancies, and I just thought to myself, "Shut up, be quiet, learn and serve." I loved what was going on in the wards. I loved the people I was working with. The workers were wonderful to me, they were very kind and gentle. The people on the ward were "crazy" wonderful. Even if they tried to kill themselves. I just had endless patience, and I was there for them. And they were there for me—it was an interesting mutual healing situation on some level. If I could help them, they were helping me, on some level. Which is part of one of the things that you want to get rid of as you get more professional, is to not be co-dependent on the people around you to fix you. At that time I was still green and still coming up.

What I was saying before was that the workers in the ward were really family. They were antebellum family. They were black. They all had at least two hospital jobs. They worked two shifts a day because that's what it took to make ends meet in this "plantation" mental health facility. That hadn't changed since the beginning.

Cowan: And yet they were the ones that were truly training you.

Bronston: Absolutely. I got the theory at school. But I got the care strategies and the support and the connectedness, the friendships and the collaborative partnerships, the comradeship there on the ward.

[Tape 5, Side A]

Bronston: This was really the first time that I really got submerged in the whole world of psychiatry and began to appreciate the richness and the complexity and the struggle of working with people with what was called mental illness, and to try to understand their plight and the vocabulary and the strategies of somehow making a difference in their lives. Now remember, I'm dealing in a hospital-based program. I've been raised really to value non-hospital-based programs. I've also spent the last year developing this exquisite allergy to private medicine, to fee-for-service medicine, to drug-based medicine.

I've come to Kansas to become a philosopher-monk. And to somehow follow in Freud's philosophical footsteps. I came with a bias, a thorough kind of influence of socialist and pacifist and activist, working-class, union-allied, family-based tenets of taking care of business. I come into this old-world, traditional, hierarchical, authoritarian, very devious setting, devious in the most extreme possible way. Right away the gossip, the stuff you didn't hear about, about how anybody at Menningers who was opposed to anything, or who doesn't fit in and gets smoothed over gets labeled as a psychiatric problem. Everybody.

Cowan: You mean, interns, or residents—

Bronston: That's all there is. The patients in the hospital don't count. They're finished, they're already packaged and the expectations are set for them and their roles are set for them by their diagnoses. The people who come as residents are fair game, not to mention the attending staff, all the way up and down the line. So the way in which the culture and pecking order works is that people analyze each other and have diagnostic rationales for why things aren't working and what the problems are. It's very incestuous, a very sick way of handling, a very anti-democratic way of handling conflict and differences of opinion.

Cowan: Just label people who dissent or disagree as "crazy."

Bronston: As having some sort of personality problem, as neurotic, or whatever it is. This is part of their psychopathology.

Cowan: You began to notice this right away?

Bronston: Oh yes. It came quick. There I am. I'm in my ward every day. And I'm learning every day. I'm just kind of taking it a day at a time, and everything is okay for a while. I volunteered at least to be on the Resident Advisory Committee that met with my hospital director, a guy named Bay, who was of course, one of the faculty at Menningers, and was the administrator M.D., psychiatrist administrator at Topeka State Hospital. I became the secretary for the Resident Committee in that I kept the minutes for them. I learned early on that he who takes the minutes defines the issues. I used that effort, rather quietly, to try and build up the Resident Advisory Committee agenda and to learn more about and test the limits of the situation; not with any purposeful idea or strategy except to make things a little bit better in our work place and bring out discussion and dialogue. I began making friends in there.

Involvement in hospital strike reawakens activism

Bronston: Lo and behold, in Kansas City, Missouri, which was about ninety minutes drive away, the workers at the workers at the Kansas City General Hospital had a strike. All the workers went off. All of a sudden, my ward workers wanted to go on a sympathy strike. I can't remember clearly what all it was that preceded in my political experience with unions and job actions. But I realized that they would be slaughtered without a union if they went out on strike, because they weren't organized, they weren't ready. Through Dick Koch at Children's Hospital, and through my work with the SHO and the civil rights movement, I met some major union people, especially Lillian Roberts, a senior leader of the New York-based District Council 37, the American Federation of State, County and Municipal Employees, and became very close friends with all the top leadership, both at Local 1199 and at District Council 37 in New York. What was clear to me was that if you didn't have a well-organized union, with a good communication system, and a way to function independent of the communication system of the bosses and the administration, they would take you apart. Because they could come after you one at a time and threaten you with firing and threaten you with suspension, all sorts of things. If you didn't have a way to check to see where your group was, on a minute-to-minute basis, they could terrify and squash you.

My charge aide, Emerson Stamps, was really the senior leader of the group. He was an amazing man. He was black as black can be—almost blue, he was so dark of skin. And he had this terrific exotropia, one eye sort of a wall-eye. He was always laughing and had this wonderful gait, a very distinctive way in which he walked. He was beloved with his peers. He was a beautiful and wise man. A mature man, in his mid forties. He had been a hospital worker forever. He was the respected leader in my hospital amongst the charge aides.

In making friends with him, I had been passing him all my progressive literature, the Black Panthers newspaper. None of this stuff was ever seen in Kansas. This stuff was from another world. All the talk about the Vietnam War and imperialism, and male chauvinism and capitalism and racism, all that stuff that was being invented in the American vocabulary in this particular time in our history by the New Left, was like a breath of fresh air. It helped explain things, and helped align people in terms of good and bad, progressive and reactionary, and began to make concrete why things happened, how they happened, who made them happen. What was going on. It was an incredible effort to become political, to make America political which had been damped out really significantly since the progressive movements were stomped out in the days after the CIO [Congress of Industrial Organizations] was somehow purged of its communist and Marxist and socialist elements as much as possible.

Cowan: So Emerson was a leader for people to go out and strike?

Bronston: Yes. And I somehow impelled him not to do it and said, look, I know you've got grievances. I know things are bad here. I know there's underdevelopment, I know you're working too hard, I know the conditions are dangerous. But you've got to organize and we've got to build a union. Because if you don't have a union—.You've got to have a communication apparatus, an administrative apparatus, an organizing apparatus and clear-cut leadership lines that you can draw the line between you and the bosses.

So I traveled to New York to meet Lillian at District Council 37 and arranged to get AFSCME, the American Federation [of State, County and Municipal Employees], to identify a organizer in Topeka that would help us organize a union and teach us how to change the conditions at work. This white cracker guy, a Republican guy, was the existing head of the AFSCME Council 50 hospital workers' union in Kansas, and of course, he was part of the problem. But the ward workers began to organize a union. They set up their own newspaper which was mimeographed and began having meetings and began dealing with their situation.

Within six months we had been able to articulate a comprehensive program of reform. I was just acting as a friend and advisor of the movement. I was already in the beginning of my second year of residency. Topeka had become a kind of home. I was home. I was very much in love with a recreation therapist woman that I spent a tremendous amount of time with. She was my comfort. I was still technically married with my wife, but there was almost no contact between Jan and I. I felt like a single man that's been abandoned at some level by my wife who opts to stay back home. I was very very hurt by all that. I didn't do much about it, didn't say much about it, and never went home to visit, of any import. I was out there alone and undergoing a tremendous amount of personal psychotherapy, the first year, because somehow I wound up being so depressed from having lost my way.

Cowan: So you were doing psychotherapy?

Bronston: Yes. I was being psychotherapeutized by a guy named Bud Hall who was the chief of the Menninger Outpatient Department. He was this incredible, gentle, and brilliant kind of a guy. Very elegant, kind of patrician kind of a guy. I went from about the middle of my first year for six months until the beginning of my second year, during which time I stayed out of action. I stayed in touch with what was going on, with the student movement, because I was constantly involved in polemics and writing and articles and telephone calls. I knew more or less what was going on. I was in my learning monastery.

Cowan: You were taking classes and running your ward and then along comes this strike.

Bronston: Along comes this strike. After the strike was resolved in Kansas City, we then had the rudiments of a union, and workers in Topeka began organizing a union and we began to articulate what our program was, which included upward mobility at work. It included increase in pay, so that people didn't have to work two jobs. It included a meal on every work service. It included a whole range of reforms that would make caring better, that would make career development better, that would make livelihood better, that would make the community better. At a point, the situation began to heat up really terrifically.

Cowan: Were the people in charge aware of your involvement with this union movement?

Bronston: Probably, but I didn't pay much attention to that. I just worked with the workers. I was a peer with them. I was this kid-in-training, and the ones that really had their head on straight were these black workers that were perennially taking care of these crazy folks and who knew the procedure and who ran the wards. Because I didn't know how to run a ward, and my predecessor didn't know how to run a ward and my successor wouldn't know how to run a ward. THEY ran a ward. There were senior psychologists but not in the public hospitals because these places were back wards, where despite the best available, it was still not even up to the minimal threshold of good human care, and certainly nowhere near what I was being taught day in and day out in terms of real psychoanalytical treatment modalities at the Meninnger's Institute where I was going every day for class and paying money to go every day to class.

So what happened was, and I'm not sure exactly how it all got there, but the new AFSCME union was continually struggling to negotiate with management. But management had its own union called the Kansas Association of Public Employees, KAPE. Sort of like here in California where you have the California State Employees Association. It's a management union that has managers in it as well as workers. So there's no way to deal with grievances and problems with working conditions at that level. The ward staff and service workers needed a separate genuine union. They were all paying dues to KAPE, but our AFSCME union was not recognized as a negotiating instrument because it was still extra illegal. KAPE had a contract with the state of Kansas, naturally, so they could control what those negotiations and concessions were like in terms of working conditions and salaries and so forth, which is why things were so abysmal.

In 1968, there were some enormous explosions. First of all, there was an extraordinary aggravation of the antiwar movement in the United States, a building and development of that movement, especially around the presidential election. You know that the seminal political moment was not only the incredible blast around the Democratic Convention and the Chicago Eight trial. In France, there was a huge opposition movement which led to a set of strikes and alliances between the students in France and the organized workers, the Communist Union, the CGI and so forth in France that challenged the Charles de Gaulle government. Some strategies and some political developments occurred there that were absolutely awe-inspiring to me. The students, the university students that were very much a part of the voice of that anti-de Gaulle, supported the nationwide effort to call a general strike. They explained and exposed the real, down-to-earth, self-interested agendas of the capitalist establishment who wanted to crush any kind of dissent or any challenge to the status quo.

The thing that was so impressive to me was that the workers and the students actually, instead of striking the businesses and the plants and the schools, seized them, seized the means of production and confronted the system directly by moving to implement reforms under their direct control. That this approach, to leave the major means of production to the people who privately own them, when that ownership was defined as illegitimate, was really amazing to me.

I had always struggled with the whole problem of when you want to make health care better. If you strike a hospital, you’re absolutely doing exactly the wrong thing in every way. Number one, you’re saying that the hospital is legitimately owned and controlled by the administration class. Two, that the workers have strength apart from the people that they’re caring for. What I always felt in my heart was that if you’re going to fix something in health services, you have to have an iron-clad bond with the people that you’re caring for. That’s where the unbreakable bond has to be made. Rather than removing yourself from direct caring contact, which not only is crucial for patients but is also crucial for the patients’ families, and the community health workers must link to those who are really the open-ended population whose attitude and support or opposition to your action is crucial for the outcome of that action.

So when the students in France began talking about seizing the means of production and about exposing what the real agenda of the French, Gaullist government, it made a terrific impression on me. We were riding a similar situation where our demands for union recognition and the basic reforms that we needed in order to humanize the work in the hospitals existed. The workers were moving forward with this thing—they wanted to go out and strike, they wanted change now, they were ready to take action. The situation was really heating up and we were dealing with a bureaucracy in Kansas which was controlled by a three-man Republican white board of old boys that essentially determined salaries, and benefit packages and the very definition of the relationship between employer and employee in the state. Here it’s becoming very obvious that Menningers is this gigantic corporation, like a big HMO or a health medical corporation with this vast work force, running these plantation-type jobs with negligible salaries, negligible benefits, no training for the workers, no upward mobility.

Three generations of workers in the hospital and forget the victims. The victims are the general community that have to rely upon these programs. Here is a state of the art example of what it should be, right there dead in the center of the operation of the

Menninger Hospital, at this high salary, high caretaker-to patient-ratio in terms of care. Then we decided that we had to draw the line. The ward staff decided. I was honorably included. It was always a privilege to me, because these were people that were already ten to twenty years older than I was. People that were just as beautiful as people get, elders, big extended families, black community leaders, and the civil rights movement is boiling in the country, but Kansas is somewhat...

Cowan: Backward?

Bronston: Sort of, it's cushioned, it's separated from the intensity of that stuff, but the same institutionalized racism is rampant there. The Ku Klux Klan wasn't quite out on the street, although I came to learn that they're right there, when we took the next set of steps. What happened was that there was this one dramatic moment where one of the heads of the union, one of the black leaders, who was an older man, who was a bellhop at the main hotel in Topeka and then worked a shift in the hospitals as a psychiatric aide, had three sons that were in Vietnam. The boys, the three boys came back from Vietnam, and the father offered to get one of the boys a job at Topeka State Hospital, and the boy said to the father, "I don't want to grow up to be like you, Dad, that is not what I want. You're in a dead-end job, look at you." This is now a child of the civil rights movement who's just come back from Vietnam, depressed as hell, on drugs. Because all the kids came back, damaged beyond belief. These were giant young men who are all state athletes.

The father was one of the great sports coaches in the state, but because he was black, he couldn't get a job at a school. So he would coach the black children in the state, one after the other, including his own kids, into being all state athletes. You know, the kid who gets the best basketball player, the best football player in the state. So here's this incredibly proud, incredible father who's a bellhop and a psychiatric aide being told by his son, "Your life's a failure, Dad." That really changed the situation. At that point, he came so hurt, and so angry, to our meeting, and said, "We are going to strike!" "We are not going to take this anymore, we have to change this. If I can't have my son honor and respect me for who I am and what I am because we have not taken care of our own business here in order to make our lives responsible and comfortable and respectable for our children, then what do we have in this life?" "What have we done?" He was just beside himself, it was one of the most moving experiences imaginable.

Seizing of hospitals leads to expulsion and firing from residency

Bronston: The union delivered an ultimatum to the state management that said, if you don't meet these ten demands of ours, we're going to take action against you. And of course, the state didn't, because they thought, these 'uppity niggers,' it was just at that level. We had this amazing meeting of the executive committee of the union and I told them that if there was any other way that we could bring about change rather than <u>striking</u> the hospitals that we ought to try and do it and that I had an idea, that we could <u>seize</u> the hospitals. Even though the union was still very weak and only had a limited number of members, that if we would take that action, it would have a profound impact on pulling the workers together rather than allowing the more frightened and conservative workers from distancing themselves from the militant element within their group.

Cowan: What does "seizing the hospital" mean?

Bronston: Well, here's what it meant. The plan was that we identified a ward in each of the mental hospitals in Eastern Kansas around which we had jurisdiction. The union had potential jurisdiction, that was a free-standing building or place that we could make a demonstration action. Instead of striking the hospitals, which would expose our pitiful weakness in terms of membership numbers. The plan was that we would bring in the night shift and the afternoon shift into the morning, so we would have the full compliment of people that were possible on that particular ward and implement all aspects of our ten-point program that we were demanding of the state. We'd move patient care properly, we'd get people into program properly, we'd get them dressed and washed properly. We'd have all sorts of operations going on including a union school that we could demonstrate. So we would create a piece of theater and we would come in and call this thing a "Hospital Improvement Action" and notify the administration, formally, from the union, that we were not any longer going to respond to any of the directives from the traditional administration; that the union officers would become the new administration; that the doctors and nurses were invited to continue to serve because that was why they were there. They weren't there to be vassals of an administration, they were there to take care of people. The union's motto was "We Care" and so the plan was that we would come in and demonstrate with eight people on the ward instead of two people on the ward what it would be like.

Were the people to do that, the authorities, who we knew would react, would target <u>all</u> the workers, whether they were with us or not with us, because you couldn't tell—I mean, we didn't have one hundred percent membership on any given ward. But we knew that if we picked the right ward, that there would be a preponderance of union members and that the repression would come down on everybody because the administration wouldn't care who was union and not union, they would only see black, black workers. So, one morning, we all came to work—I was the only doctor involved now, there's nobody but workers involved in this thing. There's a couple of school teachers, but I'm the only one that's really tied to the union now for about eighteen months.

Cowan: And has the administration been aware this whole time that you were—?

Bronston: Well, sort of. The union is out there doing their own thing, and I don't go with them to their negotiating meetings or their meetings with management and so forth, I'm just there. I don't know what they know but I'm surrounded—anyway, one morning we came to work with our "Hospital Improvement Plan" fliers and we planned this whole thing and the night shift and the afternoon shift all came in and we took over facilities on about six hospital grounds.

And man, it was like dropping an atomic bomb. It lasted about two-and-a-half hours and then the system—I mean, we leafleted everybody, we explained exactly what we were doing, we held a press conference on the ward. The newspapers were like thunderstruck to have the "nigras" do this in Topeka. You know, what was this all about? Front page news, this fabulous picture of Emerson on the front page with his wonderful crossed eye and his graciousness and his wisdom. I mean the guy was an elder statesman, even though he was in his late forties, mid forties. They arrested everybody and they wound up suspending sixty-five women and men.

Cowan: How did they do that?

Bronston: They just came in with cops everywhere and everywhere where there was an action—I mean they had got it pretty quickly that we had got them pretty quickly. Everybody was arrested. We all wound up in jail, in court. I was arrested too, I think, at that point, because I was helping them, so I was brought into court. We have photographs of all of this. They suspended about sixty-five workers.

[Tape 5, Side B]

Cowan: So they suspended sixty-five, is that all they did, and didn't fire anyone?

Bronston: Yes, they suspended them initially, it was part of the whole civil service thing. They were going to fire them but they suspended them first because they had to have some sort of evidence. They didn't quite understand what all was going on and they needed to do some investigation. Meanwhile, remember, our purpose here is to demand recognition of a union, a real workers union in the hospital system and to address the profound contradictions that made the work and the job too injurious to both worker and patient.

The newspaper coverage was just stunning, every day, every day. We became embroiled in this incredible struggle, this propaganda struggle at the height. Remember, this is 1968, at the height of the nation's explosive developments. There were huge riots going on all over the United States where cities, Los Angeles, Detroit were being burned down as a result of the civil strife that was going on. Then out of nowhere, Martin Luther King is shot and killed. Well, not out of nowhere, but King is killed, shortly before our action, which only takes the thing to an even higher level.

Our union headquarters was in this gigantic AME [African Methodist Episcopal] Methodist church run by this young, militant minister who was maybe in his early or mid-thirties, who was just a saint of a young man, militant—

Cowan: Do you remember his name?

Bronston: No, I don't remember his name. I've got all this in my records. Just an incredible young kid. He was really beautiful. The union has two or three hundred workers and the church is this gigantic square block citadel of a church, and all around the church are white citizen council trucks parked. White boys with shotguns. Klan, that have come to surround the union and to be there as a terrorist presence about the gravity of what was going on. The administration fired me from the hospital at that point.

Let me just jump back real quickly. This was at about the ninth month of the year, of my year. So it's around January or February, roughly. What was interesting was that I had been expelled from the Meninngers School of Psychiatry three months before that because I had gone to a national Student Health Organization meeting in Detroit and, as the elder statesman in the student health movement, had made a major keynote presentation and denounced the AMA [American Medical Association], thoroughly as a "criminal organization" in terms of its true role in the country in terms of health care.

Cowan: What grounds did they use to expel you?

Bronston: That one could not bite the hand that feeds one.

Cowan: [Laughs.]

Bronston: What happened was that the AMA called up Menninger's board and told them to get rid of me. They told me this. They called me in and said, "We're expelling you from your residency program, and you're going to have to leave here at the end of the year because you have betrayed your fundamental role and compromised your image and compromised our image by your activities." They reacted at that time caught between my militant position about demanding national health care and social medicine and attacking the AMA as being the enemy of health care in this country, which it is, and my extreme anti-racism activism in the fair housing movement in the city of Topeka, and my obvious relationship with the black community both socially and politically and in every way.

Cowan: And were they aware sort of, of your involvement with the union by that point?

Bronston: Oh yes, by that time it was pretty out in the open. The day of our action two months later, they expelled me from my residency at TSH, which cut off the completion of my second year of residency, which required me to redo my second year because I had to have, for specialty boards, two consecutive years in psychiatry and neurology to get my boards. So I would have to go and do my second and my third year in the same place. And they were very clear about that. They wanted to get me out of the practice. They didn't want an interloper. And part of that was that I was continually challenging them and challenging Karl Menninger himself, openly in classes, where he would teach, about the disparity that existed in the model at Menningers which was essentially a model of training, what I would call dominant ruling class, economic control class interest, in psychiatry at the expense of providing services to community-based organizations, working class organizations, and organizations of poor people in the country.

We were being taught to train police. We were taught to train ministers. We were taught to train major corporation leaders to understand and use psychiatric and psychoanalytic strategies and techniques in order to dominate their workforces in negotiations and management. We were involved at every level with the pillars of authority and control in American society as instruments, as collaborators to use our medicine to promote a certain class position. Whereas there was no support going to use all this fabulous theory and philosophy to serve the trade union movement, or in the community movement, or in the civil rights movement. Here there was enormous struggle going on, enormous consequences to the stress and the danger and the brutality. Here there was a huge need for having healing and support going on which I had been part of for the last two years through their Medical Committee for Human Rights and their medical presence in the South. We were steeped in an understanding of the magnitude of problems that occurred in the civil rights community and the need for doctors and psychologists and psychiatrists, totally ignored by Menningers.

For example, one of the great doctors in the South at the time, who was part of our organization, was a guy named Alvin Poussant who was really a leading psychiatrist, and really the only major black psychiatrist that was down in the South, working, living in the South, helping the civil rights movement by using his technology. And here I am at the citadel of psychiatry, largest psychiatric training force in the world being trained and they're cranking out programing completely one-sidedly in order to serve the dominant economic capitalist class and its authority-controlled apparatuses, the church and the army and the police. So they got that I was not with their program.

Cowan: Well, I wonder why they didn't get that at the beginning. I mean, why did they ever allow you to come in?

Bronston: They really didn't know.

Cowan: They really didn't know that you had this national—?

Bronston: They didn't know, they were in Kansas. The system isn't held together that well. The struggle hadn't gotten to the point where that kind of intelligence—I mean, people are very arrogant, you'll see as the story unfolds here, as the New York piece of this thing opens up later. Later, the only way I could get a job was to go get a job in a backwater mental retardation institution. And the guy that ran this institution lived in this Staten Island enclave, just as these people lived in their enclave in Kansas, thinking that the world starts and stops outside my door, and "I'm the pasha," and here comes this young, interested, articulate doctor with top training out of Children's Hospital, incredible credentials. They didn't know.

Cowan: So you were expelled from classes but not yet fired.

Bronston: Right. So in the meantime, I no longer go to class, but I still go to Topeka State Hospital because that's where I'm doing my residency work and they let me finish that work because it's work. The other interesting part of that is that I'm there on a two-year obligatory, "alternative military service" assignment as a conscientious objector and have to finish two years in serving the public community as a doctor instead of going to the Vietnam war, which is something that never came up, interestingly enough. It's like nobody was watching, nobody cared, nobody was monitoring. Or if they did, they didn't want to mess with me. I was just out there. But I was clear that I needed to finish my two years. They dispensed their generosity [laughs] to let me finish my training program.

In the midst of that last six months, that explosion around the union and union recognition and union struggle for working rights, better patient care, community development, and to challenge this oppressive, exploitative, impoverishing, system came up. I felt the struggle was really a paradigm struggle in Kansas; a struggle that only had as its antecedent, the uprising of John Brown in the civil rights movement. Since John Brown, there had not been a conscious mobilization of the general populace on behalf of social and civil rights. I framed that struggle as a social and civil rights struggle, not as an economic struggle to do some minor fixes in the shit-hole hospitals that Menningers ran in this imperious way in order to have this economic game going, which to this day is going on. I mean, nothing has changed back there, it's still business as usual.

Cowan: On what grounds did they fire you?

Bronston: Well, they fired me because we struck the hospitals and that was it, they had had it with me and I was the only doctor. They removed me from my quarters in the dorm, of course. And so I moved in with “my family,” the black family, with the father and the sons and the daughter and all that. The mother also worked as a psychiatric worker in the children’s hospital, and was this incredible woman who I just worshiped. We would play bridge and Hearts every night. It was like my family.

During this time, Dr. Howard Levy, a captain who had been made a green beret physician, had publicly refused to teach green beret troops to use dermatological technology as part of their pacification work in Indo-China during the war. And the government came out after Howard and arrested him and he was sent to Leavenworth Prison as a high-level federal political prisoner, in Kansas. I was one of two people to be a liaison between Howard and the outside world, because I lived there, and because I was trusted by the national movement.

I went to Leavenworth to visit him and to bring out his writings and to keep Howard in the public eye, nationally for a while. The first time I went to go visit him in my little VW, the whole reality of my situation kind of came down on me. Why was Howard in jail and not me? Was I doing the most that I could do to stop this atrocious war, and to challenge this atrocious policy in this country? I was very moved and very preoccupied, traveling to the jail, spending a great deal of time with him, taking out a lot of papers that I was carrying with me and driving home.

Cowan: Is this before, during, or after the strike?

Bronston: Before the strike.

Cowan: Before the strike, before you were fired form Topeka State Hospital.

Bronston: Yes. This was in fact before I was expelled. I was driving home from the visit to Leavenworth. It was late in the afternoon, I had very much wanted to see my girlfriend that evening, she was unable to spend any time with me. I was just really preoccupied, and there was this big semi-truck in front of me, and I floored my little car and drove around this truck. When I got to the front of the truck, the highway made an extreme right turn, and there was no way I could negotiate the turn and my car rolled over and rolled off the highway. I wound up miraculously sitting outside my VW with my face literally torn off in my hands, from having come out through the roof of my car. The next thing I knew I was in a hospital in Topeka, in emergency surgery with a plastic surgeon working on my face. I woke up in the hospital the next day with a fractured clavicle and terrible bruises, amazingly unhurt from the severity of the accident. My car was completely smashed.

That completely changed my life. What happened as a result of that accident was I had the most incredible series of explosive rage outbursts. It was the most cleansing, purging, event. I had an epiphany of experience from this accident. I had this feeling that the self-destructiveness in me and the sorrow in me, the sorrow about the war, the sorrow about my own life, the sorrow about the civil rights movement, the sorrow about the people that I was taking care of—I was just so filled with sadness and fury about what was going on around me, despite the struggle and the effort. There was still this underlying sense that life was not the way it should be for anybody. So when I went to Detroit to the Annual SHO meeting the week after I got out of the hospital, I was in a sling, with a cane.

Cowan: The Detroit SHO meeting that got you expelled?

Bronston: Yes, the SHO. I was explosively articulate and angry and clear about where everything was and the words just came and the rage came and the clarity came and the politics came. The AMA knew exactly what they were doing, and if I were them, I would have done the same thing, because as far as I was concerned, it was, it always has been a no quarter battle between us. If there's a block in my situation, I pit myself against what I define as absolutely evil and destructive to the human condition. And greed and capitalism is when it comes to health care and medicine.

So basically what happened, just to try to make this thing linear, it was the SHO national meeting and my polemical declaration of war against the AMA, that led, irrevocably to my expulsion from my residency program, because they saw right away that I was not on their side, in any way, even though I was totally in love with my studies.

What followed that was the set of events that had been percolating and maturing around the organization of the workers union and the reform of the hospital system there in Eastern Kansas and the recognition of the union which led to our "Hospital Improvement Action" and our seizing all the hospitals, the arrest, the suspension of the participants, my firing, finally, and expulsion from my Topeka State Hospital dorm situation. Then a sixty-day period of struggle where I continued to stay in Kansas. It was really one of the most extraordinary health care struggles in the United States of its time, completely blacked out by the news media.

We had at one point, a month into the hospital struggle, maybe eight hundred or a thousand young black men flow into Topeka. The administration had decided to fire, as the culminating, and terminating event on their part, twenty-five of the worker women in the hospital work force. Up till that point, they had been picketing, in large numbers outside the hospitals to encourage people to go in and work and take care of the patients because it was "we care" and that was our position. Anything we could do to protect patient care and community integrity, was part of our political position and part of our line. Whereas, the administration was seen as doing whatever they had to do to retain power and control and to deny the legitimate and just demands that we were making to make work decent, to make patient care safe and ensure healing.

So the result of all that was that when they fired the union women, there was this decision to strike the hospital, finally. Prior, we had never taken a strike vote. Right after that, this is all documented in the Kansas newspapers at the time, this enormous wave of young black men came to Topeka from Leavenworth, from Lawrence, from Wichita, from Kansas City, Missouri, from Kansas City, Kansas, they came to burn Topeka.

We had a meeting in the church that night with this vast army of young men in dashikis and Afros. The country was going up in fire and the firing of these women, was like the last straw for the men of the black movement, the black community of Kansas. It was this big slap in the face. Remember this is front page news, every day, because this hasn't happened before and we're handling this thing at a very high level. The Southern Christian Leadership conference sent in their top speaker, and there was a debate in the church that night with maybe a thousand plus people there, all the workers, the union, everybody. To burn, or not to burn? And the men left the decision to the union. One after another, the workers would stand up and testify about their judgment about the implications of what we should do to advance the struggle for union recognition, improvement of quality of life, improvement of health care, and to address and expose the inherent evil of racism in the system. The vote finally came to <u>not burn</u> because if they burn, the union struggle would be submerged and something else would be articulated.

Thoughts on status of disability rights movement in 1968

Cowan: At the time, what were you aware of that was going on with people with disabilities and the civil rights and independent living movement for people with disabilities. Were you conscious at all?

Bronston: Not at all. It's interesting, I didn't know if anything was going on at that time. It was absolutely yet to come. The disability rights movement succeeded the principle wave of the black civil rights movement. The black civil rights movement was just reaching a point where the system had really beaten it down by killing so many of its main leaders. So much had happened as a result of laws beginning to change. It took some of the edge, some of the inspiration from it, and it began to get to be real hard work. It was then two years later, all of a sudden, that the disability rights movement began to happen.

Plus the other issue you're looking at here is a particularly interesting consciousness in key generations and the antecedent development of certain breakthroughs that lead to new understanding and new consciousness and new voice and new vocabulary on the part of the disability rights community. Without the passage of Public Law 94-142 [Education of All Handicapped Children Act] and the Right to Education for All Handicapped Children Act, you would not have had a brand new population of babies, kids, children that grew up more or less entitled to integration and more or less entitled to individualized instruction.

It's those children that later became the militant activist leaders, I think, of the key radical organizations in the disability rights movement. Certainly, there were leaders like Ed Roberts, many who were exactly my age, many who at that time, were still struggling in-between surgeries, in-between doctors and hospitals, in-between specialized support programs and trying to come to grips with the magnitude of their conditions. Before, there was technology miniaturization, before chip technology really took off, kids with severe disabilities were still confined to home. Ed always had his big iron lung, which was this big dinosaur metal tank which came from early on in his post-polio life. The disability movement did not exist, not even an appropriate disability rights movement from Vietnam. The Vietnam veterans community really represented the first great across-the-board breakthrough in mobilization of a disabled population since World War I. People with disabilities, psychiatric, drug problems—they really crashed into the US consciousness with a lot of problems that needed compensatory help.

All these pieces were brewing. The disabled vets in Vietnam were very key players in challenging the status quo. But they weren't necessarily demanding rights for themselves, they were demanding an end to the war. They were still building an understanding that there was another unique contribution that their reality was to play in the country. The Olympic games, for example, was wholly segregated, and nobody was even beginning to talk about the whole question of having disabled and able-bodied athletes working together, it just wasn't there. Everett and Jennings was still generating their wheelchairs and they had a monopoly on manufacturing chairs and that was that. All chairs had big handles and people pushed people in wheelchairs. There was no independent mobility chair design yet.

Cowan: How were you viewing your patients on the wards, what were you thinking of them?

Bronston: Not as a political group, not at all. I was more concerned with the workers and with the black community and had just a profound bond to the black community. This has just been a steady stream in my life. I was raised by black people when I was a kid. And my bond, even though it has a certain kind of an antebellum quality to it also, a very traditional quality of a young white master being raised by the black workers—what happened to them happened to me.

Cowan: You were very connected.

Reflections on the struggle in Kansas

Cowan: Then before we move on to New York, do you have any thoughts on what it meant for you to be doing your residency?

Bronston: That struggle was a towering struggle. It was really a struggle of national significance. Even though nobody knew about it, the level of sophistication that came out of that, the opportunity to learn, to grow, to see people change was just astounding. It instilled me with a sense of absolute confidence and ability in being able to challenge overwhelming opposition successfully. The thing that was so moving to me was I had, without even thinking about it, the most abiding respect and appreciation for the collective. I was just another color, another strand in this gorgeous tapestry of people whose personal growth during the struggle, the whole union struggle against management and the kinds of oppression and sanctions that were channeled against people and the way in which they expressed their nobility and their fineness and their warmth and their love and their commitment and their disappointment and their hurt and their integrity was incredible.

For example, at the end of that whole struggle, the union was finally recognized, the workers were finally reinstated by court order, even though I was going to be arrested and I'm sure the key thrown away if they had ever gotten me in court, which is the reason why I left Kansas surreptitiously even with a warrant out for my arrest at that point. After I was arrested in that struggle I had to leave the state because we had essentially won in the short term the reinstatement of the workers and I thought that the movement was in very good hands because there were now close to a hundred workers that had been steeled in this tremendous struggle. The whole community had arisen to support them. We had these incredible moments like I was describing with regard to the decision whether to carry on the legal struggle and the working class struggle and the strike versus turning to military consequences which would have hurt the community terribly.

So I left there. I don't even know how to describe it. I left like a dirigible, a lighter than air blimp so filled with gas and stuff from the event and went off to New York with no idea in the world where I was going, what I was going to do. I just knew that I had to leave Kansas because I had no choice.

Cowan: You just left, you didn't have anything planned for New York? You just left Kansas?

Bronston: Yes. Fortunately, my younger brother was living and working in New York at the time and he was gracious enough to let me move in with him for a week or two until I got my feet under me. I didn't have a job. I didn't know very many people. I had all my union friends from the old days. I drove into New York, and unbeknownst to me, came forty of my doctor SHO brethren, who had now reached the point of graduation and were now going into their internships and residencies.

Cowan: Brethren from California?

Bronston: From the SHO. They came from Chicago, they were there from New York, they came from California. Forty of us, forty radical doctors came to New York at the same time in 1968.

<u>Move to New York City, 1968</u>

[Tape 6, Side A]

Cowan: You moved to New York in 1968, but you still have two consecutive years of residency?

Bronston: Yes, that I theoretically should have done. But I opted not to do that. I figured I'd learned an enormous amount in my two years in psychiatry, I really did. I thought that the third year would only be a year where they tried to teach me how to be a business man. That's not the part I was interested in, how to handle a private psychiatry practice.

Cowan: Could you get your license without it?

Bronston: Yes. A license doesn't require a specialty board. So I had my license already. I had my California license to practice when I went to Kansas already because I already finished my internship. Then I had my Kansas license to practice under the aegis of my residency and then I applied for a New York license when I got to New York. So I had a Kansas, California, and a New York license at that point because I had passed the National boards, which allows you to practice as a generalist and get a medical license.

Cowan: But you could not practice as a psychiatrist though?

Bronston: I could not practice as a psychiatrist per se. However, my first job in Harlem, in Washington Heights, I was hired by a small poverty agency called the Puerto Rican Guidance Center which was headed by this gay wonderful poverty program entrepreneur [laughs] by the name of Reuben Mora who was a psychologist and he was really a nice man, very sweet. He hired me because he had just gotten a contract from the City University of New York to do whatever was necessary to provide support for black and Puerto Rican students in the City University system, to cope with the "open enrollment" policy, and the fact that the university was taking in a ton of kids that they perceived as not being able to cut it, and they needed to have all sorts of psycho-social support structures in place. So naturally they came to this community poverty agency to help them keep the kids in school by any means necessary.

So I was hired as a mental health worker. For all intents and purposes, he perceived me as a psychiatrically-trained physician, which I was. He's a psychologist, so he needed an MD in the crowd. He had half-a-dozen psychologists that he was supervising who were working with him, counseling black and Puerto Rican kids from the City University system in New York in order to support the open enrollment program, the zero reject program.

I, with my politics, realized that one-to-one treatment would never work. We're talking about a hundred thousand kids or more. I mean, me? [Laughs] I ended up hiring an artist, friend of mine, who did silk-screen art, lithograph art, a black and a Puerto Rican community organizer. I don't know where they came from, I don't know how I found them. It turned out that both of them were cops.

Cowan: You mean, undercover cops?

Bronston: I wound up hiring these two cops to work with me in order to help in the schools which solved a whole bunch of problems at one time. They wanted to make sure there was good police control and surveillance of this uppity crowd of black and Puerto Rican kids who were demonstrating every other day against cuts in the City University system and increases in the tuition rates. So they had these two young gorgeous, handsome beautiful men. I had no idea that they were cops. I wasn't quite that sophisticated then.

I wound up totally ensconced with the Black Panther party leadership in New York at the time. It was an amazing situation. My strategy was that if I could put community organizers and a community artist at the service of the black and Latino clubs in the colleges, in order to assist them to organize and mobilize their kindred populations, to build support for themselves in the colleges, that I could cut a deal with them to refer to them those kids from their schools who were breaking down and having trouble, for them to do, in their vernacular, whatever was necessary to keep those kids in school. I traded them a graphic arts workshop and two fabulous young organizer men, who were very effective, within their undercover work, in exchange for them taking referrals from me so that I could essentially close out a whole school and provide support for the fragile kids.

There was never an evaluation into whether my strategy worked, but that was my strategy. Instead of one-to-one "shrinking" these kids, and making them wrong, at some level. If the issue was that they were failing in school partly because they just didn't have an adequate peer group, they didn't have a sense of connectedness, then there would be some kind of social support network from their own age group who were the leaders and the activists, to help tutor them, mentor them, and keep them in school. That was the objective, "Don't fall out of school, stay in, get your chops, build it."

Cowan: Would kids with disabilities have turned up on this?

Bronston: No, zero. The disability issue was not there yet. After a year of working in that operation, I was fired because I was so outspoken and critical about the fact that they were doing this enormous hundred thousand dollar evaluation of this program when we needed more staff and more program support for the kids themselves.

The other thing was that I requisitioned a printing press. A real printing press that we had in my office that we were using to crank out thousands and thousands of leaflets for the kids, announcing their events and their activities plus doing these beautiful color posters that came out of my artist's workshop right there. At a certain point, when I knew they were going to come after us, the printing press was mysteriously stolen and wound up in the hands of the kids somewhere, somewhere.

So that was the last straw and they dumped me after a year. I wound up getting another job for another year in another extraordinary venue. My wonderful teacher and friend, Alan Butler, was the professor emeritus of Harvard in pediatrics had been hired by the city of New York in order to anchor the National Nutrition Survey which was Senator George McGovern's program to test the level of hunger in America. Alan Butler was this elder statesman, this patrician, wonderful, progressive, socialist physician. He knew that New York City was not going to do it right and he was going to quit and not be a part of the apologist thing. But part of the trade-off was that they would hire me and he would quit.

They hired me to be a community development officer for the national nutrition survey in the city of New York, taking a front position and going to visit all the communities that were targeted for study in the city of New York in order to get compliance and cooperation with the study. Because these white folks are coming in and doing their study in these black and brown communities, these bombed-out communities. It was a very highly sampled population. So if you lose one or two people, the whole validity of your sample staggers. You're only looking at twenty, thirty, forty people all together, representing a population of a few tens of thousands. So to keep it statistical, we have to have maximum compliance. We would pay people money, but we had to get a blood sample, had to get in the door in these communities.

Meanwhile, I was already deeply connected to the Black Panther Party as a mentor to them, in order to teach them barefoot medicine kinds of activities and to help them. I was an agitational writer and pamphleteer for the Panther Party and deeply connected and very close with the New York Panther leadership, all of whom were key young militant organizers, trained by Malcolm X before he was murdered, as part of the Organization of African Solidarity, the OAS, which was the organization he created after his orthodox Muslim years.

So after Malcolm's death, these young fabulous kids, many with Ph.D.'s and master's degrees, were all incredibly middle class originating, highly successful, highly academic, highly intellectually evolved, radical organizers that were doing housing organizing, health organizing. They're incredible young people who were in their late twenties and early thirties, who were just an anathema to the system. J. Edgar Hoover and the FBI just needed to smash not only Malcolm's group but also the Black Panther Party. So, there was this enormous bust, this arrest of the "Panther Twenty-one" in New York. I was intimately close with most of those young people as a loving supporter. I was giving them whatever I could in terms of time. I lived in Harlem, on 154th Street, in Babe Ruth's old home, which was owned by a couple of elderly black ladies. I lived downstairs and had this big Malamute dog that was my partner. I became very heavily embroiled with the Black Panther Party.

Cowan: You used them to conduct this hunger study?

Bronston: Exactly. I wound up hiring Panthers from community to community, Brownsville, South Bronx, Lower East Side. Wherever the system had targeted, ten years ago in the national census, bad areas that really were potentially representative of places where hunger might prevail. I was to go in there and get cooperation from those families before the actual surveyors came in. I had money to hire ten-to-twelve community workers each time. I would continually pick up Panthers in order to train them under their western names. They all had African names that they had taken on, but they came in with their real names. I was able to channel money to them to teach them about building relationships and have them carry the propaganda of the party deep into these poor communities, into doors, under a legitimate guise.

I got fired from that job after a year, not because of that, but because the National Nutrition Survey was so controversial. The established powers just didn't want it to happen. At the end of the first full year of that, they terminated my position. Most of the survey was already done by that time. I then began to come to the reason you're here. That is, I got a job at Willowbrook State School. The reason I went to get a job at Willowbrook should be more or less obvious. I was already involved in maybe ten hospital strikes in New York during this last eighteen months while I'm in New York. This is now late 1969, early 1970.

Cowan: How were you involved with those hospital strikes?

Bronston: I helped organize them. I went from hospital to hospital, depending upon where the struggle was, and added my small contribution of having been in a national strike in Kansas. That experience was unbelievable. We mobilized thousands of people in Kansas, onto the street in major demonstrations and actions during that whole struggle. I ran the daily union newspaper. I ran the school training program. I coordinated everything for the new AFSCME union in Kansas. I was right on the ground floor. Remember I have forty of me, in New York now—SHO activists who have come to New York for their internship and residencies. We're on the streets around the antiwar movement, 1968, 1969. This is the headiest time in the civil rights movement and the antiwar movement imaginable. Attica massacre happens in all this situation and more friends are killed. So much violence and repression and struggle going on. More and more, tens of thousands of people, are taking to the street which requires more and more of us as doctors on the street in demonstrations to deal with medical presence. In the

South, and in the streets of New York, and in the streets all over the country, and I am part of the only radical medical organization of really "Young Turk" doctors that are really good.

We are also working on these community worker alliances. We built radical professional community worker partnerships in order to save the New York public hospital system which was under attack at exactly the same time, by the major university hospitals that wanted to take over and privatize the city hospital system in order to subjugate them into becoming backward kinds of warehouses for undesirable old people, stroke patients, disabled people. Then they could add to having all the rich and well-insured people served at Columbia, served at NYU, served at Flower Fifth. Each one of the private or big non-profit volunteer hospitals was trying to grab a public city hospital in an "affiliation program" that had been engineered by an old ally of mine by the name of Gerard Piel, who was the publisher of *Scientific America*. New York hired him to engineer this unconscionable and unethical "affiliation" program.

We were organizing in Bed-Stuyvesant, South Bronx, in Lower East Side, in Harlem hospital, we were everywhere. We were an army, a platoon of radical doctor organizers that came out of the SHO from all over the United States, absolutely going to the wall to protect against the seizure of these hospitals, their privatization and the advancement of a bond between us as ordinary people, the patients, and the lowest-down workers, janitorial and ward workers as the team that makes health in America.

Cowan: Was that pretty successful?

Bronston: Well, I don't think so. We didn't have a well-disciplined or a funded army. This was just radical activity and there were too many things going on. When the Vietnam war finally ended, things really came unraveled. In the meantime, I'm on the street all the time. I'm not doing medical work—I didn't put a stethoscope to anybody's chest for two-and-a-half or three years.

Cowan: You're just an activist?

Bronston: I'm just an activist, but I'm a physician, and I'm hired as a physician. During all this time, we were "liberating" hundreds of pieces of medical equipment from the hospitals in order to keep them in the community, to service the Harlem million population, in any way we can, through the Panther Party. As a group of radical physicians, we all were doing blood screening, diagnostic work, nutrition counseling, just to provide something of a sense of militant hope. We were very much inspired by the writings of Franz Fanon and the whole issues that were raised in his books called *Wretched of the Earth*, *Black Mask, White Mask*, the story of the Algerian and African liberation struggles that had been finally documented by a great psychiatrist and physician, this black physician from the Seychelles. This amazing man died of leukemia in his late thirties. He was just a genius of a guy. He laid out the whole structure of how the white system in the twentieth century has subjugated and colonized, directly and indirectly, poor people and people of color in the world. There was so much crossing over in all of this with us.

Willowbrook State School, Staten Island, New York, 1970-1973, goal to work with mental retardation, organize workers

Bronston: When I started looking for my third and last job in New York, I had to go to a place that I felt more or less comfortable with because I knew that I was already way behind, medically. I had to go to a place where I had chops, and that was in dealing with people with mental retardation. I knew that field, because I had been a researcher and analyst and been trained by Dick Koch. All it was was a stop-gap. The other thing is that I had to bank on an employer not looking at my prior record. If they called up for one referral, they would have never hired me in a million years. They couldn't have called anybody to ask—any employer—"Hey, is this guy a regular doc?" Because they would have found out instantly that I was not a regular doc.

Cowan: So how did you know Willowbrook wouldn't do that?

Bronston: I didn't. It was just a backwater kind of a place. I chose Willowbrook because I figured I'd go and try to get a job there, it was in Staten Island. I moved to Staten Island. I moved with two of my doctor colleagues who were from the SHO, working in Staten Island and organizing there. Mike Wilkin and David McClanahan. David was a surgeon and was working at the local public health hospital, and Mike was the worker's physician at the US public health hospital. Then David moved to a local proprietary, voluntary hospital to do surgery, post-residency. Michael stayed at the USPHS which we began organizing which was another story. Later I recruited him to come and support me at Willowbrook State School, once I began to realize what I'd gotten into. It was so massive and so impenetrable that I needed another organizer to help me on the inside that knew the score.

Cowan: Okay then, starting at Willowbrook, you applied, you picked it out, and applied and got the job as—

Bronston: A ward physician.

Cowan: And this was what year?

Bronston: 1970. First of all, I was very grateful to get the job. I knew Pacific State Hospital here in California. I knew it was going to be awful, my standard of awful. I knew that the right way, was community-based services like I had been taught—nothing had changed. I hadn't been in touch with Dick in all these years. I hadn't been involved in the disability rights movement in all these years. It was a whole different thing. When I hit Willowbrook, I tell you—they hired me because I was white, American, young, and I was hot. And I knew penicillin from aspirin. That was about all they cared about. The guy that hired me was Jack Hammond. He was the Regional New York State director over Willowbrook State School, for the State Department of Mental Hygiene. The director of this incredible, infamous place that I didn't know much about.

But it was in Staten Island and I had just moved there with my family. I was living in a large collective home that we all bought together. Three doctors with our wives. We were doing organizing work, because we were basically radical organizers, interested in revolution. Good health care was a pillar of that revolution. A lot of things were going on all the time. We were constantly taking the ferry back and forth into New York in order to deal with all these struggles going on with the Panther Party, with the Young Lords Party, these hospital emancipation programs and anti-affiliation programs, the civil rights movement. The country was in REAL turmoil.

Cowan: So you were looking at Willowbrook as being your day job, your support job?

Bronston: Right. It was just a source of income. And I went in there because it was the largest black factory in the city of New York. I figured, I'm going to scoop up the Panthers in there and provide support for them and help them in whatever way they wanted. It turned out, there was not a single Panther in the entire place, which absolutely overwhelmed me. I could not believe that in a work force of three thousand black people, there wasn't one Party member. In fact, there wasn't even a real union structure. There was the CSEA [Civil Service Employees Association] crowd, the state employee workers. Then there was this black nationalist caucus, of radical black workers, who had a separate signed dues check off, but they weren't legally able to negotiate. The black caucus in there was monitored by the Attorney General directly!

Appalling conditions on the wards: "This was hell"

Bronston: When I went in there, I went in there to organize a union. That's what I went into Willowbrook to do, to organize a union. And to reconnect with the black radical movement, which was the only reliable ally in the struggle in the city. When I got there, I was thrown into this building with two hundred of the most broken people I've ever seen in my life. One nurse in the day, one nurse in the afternoon, no nurse at night. Two ward workers on each of four wards of fifty people each. No programming, no backup medicine. No clothes. Everybody was in these gowns or nothing because there was not enough support to dress them. The minute the clothes would come in from home, they would disappear. This was a closed system. This was hell.

Cowan: On your very first day, this is what you saw?

Bronston: No, not my very first day, but it came—

Cowan: What did it look like when you started?

Bronston: When they walked me through—I'm trying to think of the name of the doctor, I can visualize him so clearly. He was the head doc of a particular building complex. There was a set of five buildings, they were called the "baby buildings." They were a set of relatively newly constructed holding centers for the people in the wards. They weren't part of the old building complex. They were one-story buildings. I got introduced to my building, which was Building 16.

[Tape 6, Side B]

Bronston: Willowbrook was a facility of about sixty buildings scattered over this enormous pastoral, park-like terrain. The grounds were similar to Topeka State Hospital. I'd already gotten the picture of what state hospitals, state put-aways, were all about. They looked like something straight out of a nineteenth century pastoral painting. But, in fact, they were really places of such towering misery and human humiliation and violence. It's incalculable even to describe and litanize the magnitude of the anti-human, cruel circumstances, even in its most essential form.

Cowan: How many people would you say there were?

Bronston: Five to six thousand people with between two and three thousand workers, split among three shifts. So at no time were there ever more than three people on a ward to take care of fifty residents. There was no program. People never got outside of the buildings because there wasn't enough supervision to take a group of people, and we couldn't take all fifty, some had to stay behind. It was a long period—it took me about a year to learn the ecology of what state institutions were all about—what segregated, congregated, holding centers our residential programs were for unwanted and devalued people in America. That's what I began to learn quickly.

What started off was my incredible apprehension. Remember, I came out of Children's Hospital. That's really my last real medical training. Menningers was something else. It was not a fine, high-level medical setting. And its whole purpose was different. Children's was interactive and verbal with constant talking and the meeting of professional people. Willowbrook was a place where there's no talking, where you're just dealing with the stuff of humanity, the physical phenomenon of two hundred people with the most amazing differences in how they look, how they act, how they are, very limited verbalness, enormous spasticity, enormous contractures, enormous stereotypic movements that come from—which I learned later—relentless environmental deprivation. It makes people crazy and bestial. Just to cope and survive.

Cowan: Were people segregated in terms of function or age or anything?

Bronston: More or less age. But it was so gross that I had kids from roughly about six or seven to about twenty-five. It was more based on their ease of handling and their physical size. As soon as somebody got too big or too rough, they were then moved from the "baby buildings" to deeper into the institution, into the adult buildings, or the older buildings that were more physically containing and repressive.

Cowan: Just for a moment, could we go back to that first day when doctors walked you around, before you had a clue? What were your impressions?

Bronston: Well, I had never seen anything like it before. I just stood there and tears welled up in me. I'd never seen such squalor, and excrement smell. The place was all concrete, with no furniture, nothing to soften the sound. There were two rooms, there was a day room in each ward that was a big terrazzo-floored place with these wooden chairs and benches that were too heavy to lift. There were also some fiberglass chairs but those things would fly—people would throw them around. It was absolutely like something out of Dante's *Inferno*. These were wretched "shades" in every form of disrepair, misery, withdrawal, and inhuman state imaginable. At first you don't get the full magnitude of it. It takes you day after day to fathom this "hell."

What I was presented with that first day was shocking. I said to them, “How do I find out who these people are? Where are the sign-off notes? Did my predecessor leave exit notes of who each case was?” “Well, no.” I didn’t even know who the hell was the doctor that preceded me. So I started trying to figure out, how in the world I was going to find out who these people are that I’m responsible for. What’s wrong with them, and where are they going? The fact of the matter was, it didn’t matter. It didn’t matter who they were, because they weren’t going anywhere. They were just being held there as “hostages” in order for the state to collect “public ransom,” federal Title 19 reimbursements, in order to keep them there. It was a self-fulfilling economic nightmare. I came to find out the violence, little by little, as I went along. The doctor had to daily review any problems that arose on the ward, and every week renew all these massive tranquilizing drug orders.

So I began to look at the charts. The charts were four to six inches deep, multiple charts. People had been there for years. They’d been brought when they were three, four, five, and they were now ten, twelve. The charts were filled with incident reports, “pink slips.” Week after week they accumulated, about a cut here, a bruise there, illnesses— The place was rampant with tropical diseases that had been either instilled purposely for study purposes, like they were inoculating kids with Hepatitis A in order to study how to develop a possible hepatitis vaccine, or German measles, or rubella. They had every kind of intestinal parasite that you only see in the center of Africa, Giardia, lamblia, amoebians, worms. We’re constantly sending kids for blood work in order to make these diagnoses in order to put them on these relentless amounts of rare antibiotics in order to knock out all of these diseases that are strictly diseases of hygiene.

The place smells like excrement all the time. Or this incredible sickening odor of Pinesol disinfectant, which came in industrial cans of twenty, thirty, fifty gallons. It was mopped out on the floor by the inmates because there weren’t enough staff to clean the place. So the staff would commandeer the labor of the people that were being incarcerated there. Even the young ones. The chaos. The place operated just a cellophane’s width above absolute chaos. Shrieking, physical outbursts, people struggling against the imposition of the tranquilizing drugs that are car-loaded into them. Any excess movement, any resistance, any human anything is immediately met with a two hundred or three hundred milligram shot of Thorazine to knock them out.

The only heat in the place came from radiators that were scattered around, built into the walls with metal sheets in front of them. Because of the coldness of the place, especially off the summer, people would get their drugs which they were forced to take in order to have two people be able to handle fifty people doing nothing for the rest of their lives. They would drag themselves over to the radiators, and they would fall asleep in heaps against and in front of the radiators. So A, they were laying on the floor, which has this veneer of caustic, Pinesol chemical disinfectant that’s not being cut or diluted. There is always a thick, gummy, slimy film on the floor, after they clean the floor, and it eats away at the drugged residents skin so that they have these huge swaths of terrible rashes and psoriatic-kinds of crusts on them. They have burns on them because they fall asleep against the radiator, because they are drugged out. For maybe a half an hour, or hour before the dose gets low enough for them to break through the suppressive impact of the medications.

You see a range of conditions and diseases at Willowbrook that are given all sorts of misnomers, that are really a function of concentration-camp existence that are imposed idiopathically by the physicians—by the context. The very manifestation of bestial behavior is really a learned coping behavior that flows from the very organization of the place. No programming going on, the most token schooling happening, no support or continuity for the schooling. The minute the kid reaches beyond school age, the deeper they go into the institution. No school, no future, no exit. They've got to die to get out.

Cowan: And no treatment for their diseases, just medication to tranquilize them?

Bronston: Right. And I'm fighting the administration every day because I need more soap, more suture material in order to sew cuts. I'm on once a week through the night. Like doctors, we'd rotate through. I see it all. Little by little, I begin to see it all.

Cowan: Once a week?

Bronston: Yes, once a week, we work on across the night, so I would sleep at the institution.

Cowan: But you were there in the days as well?

Bronston: Yes. I was there every day, and then once a week or every two weeks I would have to do a night shift where I would be on call for the entire place.

Cowan: All sixty buildings?

Bronston: All sixty buildings, right.

Cowan: Were you mostly working with adults or children?

Bronston: Initially, children. What happened was that after about four months the doctor who was responsible for the baby complex finally got fed up with my continuous demands for hygiene help and they had me transferred to another building, I think it was 176. It was a model "hospital improvement program." It was ironic. I called my action in Kansas. The "Hospital Improvement Program." This was part of a hospital improvement program federal grant to fund institutions to set up model programs. The state of New York and Willowbrook had this HIP program that took very young kids and put them into somewhat smaller cohorts, around 100 children with slightly more staff—it wasn't much better—in these temporary buildings that were these star-shaped trailers, mobile homes, where they slept and programmed, with kind of a central playroom and a couple, three classrooms.

They put me in charge of one of those buildings. I had 135-138 kids that I was responsible for. These were younger kids, twelve to twenty-one years old, and they were all ambulatory, and they were all more capable, more mentally competent, so far. I began to wage a war against disease in my building. I kept duplicate records. In addition to what I wrote in the chart, I kept a log-book of every single treatment that I did, by ward, by kid, by disease. Because there was no way of tracking or following up. If a kid was presented to me with a raging infection, I treat that infection, but then I would lose track of that kid, because they would not keep coming in. There was no way to go back to see what was happening. Or if I sent a kid to a specialist to be looked at—a specialist came from the community to look on a consulting basis, it was just part of the act—then they would order a treatment and there would be no necessary follow-up.

So I needed to keep a book to look at the statistics of what was going on with the effectiveness of what I was doing. I urgently wanted to reduce tranquilizers in these kids. These ward workers were lobbying me, forcing all the doctors to just sign off on these car-loads of tranquilizers so they could play cards and do whatever they needed to do because they were out of control, too.

Over a period of about eight months, I cleaned Building 176 up, completely cleaned it up. I reduced the illness and infection rate to almost zero, which was unheard of. I reduced the tranquilizing rate to the point where I could actually look at the kids in my building and rethink how we could begin humanizing their environment, and begin a real developmental training program and maybe get them out of there. So I regrouped all the kids on paper by putting them in proper developmental groups related to training power needed. And I proposed to change the staff around. In the meantime, I had begun meeting with their parents. I was always dealing with the parents. They'd never been allowed in, before, never been talked to.

The whole thing that happened between the parent and the kid when they put the kid in the institution is a whole other story of how the system engulfs and literally liquidates family relationships and the incredible distortion of what happens in the lives of families that are forced to institutionalize their family members in our current system. The kind of sadness, the ambivalence, the hatred, the resentment, the love, the helplessness, all of that is all playing and these families are so injured and so filled with sorrow as they watch their kid literally being ground into misshapen—I mean, cauliflower ears, smashed and disfigured noses, blinded eyes, teeth all knocked out, scars everywhere, huge weight gains, huge weight losses, constantly being drugged, no clothes, no soap, no suture material, two or three different doctors overseeing their kid, who don't care at all about the kid, don't want to touch the kid, don't want to be in the same room with the kid, just do whatever the nurses say, don't speak English. It's just incredible, I can't even begin to tell you.

Cowan: How does the violence happen? Is it between staff and patient, between patient and patient?

Bronston: You have a closed stone room with fifty-three people in it, day in and day out with nothing to do, inadequate food. NOTHING to do, and majorly, continually drugged into insensibility. It is a powder keg of people just lurching into one another. Then you have control problems, where you have a staff member working a midnight shift, getting another resident, who's slightly more capable to take out some other resident, or murder them, or rape them, or hit them with a ball of keys, or whatever has to be done in order to make the time pass. Because nothing else is going to happen. You have a situation of living death. It was so extraordinary.

So I was moved from my sojourn in the baby buildings, right away, to this HIP program, Building 176. I became so intimately involved with every single kid in there, I knew every kid, they were like family. I knew every child in there, they were like my kids. I knew that if I didn't take care of them—I dreaded being off-duty because I'm off-duty every so often and then the other doctors in the hospital would cover my kids and they would put them back on tranquilizers. I would come back to find maelstrom again, when I was just away for one day.

So I kept these meticulous records. I tried to reorganize the building, and in the process of really trying to turn the place into a developmental center in the school system, all hell broke loose. My building nurse and the chief nurse in the institution both came out and went to the director and absolutely demanded that I be removed. I had this titanic struggle with the director who brought charges against me for insubordination. I was abruptly moved into taking care of two women's buildings, adult women's buildings, that was four hundred people, and cover another three buildings. This meant that once every four days, I was responsible for a thousand adult women, with a death rate that was nine times the death rate of the city of New York.

All these buildings were barren, stone rooms, two stories, two staff, on each of four wards, one-and-a-half to two nurses, whose job it was just to car-load out the drugs and make the records, and to keep the records for federal reimbursement. We were then being instructed to maximize the description of disability for every single person in the institution in order to increase the remuneration of the state hospital by federal Title 19 programs.

Little by little, I began to get it. I began to see it. I began to make breakthroughs in understanding what I was dealing with and that the primary source of illness was the place! The place made illness! It made every kind of illness you can imagine! And nothing was what it looked like. I had a situation where I had a number of people with extremity amputations in their thirties. Amputations that were normally a result of circulatory problems and chronic infections that you don't see until people get to be eighty. What was happening, I finally figured out, little by little, by just seeing so many people, was that these people were developing these incredible fungal infections from the athletes feet that was just in here on the floor everywhere, coupled with the erosion of their skin from the caustic detergents scum used on the floors, creating fissures, and they were beginning to develop cellulitis of their feet and legs and then superficial vein thrombosis and then deep vein thrombosis until finally the leg and the circulation was destroyed within a decade from being in these buildings.

They had a disease that they called Mongoloid Dermatitis, which was supposed to be some kind of strange skin disease associated with Down Syndrome. All that this stuff was, and had been treated for years by the dermatologic specialists, and this stuff would cause this heaped-up, intertrigenous rash, like the spaces in between your fingers and on your chest and legs and shoulders, these scaly, terrible, psoriatic kind of crusts and rashes. The chronic treatment, which had essentially been created by the steroids that were used to try and combat what was thought to be an allergic dermatitis that was somehow linked to Down Syndrome. The minute I saw this stuff, I couldn't understand what the hell was going on and why doctors were treating it as if it were an inflammatory disease because the distribution didn't fit. So I brought in a gallon of Kwell, which is what you use to deal with skin mites, and the stuff cleared up overnight. Thousands of people in Willowbrook had been treated improperly for years by professional dermatological specialists that never made the diagnosis that the problem was environmental infestation with skin mites.

Cowan: They never touched them?

Bronston: They never touched them, never looked at them. So they were suppressing this stuff with steroids, and the mites were continuing to grow and people had these allergic reactions to the saliva proteins of the bugs. The shit cleaned up overnight, with the right treatment.

Cowan: They'd been treating them with steroids?

Bronston: Steroids and anti-inflammatories, like they were treating psoriasis or allergic dermatitis. The wrong diagnosis. This is just typical. I have volumes of photographs because I photographed all this stuff and watched it all. In the meantime, I'm meeting with parents and trying to figure out how to keep that parent-kid hopeful, how to explain to them that it's going to be okay, that I'm going to take care of their kid, that they have to keep coming, they have to keep being there. They've got to take their kid out because this place is a death watch. It's set up to be a one-way slide into oblivion.

Cowan: But they can't take their kids out.

Bronston: Well, they can on the weekends, or on visiting days, but Willowbrook had to give them permission. The state doesn't like that because then the state loses the money. It's like ADA, school average daily attendance. They get a stipend every day for people being in the institution bed. They can only let people out for so long.

I gradually began to see and find out about Willowbrook—because this isn't my whole life, this is just what's going on in the daytime. In the evening, we're organizing radical students at the Staten Island Community College. We're organizing a community take-over of the USPHS hospital, and my wife is building community-controlled day care. One of my other colleagues is running for borough president in Staten Island. We've got the antiwar movement blazing in New York City. It's a big long day!

Cowan: How could you go home, after being an observer and a participant in a situation like that and have anything left over? Didn't you just want to go home and crawl in bed?

Bronston: Well, That's just not me. I lead five lives, in any given day. That wasn't what got to me. What got to me was that I was alone amongst all my peers, working with a population that was completely invisible, completely undefined. No doctor that I knew, except Dick Koch and, then of course, Gunnar Dybwad had anything whatsoever to do with mental retardation in the United States. There was not one radical physician, and I knew them all, that was in the world that I was in, in that institutional pit, dealing with a population that I still had to figure out what role they had to play in America.

That's the level that I'm looking at stuff. I'm not superficially anywhere. I get the whole thing all the time in the most complicated way. I'm dealing with all sorts of subterfuge of the counter-insurgency movement, FBI's always around us. We are in deep political soup all the time. I've got new babies, literally, my twins are born around this time. My house burns down one day and we have to move to another house. We buy this big giant square block four story house, and five families are living in it. We've got eight cars, we've got eight children. It's just amazing. We live in collectivity, these are all doctors and nurses.

We have these profound family relationships with the people we work with. There's no class separation. I'm as close to a janitor as I am to another doctor and closer. I live and deal with working class and poor people because they're my heart. I'm more comfortable, in those days, with ordinary people. I never wore a tie. I wore jeans most of the time, a leather jacket, turtlenecks. I had longish hair, a full beard. I'm preoccupied with what I'm doing and I'm not really aware—I'm just totally gripped by the drama of my everyday life, the smells and the sounds and the relationships and the adventure and the excitement. It's very exciting. This is a real romantic trip every day.

At some level, regardless of how awful it is, there's kids, there's my dog, there's my wife, there's my friends. there's snowball fights, there's planting flowers. We're living, living fully, as political citizens, totally linked to what's going on in Vietnam. Deeply connected because friends are bringing, I mean, Gloria Steinem doing her stuff, [William] Kunstler is one of our lawyers, I mean, we're just close to everybody. It's a small group of us. There aren't a hundred articulate, left leaders. It's not communism. We're radical. It's radical understanding that things connect. The environmental movement hadn't really been invented yet. The disability rights movement really hadn't been invented yet. So this goes on, and at a certain point, the institution has had it with me.

Cowan: One question though. Was Willowbrook exclusively for people with mental retardation, not mental illness?

Bronston: Yes, not mental illness. But half the people are made crazy by the environment. And there's no fine diagnostic differentiation. There's this way in which the state warehousing cannibalizes people. It is an economic wheel that turns. You can't look at it as a substance wheel. It's an economic wheel. State hospitals were set up in a way that in order to support themselves, they had to have a continuous population on which to feed, that is, to draw Title 19 dollars.

III. WILLOWBROOK STATE SCHOOL, NEW YORK, 1970-1973

Title 19 dollars support deeply flawed system

[Interview 3: December 7, 2001] [Tape 7, Side A]

Cowan: Do you want to explain a little bit, what Title 19 is and why the funds were from there?

Bronston: Well, in the mid-1970s, when Medicaid and Medicare were invented, the policies of how public monies were to be channeled into medical services was hammered out for the United States, and we are now seeing the incredible consequences of that, twenty-five years later.

Cowan: By now do you mean, today?

Bronston: Yes, 2001. What happened then was that a system was set up to kind of bring a threadbare blanket of public insurance coverage, social coverage, tax-based coverage to meet the partial needs of certain constituencies in the culture that were weighing heavily on the medical economy, that were costing the medical economy so that the private sector needed to figure out a way to get public subsidy. The decision that was made about handling devalued populations in America, the preliminary decision, was the most profound policy thrust. In order for the public sector to subsidize services for the poor, especially for residential services, those services had to be provided in an <u>out-of-home</u> placement.

The policy option to give money to families in their normal relationships was essentially seen as "Bolshevizing" the American family. So conservative, and so inhumane was the dominant body politic in the country, which emanated from the Eisenhower regime, through the Nixon regime, that the major part of the national Medicaid Bill, that addressed the issue of domiciliary services, Title 19, and other aspects of the program that established Medicaid, required people to be served outside their family home in licensed, certified, formal institutionalized environments, nursing homes, long-term care facilities, intermediate care facilities. Then Title 20 of the bill established the whole social service system for smaller programs that included issues of adoption and respite care.

There's a whole range of aspects to that public policy and the way funding was determined. Money was cut loose in the billions to invent a "social security" system for people with special needs that essentially invented and promulgated a domestic refugee population of massive proportions that was then funded. The management system for that domestic refugee population was then funded through these gigantic bureaucracies, the Departments of Developmental Services, and Departments of Mental Retardation, Departments of Mental Health that were there, to police this human oil spill that was promoted by public policy—out-of-home, congregate, segregated placement.

Cowan: So Willowbrook collected money for every individual they had incarcerated.

Bronston: Yes. The state was given federal dollars in order to manage and service, on its terms, the needs of the population entrusted to it by families, taxpayers.

Cowan: And yet it sounds like the money didn't get to the care portion of the institution.

Bronston: Right. That's interesting, That's the mystery. That's the show-game. You have to watch where the money is under the cover of the shells that you're pushing around. We never really could understand where the money disappeared to. I never really saw—all the stuff was new to me, you've got to understand. I'm a doctor, I'm in there, I'm holding people, I'm hugging people and taking care of people and writing prescriptions and sewing up lacerations. I didn't really think about, didn't understand radical economic research.

What I did find out, little by little, was that there was a whole economic, financial, big-money aspect to what the hell was going on. That the institution at Willowbrook, that institutions in general, were major economic centers that hired thousands of people, purchased millions of dollars worth of stuff, paid very handsome salaries to the concentration camp managers in this thing. That these were all professionals that had to be properly ideologized in order to be complicit with this antisocial scheme and feel and believe that they were doing "good," and to operate in compliance with policies of deprivation and reduction of resources on a continual basis.

Cowan: But you didn't see that kind of money come through in terms of increased supplies, or increased program materials?

Bronston: No, what was happening was something else. That place was a sink-hole. That is, it wasn't that millions of dollars worth of drugs weren't coming into the place, it wasn't that millions of dollars worth of soap, towels, food—every conceivable kind of wherewithal was being expended, but where it all went, and what the proportion of that was in relationship to say, salaries. The state would establish a budget, based on this federal dollar off-set, and apply the budget to the New York State Department of Mental Hygiene, run by Alan Miller, and below that whole bureaucracy was this guy, Frederick Grundberg, as the Commissioner for Mental Retardation and Institutional Services. It was a subset of the Department of Mental Hygiene, run by psychiatrists on a psychiatric model, connected to the big universities and the medical school chairs. All that money, by the time it got down to this flotsam and jetsam part of the populations, which were these tens of thousands of absolutely destroyed lives, destroyed people living in essentially concentration centers.

Cowan: Not just Willowbrook?

Bronston: Oh, sixty of them in the state of New York, with no group homes. There were no community-based services in New York. Once a kid was extricated from the home, the only place they really could go was to some sort of a hospital institutional model.

Cowan: And those did not improve, I mean, there must have been a big difference between what New York had been doing as a state, and when Medicare dollars began to come in.

Bronston: First of all, what happened was that the state now had a guaranteed source of "ransom." Well, It's the title of my book, *Public Hostage, Public Ransom*. The people that were assigned to these facilities became "public hostages." They were held there for "public ransom."

Pressure to maximize diagnosis to maximize dollars

Cowan: You mean in terms of the Medicare money?

Bronston: Reimbursements. Right. And the reimbursement game was crucial: A) people had to be there in order for the reimbursement to come; B) the more damaged they were, the more damaged they could be depicted as being, the more money New York would get because there's a Title 19 formula saying you get more money if you have to do more care. That didn't mean that the state would do more care, just because they were getting more money to deal with a more involved individual. What happened was the more significantly disabled the individual was, ironically, the less programming and the less staff presence existed.

You would be operating with fifty people in the middle of the day shift with two workers on the ward, unable even to connect with each of those fifty people. They had to be fed, bathed, clothed, toiletted. Forget programming. Just in terms of the number of hours, people are only on eight hours a day, and you're dealing with people that cannot, in large part, or are prohibited from, because of the environment, be a part of their own self-care, apart from just wandering around. Yet the budgets that were allocated to the state programs went up and up and up.

Cowan: How was their level of disability or retardation determined?

Bronston: There were formal, affidavit-based forms that the physicians had to fill out and certify, individual by individual, that this resident was severe to profoundly involved, and required maximum support, maximum service. We were instructed by our administrators to maximize the degree of impairing diagnosis to the max.

Cowan: How were you instructed, verbally?

Bronston: Verbally. We were told, in a meeting, "We want you to make sure that as you go through these things, that you check the box that says, severe to profound mental retardation."

Cowan: Instead of moderate.

Bronston: Yes, certify "danger to self," all that stuff. Which was another whole part of the battle at Willowbrook, because Mike Wilkins and I, in that command doctor's meeting, stood up and challenged that whole fraud. It was fraud, it was blatant fraud. Because we were not allowed to properly assess the individual. We were not given the tools to properly assess the individual. The records were completely trumped up and fraudulent, in order to maximize the appearance of disability and to essentially establish a hopeless prognosis for the people there, which then became a self-fulfilling blueprint for the way in which the system then responded to those folks. It was all around dollars. And you know the irony of the whole thing?

It wasn't even the dollars coming to the program, to the facility, we're talking about New York State imperial politics, Rockefeller politics. The people at the top of the political system that ran the emperor's ransom state of New York budget and that had major family alliances between the entire capital banking system, Chase Manhattan, Sachs Goldman, all those bond-making, loan-making, global banking system institutions that were essentially benefiting from, through interest rates on loans, and fees for selling bonds, and professional fees for establishing building projects—all that stuff that happens in the centers of the wealthy—

Cowan: Fed off those dollars.

Bronston: Exactly, off the top.

Cowan: So as well as Medicare funds, the state floated bonds to support institutions like Willowbrook?

Bronston: Absolutely. Not Willowbrook per se, because Willowbrook was already an old place. The state built twenty-five or thirty brand new institutions, while I was there, in three years. Such an enormous effort was leveled because Rockefeller obtained this billion-dollar authority from the New York state legislature when he came to office that could be used for public works buildings. These public work projects were building public housing, building universities, building schools, building mental health facilities, building mental retardation facilities, like Willowbrook. Essentially, Rockefeller would have his fiscal intermediary bureaucracy that was part of the state government, work out plans for construction, little by little, for these enormous public works projects. These would come out in packages of a hundred million, two hundred million, three hundred million dollars worth of projects at a time, maybe fifteen or twenty projects.

They would go to the bond market, where there would be bidding from the various different private financing bureaucracies like Sachs, like Chase, like Citibank, Chemical Bank and so forth. Whoever would provide the lowest interest rate to the state would get the bid. It was like half a percent, or three quarters of a percent, or point four of a percent. Then that private financing system would loan the money to the state, sell the tax exempt bonds privately, and recoup the interest rate from the investment of all that state money.

Cowan: But the investment was essentially going for construction, not for services.

Bronston: Yes. For construction, not for services. No, there was no service budget in the creation of these places. So Brooklyn State Hospital was built, Broom State Hospital was built.

Cowan: While you were at Willowbrook?

Bronston: While I was at Willowbrook, twenty-five state hospitals were put on the ground while I was working in New York.

Cowan: Did that reduce the population at Willowbrook?

Bronston: Oh no, on the contrary. All it did was—it was a "public hostage" operation. What would happen would be that since there was no other place to go on these huge waiting lists, New York began to fill up these facilities in order to get this Title 19 money, in order to pay off their mortgage payments, the bond payments.

Cowan: For the construction.

Bronston: Right. And these were very lucrative, massive, in those days, relatively speaking, amounts of money. So what would happen would be that the budgets for these places—and then, of course, some crisis would happen, somebody would be killed or somebody would die, and all of a sudden, there would be a little investigation somewhere, and somebody would throw more money at the problem to "clean it up". So the budget began to grow so that we would be getting at one point, about eighteen to twenty thousand dollars a year, per bed, as part of the institutional annual budget. That piece of money, the cost of that grew from $25,000 per bed from the time I was there, to $125,000 dollars a bed because of the crisis that was constantly going on, inflation that was going on, and the rip-off that was going on. You could have literally handed a family the individual's annual budget of what it cost to run these institutions and they would live in the upper middle class.

Cowan: The amount of money that was spent on their child.

Bronston: Allocated to the program by the legislature. Now what actually got to the kid was mush-gruel food, no clothing, no soap, no privacy, no home, no nothing.

Cowan: Were the scales falling from your eyes, so to speak, was this all a revelation to you, or were you already familiar with this because of Kansas?

Bronston: No. The Kansas thing, I knew something, but I tell you, every day, every week, some extraordinarily painful, new revelation would occur that would be this giant, a-ha! Like I was beginning to understand the disease pattern in the place as being directly a function of the environment. Nothing else! The environment was the cause of the whole epidemiology of the place.

Cowan: You mean by the environment, the mites, the dermatitis?

Bronston: The crowding, the filth, the inadequate food, the inadequate exercise, the inadequate nurture. All of the psychological and physical trauma that was avalanching down on this wretched population of people manifested itself in a whole spectrum of physical and emotional manifestations, behaviors, that would be defined as severe mental retardation, rather than as violent oppression, violent environmental trauma, damage to them. All of the problems that happened physically to people with neurological disabling conditions, the contractions, the weight-losses, the fractures. The violence of the environment was unbelievable. New York creates a closed, secret environment that is unaccountable to anybody in the outside world and run it with an inadequate budget to manage the situation and then threaten the people managing it to not cause problems. You have the most amazing things that are hidden.

Cowan: A couple of questions occurred to me. One of them is from what you just said, for people not to stir up trouble. Why did other doctors on the staff not make waves?

Bronston: Because they couldn't get a job anywhere else, didn't want to get a job anywhere else. These were mostly elderly physicians who were not able to practice privately. They were mostly foreign doctors who barely spoke the language, mostly, eighty-five percent. They had been thoroughly indoctrinated by the system. They were completely complicit with the institution's agenda. It wasn't that they were evil, it was that they hated what they were doing, they had no sense of identification with who they were serving. The environment was very dangerous, physically and medically. They were reinforced, essentially gathered to be part of the problem. They were not there to fix or change anything. They would have lost their jobs, had they raised a fuss.

Cowan: Did you ever try to enlist their help?

Bronston: Yes. A number of times. I brought Michael in early on, Dr. Mike Wilkins. Mike was part of my collective in Staten Island. We had a third major physician, a surgeon by the name of David McClanahan, who was the third part of our group. David's now working in Seattle as a physician, Mike's working in St. Louis, Missouri, as a physician there.

Cowan: Did they both join you at Willowbrook?

Bronston: Only Michael did. Michael was the staff services physician at the US Public Health Hospital. When he completed his tour at that post, I impelled him to come to Willowbrook, because I explained to him, I needed help organizing. He came for political reasons, not for career reasons. I had already been there about five or six months, already had the lay of the land, and urgently needed help. I explained to him that this was an incredible opportunity to reach three or four thousand health workers in the city of New York, and that it was an absolute ripe plum of opportunity for us to organize an underground union, a radical union in there. When he came in, he was assigned to Building Six and Building Eight in the institution which were adolescent boys, essentially, that were all ambulatory kids.

Cowan: Was he as shocked as you?

Bronston: Oh, yes. You couldn't walk in there and not be overwhelmed. But Michael is a soldier, and he just rolled up his sleeves and began doing what I was doing. We were really good doctors and we were there to clean the place up. And to bring our own humanity and our own sense of equanimity to the environment. We went in there every day, bright-eyed and bushy-tailed, to heal, to fix, to correct, to undo the damage, to ease the suffering. We didn't even think about that, that was just our orientation. We were filled with energy to make things better.

Cowan: Did the two of you go to the administration and ask for things to change?

Bronston: Yes. Repeatedly. I more than Michael. I was constantly writing memos to Joel Hammond, to the administrator, the director of the facility, and to the nurses about the need for soap and the need for clothing, and the need for suture material, the need for certain kinds of medications, the need for staff support. I have in my book, the book I wrote, *Public Hostage, Public Ransom*, which hasn't been published yet. It's still sitting on my shelf, six hundred pages. We documented all the problems, little by little as we were going along, and really were not in a gun-fight with the administration, although the writing on the wall was beginning to show up.

The fact that I had been now moved repeatedly, from site to site, every time I got to the place where I really was pressing to make a change, Hammond would call me in and try and straighten me out and try to cool me down and to tell me how hard he was working at these things, how much effort was being put in. Fundamentally, the paradigm that he subscribed to included living in a plantation mansion at the top of the hill of this underclass reserve of wretchedness; operating in an administration building, never going out amongst the wards; being the big Macher, the state bureaucrat that essentially had to review any budgetary or economic issues in the county on behalf of the state of New York for the State Department of Mental Hygiene; going before the legislature; having been there for a long time. I mean, he was in the role. He lived being the head of this institution at some level, a suffering, proud warrior on behalf of this terrible part of the population that he and only he understood, and was willing to go to bat for. But going to bat, for him, was operating within what he was going to be given, and never really drawing the line and never putting himself at risk with his superiors, the commissioners.

Cowan: By demanding more.

Bronston: Right. Or being in outrage about this thing. So the fact that I was just a nobody physician in that mix gave me tremendous power, because I was beholden to nobody. The worst thing they could do was fire me. They had to fire me for a cause, so what were they going to do, fire me for caring too much? For working too hard? They tried. That's exactly what they tried to do, two or three times. Which involved huge legal battles with them in order to demonstrate that it was precisely caring that was the institution's enemy.

Cowan: Was Hammond ever in the trenches, did he ever come down to the wards?

Bronston: Everyone once in a while, when there would be enough trouble, he would come. Or when there would be visitors, he would come. He was a diplomat, he was an apologist for the system. He was a very interesting fellow, he was rotund, and very self-confident. He was just an interesting character. He was kind of a tragic figure. He never really got that we were not going to be beaten, we were going to bring the place down. He wasn't mean enough, he wasn't conniving enough, he wasn't smart enough.

[Tape 7, Side B]

Cowan: Just to go back a minute to when you were talking about the evaluation forms, that the more retarded, the more severe the case, the more money came into the state, but not into the institution. You said that at a meeting, you and Mike Wilkins protested being told how to fill those out.

Bronston: Right. We wrote a formal protest to the administration, at that time, and tried to get the doctors to sign on to this petition, that essentially drew the line and said that we're going to have to proceed based on our medical oath, to tell the truth, and to try and provide the most accurate assessment of people. Because that was part of the problem that I'd been experiencing from the very beginning, is that the records were completely opaque. You couldn't tell, from an inch or two-inch or five-inch chart, anything about the person. It was all institutional lingo, that was all part of checklists.

Cowan: The records that had been left by previous physicians?

Bronston: Yes. The way in which the record-keeping system and the history of individuals were retained was really highly, highly bureaucratic, which would continually categorize the individual for a certain level of funding or a certain level of care, without really talking about the individual. And since the entire life of the person was confined and constrained to this pin-point of existence inside the walls of this institution, there was no family life, there was no other forces that played upon this person's evolution, or their growth and development. So with nothing happening in the life of an individual, nothing was recorded except those events that impacted bureaucratic management, injuries, accident, drug use records.

Cowan: So your evaluations were what was recorded?

Bronston: Yes. The bosses wanted to maximize income from Title 19 and from the state, and there was this big, what was called the "utilization review" and we had to fill out a "utilization review" on every single person in our care, within a period of about two or three months, in order to ultimately have the state, at the top, use all this data, bubble up, in order for it to develop its budget for billing the federal Medicaid reimbursement program.

Cowan: And you were actually told, at a meeting, to maximize those diagnoses?

Bronston: Yes, literally to falsify the records. We were pretty much told, regardless of what we saw, to falsify the records. So we drew the line and said, "I'm not going to do this." "I'm simply not going to do this. If you don't like it, do something about it." There's not much they could do. They just thought that we were just uppity young hot-heads. They didn't really realize that there was more than just a cantankerous, young, romantic at the other end of the gun barrel here, at that point. It hadn't gotten to the point yet, where it was clear that the whole thing had to be brought down and that we were going to be the instruments to bring it down.

Cowan: So that was something of an evolution. The first time you had to fill out the evaluations, did you go along with it because you hadn't done it before?

Bronston: No. From day one. I had been struggling in the first place to try and get some kind of individualized record-keeping system. So that if I got moved to another building, which I already had been moved now two or three times, that the doctor that would come in would be able to recognize from the chart, what I thought about this individual resident.

And as we went in to evaluate, and put all the pieces together, that involved summoning up what medications residents were on, what program they were in, what their capacities, strengths and weaknesses were, but everything was always pre-printed, in terms of the liabilities of individuals. We just had to check the boxes, self-abusive, violence, self-feeding, requires assistance, requires total assistance. There were like fifteen pejorative features to choose from.

Cowan: It was a checklist.

Bronston: A checklist, yes. And then you could write in a sentence or two additional notes or observations or whatever. Then it would lead the bottom to what level of care, and we would sign in and date it and that would be the end of it. So I wanted to use this rare opportunity where we were forced to look at every single individual with the team, whatever the team was, in order to establish an individual identity for the folks. And to give me the sense of having to review the chart, look at what was going on, before we went to evaluate. For me, it was a total breakthrough. I was not going to cut corners here, I really wanted to know who these people were that I was responsible to.

Cowan: What was the reaction when you refused?

Bronston: There was no reaction, it just further deepened the line in the sand between myself, Michael and our doctor peers. It became clear that our peers were not going to, in any way, oppose any order that they got, regardless of the danger or the consequences that that had in the lives of folks, and that nothing was really going to change. But we were going to run our own operations, because we had big operations. Michael had two buildings—that's four hundred people. I had, at that time, I'm pretty sure I was already in the women's buildings by then, it was getting pretty late in the game, and I had a thousand people. So we had big hunks of Willowbrook's population. If we could do our work well, it would be very good. Now it wasn't that in fact, the assessment that we had, varied too much, because the folks were severely and profoundly impaired. The irony was that their status, their being, was what it was because of the lack of programming and the deprivation of the environment, and the incredible unprofessional and ignorant kind of services that were not available or available to them.

Doctors, nurses and staff undermining efforts to improve conditions

Cowan: Did you get support from the staff? When you say peers, you mean doctors, but what about nurses and people on the staff?

Bronston: Very interesting question. The fact was that we had very wonderful relationships with most of the people that we worked with, and were intimately close with our workers, the psychiatric aides on the ward, called psychiatric aides. There was a psychiatric model although nobody's trained in psychiatry. We're not talking psychiatry here. There were a few workers that were higher-up workers, supervisory workers, charge aides, that had somehow worked their way up in the pecking order to a place where they got some authority and some flexibility and could work the system, that didn't like what was going on. The nurses that we were dealing with that were the charge nurses on our ward were particularly thorny because they were white, whereas most of the workers were black, and they didn't want the boat rocked, and didn't understand the boat rocking, and the people that were their nursing supervisors were monsters. The executive nurses in the place were really *One Flew Over the Cuckoo's Nest*-quality monsters. They were part and parcel of keeping business as usual, and they administered this awful place loyally, systematically, cruelly, and slickly.

Cowan: So you couldn't expect much support from the nurses.

Bronston: On the contrary, every time we really got to the place where there was a major breakthrough, clinically on the wards where we could really begin to reorganize programs—in my case, my nurse went to her superior who went to the director, who transferred me from the building.

Cowan: What was the use of it?

Bronston: I had cleaned up the building of all the diseases after about a year, in my kids' building, Building 76. For the first time, I could look at people spending time working with developmental programming, rather than just crisis-medical management of doing compresses and lancing abscesses and sewing sutures and we had gotten to a place where there was only six or eight kids that had medical problems, instead of eighty percent having medical problems. All the tropical diseases were cleaned out, all the infectious diseases were cleaned out.

Cowan: And this was just in your building?

Bronston: Just in my building. I had five wings to my building, and I wanted to regroup the people on the wings so that we could have a coherent program, addressing the needs of a coherent population. Now granted, even that was a terrible compromise, but I wanted to, for example, put more of my pitifully small staff into places where the kids were more severely impacted and required more one-on-one attention, and have the kids that were really more capable all in one ward, and out the hell during the day to a classroom, so they didn't sit around because they were mixed in with kids that were still completely incapable of coping with the way the environment was organized.

Cowan: On what grounds did she take that to her executive supervisor?

Bronston: They didn't want change. I was talking about moving workers from night shift to day shift. What I did was I sat down with a half a dozen of my most beloved coworkers, women who were ward aides and so forth. Remember now, I have this whole "utilization review," so I have rigorous data on everybody. I've been double-recording every treatment for about six to eight months; every referral to a specialist, every treatment modality. I have clinical records in my possession, all in one place, to tell me what I have and what I don't have in the way of disease. The public health kind of control, kind of database.

So I also knew all the thirty or forty or fifty workers that were part of my building's staff. We began looking at who the workers were, what their skills were, what their temperaments were, and tolerances. What programs we could set up, where we could begin to humanize the environment, because there was no furniture in the place. I began working out with the city dump, a strategy to bring in fairly good quality furniture into the place in order to make a living room out of each of the facility's wings. I had our whole plan written out, detailed, written out, that was strictly based on our intensive understanding of every kid, every worker, and then matching certain kinds of workers with certain kinds of kids. The nurse felt—

Cowan: Threatened?

Bronston: Exactly. Well, what I was doing was stepping across into her jurisdiction, and that was not the role of the doctor. So they essentially extruded me, they exiled me, they got rid of me because I was working "out of class." So I said to them, I'm in charge of this building, I am the clinical director of this facility, this building of ours, and I'm not just here to clean up disease, that's the lower half of my responsibility. I'm here as a developmental specialist. But nobody in the whole place ever saw themselves as a progenitor of developmental competency and ultimately matriculation from the place. They were just there to hold the line. They had never seen anybody that had any background in developmental technology like I had.

Cowan: Did you have that in mind all along?

Bronston: No. It came out. It's very interesting, I went to work, day to day, not knowing, from day to day, what the hell was going on. It took a long time. I'm slow, it took me a long time to understand and to see what my role was to be. I tried to do as much as I could in any given day. I understood clearly, from my training at Children's Hospital, and from the Child Development Clinic, and from seeing what was going on in California, a decade or eight years prior, what was possible in the field of developmental child-rearing. Working with people that were in semi-coma, you could do anything.

Cowan: You evolved to that. It was coming along.

Bronston: Right.

Cowan: And still they kicked you out of that building.

Bronston: Absolutely. They did not want reform. There were other reasons for that I mean, what happened was that something of the adjustment of the workers in the place was exposed, and I began to see for the first time the gravity of the corruption that was masked by business as usual. Workers came to work armed. Women with guns, threatening other workers with guns to not oppose my removal from the building.

Cowan: What?

Bronston: What was happening was that we were beginning to get at the graft in the building. By reorganizing the building, theft, loss of medications, all this stuff that was going on at night would be exposed. The robbery, the corruption, the brutality, the perversion was hidden in the way in which people were organized on the wards, in terms of day, afternoon, night shift. What kinds of alliances remained, what kinds of things drifted out through collaboration amongst dishonest workers. God knows this was multiplied sixty-fold in every building in the institution.

Cowan: It's a chronic problem with graft you're speaking of within the staff on the grounds.

Bronston: Right, it was a closed system and people could not survive just on their salary and in that kind of a context was so dehumanizing, so distorted, so perverse, that issues of death, issues of loss of whatever it is, medicine, people's belongings, issues—at every level. Sexual perversions. Lots of lots of residents in the institution got pregnant.

Cowan: Do you mean the inmates?

Bronston: Right, the clients, the people. And beatings were going on constantly. Terrible beatings, in terms of imposing controls and keeping the explosion under control, down. This stuff, I never really saw it totally cold, totally open. But this opposition to doing the right thing in this one building, was the most profound eye-opener for me, it really shocked me. I really put in an enormous amount of work. I had this twenty-page study I had done, everything documented of the whole rationale of why we should reorganize the kids, why we should reorganize the workers. I worked it out with the progressive part of my workers. They even were afraid to tell me of the gravity of the stuff that was going on. And were always frightened, always frightened at some level, never really believed that I could pull it off. I just said to them, "This is what we're doing. We're going to make this happen. I'm going to make this happen."

Cowan: When they moved you, that was really—

Bronston: Things went back to hell.

Reality of institutional life: devalued, stigmatized, less than human

Cowan: The workers from that building didn't get to move with you, they knew it was going back to business as usual. Would you compare this to prison system? That's what it sounds like, where there is, at the inmate level, violence and theft and corruption.

Bronston: No, I wouldn't. I think you lose something very important, if you don't understand the reality of what institutional life is like for people who are in there with paradoxical identities, you miss something very important. When you put somebody in jail, the going paradigm for people in jail is that they're there for punishment and they deserve what they get, and that the whole thing is put in as a confinement—there is a conscious commitment to dehumanization, a conscious permissiveness for dehumanization, because people deserve to be punished for being bad.

Now, you're dealing with a different population when you're dealing with devalued people that are there in order to either protect society or to protect them from society. You have at some ground, the need for some kind of a coherent service model. Is that model education, is it health, is it punishment? What is it? Is it domicile? And the problem with mental retardation service and institutions is that they fit into none of those categories. Therefore, there is a fundamental disorientation that is imposed upon all the people concerned with the model that allows things to happen that are completely insane. Allows interpretations to be made that don't make sense, that go against common sense, and go against common observation. You do not have a health facility, and the workers don't see themselves as health workers. You do not have a school program, and they don't see themselves as teachers. You don't have a punishment environment, and they don't consciously and upfront commit themselves to punitive intervention.

What you have is a mixed model of people who perceive their roles as managers and controllers of a domiciliary population who are not there because they are criminals, not there because they're sick, not there because they're undereducated. They are there because society doesn't know what to do with this population. The message to all the people working there is that this is a highly devalued, stigmatized, less than human, and that is crucially important, less that human population of people that after a while all merge into one big mush of humanity that has to be somehow maintained.

So there isn't an advocacy orientation, there isn't a prison guard orientation, there isn't an intellectual, professional, career orientation, like in the health-worker kind of a thing, to in any way re-orient, re-humanize the workers who are working in this place, nor anybody who has the place interpreted to them for what, in fact, it is. It is an end-game, it is a corrupted humanitarian program run by the government in the social contract, to service a population whose care is an act of largess on the part of the society, not a matter of right. So that whatever they get, is all that they sort of deserve, and the problem is that they don't get enough to basically survive the violence, consternation and turmoil. That impasse becomes the message to the community of workers, both administrative and on the ward that are responsible for the population. The message to them, by virtue of the architecture of the space, by virtue of the definition of who it is that they're supposed to be taking care of here, allows them to do things that they would not even consider doing in relationship to their own families or were they working in hospitals or were they working even in prisons. Even a prisoner has certain rights and certain standing that the people in Willowbrook, in the state's mental retardation warehouses didn't have.

These are people that have no identity, no future, no hope, for no reason. It's not that they're there because they murdered somebody, and there's a reason why they're there, and there's a certain, coherent relationship that's set up between a murderer and a jailer. These are people whom the folks that are taking care of them don't even understand why they are there other than that they can't make it on the outside because they're less than human. So they're going to be treated and seen as hopeless, helpless, "something-elses." Not even dogs and cats, They're not even seen as animals, because animals don't get treated like this.

A major professional came from Copenhagen, from Denmark, to look at the commissioner of mental retardation during the John Kennedy regime, and he came to Willowbrook and he said, "You know, we don't even treat our cattle like you treat the people here at Willowbrook." I mean, it was an extraordinary scandal that happened about ten years before I got there, but nothing changed. Because the model is fundamentally insane. The model is insane. Nobody understands the model. So you don't have the right kind of workers, you don't have the right kind of administration, you don't have the right kind of expectations, you don't have the right kind of medium to work with the people because the model is one of dealing with an indescribable constituency, population that have no place, no role, in the society.

Cowan: Who created that model?

Bronston: There was a fundamental shift, historically, in the beginning of the twentieth century, from looking at this constituency as requiring protection from a marauding society. The agenda of the progressive psychological community believed that this was a rehabilitatable constituency that could learn and be returned back to society. That competed with the notion of genetic cleansing, ethnic cleansing at a certain level. People began to see this constituency both from a religious standpoint and from a political, economic standpoint as a burden on society, and as a source of the pollution of the race, with the whole, what's the word—

Cowan: Eugenics?

Bronston: Yes, eugenics movement in the United States, you began to have an entirely different cast put upon this community and they became more and more out of sight and out of mind.

Cowan: In the 1930s, 1940s, 1950s—

Bronston: Yes, up until about the 1950s. In the 1950s, remember, you finally have the National Association of Retarded Children founded. Up until then, you have voluntary organizations, parents organizations, professional organizations that are involved in dealing with charitable concern for people in asylums. The professional organizations are the directors of asylums. It's what they are what they are called. Asylum, an asylum is a place where people seek asylum or is it a place that is nothing but a nightmare where people are sent to hell?

Cowan: But those organizations didn't help to set policy, they just were in a protective sense?

Bronston: They reflected the going philosophy of the profession and the social policy of the body politic in terms of what it was willing or unwilling to deal with. And the fact was that there was this constituency in our culture, and in other cultures, that were really seen as totally superfluous and expendable. I mean, the first group of people that Hitler eliminated from his eugenics-perfect society were people with mental retardation.

The whole strategy for the "ultimate solution" in Germany emanated from people working in mental hospitals, from psychologists to social worker theoreticians that had developed the strategy of eliminating, of killing, the inmates because they were perceived of and referred to as "mentally dead." So you had a paradigm-shift that was so established in German culture, German politics that this became the plan, the groundwork, the initial demonstration of the final solution that was then applied to the Jews and the Russians and the workers and the communists and everybody else that the German super-class wanted to distance itself from.

[Tape 8, Side A]

Cowan: What happened after the protest and you were moved to another building from the children's building because of opposition to your cleaning it up?

Bronston: Right. I was moved from the Hospital Improvement Program, Building 76, because, as I said, I had completely changed the clinical reality of that situation and wanted very much to impose the next step because I was bound and determined to return kids back to the community. The nursing administration and the administration of the hospital, of Willowbrook State School—it's not a hospital—essentially transferred me, precipitously from my building to be in charge of two women's buildings that really represented end-stage domicile for adult women in the Willowbrook. It was clear to me, first of all, ripping me away from children that I had really become terribly close to. I knew every child in my building, a hundred and thirty-five children. I was there every single day. I touched them every single day. I interacted with them, I watched their progress. I handled them when they were sick and dying. I mean, they were my family. I'd become very close with the workers, I'd really—I'd put a profound amount of work in.

Cowan: How long were you there?

Bronston: About nine or ten months. Almost a year. And I had also become very close with all the parents of those kids. And I was taking care of another children's building right next door which was even a more elite population of even younger kids that really didn't belong in the institution, Building 78.

Cowan: A little more functional.

Bronston: Exactly. So I wound up being thrown deeper into the Willowbrook hell.

Cowan: Just in a day's time?

Bronston: Overnight, they moved me. I couldn't believe it. I was so anxious. It was such a traumatic, emotional, move. I was struggling to figure out, what is going on, what does this mean? Because I always blew ahead, assuming that I was untouchable. And then something happens, and I suddenly realize that there's been these devastating consequences. So I wound up filing a grievance against the administration on the advice of a beloved friend lawyer of mine who was the leading progressive labor lawyer, a member of the Lawyers Guild in New York. His name is Eugene Eisner.

Cowan: Do you think you did that because you always would have done that or because Willowbrook has changed you, or you've changed, along the way, your thinking, so you were more willing to bring a grievance and fight?

Bronston: I was a warrior. Coming from my SHO history and the struggle that we had in Kansas, I learned how to fight. I also felt impervious to bad consequences. I'd had such a fair-haired life, as a change agent. I mean, I knew so many people. I just wasn't afraid of anything or anybody. I was a true believer. I had a righteous cause, and that righteous cause cloaked me in a context where I would take on anything and anybody, behind my humanism.

Cowan: But did this move shake you?

Bronston: It was incredible. I literally called my lawyer twice a day. And I told him, "Gene, I'm calling you because I need some mental health help. I need to be able to call you because I'm so anxious and the situation is so challenging. I just want to make sure I don't make a mistake. I'm willing to fight the fight, but I've got to be told that I'm not crazy, and that I'm doing the right thing."

Cowan: Who suggested the legal action?

Bronston: I went to a lawyer. He was willing to take on my case, pro bono, and defend me. He never charged me a dime, and we must have spent an hour a day together, every day from then on, for about three or four months, minimum. It finally came to the administrative hearing, where he and I sat with the Director, Jack Hammond, for about five days, going through the aspects of this administrative hearing, with a law court, administrative court judge in the room. It was extraordinary. Hammond had his state lawyer, his New York State Department of Mental Hygiene lawyer. Him, me, my lawyer, a recorder, and an administrative court judge, sat in the administration building at Willowbrook in order to hear my grievance.

It was really extraordinary, because Gene was a really sophisticated progressive lawyer. We filed a grievance that my move was punitive. It was aimed at stopping my efforts to improve the circumstances in the Building, because there was another value system and another policy in place that had nothing to do with what the institution was all about. I came in as a contemporary medical worker with a contemporary philosophy and a contemporary technology in order to promote developmental science and child-rearing in that place. That notion ran at cross purposes with the going-nowhere, dead-end, end-game operation that prevailed. The only way you leave the institution is feet-first.

So ultimately, in a hearing, we went through all the work that I had done. I showed all the records of all the disease control operations, talked about in detail, the program that I put in place, talked about the responses of the workers, the responses of the administration, the response of the head nurses, about the implication with the parents. There were no witnesses, it was all just in this administrative hearing between the director and I. And when the hearing was all over, the trial record, the administrative hearing record went off to Albany and came back a letter a month later denying my appeal.

In the meantime, of course, I was plunged into the two adult women's buildings and began to establish my whole grip on what the hell this new job was. Meanwhile, Mike Wilkin, of course, is on the other side of the grounds in the men's buildings, still doing his thing.

I walked into these women's buildings, I tell you, it was so antithetical to where I had been and what I'd been doing. They did it for punishment, they put me into the worst possible environment to get me to quit.

Cowan: Why was it the worst?

Bronston: Because it was hopeless. Because this was truly the last place that these women were ever going to be. There was no developmental anything going on. There was no school programming going on. There was just wretchedness. Wretchedness and suffering and insanity and inhumanity that is. It's legion. It's the max. Short of Dachau or a concentration camp in Germany where they were actually burning people every day—

they didn't have to burn people everyday here, because they needed to keep them alive because they needed to make money off them.

Cowan: How many women?

Bronston: A thousand women in five buildings ultimately that I was responsible for at least once a week, and under the normal circumstances, there were four hundred women, two buildings of two hundred each. Each ward was fifty. I had four wards in a building, two-story buildings, two downstairs, two upstairs. Two buildings.

Cowan: What did you do?

Bronston: What I did all along. I just rolled up my sleeves and began, I met with the workers, and got acquainted with the building, they all knew there was a fight going on. They all knew me, because I had already circulated through the entire institution because I did my rotation, once a month, all night long, covering all the buildings so I knew all the night-shift people. I had already begun to develop a reputation on the grounds, because I was very much attached to, and very loving toward the workers, very understanding, very kind, very responsive. I took care of them. I prescribed medicine for them. When they were sick, I took care of them the same way, which we weren't suppose to do, but the hell. I was there to organize, I wasn't there to play some kind of finite role of a physician.

Cowan: Now when you say that they knew there was a fight going on, how was the fight continuing?

Bronston: I was in the midst of these continual administrative hearings that we were having.

Cowan: That wasn't final?

Bronston: No, no it kept going, and there was appeals. The historical events began to roll forward. Once the administration moved on me, and the gloves were off, which came off when they transferred me out of the Building 76, which I saw as absolutely punishing in the extreme. I couldn't go back to my buildings, I was not allowed back into my old buildings. I was prohibited from returning to those buildings, so fierce was the struggle that went on and the lines that were drawn. Now I had my informal friendships with many of the workers in there, and we kept in touch, and I kept tracking, but all of a sudden, I was confronted with this whole new assignment in this whole terrible place.

Parents and politics are key to bringing Willowbrook down

Bronston: Meanwhile, there's a lot of things that are beginning to happen. I'd been inside Willowbrook now between a year and a year-and-a-half, clear about the fact that I'm in there to bring the place down. And the way I've been doing that is by developing as much of a relationship as I could with the community-based parent organizations, especially the Down's Syndrome organization of Staten Island, whose chairman has a young boy, his name is Bobby, with Down's Syndrome. He also had Hirschsprung's disease, which is a condition where a baby is congenitally born without neurological enervation of the distal end of his colon and rectum, and so he can’t poop. What happens is that feces builds up. The waste matter builds up and builds up and builds up and Bobby had to be evacuated by hand. The kid’s pediatrician, because he only saw the kid as having Down’s Syndrome, just assumed that was part of the picture, didn’t know enough to know that Hirschsprung’s disease is a very common part of Down Syndrome, which I knew instantly. So the kid was four or five years old when I met the family, and the mother had been pulling out this kid’s poop by hand once every week or so. The kid was ashen, terribly sickly, thin little spindly arms and legs and this just huge, distended belly and the hair not growing, Kwashiorkor like. This family was just in hell.

Cowan: Was he an inmate?

Bronston: No, he lived at home in the community.

Cowan: How did you make contact with this community?

Bronston: I don’t remember exactly how it happened. But I was very active in the community. We were organizing all over the place, and I somehow met this marvelous family. The family’s name was Marcario, and Mark Marcario was the dad. Mark became my savior, my salvation while I was in Willowbrook. He came to pick me up almost every day, at Willowbrook, and take me to lunch. We would have lunch together, the father and I. Anyhow, what happened was that I urged he take his kid to Columbia Presbyterian and they’ll fix him overnight, which they did. They walked into Columbia Medical School Hospital, and they put him into a real pediatric examination. They made the diagnosis instantly, and they operated instantly, and the kid became normal, overnight. And the parents couldn’t believe what had happened.

The point I was making with the family was, once a professional sees your kid as “not human,” as not a valued kid, then they’re not going to be thinking about service or care the way they would think if it was their own kid. This doctor would know Hirschsprung’s in a minute if the kid didn’t have Down’s Syndrome. But the fact that the kid had Down’s Syndrome, it was missed by the doc. Then, he blamed the mother for not being a good enough mother, of not being willing to handle this terrible task of regular evacuation, when the mother knows that something is gravely wrong, and has to internalize the sense of sorrow and oppression of having to deal with this problem, this terrible problem.

Because he was such a remarkable, civically-oriented guy, he ran a heating oil business. What came out of that was that through Mark, I got introduced all over Staten Island to the Italian community, and to the parent community. Mark was just, he was like Clark Kent, he was like Superman without the cape. He was just the most wonderful, sweet, marvelous man. I began connecting with and explaining to the community, through informal gatherings and meetings and so forth, the terrible toll that the existence of Willowbrook had on the evolution of community-based services, and talking to them like from another planet on what community-based services were like, talking to them about Children’s Hospital in Los Angeles, talking to them about Child Development Clinic, and the fact that the dominant mode of service in California was community-based services and home-based services with a multi-disciplinary team providing the support.

But what began to come out, the really important issue here was the politics of disability. Being a part of a devalued national minority created a prejudicial and discriminatory relationship that was towering and omnipresent in every aspect, not only of the individual's life, but of their family's. Their families were "retarded" also. The kid isn't just retarded, the society and institutions retard. That became such an enormous breakthrough in my understanding. Because all of a sudden, it became clear that it was only through political action, through social action, through the building of mass organization, and consciousness to change the paradigm to show that the least, this crowd who society had marginalized and absolutely put into the most vile and inhumane context could, in the right context, become a transforming presence in the culture, that would promote all the most ideal and almost utopian relationships. The challenge was to have people with disabilities seen as contributing and leading members of society strictly by virtue of the change of attitude and the change of definition towards them by us, by typical people. Out of that constituency would come an inclusive, customized and individualized culture, a culture that would not waste anybody, would not dispense with anybody. A culture that would have individualized education, a culture that would have customized transportation, accommodated and adapted living domiciliary circumstances, a fundamental transformed universal rightful healthcare delivery system with no sink hole to it.

Cowan: So that's what you were informing these parents, starting to light a fire under them, because your own thinking had changed.

Bronston: Right. And it had nothing to do—I didn't have a word for it, I didn't have a word for it yet. All I knew was that "the they" were like me. Those kids were me, I was them. The only difference was, they were in, I was out. They maneuvered language differently. They thought about things differently. The question was, how to bring common sense, how to bring typicalness, how to bring normal expectations with a little "n," and when? Shortly down the line here, I learned about Wolf [Wolfensberger], and the Normalization Principle, with a big "N," theory. All of a sudden, I had a framework for the whole thing, that I could not absorb fast enough, or enough of in order to legitimize, formalize, arm my intuition in order to deal with I saw in the institution, what we were dealing with. Because the arguments that I was making were arguments that came from just a sense of, how can you treat people like this? How different are your expectations and your relationships to these incarcerated folk, who are in the most abysmal circumstances, when basically, I mean, I came to understand that you— Jesus, I just—

Cowan: Yes, It's overwhelming. Who were you making these arguments to?

Bronston: First of all to myself. First of all, I have to have the breakthrough in my own mind to understand what I'm dealing with because I'm walking around thinking, why is there such a disparity between my feeling and my intuition about things and the way that reality is set up? Why are people kept in these big buildings? Why isn't there furniture? Why are there so much drugs? Why is there such wretchedness? Why is there such suffering? What's the problem? Why aren't they getting money? Why can't you make a case to emancipate people? Where is the school program? Why are the workers so cynical? Why do people not have any value for anybody in this place, the workers included? The workers were only one-half step above on the social strata of value than the residents themselves, and they did this desperate dance back and forth as to who was the worker and who was the incarcerated, because the workers were incarcerated the moment they went to work!

Cowan: Did you ever try to make that case to the workers?

Bronston: Constantly. Constantly. It was a perpetual program of re-indoctrination. Constantly. And they got it, because they wanted to know, why would a young, hot, highly-trained doctor come here? Why wouldn't you go out and get a real job, where you are a real medicine man? And I'm taking care of people like they're Rockefeller's family. And I'm saying to them, "Look, this is my kid, this is my sister, this is my mother, this is my father. I can't take care of people if I don't see them as me, if they're not a personal extension." We're all one, on some level.

Cowan: But your efforts to organize the staff into a union, an effective, powerful union, that was not successful?

Bronston: No, because the workers were caught in an impossible dilemma. They came to work and were paid in every sense of the word, and administered in every sense of the word, to see the world through the old paradigm. For one of these people to lift themselves out of the expectations that they had internalized and were virtually unconscious of, was an impossible thing to ask. The fact that there was still some residual of human instinct and human intuition after the institutional indoctrination, and after working there for six months or a year or two years or whatever, was a miracle. So who then, in the equation, still has some hope? The parents!

So it became clear that we had to begin reinforcing in the parents, the sense that their young person, their son or daughter, their relative that was in the place, was being savagely mutilated in every aspect, by the place, and that the history of the way in which the place had treated the family by keeping them at arm's distance, keeping the families outside the buildings, keeping them groveling, keeping them supplicating for the least aspect of connection to their kid, starting right away when the kid came into the place. The rule was that the family could not see the kid for the first three months as a way of breaking that bond between the family and the kid and imposing a dehumanizing condition on the family. These practices were all part and parcel of trying to get the family to accept the old paradigm, the professional knows best paradigm.

Cowan: And do you think that was deliberate policy?

Bronston: Oh, absolutely!

Cowan: On the part of the New York Department of Mental Health?

Bronston: Absolutely! They understand that they cannot have a caring family meddling in a situation that has so few options to make accommodations for the human needs of that individual. They have to somehow create a condition where they can submerge and homogenize everybody who comes into the institution, into an institutional culture, where it is clear that the lowest-down worker in the institution has hegemonistic control over every aspect of that person's reality, over the family. You cannot have an "accountable" warehouse and have it not be challenged.

Cowan: Were these families prevented from knowing each other as families?

Bronston: No, the families were organized in a thing called the Willowbrook Benevolent Society.

Cowan: How did that happen?

Bronston: It was part of what had been going on since way back. It had always had a parent organization, but the parent organization essentially was paralyzed. This is a very complicated story. The parent organization was administered by the New York State Association of Retarded Children. The executive director of the ARC was a guy whose name was Jerry Weingold. This guy had been the executive director of the state organization forever. He was also a paid legislative consultant, a clear conflict of interest, and he was part of the problem.

All these professional parents advocates started off meaning well, but they finally and quickly get into positions of privilege and power, rubbing elbows with the Hoi Polloi. And they wound up buying into the existing paradigm and playing ball with the system. They become apologists for the system and collaborators. Now underneath the State Association, are the state institution parents organizations who, God knows, where it started. They may have been created by the institution. They were Italian families that stuck together and Irish families that stuck together and people who were accustomed to being part of community organizations from the old country and these were all, mostly old country folk. The families of the institution were still kind of first or second generation American-born people in large part, you know, old immigrant New York population.

Here sits the Willowbrook Benevolent Society, and the Benevolent Society is run by a marvelous guy, and his name was Tony Pintore. A marvelous guy, who ultimately turned out to be a tremendous progressive hero, once he had a context and support to turn his thinking. Because the parents intuitively knew the truth. They had been told from day one, get rid of your kid, put your kid away, and they had put their kids in those institutions at incalculable costs, incalculable costs to them, emotionally, intellectually, culturally.

[Tape 8, Side B]

Cowan: Just to sum up a little bit, you are now at the two woman's buildings, appealing the decisions that were made to move you from Building 76 and seeing that bringing Willowbrook down, the key is through organizing among the parents.

Bronston: Right. Because I'd been organizing parents back in Building 76. One of the things that happened was that it became clear to me much earlier that trying to organize the workers was not going to work because there was essentially a company-controlled union, the State Employees Association, that held more than half of the workers. A small minority of workers, black power workers, were in a very nationalist kind of reactionary focus that, whether it was intentional or accidental, was tightly surveilled by the attorney general of the state's through control of their rosters and monitoring. They didn't have the right to bargain for their workers but they were taking union dues, which I didn't understand at all. It was just the most incredibly corrupt thing I could imagine.

The only constituency that still potentially had their head on straight to make change were the parents.

Cowan: Could I just ask you a question here, and that's when you said a minute ago about bringing Willowbrook down, was there a moment when you said to yourself, this has to come down?

Bronston: Yes, right at the beginning, when I got there. What happened was, I don't know if I mentioned it earlier, but I made a girlfriend there that was a school teacher—

Cowan: At Willowbrook?

Bronston: At Willowbrook. The teachers there were on consignment from the New York School System and provided a limited amount of token classroom programming for certain selected children in there, just to maintain the facade that education was going on there for school-age kids. The teachers all submitted a petition demanding that there be more respect for their work, more continuity and preservation of their work after classroom time, at the ward level. They demanded that the workers be expected and instructed to maintain certain of the skill sets. This petition was given to the director, to Hammond, as an ultimatum, that if they didn't do it, the workers would quit. Instead, Hammond just fired them all!

Cowan: This was right at the beginning?

Bronston: This was right at the beginning, this was within the first three or four months that I was there. And remember that I came in as a seasoned radical organizer, I mean, I've been through some real struggles. So I said to them, "If you don't have a fundamental bond and alliance with the ward workers, then you got no way of pulling this out." They rejected my advice and really felt that the ward workers are the problem. I said, "You don't understand, the ward workers are the only force that will protect your jobs." You have to frame and ally your concerns from the two of you to the administration, not against the workers.

"You're making the ward workers the bad guys, the guys that are selling out the kids, which may in fact be partly true, but not because of anything other than their own lack of clinical or political consciousness and awful conditions. There's been nobody to work with them in order to sort this out." Before the teachers got fired, which happened within a week, it happened so fast, I said to them, "Don't do this, you're not ready to do this, you are not ready to come out and give an ultimatum because there's only twenty-three of you and they can get rid of you in a minute because they don't need you in the first place. That's not what this place is all about." And sure as hell Hammond fired them. He fired them, fired my honey, fired them all.

Cowan: So that's when you saw—

Bronston: I saw for myself, this is it man, this is it. I'm going to get this place, this place is really cruel! This is a bad place.

Cowan: Okay, so leaping forward to your alliances with the parent's groups and how that was going to help you.

Bronston: So there was a lot of parent involvement as I began cleaning up Building 76, and I began to have parent meetings on the grounds, and began to make deeper and more legitimate connections with the Benevolent Society parents and began working in the community with the parents who still had their involved kids at home. Remember, we're organizing all over the place anyway, It's not like this is all I have to do.

Cowan: Is Building 76 the woman's building?

Bronston: No, Building 76 was the Children's HIP building that I was kicked out of. My women's buildings are twenty, twenty-two, twenty-three.

Cowan: Are there parents for those older women who were just at the end?

Bronston: Not as many. It's a touch and go situation. I remember, I mean, I was constantly interacting with families. Every day I would sit with two or three families and just talk to them about, just to reassure them that I was there, that nothing was going to happen to their daughters if I could help it—I insisted that the ward workers let the parents into the buildings to see. They wouldn't let them in the buildings. They were afraid to let the families see one foot behind the entry ward steel doors.

Cowan: That's unbelievable. No parent challenged that?

Bronston: No. They felt that they had no grounds, no standing, lest the institution would dump their kid out. It was so medieval, it almost defies description. It was a given, it was just a given. The psychology of the families was a world unto itself. These are people who have to have felt, at some level, either towering, towering guilt for putting their kid into the place, and "abandoning" the kid, or a towering ambivalence and rage that they could not face because of their hatred of what the universe had done to them in imposing this burden in their lives.

Yet, because of the paradoxical psychology of it, parents would often turn that around, bury the hatred and becoming obsessively committed to the kid in a very perverse way that essentially reinforced the institutionalization. Their kids were there. They weren't able to cut the kid off, and nobody was there to help them work through their mixed feelings. Or families that had been completely intimidated by the medical profession and by the state hospital, the state institution's professional, dehumanizing and alienating orientation that constantly goes on about, "We're doing the best that we can, but what can you expect? You should be grateful for what little you've got because God knows if we put this person out on the street, they would die on the street so be thankful."

The system created all these guilt-trips and all these distortions of reality. The issue of rights were not on the horizon. Nobody talked about rights. Nobody even had a notion of what that could mean.

Cowan: You mean something as basic as the right to decent care?

Bronston: Yes! Clothes, food—the parents couldn't hold the institution accountable for the fact that they would bring a pair of shoes one week and the next week they were gone. And bring another pair and that pair would disappear. The families brought lots and lots of stuff, but the stuff went into this pool of a common laundry, a commons—it was a pit. It was like a garbage dump, it was like Great Kill's dump [now called Fresh Kills], which was just down the street from Willowbrook. Which was the burial ground of all the garbage in all of New York City, came to Great Kill's in Staten Island, which is where the World Trade Center refuse is being buried now. So the paradigm was right there, just so much unwanted life.

The isolation, and the imposition of the devalued and stigmatized paradigm was everything. You must understand that as long as we see, there's a thousand features, facets, to how we see people as "less than," which is really reinforced by deviously funding streams, by the warehouse-like buildings and the spaces that people are consigned to, by the location of where all those isolated spaces are. The way in which care programs are defined, goals are set, expectations are provided, these images create the absolute defining ground of our relationships, whatever they are, for better or for worse.

Cowan: What was your intent, then? Did you have a formulated idea of how you were going to move the parents to an effective role?

Bronston: Those are hard questions, they're hard to remember. My plan here was to rehumanize the parents, and to reinstill in them a sense of the rightfulness and the urgency of their relationship to their relative that's stuck in Willowbrook. I didn't really have a clear idea of how this was going to work, but all I knew was that the more people that were in motion, and the more people that were outraged, and the more people that felt that they had cause to call the administration to account for the impossible circumstances that existed there, the better. Little by little, I began, and these are things that are a little bit remote at this point, but I soon met Bob Feldt, who was the lawyer for the Staten Island Legal Aid Society, who had been representing a number of Willowbrook families and knew something of the tragedy inside.

And somehow or another, through the Benevolent Society, I don't know exactly how it all happened, but there weren't that many of us, it was a small county. At a meeting here or a meeting there, people began to show up and I began to meet lawyers that were really interested in what was going on at Willowbrook, and I was more and more interested because I was so isolated and so starved for contact with activist and civilized people in my field. I joined with professional mental retardation organizations and would go to seminars that I would get Willowbrook to pay me to go to such as in Pennsylvania, at the Deveraux School and so forth, where they would bring great scholars in the mental retardation field, where I met Burton Blatt for the first time.

I also heard Wolfensberger for the first time, Gunnar Dybwad kept showing up, who I knew from my work in LA. And remember that I had this enormous pedigree through Dick Koch and Children's Hospital, these many years ago, that gave me a familiarity and a standing. I had an original paradigm of community-based services that was my origin. I was suckled on the opposite of what I was dealing with. I felt very, very positive about, convinced about the validity of non-institutional services. This Willowbrook, as Topeka State Hospital, was a whole new experience for me, being sunk in this pit in order to deal with it, and only have an insider view.

Cowan: Was anybody else from Willowbrook working with you? Was Mike Wilkins?

Bronston: Yes, Mike was also. But Mike didn't have any clinical and ideological disability services history. Mike was just a straight doc, he was an internal medicine specialist. He didn't have the same kind of technical understanding of the developmental breakthroughs that were happening in the education field or the history of how we got there. Mike didn't participate with me in the forays into the new developmental sciences scholarship that was unfolding; the new theories of normalization and human services, the work that was coming out of Scandinavia, the work that was being developed in Nebraska. That was all new for me too, and as I began to hear about these things—and actually the turning point really was, I read two books by Burton Blatt, that I mean, Blatt was continually writing incredible books about institutional living [*Christmas in Purgatory* and *Exodus from Pandemonium*].

I don't remember exactly how I first met him, it was probably at a seminar, at a professional seminar. His book, *Exodus from Pandemonium* was literally my experience in the institution. He talked about stuff that absolutely resonated with me in every aspect about the alienation, about the sadness, about the unprofessionalness, about the total misappropriation of resources, of the mistaking of the way in which technology and programming and educational training took place. He was an education professor and chair of the Special Education Department at Syracuse. Little by little, I began to come out of the primeval mud, like an amphibian turning into a reptile, it was truly a breakthrough.

I began to have a conviction about what I was doing and a political and policy framework. Without that framework, without the professional framework to essentially challenge this thing systematically, the challenge was leveled emotionally and sentimentally against abuse. If you don't have any reinforcement for that, they think you're a "bleeding-heart liberal." That wasn't the term in those days. Principles were critical to raise the level of rightfulness, systems of application, so that you're talking about the way a program should be set up for every human being and the way in which it can be held accountable to science and the public at large.

Cowan: Then it's actionable too. Were you communicating these ideas to parents and saying, here's some action you should take?

Bronston: Yes.

Cowan: How did you do that?

Bronston: I said to the families, "We've got to meet, we've got to talk about what we can do. We've got to look at your kid's progress." The part I'm having a terrible time reconnecting with right now is that period between the end of the appeals and the final rejection of my appeal to return to Building 76.

Cowan: Well, talk a little bit about that. You didn't say that your appeal had been rejected.

Bronston: Well, at a certain point, I petitioned to be returned to the building, and I was refused by the Commissioner for Mental Hygiene himself, Alan Miller. I received a formal letter through the administrative law procedures of the state system. Then the question was whether we were going to take this to court and fight beyond the "fix."

Cowan: So this is after you'd had the meeting with Hammond and it had been appealed, and the appeal was turned down, and now you were going to court.

Bronston: Right. And I don't remember why we didn't go to court, but I think it just may have been that the situation escalated and it wasn't more than six months from that point when the shoe finally dropped and Hammond fired Mike Wilkins and Elizabeth [Lee], and the struggle immediately shifted from me being at the point of the struggle on the inside, to Mike and Liz being on the point of the struggle on the outside in the public eye.

Cowan: Well, say who Elizabeth was.

Bronston: Elizabeth Lee was a social worker that was working in Willowbrook. She was the social worker assigned to Mike Wilkins' buildings, six and eight, the young men's buildings on the other side of the grounds.

Geraldo Rivera exposé of Willowbrook hits TV "like a bomb"

Cowan: What had they done?

Bronston: Well, what happened was that there was a whole series of exposés that came out in the Staten Island newspaper, in the *Advance*, the *Staten Island Advance*. And there was this remarkable writer, a woman journalist for the *Advance* that had been following the struggle. The strategy that I had was that we would invite super-star leaders in mental retardation to come and speak to our family organizations in the community about what needed to happen for their kids, and in passing, talk about the consequences of having all the money sucked up by the state institution, that should have been going into community-based services. We needed to make clear that as long as you have these big lock-ups, these big warehouses that cost such incredible amounts of money, you could never properly fund community-based services. Segregated institutions were an absolute cancer!

Little by little, the *Staten Island Advance* began seeing and covering the big story. Plus there was a long history in the *Advance* of shocking news about the institution, and it sold newspapers. This particular writer, her name was Jane Kurtin, was absolutely extraordinary. I mean she should have gotten the Pulitzer prize because her stories lead to the administration to fire Mike and Elizabeth for allegedly leaking information to the press that essentially was privileged, private information. Michael had been working with this lawyer, Jerry Rivers, around the struggle that we were waging at the same time at the US Public Health Hospital to unionize that hospital and defend a group of Native American vocational nurses seeking pay parity.

Cowan: Different from—?

Bronston: Different hospital, different place, we were all over the place in Staten Island.

Cowan: Also on Staten Island?

Bronston: Also on Staten Island. A major U.S. Public Health Service hospital. A magnificent hospital where my twins were born. This lawyer had just gotten a new job, with ABC Television and changed his name to Geraldo Rivera.

Cowan: That's such a great story.

Bronston: So Geraldo, Jerry Rivers, at the time, was helping us with a lawsuit that Michael had organized on behalf of these American Indian, native American licensed vocational nurses who were not being paid the same as regular, Caucasian workers at USPHS. So Mike was very close to Geraldo. He was a progressive young public interest lawyer in New York City. So he had just gotten this job, at ABC, I don't know, a year or half a year before, whatever it was, and he was struggling along as a news reporter. He came to Willowbrook with his camera team at midnight.

Cowan: Out of the blue, or did Mike call him?

Bronston: Mike called him.

Cowan: Because they'd been fired.

Bronston: Because they'd been fired. He was one of us, we were all buds, we were all friends—justice hungry advocates.

Cowan: So he called Geraldo and said—

Bronston: I've been fired and this place is absolutely abysmal, you've got to come and see it. And Geraldo came with a team, with a flying camera, lights—Michael had the keys, of course, and Mike walked him through the whole place in the middle of the night.

Cowan: How'd he get on the grounds?

Bronston: Just drove on the grounds. There was no security, the shit hadn't hit the fan yet. This was the first breakthrough. So he came, he drove on the grounds—there was no kiosk, there was no security, you could just drive on the grounds. It was like Great Kill's dump.

Cowan: What building did he take him to?

Bronston: Six and eight, he took them to his buildings. Michael was on duty all that night. Plus we had keys for everything, and there were only three keys to get you in every door of the whole place, totally. We had the keys. Mike walked him through a lot. The next day he walked him through more. The stuff hit TV New York and national ABC News audiences like a bomb. It was the sensational story in New York and the country, for about two weeks. The ratings, the ABC ratings, and Geraldo's ratings went off the chart. It became the great humanitarian story, the great exposé, the great scandal of the day.

Cowan: Tell me what the cameras saw.

Bronston: They saw the nakedness, the filth, the inhumanity, the lack of any comfort, the unwillingness of the staff to be seen. Just the inhumanity, the gross, gross inhumanity of the place. Like opening up a dank cellar and finding human beings that had been stored there to live for twenty years with nothing, and have become reduced to absolute wretched souls, out of the worst nightmares that you could possibly imagine in fiction books of drawings of—

Cowan: Bedlam.

Bronston: Yes, Bedlam.

Cowan: The public was moved to write to their—

Bronston: No. It was just the exposé. So here's the governor at the point of the knife, here's the commissioner of mental hygiene at the point of the knife. The truth comes out about how bad this is; that hundreds of millions of dollars are being spent, and everybody mindlessly thought everything was okay. And then, you open up and see this festering, purulent, wretched reality, this miserable, this violent, this savage way in which the State of New York is taking care of its own. For every captive in the big house, you've got two identified people with disabilities still living at home or on the street of New York City.

The state couldn't allow that kind of truth, that kind of reality, to spill out, because there's no telling where it's going to go when it comes to the ballot box. You just don't want scandal. You don't want to be responsible for appearing like you're God and you're solving the iniquitous problems of the world and then all of a sudden you get exposed to be some kind of inhumane monster—every horror, imagination and fantasy in the world of you being a human abuser, which is right exactly what they were. They would go to interview these guys and they didn't come across well at all on television. It just became the scandal of New York, for the year—it was the world's worst thing that possibly could've happened from their perspective and possibly life saving for the "hostage" population.

It was like the planes flying in on September 11 to the World Trade Center. It was the same kind of outrage and consternation of how can this be, right here under our noses, so many thousands of people violated. Before that, you know, there was a much greater effort to get us at a certain point before Mike was fired. There was a whole period of time where the institution was so threatened by the success that we were having in mobilizing parents, and especially some very outspoken and very theatrical parents, like Malachy McCourt. Malachy's wife, Diana, had a girl who had been in the institution since she was two or three because there was no other place to put—their girl had severe CP.

We became very close to the McCourts. Malachy was this great giant, red-bearded, fiery Irish curmudgeon of a guy, who we adored. It was a mutual admiration society. I mean, he was a fighter. He went storming into the administration office, called the press. At the point, I remember, returning to the story, the way we got on to the Dick Cavett TV Show.

Cowan: Why and what happened that you got on TV?

Bronston: After the exposé, the administration mounted a really powerful and fairly sophisticated campaign to discredit Mike and I, as the stories were coming out in the newspapers, and as we were fighting to mobilize the parents. Because, more and more, the parents became a real force, a caring force to be reckoned with in the institution. At some point, in the battle for reform, there was a workers strike—there was a workers' strike on the institution grounds, called by the management-controlled union. Something happened, and the parents came in to man the wards until the workers' action was over—in a way to support the workers. Parents weren't antagonistic to the workers. But the administration used that as a way to intimidate the workers and say to them that the parents were there to knock them out and that the whole purpose of this thing was to get rid of all the workers, rather than to get rid of these administrative policies and vile practices.

So the workers were very easily manipulated and maneuvered into a conflict with the families. This was going on in the City of New York at the same period as an epic battle between the teachers union and the poor parents in the South Bronx and in Brooklyn and so forth. There were enormous struggles going on between white, black and Puerto Rican political interest groups in the City of New York to vie for some kind of social reform and adjustment and service programming. So this was in a very politically explosive context. Our little battle was a little tiny battle off to the side, around parent control, around accountability, around community democracy, against these monolithic institutional structures.

The result of all that was that, at one point, the administration mobilized a day-long teach-in, run by their lackey workers and the churchmen on the institution to speak out against Mike and I for agitating against the jobs of the workers, in alliance with the parents. They sent a whole fleet of buses that the administration broke loose, under the rubric that this was a "workers' action," to Albany, to protest in Albany, against all the things that were going on in the institution. This was just after the exposé.

Cowan: After the Geraldo Rivera thing.

Bronston: Yes. So Michael had been fired and was struggling for reinstatement, and they were calling for the administration to uphold the firing and not let Mike and Liz back on the grounds. Mike was fighting to get back into the institution, with my lawyers. There was this enormous tumult that was going on there to block him from coming back. The administration was organizing the workers through their lackey workers, their special supervisors and friends.

An extraordinary phenomenon happened where a number of progressive black young men, who were new workers on the wards—the leader's name was Felton King—stood up on our behalf in an afternoon rally, called by the administration. Spokesperson from the churchmen there, the rabbi, the Catholic priest, the Methodist ministers that were institution chaplains, and key workers in the place that had been rallied to speak out against us and misrepresent what was going on. The young men stood up, Felton and his coworkers stood up, and said, "I'm not going to stand for these lies that you're telling about Mike and Bill. They're the only two doctors on the grounds that come when we call. Everybody here knows that they care more than anybody on the grounds, that They're constantly taking care of the sickest, that they're not like any of the other doctors." It was explosive and the rally was immediately dismissed and the workers sent back to their wards by the bosses.

[Tape 9, Side A]

Cowan: What was the administration's reaction to the media exposure? Did things begin to change?

Bronston: No. Definitely not. Well, there were attempts to make it look like it was going to change. But the whole purpose of this thing was to absorb and stop any kind of real transformation. As a result of all this scandal, the television exposé, the tremendous turmoil on the grounds, Hammond was removed from his position by the higher ups. Meanwhile, Mike and Liz were out in the community and the newspapers are all over Willowbrook, and I'm still working on the inside.

Cowan: Because?

Bronston: They couldn't fire me without cause.

Cowan: You had tenure?

Bronston: I had just eked through my probation period but Mike hadn't. They fired Mike because he didn't have tenure. They were able to fire him without cause because he didn't have tenure. They couldn't fire me without cause. And I had great lawyers and I had already battled them to the ground a couple of times. So it was a very explosive situation. They brought in two or three new temporary administrators until they finally got this one guy named Miodrag Ristic, who was a Slavic-born guy, with a British accent. He was either Hungarian or Bulgarian, or Czech, I forgot where he was from. Very kind of a dandy little guy. Very well-dressed, very handsome, clean-shaven, little guy, who was just a piraña. An evil little man who was totally absorbed with his own importance and his own significance. He would bring me into his office and say, "Look at you and look at me. Look at the difference between where you could be and where you are now. You could be where I am now, sitting in this seat."

And I said, "Miodrag, the only reason you're sitting in that seat is because of me. You'd better be real clear about that. And if you don't clean this place up, you're not going to be sitting there long at all. Understand where the power is. You've been installed by the state as an effort to do damage control. You can't fire me because you'd have to bring charges against me for which you can't invent cause. I, on the other hand, have all the press, and the families, and righteousness on my side, because this place is a shit hole. And what's going on here is unspeakable, and you either to clean this place up or you won't have a job here long."

And he didn't get that. He thought that he had the power because he was in the seat. I wanted to just back him off me, because life was hard enough as it was. To have this guy think that he had an edge on me, and to let him think that, or that he was in any way intimidating. I had such contempt for the guy, it was just a problem having him there because I never knew at what point I would step really over the line, and he would get me for insubordination or whatever it was.

Cowan: Did he make any changes?

Bronston: Well, you know, they made a lot of cosmetic changes. They brought in a little more soap—but, you know, nothing significant really happened. I was so tired to my deep core with the ethos of the place. Whether they fixed something for one kid or three kids, it didn't really matter. The federal class action lawsuit was not in place yet. The thing that was so desperate to me was that the more we hammered at how bad the place was, the more money would come in to this horrendous place to fix it. And we didn't want it fixed, we wanted it closed once and for all. It was a concentration camp, you weren't going to rehabilitate this place. I was clear that what was missing was individualized, integrated community-based services.

Lawsuits, media, and organizing close Willowbrook

Cowan: What was your next step then, to get it closed?

Bronston: I realized that we had to have an affirmative position, and that there had already been a few key national class lawsuits filed. A Washington, DC, suit had been filed by Stan Herr for "right to education." The Pennhurst case had been filed against states for constitutional violation of rights in Alabama. There was a major lawsuit that had been filed against Belchertown in Massachusetts, another snake pit that was up there. I planned to bring together all of the lawyers on the Eastern Seaboard that had filed class action lawsuits against states on behalf of people with mental retardation, because it was very clear to me that there were major problems with these class action lawsuits. They were pioneering litigation that were being filed in conjunction with the US Department of Civil Rights as amicus in these cases. There was an incredible lawyer in the US Department of Justice that was really with us [Mike Thrasher]. It was amazing to me, because I had grown up now seeing how the FBI and the Department of Justice and the US government were absolute the enemy, the enemy of the world, Vietnam, I mean, civil rights, the whole thing. I think Michael lives and works now in Omaha, Nebraska. He was absolutely incredible.

Cowan: This concept of a "right," was that beginning to develop now? That's what all these suits were about?

Bronston: Yes. Right to treatment, right to due process, and so, I figured if I could get all the lead plaintiffs' lawyers, of which there were ten, twelve, fifteen, into one room, to talk about what was working and not working in their cases, we could examine what had been in operation now for about a year or two. These very significant developments, which we were watching very closely, that maybe we could frame a case at Willowbrook that would really be perfect, the perfect case, based on the experience of everybody. So I found a little monastery retreat in Staten Island and put together an invitation with our friends, Mark Marcario and other friends that were working together. We invited the cadre of parents that were the most active and outspoken parents that were fighting against Willowbrook, making testimony in the state legislature and so forth, and all the top radical professionals, progressive professionals in the field, and all the class action pioneer lawyers.

I broke the meeting up into three groups. Gene Eisner agreed to be the moderator, the chair, my lawyer became the moderator for all the lawyers in order to facilitate their putting together a class action lawsuit to file on behalf of Willowbrook against the state of New York. There were lawyers ready to make this move. Bob Feldt and Bruce Ennis, from the ACLU had already been thinking about working on this challenge for a long time. They just didn't have the context and the political focus to really make it happen. It was a two-day-and-night conference, which was absolutely an historic meeting. When the lawyers came out of the room, they were ready to file the New York State lawsuit against the governor and Alan Miller, and the Department of Mental Hygeine, on behalf of Willowbrook parents and residents, *Parisi et al v. Rockefeller et al*. Much of that story is then translated in the subsequent books that were written.

What happened with me in that instance was that I wound up going back into work every day. I found that I was less and less able to navigate the days. They were nightmares for me. I would close myself in my room. I was depressed, but I didn't realize how depressed I was. It was so painful, it was so awful. What happened one day, very moving to me, I was continuing to instigate major visits from VIPs. People would call me up, major people in the field, and want to come and see Willowbrook. They wanted to come and visit and see what all this fuss was about. Well, they knew, but they wanted to come and see it. So I was constantly setting up these very high-level tours.

Cowan: You were allowed to do that?

Bronston: There was not much they could do about it. These were dignitaries, high professionals, professors, heads of universities, major people, major professionals in the field of mental retardation wanted to come and find—they knew that this was a historic fight. It was a big fight, like I said, at Pennhurst, a big fight in Alabama. The big suit in Massachusetts—I mean, there was extraordinary historic work going on.

Cowan: I would have thought that the new administrator would give you a real problem about allowing even more people to see Willowbrook. He was just so sure of himself.

Bronston: We were out of control. We had a liberated zone. We moved with aplomb on the grounds. This was a no quarter war. We had Senator Jacob Javits on the grounds, we had, I mean, we had everybody on the grounds. They came to put the fire out. This was a serious fire in the Republican camp. You had Rockefeller sitting there who was the fair-haired governor of New York, who had just finished building a gold and white marble palace for his regime in Albany, two or three billions of dollars. That was an absolute obscenity where all the money went to they saved when they had a job freeze. This was heavy duty, we had triumphed on the Dick Cavett show, we talked about how the money was mishandled about this whole building bond financing issue. We talked about all these guys are what's the word for it—?

Cowan: Corruption?

Bronston: These were death-makers that were in charge of the state's program to rehabilitate people with mental retardation. They were fundamentally betraying the public trust. They were aiming at us every drop of red baiting kind of effort they could. The clergy at Willowbrook were given thousand and thousands of three-page stapled, unmarked, red-baiting allegations against Mike and I—that we were Maoists, that we were going to poison the water supply of Staten Island!

The clergy gave out thousands of these fliers, stapled fliers, on Sunday morning from all their churches in Staten Island. Staten Island is like the paragon of reactionary politics in the United States. All the largest Mafioso families had homes on Staten Island. Staten Island never was won during the American Revolution and always remained a Tory stronghold. During the Second World War, there were Nazi organizing offices on Staten Island. This was a bad place to be indicted as a leftist in the public. And we lived in a big wood frame house, and I expected the house to blow up, you know. We had children there, we had like five families living there. So we had to figure out how to contradict this thing. It's just amazing. It just shows you the extraordinary status of the situation and creativity required. Literally overnight, within three days, we were able to get on the Dick Cavett Show.

Cowan: You contacted them?

Bronston: No, Malachy McCourt did.

Cowan: Did you say he was a radio person?

Bronston: He was a television personality, he was a bartender, he was an actor. He's Frank McCourt's younger brother. Frank wrote *Angela's Ashes*, Malachy wrote *Two Monks Swimming*. The two brothers are these incredible Irish ballbusters who are theatrical. They're poets and writers.

Overnight. Literally overnight we got on the Dick Cavett Show. And we had a program. Geraldo was sitting there, Diana McCourt, Malachy's wife, Bernard Carabello, who Michael had somehow pulled out from the pits of one of the buildings that had severe CP but had typical intelligence, myself, and Mike Wilkins. There's five of us. And a bureaucrat by the name of Robert Hayes.

He replaced Fred Grundberg and was the new State Commissioner of Mental Retardation, and a guy by the name of Wolf, who was the PIO, the Public Information Officer for the State Department of Mental Hygiene. These guys literally came in spats, black suits and vests. They looked like morticians, they looked like undertakers. We were all thirty-somethings, in soft sweaters, hair down to our shoulders, beards, doctors. We were just warmly dressed, softly dressed. We looked like we'd just gotten off the boat. Here's Bernard. Diana, this beautiful kind of dark-haired mother was there, his very heavyset Puerto Rican mom, Bernard's mother. Here we all are, all on this couch, this bunch of gypsies, talking about life, talking about love, talking about decency. These NewYork State old boys are talking about their bureaucratic reasons why this place is a tolerable and excusable shit hole.

Cowan: Were there pointed questions? Did that help sell your case?

Bronston: Yes. It did. We, in fact, read on national television, the red-baiting sheet. Cavett said, "Is this true?" I just roared with laughter. I couldn't answer it, really honestly, because it was true. I mean, we weren't trying to poison the water supply, but we were communists, we were Marxists, we were self-conscious revolutionary organizers. What that meant was to do the right thing by people, to make sure people don't suffer, and challenge state power. But reading their propaganda or national TV showed the absurdity of their attempted escape.

Cowan: What was the outcome? How did this change what was happening?

Bronston: We were able to take the gun out of their hands. We were able to seize the initiative. Once they couldn't play the communist card against us in an effective way in order to garner legitimacy and to essentially cut the ground out from under us, they had nothing left to play because the facts were what they were. The place was absolutely inhumane in the extreme, it had been that way for three or four decades. There was a group of people sitting at the top who drove around in black Cadillacs and chauffeur-driven limousines and black suits and bureaucratic elitism, all the way up to the governor, in league with the banks making millions and millions of dollars on the suffering of all these people. And on the other end of the spectrum, was the horror that Geraldo was hammering into people day after day on the television.

The whole city was completely galvanized by this struggle and that television show was an absolute strategic turning point because from then on—I mean the reason why they did what they did was guided by the FBI and the local congressmen. They had a meeting on the grounds with the FBI and the secret police and the congressional leadership in New York. The State Department of Mental Hygiene and Hammond had a meeting in his house with all these people in order to set the ground for how to get Mike and I off their backs, how to discredit us, and how to go back to normal. And it didn't work. And when it didn't work, at that highest level, when they played their best card, they tried the workers revolt, it didn't work. They tried the red-baiting thing, that didn't work. It was over for them.

They had lost the big fight. Now all they had left was to temporize, was to try and stall and to maybe try and put "under new management" banners on the front of this concentration camp, over and over again. So there was a whole set of administrators that they'd put in there to try and hold the ground, and assuming that people would lose interest, would forget about the situation, after a little while and that things would return back to normal and we would ultimately leave. But we locked the federal suit in and the federal suit became the perpetual ground for revisiting the problem. And accountability. And a judge, that even though he was civil, was not friendly to the State of New York, and forced the whole system under a federal master's hands in order to clean the place up, but it then took twenty-five years. It took twenty-five years before the place finally was closed.

Cowan: It's closed today?

Bronston: Yes. It's been converted into a community college with every conceivable attempt possible to eradicate any history of the infamy that existed there. There is not a sign, there is not a memorial. They have tried to re-architect the buildings by removing doors, removing staircases, changing entryways, putting in new floors, new ceilings, to make it into a community college. It's Staten Island Community College. It's very interesting, because I was there just about a year, a year-and-a-half ago for the twenty-fifth anniversary where the three New York governors, that ministered the transformation of the place from a concentration camp to the community college were honored. It was very powerful.

We were so close. So many scores of families were so close when we fought for closure and lived such an incredible struggle with such hopefulness. And here, two-and-a-half decades later, these families are now being confronted personally with being put into nursing homes themselves. Their children are now themselves in their forties and fifties, potentially confronted with being put back into institutions, back into nursing homes because they're old, and because Title 19 is still in place. Nothing has changed in national policy except that the whole financing system for medical services has gotten incredibly more greed and profit driven.

The scandal that exists now, and the sadness, the underlying sadness, the despair, the somberness of the collected families, and the lack of any pointed rage or any strong challenge to the system had been somehow beaten out of them. All these years of piecemeal struggling against this implacable bureaucracy that moved as slow as it could possibly move by any imagination in rectifying and fixing the situation. Like wiping your behind with wax paper, spreading the problem from Willowbrook, a single concentrated place, where you could see how bad it was, to five hundred smaller institutional places of ten and fifteen and twenty people.

Alliances with the early disability rights and independent living movement

Cowan: Okay, so let's go back a minute to before the closing, twenty-five years before the closing of Willowbrook and talk a bit more about that class action lawsuit and your own lawsuit.

Bronston: The thing that was very interesting was that during all this time, we really became incredibly visible in the New York scene. My job, self-styled job, was to establish alliances with every conceivable ally that we possibly could, every partner we could make. We became very close with the disability rights, independent living movement crowd. These active, young adults who were babies in 1950, were now in their early twenties, or very early thirties. Most of whom had physical disabilities, most of whom were folks with post-polio, or spinal bifida, or cerebral palsy involved kind of folks, and had put together political defense organizations and advocacy organizations, in order to advance disability rights.

It was the beginning, the embryonic development of a true primary individual disability rights political movement. Up to now, the whole struggle had been waged under the rubric of mental retardation families, which, of course, included all sorts of different kinds of folks, people with autism, people with cerebral palsy that had a cognitive component, that had a learning disability component to their neurological injuries. The families were divided, and continued to be divided in five hundred different tiny groupings, defined by diagnosis, defined by the way in which they came upon their devalued status, which was a diagnosis. So the multiple sclerosis crowd groups into their defense group, the muscular dystrophy crowd, the cystic fibrosis crowd, the mental retardation crowd, the down syndrome crowd, the learning disability crowd, and on and on and on.

All in a more or less vertical hierarchy of status with the post-polio crowd being at the top, the most elite group of the disabled community and mental retardation at the bottom. And here and there you have other big pockets that are not connected at all like the disabled war veterans, who totally don't relate to this civil rights movement at all. But little by little, as the children with congenital disabilities, that is, that had disabilities from birth or close to birth, who are now in their twenties, in the early 1970s hit the street, you have the burgeoning of a whole new consciousness, a whole new youth movement that is speaking to needing to carve a major place, dignity, and a rightful role in society.

That was not the case with the disabled veterans, who acquired their disability and always felt that they were very much dehumanized, or somehow—they didn't identify with the disabled community. They didn't identify with the societal disability crowd, with the congenital disabilities crowd, with the crowd that grew up with their disabilities. So what's happening at that time in the country is we're filing these atomic suits against states, driven by federal civil rights hammers, and mobilizing parents in New York and linking the movements through the progressive professional structures. For example, a thing called The Association of Persons with Severe Handicaps (TASH) comes out of the water. Which are the really guerilla educational system professionals that are working with the most significantly involved children. The American Association of Mental Deficiency, which is kind of a moderate group that came out of an "asylum directors" history, and it begins to move and begins to look like its going to embrace the new Young Turk professional community that is primarily an education-based membership rather than a medical-based membership.

Remember that all of the prior advocacy structures were all driven by professional associations to advance professional standing. So what's happening is that as you have more and more people finding jobs in the field of serving folks with disabilities, you have new cohorts, new groupings, new identities, new types of work opportunities that lead up to very high status jobs. If you're in the education stream, you can go right up to being a professor and a chair of a university of education or special education, as opposed to being a physician, a psychiatrist, who could wind up running an asylum.

So the special educational model pros really began to organize. They had temporary rapprochement with the medical crowd in the AAMD, the parent movement is sitting out here, the ARC, the National Association of Retarded Citizens, United Cerebral Palsy, National Epilepsy, Autism Society, sitting out there. The next thing that begins to happen is that the "Developmental Disability" rubric gets articulated and put into federal law, which sets up a national categorical funding program. The "Regional Center" system in California is evolving under the leadership of Dick Koch, Gunnar Dybwad, and guy named Ed Pye in Northern California. Pye set up a social work model of a regional center, developmental service system that was different from Dick's medical model hospital-based multi-disciplinary child development program at Children's Hospital in Los Angeles.

All these phenomenal happenings are cooking around the country. All this is happening in the shadow of the Vietnam War, in the shadow of the civil rights movement. Social activism is the norm, all over the place. People are doing something about something, somewhere, and part of the something that they're doing is inventing new words to describe new relationships that have to be put into place that change the way in which people are seen, the expectations around how they're seen and the role that they're going to play, and the resources they're going to have at their disposal, and the influence that they're going to exercise in everyday life in America.

All this is going on between 1971 and 1978, that five or six-year period. We, the disability movement, at some level, pick up a significant part of the human rights struggle in America, in tandem with the African American civil rights struggle. In tandem with an emerging woman's rights movement. All this stuff is bubbling in the late 1960s, early 1970s, that has all been broken loose by the protest against the war. This terrible Vietnam war woke up so many people all over the world! We have a very interesting take from underneath, a look at schools, the domiciliary resource system in the country, the medical service delivery system in the country, community access issues in the country—because our constituency has been either locked in to their homes or locked out of society.

Cowan: By "our take," do you mean the disability community in general?

Bronston: Yes, the disability community in general. Because so many families, walking around, have kids that can't get around, young people that are so broken, physically, in large part because of the imposition of institutional living that has confounded and compounded in extreme, their disabling conditions.

[Tape 9, Side B]

Bronston: So our role in holding up our piece of this complicated puzzle was to prosecute this federal suit. And Bruce Ennis, from the ACLU and Bob Feldt, from New York Legal Aid, put together this incredible challenge case, with the help, not so secretly, of all the other lawyers in the country that were working with us. All these lawyers that were filing class action lawsuits were talking to each other, more and more as a result of the model we established at the monastery meeting. Little by little, more big class action lawsuits were being filed in other states as well.

In the meantime, Wolf Wolfensberger is wailing away, out of the National Institute for Mental Retardation in Canada, where he is the senior training consultant, out of Nebraska, the Eastern Nebraska Community Office of Retardation. Wolf set up this absolutely state of the art community-based program, including the most severely involved kids. Wolf was also at Syracuse University, where he was also an adjunct professor under Burton Blatt, training scores of us, all the top activists in the country, in understanding the big picture of how it is that people with disabilities have been so profoundly marginalized and how the system works to dehumanize them with aplomb, with permission, and with all the professional support possible. He provided a philosophical and a programmatic recipe for us to first of all define the iniquity of the existing model and to turn it around, to untangle it. Meanwhile, anti-institutional lawsuits, and all the social and community activism is bringing together and bringing out all sorts of interesting active people from all sorts of crevices. In New York, I'm on the street constantly, with the Black Panther Party, with the Young Lords Party, and with a group called Disabled in Action.

Cowan: Do you remember any of the names of those people?

Bronston: Well, Judy Heumann was a member of DIA in those days. Most of them are here now, in California, due to Ed Robert becoming Department of Rehabilitation director in 1975. But what was happening at the time was that there was a strong mobilization of a brand new constituency in the equation that were no longer the parents. They were actually the young people with disabilities themselves, now grown, with new words, with a new paradigm, which had to do with independent living. They didn't want to be "dependent," safely, dependent like the developmental disability movement. They didn't want to be patronized. They wanted to call their own shots, they wanted their own apartments, they wanted their own accessibility, they wanted to get into subways, they wanted to get into movie theaters, they wanted to get into restaurants, they wanted to be part of America. Now.

They had lots of examples of civil disobedience. The interesting part was that the police forces simply didn't know, for a whole lot of years, how to cope with a person in a wheelchair chained to a bus, or demonstrating against being locked out, or not able to get into any kind of a public facility.

Cowan: Did it have any impact on how this lawsuit closed down Willowbrook?

Bronston: The interesting part was that what I call the F-1 generation, the new kids, the new radical progressive disability civil rights human rights activists, were really not part of the Willowbrook battle. That was old business to them. As atomic as it was, as pioneering as it was, for us to fix the institution, it was completely irrelevant to the Disabled in Action other than they wanted to see the old way exposed for what it really was. The Willowbrook suit really provided this toweringly legitimate channel to challenge the State of New York's imperious and implacable institutional bureaucracy, and to require the communitization, the release, the matriculation, the relocation of more and more people, ultimately, all the people at Willowbrook and the Willowbrook class throughout the state.

The problem was, our federal suit jurisdiction was only confined to Willowbrook per se, and you had these other fifty-nine New York state institutions that were still cooking along fine. The state was able to temporize indefinitely, in terms of, "give us a year to work on this problem," a year would come around and the problem wouldn't be solved. Give us another year, because it was some other minor point—it was an unbelievable campaign waged to depopulate Willowbrook. But the important thing here is that, at least at one level, the mortal spear was in the heart of the beast.

Cowan: So they had been ordered to empty out and close down by the federal court consent decree?

Bronston: Right. And meantime, from my standpoint, I had to go back to work. I simply couldn't take it any more. I had used up every drop of reserve possible.

I came home one day, my wife said, "I want you to move out, our relationship is finished." I had my two three-year-old twins Aram and Darya, it was the greatest loss imaginable, which I don't think I've still recovered from, thirty years later. I'm still mourning the impact of that loss, which was directly the result of my being so preoccupied and riveted with my social activism that my private life was deoxygenated. The other part of that was that one day, I was running another tour through my old buildings and I went to go visit my original building, Building 16, that I was at with this tour. This was like a month after my federal court testimony situation.

Interestingly enough, Fred Grundberg was there. In my old baby building complex, where I first started working at. I don't remember exactly how, but he was there leading this tour. There were about eight people there, some from Syracuse University. I was standing in the front, looking over the cement wall into what was called the "playpen." It was a gigantic space of about fifty feet long by about twenty feet across with barred windows on one side, radiators all around the place, terrazzo stone floors and about ten gym mats on the floor that kids were strewn around on, on the cement or whatever it was, it was horrendous. One of the people said, "But they have no toys." Grundberg turned around and he ordered a ward worker who was standing right there. He said, "Give me that teddy bear." The ward worker reached into a crib, on the outside of the wall and took out a stuffed little bear. Grundberg threw it, like a basketball, into the middle of this floor. No kid could move to get it, because all these kids were not ambulatory. He said, "Ah, that's better, you're right."

I turned around and there were four women standing there, and they were crying. You know, I was in such a rage, and I thought, I remember, three years ago, I stood here and I saw this and I cried. I could not stop the tears from coming when I saw the state that the children were in. Now, I didn't have any tears left in me. I was so steeled. I was so bitter. I was just an instrument of war after all this time. I thought, I've got to get out of here, this place is killing me. This battle is killing me, I'm losing my heart.

I found myself closing my office door and hiding, literally hiding, not wanting to see, not wanting to talk to anybody. I couldn't go out, I couldn't look at anybody. I couldn't talk to anybody because all the professionals there kept trying to make our assault on the place wrong. To talk about, "look at all the good things that are happening" and "all the improvements that are going on." All I saw was the same terrible, terrible misery. I saw the lifelessness in people's eyes. I saw the shiftiness in the workers when they kept trying to explain what was going on as being acceptable or tolerable, and it was intolerable! I just couldn't be friends with them anymore, I couldn't take care of them anymore. I couldn't stand to be in a place so deathly, in every way.

There's a story to it, but I wound up being able to get an educational leave. I don't know how I was able to get it. I just think that the system had some changes going on. There were some new administrators there, and they just wanted to get rid of me. Burt Blatt at Syracuse said to me, "Look, if the top universities can offer Grundberg a seat at the professorial level for his service to their side, we can certainly find you a seat for what you have done on our side." So he offered and gave me a position, non-paid, at Syracuse University. The State Department of Mental Hygiene paid my salary for two years, to go away.

Cowan: So you were technically still a Department of Mental Hygiene Willowbrook employee.

Bronston: Right. I was getting my regular check from the State Department of Mental Hygiene to not be there. And I went and began working with my peer friends at the Center on Human Policy at Syracuse. For the first year, I lived in the back bedroom of Mark

Marcario's mother's home. I began to write my book manuscript, *Public Hostage, Public Ransom*, and I went to classes a couple of weeks a month in Syracuse and taught classes in Syracuse, and associated myself with Wolfensberger and began to learn systematically and rigorously the language that he understood, the analysis that he invented that was absolutely the antidote to all this inhumanity.

Final thoughts on Willowbrook, institutionalization and the disability rights movement

Cowan: Before we go on then to Syracuse and to finish up, do you have any final things to say about Willowbrook. You were done. The lawsuit wasn't over, but—

Bronston: Not over, in place.

Cowan: What about your own lawsuit that you had going?

Bronston: I never pursued that. This thing came up and it just preempted. My suit was strictly to safeguard myself from being dislodged from the struggle, and we had won. At some level we had won. Yes, we won. What happened in the midst of all that is that—major changes began to occur in the nation. The battle at Willowbrook was pretty much the last straw. The system couldn't tolerate any more hits like this. The class action suits against states came, forty of them came afterwards, over the next decade. In every major state in the union, the progressive advocate disability rights lawyers filed powerful class action lawsuits. The civil rights division of the US Justice Department filed amicus briefs, and lawsuit after lawsuit was filed against states for human abuse and for constitutional abrogation, across the board.

The Willowbrook suit was decided on the narrowest constitutional issue, the Eighth Amendment of the Bill of Rights, the right to freedom from cruel and unusual punishment. It was not a sixth amendment or fourth amendment suit. It was a very narrow suit, and it was a very rigorous, laborious, punishing trial. I testified in the federal lawsuit, I showed the scores of photographs that I had taken of atrocities on the inside, and explained each one of them, and explained the whole strategy of the institution. I mean, I knew the institution inside and out. I knew the institution better than anybody, because I had struggled to change it, so I knew why it did what it did and how it had this distortion, and how implacable the paradigm was. How unrehabilitatable the workers were, how intransigent the administration was, how locked in the system was.

Because the real issue had nothing whatsoever to do with people or mental retardation. It had to do with maintaining a bond-rating and a loan-rating at the highest level of the banking system in the hundreds of millions and billions of dollars in order to be able to provide public dollars to private institutions as a way of shifting money, tax money, into the private banking system at the highest level of the system. The Commissioner of Mental Hygiene was an interface instrument that didn't even himself fully understand, or was not even a real part of the deliberations about how to handle a Republican party, the presidency of the United States, the Congress, the Senate, where the dollars flowed, where the control was, where the billions were managed. That's where the state hospital system guarantee was. It was not in the children, not in the families, not in the professionals, not even in the bureaucracy. The bureaucracy was a fiction created in order to address an issue of moving public dollars into private pockets at the highest level of the economy, New York and elsewhere.

Cowan: Is it any different today?

Bronston: No, it's going on right now. In fact, it's worse right now. What you have now is an even more flagrant and unmasked situation where non-profit medical resource systems are being converted into for-profit systems, and the whole HMO system is in place now. You have a growing tyranny, a growing fascist development of the medical—an anti-democratic campaign of extraordinary import with profits being racked up by the drug companies and by the hospital property systems of staggering consequences. But what happened back then was that we were able to move a few thousand real people into a better understanding of citizenship.

We were able to somehow focus on the lives and fates of a few thousand very, very injured human beings whose conditions were completely ignored by the way in which society is organized and structured at the point where it results in their vilification, their marginalization from everyday life. And the part that's so bad about that is that in the creation of this underclass, we establish a management class and an elite apologist operation through the higher education system that essentially functions as a manufacturing operation to manufacture the very thing that we're talking about neutralizing or overcoming or transforming.

It's the enormous burgeoning of a professional "human service" movement which includes education, social services, medical care services that are there for the sole purpose of managing, supporting, providing care for this special population, domestic refugees, whose real needs are identical with the real needs of the rest of the population. To the extent that they can be partitioned away and defined as "special" via jobs, education, health care, decent living, decent transportation and so forth, you have an opportunity to take to the lowest possible common denominator a national policy solution, and to create special cadres, streams of money, professional resources that are always underfunded, always overpaid when it's all added up, and part of a larger iniquity of social underdevelopment and dehumanizing forces that put money and wealth over life in a very profound way.

Cowan: Would you think of those as your closing words, or your summing up of Willowbrook, or do you have something specific to Willowbrook that you care to end up with here?

Bronston: I've got to say, Willowbrook has been out of my mind for many decades. It came back in full force when I went back there two years ago, for the twenty-fifth anniversary. I was able to walk the grounds again, and that was a very profound experience and a very painful experience for me.

Cowan: Can you say if things have changed or gotten better for people with developmental disabilities through Willowbrook's and all of those institutional closings?

Bronston: If I was more a normal guy, I would say yes. But the fact is that I never see the good side in a perpetual struggle for justice. I always see what the next step is. What I saw were people walking the grounds that looked just like the folks that were there when I was there. I saw workers that were just as impoverished and just as scared as when I was there. I saw an attempt to cover over and liquidate a history that should be there just like what happened in Nazi Germany, just like what happened in Hiroshima, crimes against humanity that have perpetual significance to civilized society, being essentially covered over, not wanting to be talked about.

There's never been an official apology to the families about these crimes against humanity that were waged by the politicians and the bureaucrats and the professionals on behalf of their self-interest. There has never been a tangible memorial set up for the losses that occurred, both real and spiritual, amongst the populations that were involved in that struggle. Those families are still alive and they're dying by rusting. They're rusting to death. And they're confronted, ironically and paradoxically, with the same fate that they fought on behalf of their kids thirty years ago. The tragedy of that is astounding. The interesting part is that there is still no progressive leadership, no radical leadership to articulate what would be the solution, or what would be an offensive campaign that would lead to reinstituting a great progressive struggle.

The heart of that struggle, the center piece of that struggle has to be universal, comprehensive, rightful, single-payer health care in the United States. That is the wedge, the single most significant social policy breakthrough that could possibly be waged to fundamentally change the status of life for all Americans and especially all Americans with disabilities. No other single policy issue, no other institutional structural change could have the humanizing consequence that that struggle would deliver, were it waged, as the front end of the disability rights movement. Because it would unite my family community with the rest of the country's struggles for security and decency.

Cowan: Why do you think that disability rights leaders have not focused on that?

Bronston: Very good question. I have removed myself really actively and emotionally from the disability rights movement for fifteen or more years now, because I cannot find the breakthrough consciousness that goes beyond the narrow interest of people with disabilities getting their own thing together. The disability rights movement has almost no leaders that are clear about the fundamental identity of interest with the senior community, with the trade union movement, with the women's movement, with the civil rights movement. They remain an isolated, self-interested, disparate entity, whose leadership, having a politically narrow nationalist perspective, self-survival, middle class, benefits. They do not have working-class consciousness. They do not have socialist, progressive politics, or spokespeople and never have.

They've always been tied up in what I would see as a petit bourgeois world view. Self-interested, entrepreneurial, small-business, small solution, small break-out solution. They don't see, the disability rights movement does not see, itself as a national emancipation movement, as a global emancipation movement. They're not connected to the environmental movement, they're not connected to the antiwar movement. You don't see the disability movement standing up and marching outside the White House against the bombing in Afghanistan or the bombing in Iraq, or the bombing in Somalia, or the bombing in Panama, or the bombing in Grenada. You just don't see it.

And the great leaders, like Ed Roberts, who would go out, and who did see those relationships, and who did make those alliances, don't exist anymore. Why? I don't know. Why there aren't twenty Ed Roberts, I don't know. Judy, as wonderful as she is, and as vaunted a position as she attained, was never able to make that analysis stick, never able to mobilize her constituency and remains one of the great nationalist leaders, disability-first leaders, physical disability-first leaders. As marvelous as she is, as much of a sister of mine as she is, she does not have radical consciousness. She is a democratic party liberal thinker and organizer and does not put the big picture together. Despite the unbelievable breakthroughs that her courage and fortitude—and I use her as an example, but there are hundreds of Judys out there that are spectacular people. They never get out of the box.

Somehow, the disability life imposes a confinement of vision and an urgency of immediate physical needs that have to be met that prevent them from taking a world ambassadorial diplomatic role. Ed traveled all over the world—Russia, China, Australia, New Zealand, Europe, the Balkans, Serbia, Mexico. Ed was everywhere, speaking to the human spirit. Not speaking just to access, but speaking to global solidarity, not just to disability rights. And without that kind of inclination, you end up with quarter solutions, you wind up isolated. You wind up fragmented, you wind up in pissing matches that are too complicated. Like the parents fighting against the State of New York to clean up Willowbrook, rather than from the start, had we fought as one of our tenants for universal comprehensive individualized rightful health care, that struggle, had we built that struggle with the same energy as we built the closing of Willowbrook, because Willowbrook couldn't exist if it weren't funded to exist. And the reason It's funded to exist is because now Title 19 requires it to exist.

Cowan: Is anybody working in this field?

Bronston: Not to my knowledge. I mean, Bob Griss, in the Washington, DC, has an institute and is one of the very very few brilliant progressive people. But Bobby is gentle and he's not physically well. But he gets the big picture as does Doug Martin at UCLA. Even Justin Dart, for example, is another one of the great ambassadors. But Justin is a Republican patriarch, and even though he gets the single-payer health need, he put his cards on ADA, Americans with Disabilities Act. We've got ADA. Now we're being forced back. It's hard for me. That's why I organize high school kids now. I've been organizing teen youth since 1981, almost purely, because I can't throw my card in with categorical interests any longer. They just simply are too stultifying. They're too confining. They're too boring. They're too sorrowful. They're too pathos-filled, and I can't stand it any longer. I've got to have room to breathe, I've got to have room for large-scale visions and dreams to make society work better.

IV. SYRACUSE UNIVERSITY, 1973-1975; RETURN TO CALIFORNIA; TWENTY-EIGHT YEAR CAREER AS MEDICAL DIRECTOR AND CONSULTANT FOR THE STATE OF CALIFORNIA

The personal aftermath of the Willowbrook struggle, a two year educational leave

[Interview 4: January 17, 2002] [Tape 10, Side A]

Cowan: Bill, I think we finished with Willowbrook, so if you'd like to talk a little bit about your transition from Willowbrook to Syracuse.

Bronston: You know, at the end of the Willowbrook struggle, I was terrifically depressed, and just exhausted. I mean, I never really gauged the magnitude of that cost in terms of what was happening to me. We talked a little bit about how enormously steeled I got over time. When I realized the terrible change that occurred in me, I just knew I had to get out of there. Because I just couldn't fight anymore. Somehow or another, the struggle no longer had a hyperbole to it. It was now grinding to a relentless day-to-day kind of soldierly slog between the advocates, the lawyers, the courts, the inertia and resistance of the bureaucracy of the New York Sate Department of Mental Hygiene.

It was really just embedded in its old ways. There was no conscience there, there was no commitment there, there was no humanity there, there was no sense of any kind of concern for what had happened. The people that were being driven by the federal court to fix the situation were doing so really in the most alienated way. The fact that the struggle went on for more than twenty-five years, until they finally were able to demobilize and close the place, is just a testimony to the incredible intransigence of the status quo. There were so many forces at play in there, in terms of unions that are involved with the workers in there, the bureaucracy that, remember, is still struggling with how to hold on to the state's budgetary and financial profits and their really nefarious alliance with the private financial business sector, in which there's family connections with the Rockefellers and beyond and beyond.

In the hundreds of millions and billions of dollars where the public sector subsidizes the private hospital sector and generates public tax-based profits for these things, Willowbrook was just a cipher in the middle of all that stuff. I had just exposed a little tiny piece of that phenomenon, which is an ongoing phenomenon, which nobody really has challenged. It tends to be somewhat adaptive at some level in other areas like college construction and public housing and so on and so forth.

Anyway, what happened was that by some set of circumstances that are kind of hard for me to explain because they were pretty cloaked. The State of New York granted me an educational leave for two years with pay. There were all these new administrative people in the Department of Mental Hygiene. There had been enormous turmoil and change under the commissioner of mental health, Alan Miller. I don't know even remember whether Alan was still there or not or whether he got knocked off. I think he wound up staying for a while. But Willowbrook had gone through four different directors. The monster, Grundberg, that was the head of Mental Retardation had been replaced by another guy by the name of Robert Hayes. And then Hayes was replaced. Hayes was the commissioner that showed up with his sidekick, the head of communications, a guy named Wolf, at the Dick Cavett Show.

There were a bunch of people up there that I didn't know. Face to face, never met, never did meet, subsequently, that were in charge. Everything was handled by telephone. I just think that they were really glad to get rid of me, and so they were willing to pay me to go away.

Syracuse University, 1973-1975, Leadership and Change Agentry Institute and the Center On Human Policy

Cowan: Were you looking for a place to go, or did you get an offer?

Bronston: I got an offer. That's exactly what happened. The idea of going away, of going someplace else didn't really strike me. It didn't really strike me, but I had this enormous network of movement friends. Burton Blatt, who was the chairman of the Education Department at Syracuse University in New York said to me at one point when we were meeting at the monastery in order to work out the solution to the situation, that he would be really honored if I would come to Syracuse. He said to me, if the private university system can offer somebody like Grundberg a chair, a professorial chair in order to salvage their henchman, then he could certainly do the same thing for the champions on the progressive side of the struggle. It was a very touching and very significant offer, that he would grant me asylum. Essentially, it was asylum, that they granted me.

You know also that Kathleen, my wife, had decided to call our relationship off, and asked me to move out of our big mansion, our big house that we were living in with our collective. I wound up living in the back bedroom of one of my dearest friend's mother's home. This was Marie Marcario. Mark, her son, was my beloved patron and total support system.

Cowan: From Willowbrook.

Bronston: Yes, from Willowbrook, right. His kid was in the community, Bobby, who had Down's Syndrome. And Mark used to come and pick me up every day or every other day from

Willowbrook, and we would drive over the bridge to Jersey and get these great hamburgers and have lunch together.

Cowan: Did he live in Syracuse?

Bronston: No. He lived in Staten Island. His business was in Staten Island. I wound up living in Mark's mother's house because I didn't know where to live. In the meantime, I had begun to commute to Syracuse, once a week, or once a month, whatever I was doing at that time, in order to begin work there and to establish myself at the university, which was a totally strange experience for me—totally strange.

Cowan: What kind of work?

Bronston: Well, my relationship there was that Burt Blatt made me a visiting lecturer in the university. It was essentially like a post-doctoral fellowship at Syracuse University in the Special Ed portion of the Department of Education at the university. In the first year, I was adopted by Wolf Wolfensberger, and brought into his training department which was called—if I can remember the name—the Leadership and Change Agentry Institute. Wolfy always gave enormous long names to things, and assigned unusual and complex words to situations and relationships purposely, in order to force people to think about what the hell he was talking about in order to change people's understanding and to wake them up about the incredible numbness and the incredible unconscious acceptance that we have of the status quo and all of the built-in paradigms and stigmatic convictions about devalued, disabled people.

He had this very long name for his institute. What was interesting was that I had originally wanted to go up there to work with Doug Biklen and the Center on Human Policy, which was really a kind of crown jewel of the Special Ed Department, and was a structure that Burt had set up, brilliantly set up with Doug's leadership. Doug Biklen is now the chair of the Education Department at Syracuse, and has gotten older and moved up the ladder after Burt died.

Doug had surrounded himself with a group of the most marvelous young researchers and university intellectuals imaginable, who were pounding away, doing research on institutional and state-related services to people with special needs. They were beginning to change the whole vocabulary in the field of Special Ed and brought a liberal militancy to the campaign to expose the staggering institutionalized abuses that were the norm in the United States.

Cowan: Mostly for mental retardation?

Bronston: Yes. And developmental disabilities in general. Not mental health. They were always in the learning area because they came out of the education department. The interesting dichotomy here, which is very profound, historically, is the juncture between these two constituencies. The mental health side always labored and suffered under "medical model" terminology and medical model relationships. Mental illness and mental health conditions were always seen as accessible to medicine, accessible to doctors. The ownership of doctors, defined by doctors, psychiatrists, whereas people with mental retardation and developmental disabilities these were defined in medical jargon as manifesting chronic, non-curable conditions. There was not the same kind of upbeat excitement on the part of the medical shark community to get in there and have a feeding frenzy on that constituency. They were really the flotsam and jetsam of the mental health community.

Our big struggle, for example, in New York, around Willowbrook, was that it was the Mental Hygiene Department that was vested with the authority and responsibility to service this constituency whom they really didn't understand and didn't like. They had no notion that mental retardation was either an educational situation or condition, or a social situation or condition, as opposed to a hopeless, feudal medical backwater constituency, that would never be cured and had to be humanely warehoused.

Here, the whole mental retardation movement was beginning to revolt, a shift, from being the historical purview of the asylum movement in America, which was always under the American Psychiatric domination, to an educational model. Here in education existed the more militant and aggressive leadership. There was always a very profound educational intelligencia in the late 1800s, early 1900s that always struggled to demonstrate the role that education plays in the whole of mental retardation or developmental disability condition.

But it was always the doctors that gained the upper hand in the definition of all relationships and the management of the condition. So, for example, you have the entire parent movement in America, divided by doctor-driven medical definitions, by diagnostic categories. You have the cerebral palsy families, and the muscular dystrophy families, and the multiple sclerosis families, and the learning disabilities and the autism, on and on, polio, on and on it goes.

Cowan: So no unification?

Bronston: Never. Because the families were always organized into "defense organizations" in order to promote the interests of their particular children, of their constituency, always in competition with the other diagnostic categories, with nobody ever functioning to show the need for a pan-mental-retardation movement. "Developmental disability" was a rubric that was generated in federal law, which didn't go far enough, but aimed toward that agenda by defining mental retardation, cerebral palsy, epilepsy, and autism, initially, as the fundamental cohort that would receive federal benefits. But they left out an enormous range of non-retarded related disability folks excluded from eligible services, under the rubric of a mentally retarded/developmental disability service bureaucracy in the United States.

So all these fundamental ways of carving up the public dollars, minimizing and containing the public responsibility and liability of the bureaucracy were part of the landscape that kept everybody confused, everybody scrambling, everybody scratching for a dollar here or a dollar there, scratching for an entitlement program here or there, with very little bringing all these people together. Until the Developmental Disabilities Act, which was the first major federal initiative, there was little to begin to sweep some of these folks together out of the leadership of the parent movement, who began to understand the struggle.

Ironically, the state hospital constituency, and that whole interest group that fed off of the state hospital system in the United States was not very enamored by the developmental disability system. They were funded through Title 19, through the Medicaid system of the United States.

Cowan: When was that passed, the developmental disability—

Bronston: Oh, Jesus, girl, don't ask me that, because I don't remember. [laughs] Probably in the late 1970s.

Cowan: But that was the beginning of change?

Bronston: Yes.

Cowan: Definitional change.

Bronston: Then of course Public Law 94-142, in Congress passed the Education for All Handicapped Children Act, which really was a consequence of the enormous struggles that were being waged against segregation. Somehow or another, the progressive parent movement and the congressional political constituency and senatorial constituency wound up galvanizing this spectacular revolution in public policy around children in the United States, which we can talk about, maybe at another point.

But here I am, moving on to Syracuse and becoming involved in Syracuse with these two extraordinary leaders. Burt Blatt being the mother hen of the whole education department, overseeing the Center on Human Policy, which is this incredible two-fisted media-oriented crowd of young, special-ed Turks. Then this extraordinary, unique in the world, Nobel-quality leader, Wolf Wolfensberger, who is almost like Gandalf, in *Lord of the Rings*. He's inscrutable, he's a Catholic, prophetic, mystic in one sense. And he has the most profound grasp of the societal, anthropological, political, historical roots of why things are so awful for devalued people and how devaluation gets rooted in any culture from the beginning of time.

Concept and principle of normalization in theory and practice

Bronston: Wolf has done these staggering historical analyses and studies in his isolation and has hit upon the most profound strategy to manufacture cadre-level intellectuals and advocacy warriors in the United States and Canada and where ever he can, through two spectacular works he authored. One is his definition and scholarly work in defining and describing the concept and Principle of Normalization in human services, which is the single greatest intellectual breakthrough in the human rights movement, in the mental retardation arena, probably in the twentieth century.

Cowan: What is that concept?

Bronston: Wolfy drew from the Scandinavian experience of colleagues of his in Sweden and Denmark, the notion, the public policy notion, that people with mental retardation should be treated in every aspect as normally as possible. In a way that avoided defining "them" or designating "them" as deviant, that is, out of the norm of general society. The notion was, that one needed to be treated in a way to promote the perception of typicalness in every aspect of devalued peoples' existence. What "they" were called, where "they" lived, the whole we/they thing which is so easy to slip into, was also directly targeted as an example of how a deviant and stigmatized less than human status is devastating. These attitudes and practices unconsciously imposed upon people. Once they're labeled, deprived of their personal, individual identity, and assigned to a stereotyped group, expectations plummet.

Wolf built from the notion that people with mental retardation as in Scandinavia, should be treated in small dwellings, wear typical clothes, be groomed in as typical a way as possible—Wolf really understood that we were coming out of an era with a legacy of about sixty or a hundred years where people that were devalued, like people with mental retardation, are really at the bottom of the societal totem pole, in terms of social value, anthropologically and sociologically. Such people were essentially assigned to institutional segregated warehouse living, for whatever rationales, and there were a million rationale, but they all meant, get them the hell out of here and put them somewhere where we don't see them. Keep them at the lowest possible cost level to society because there's no pay back here.

In the thirties, Hitler went the next step and just got rid of them all. Just literally bused people with mental disabilities into ovens and eliminated all people with "mental deadness," which was the moniker assigned to people with psychiatric and mental retardation conditions. Now, we know that an enormous proportion of folks that were consigned to those facilities around the world were consigned that way because of community, economic, behavioral, cultural reasons, justifying exiling those people.

There wasn't ever the reality that because somebody was defined as mentally retarded, they were. Society was unwilling to fit the schools to deal with somebody who learns eccentrically. We were not going to fit buildings to get somebody in and out that can't use "normal" access means and the "normal" architecture. We're not going to customize transportation, we're not going to improve health care, we're not going to design recreation services for people who are really different. We're not going to make society fit the variations and diversity in which human beings come packaged.

So—I know we're bouncing around here, but public law 94-142, in its policy brilliance, crushed that one size fits all, once and for all. Maybe not once and for all, but it took that fundamental assumption, that people have to fit the system and said, wrong, wrong, wrong, wrong! The system has to fit the individual. The whole school system was required to establish a mechanism to maximize the educational opportunity of each individual, regardless of the disparity of their learning differences. Through an "Individualized Plan," which was guarded through a due-process and challenge procedure and appeals procedure. It stood by the notion that the school had to meet the individual's unique needs and cost be damned.

Now that was the thesis, that was the policy built into 94-142. Afterwards, of course, it was beat up in a million possible ways in order to maintain the status quo. But Wolf, in his absolute brilliance, and in his commitment to reframe the nature of the societal bias, understood that once you open the door and change expectations, and the purposeful, managerial shaping of the service delivery system, that you could keep pouring a new kind of human services worker through that door, until you had an army on the other side of change. And that that human services and citizen advocate army would little by little reframe the entire landscape of social services on the other side of what had been a bottleneck or a gauntlet that people had been driven to, into a point of extinction. His work aimed to shape an open society, a democratic society, where people with disabilities would become contributing members at so many different levels, cultural, physical, emotional.

Once you begin to define everybody as sacred and special, everybody having a contribution to make, you fundamentally change the whole notion of tolerable losses, inhumanity, between human beings, of institutional cruelty and exploitation. Now, it's like Christianity, it's a good idea, it's a good policy, then it requires warriors to carry it out, and it requires peacemakers to carry it out.

Cowan: He was trying to turn people who were studying in his department in Syracuse University into these warriors?

Bronston: Yes. Into these systems savvy "change agents."

Cowan: Did he have influence on passing this legislation?

Bronston: I don't know. I don't think so. But you know, it was like the hundredth monkey. A lot of things were happening at the same time all over the place. We were at wide-open war through the court system with the old institutional way. The education community was going through a fundamental transformation, pretty much spearheaded by Burton Blatt. He used the tool of a couple of major picture books. The first one was called *A Christmas in Purgatory*, which was a photo exposé of institutional life in the Northeastern United States. It blew open the dark secret and showed, in this extraordinary tabletop book, thin little book, a hundred pages or so, the absolute atrocities and inhumanity and bestiality imposed upon these segregated people in these closed systems that were out of sight, out of mind, and unbelievably expensive and corrupt and evil and destructive to human beings.

So Burt and that new educator activist movement began to generate a new kind of young professional, special ed professionals that led to people challenging the existing segregated special education system. This was still heavily dominated by the medical model of, there is only so much you can do with these folks, which was the line of the old American Association of Mental Deficiency, AAMD. The AAMD really originated as an asylum-director organization, fifty years earlier and gradually became modified, little by little, to just being called AAMR, the American Association for People with Mental Retardation. Then this brand new group of Young Turks arose, and called themselves TASH the Association of Persons with Severe Handicaps. So the language still hadn't completely been challenged, but TASH, The Association of Persons with Severe Handicaps, was really the locus, where the progressives and the radicals in education gathered, where the fearless ones came.

They believed that there was no person too cognitively involved that would not benefit from systematic, scientifically committed and based, humanely applied, normalized services as an educational philosophy.

Cowan: And this was all happening at Syracuse?

Bronston: It was, yes. Syracuse was absolutely one of the center places.

[Tape 10, Side B]

Bronston: It was an absolutely national hotbed of radical thinkers with Burt kind of being the leader. There's another institution that's in the picture. That is, across the border, in Canada, called the National Institutes on Mental Retardation, headed by the most extraordinary intellectual and progressive political leader by the name of Allan Roeher. Allan was a silver-haired, clean-shaven kind of mildly gray-suited, business-looking kind of guy, gentle, soft-spoken, incredibly middle-Canadian, who headed the NIMR. An absolute giant in the reform movement.

Allan was a major patron of Wolfensberger and had been hiring Wolfy as a "visiting scholar" since Wolf had established a major beachhead of normalization-based program demonstration in Eastern Nebraska, a thing called the Eastern Nebraska Community Office of Retardation. Nebraska was split up into a number of such geographic divisions. Wolfy was able to gain absolute design control through the Nebraska Legislature to demonstrate a state of the art, at that time, decentralized, community-based, anti-institutional, intensely programmatic, normalization-grounded service delivery system.

In Canada, Allan Roeher had simultaneously hired Wolf to set up shop to produce and train new generation of young professionals across Canada. Because the Canadians were also very sensitive about their institutional history and very committed to normalization. Normalization sat well with people of good will and common sense who didn't have major investments in segregated commodity-based human services and medical model based human services.

Wolf was simultaneously traveling, lecturing, and teaching in Toronto, Canada where the NIMR was located and ENCOR. Allan was a major, major North American force in harboring, promoting, publishing a whole new revolutionary, really revolutionary literature in the field and beginning to provide context and legitimation for this new generation of special education personnel and workers, young workers. The average age of the people working at Eastern Nebraska was under twenty, under twenty, running all the programs there.

Cowan: These are normalization programs.

Bronston: These are normalization programs created by Wolf.

Cowan: How was normalization put into effect?

Bronston: Well, first of all, the programs were theoretically designed to support individual identity, to avoid any kind of stigmatizing labeling or associated imagery, to provide services in the most typical context that did not draw negative attention to the fact that the individuals being served didn't quite fit and set up some kind of eerie sense of disconnect, or incongruity which would then create a sense of distance on the part of the perceived viewer of those services, whether it be the parent of a kid in a program or whatever. Because when a parent came into Willowbrook, remember, despite the perversity, everything said to them, that what was going on on the inside was legitimate.

Families left their sense and expectations of the typical out on the street before they crossed into the gates of Willowbrook. Because the gates themselves sent the message that this was something apart from, different from, and stressfully implemented in relationship to typical life.

Cowan: So what would happen with a parent who brought a child?

Bronston: In Nebraska?

Cowan: In Nebraska.

Bronston: Well, Wolf had created maybe about a hundred programs in their part of the state, which was maybe five or six counties in Eastern Nebraska. Kids served were put into small programs with no more than six kids in any one place. The places were all regular either apartments or homes, they didn't have names, they just had addresses. The people that were provided with services, which included not only children, but adults in that situation, were treated, dressed, groomed, programmed in a way that was immensely driven toward their typical performance, value and presence in everyday life in the community, in and amongst everybody else.

There were only two very, very specialized programs in the Nebraska model—one was a program for kids with very severe behavioral problems, like very severe autism. The other was a program for kids who were absolutely bed-fast because of the massivity of the medical aspects of their conditions. Those two programs were really very paradigmatic in certain levels, because first of all, they were tiny. They only had four to six kids in each public program, and there was an enormous developmental training dynamism.

These were kids that were normally treated a hundred percent destined for state hospitals, in any traditional setting in the United States. These were kids who were intolerable to the medical community, to the school community, to the home. They just demanded a level of attention and skill, and parenting, specialized parenting that wasn't ordinarily out there, without the kind of context support that was established in Nebraska, under Wolf's tutelage and training.

Cowan: They were taken out of their homes?

Bronston: That's right, they did not continue to live in their homes. Now that's something that I can't speak to because it's a little bit hazy at this point. I don't really recall the partition between the numbers of people that were provided support in their homes with their families, as opposed to the out-of-home model. Because remember that the way in which funding was possible for 99 percent of the families out there was through Title 19, which required out-of-home placement in order to get funding. You didn't have a program that subsidized the income of the family, or allowed them to have additions built to their home, or have intensive developmental training happen in their home, or bring staff to that home. It all had to happen outside the family home.

But what ENCOR did do, was it established the most progressive respite care model in the United States in its time, which really was a model of sending skilled people into the typical, natural, ecological environment of an individual kid or grown-up, and provide services and relief to whoever were the source of care for that individual. That program was incredibly beautifully arrayed in relationship throughout the system for parents or professional caregivers at that time. These were still the first steps in this rather primitive continuum of services. You still have the notion, under even Wolf's initial view, of a continuum of services which dominated the field for about twenty years, once conceived.

Part of the reason for the problem with the "continuum" was the notion that somebody had to move through, rather than just jump the whole thing and go right to the end point, which was typical living and supported in a typical way. We could conceive of, but were still completely addicted to, prostituted by, this notion of more or less restrictive environments, which was the rubric, which was the terminology of the day, which allowed the state hospitals to be part of that "continuum." That was part of the strategic deal that had to be cut because the state hospitals were all-powerful. They had all the money, all the service worker public union support, all the governmental support, all the public policy support, all the financial support.

As long as you had state hospitals in there, more than fifty percent of the total dollar was allocated in any given state to—and I'm being hugely generous here—to that institutional end of the continuum spectrum because of its established virtue as a model. That fifty percent, which was actually closer to eighty-five percent, serviced less than fifteen percent of the actual residential population in need. So you had this extraordinary imbalance of resource allocation because of the fundamental convictions and institutionalized values generated in law. This led to structures and financing that defined the whole acceptable environment for anybody diagnosed with a developmental disability who were then immediately thrust into this rushing segregated river that lead them to hell and away from home-based integrated family care.

There was nothing that ran the stigmatized river the other direction. Once you got in the stream towards out-of-home services, which was the critical status, you create this domestic refugee population that no longer has a community base of defense and identity support. You create a totally artificial milieu, administered and funded at the whim of the bureaucracy and the political community, that waxes and wanes in terms of adequacy, depending upon all the vicissitudes of the government financing system, alienated from the consciousness, attention, and personal identification of the general community, because somebody else is taking care of, paying for that stuff, run by people on a shift-basis, who don't give a shit, really, when it comes right down to it. Because they go off work at the end of that shift and they go to their own family which is handled differently than the family model that they are dealt by the managers and architects of those out-of-home segregated programs.

So when Wolfy set up his normalization based decentralized model, with this continuum of more to less restrictive environments, it was a revolutionary in its time. It still required relentless change, yet to come, to move that from an artificial, out-of-home model that looked at a kid as a broken, in need of being fixed, to a model where the community identified with that individual in the spirit of full integration and full inclusion in the context of planning with what was called "a circle of friends." The Wolfensberger model began the evolution that soon saw people as part of a truly integrated and inclusive milieu, as a way of providing all-around support and honor and nurture to a person, in their school life, in their home life, in their community life, in their vocational life, in their health care, and so forth. That has been the constant struggle that has been waged back and forth. Its success has turned upon the capacity of the leadership in our movement, which has been decaying pretty consistently in the last thirty years, in my opinion, to change the fundamental paradigm of services.

Cowan: Did students that you were with in Syracuse, did people go to Nebraska and work in those programs?

Bronston: Yes, well they went to visit. The programs at ENCOR were run by Nebraskans. And, of course, all those people that ran those programs, all became national leaders. One became a commissioner in Arizona, another became a major consultant here in California, Charlie Galloway. Wolf grew a national network of these brilliant professional friends. We were, there were many of us. There was maybe a hundred and fifty or two hundred of us, who were sort of the main echelon of normalization movers and shakers.

What was interesting, and I wanted to really get to the second piece of the Wolfensberger contribution. Wolfy, in his genius, in his absolute genius, concocted an evaluation system, a quality-based program evaluation system to look at any human service of any kind, as long as it wasn't a penal structure, a correctional structure, a criminal structure, prison. His formal evaluation system was able to look at any human service initially through fifty explicit criteria, programmatic criteria, program-designed criteria. Each was arrayed on a spectrum from "ideal" to "utterly atrocious" in its compliance with normalization principles. The tool is called Program Analysis of Service Systems. There was a book of about a hundred and twenty pages, a manual, that came with an evaluation, it came in two green books, these spectacular breakthrough definitions and vocabulary books.

Wolfy and a woman named Linda Glenn, who was his co-creator in this work, was another genius young woman, who didn't have the same sort of career that Wolf did, but was just the smartest and the best of the best, in the world. These two great intellects created this evaluation as a training program where they systematically, in words, defined, in the minutest detail, every intimate aspect of what went into the designing, implementing, and functioning of a human service, and created a quantitative way in which to score any program from A to Z.

Cowan: Would you give an example?

Bronston: One of the spectacular advances there was that the whole normalization theory was predicated upon how people were perceived by others. There was a whole section in PASS, in Program Analysis of Service Systems, that dealt with nothing but image-related program elements. What people were called, what kinds of places the service was located next to, what kind of financing monies, what the financing monies were called, what kind of language was used in relating to and describing the people in the program—

Cowan: What sort of language could be used? Say, an ideal language.

Bronston: A person's name. A person's name as opposed to being called EH kids, or SH kids or MR 1 or MR 2—this was not a diagnostic approach to program definition. It wasn't going to be an MR program or a CP program or an epilepsy program. It wasn't going to be a "Hill Haven House," it wasn't going to be "Hope House," it wasn't going to be "Exceptional Children's Foundation," it wasn't going to be—any one of a zillion names that were generated by the mental retardation manufacturing industry.

It was going to be value enhancing based on normalization theory. So the ideal manifestation, now remember that Wolf came up with fifty of these items which had to do with every possible aspect of the place, resources around the place, the nature, quality, intensity and coherency of the program, image-related issues, evaluation criteria, safeguarding human rights, due process features, definition of staff functions, roles, responsibilities, the nature of the staff. Wolf was able to point out dramatically and systematically that devalued people were essentially cast into conditions and programs that kept having devaluing strategies, heaped one on top of the other.

Perversity and unconscious low expectations were everywhere. In a nursing home, for example, you'd often find mentally retarded workers hired to help the dying aged. You would get elders, retired elders to go and provide volunteer services for kids with disabilities. You would get prisoners working to help people with mental retardation. People with emotional disabilities volunteering. Programs being zoned and situated one right next to another: a mental health program, a corrections/halfway house, a mental retardation residential facility, an old-age home. All zoned next door to each other in one ghettoized neighborhood. They would completely flood the local resources of restaurants and stores and whatever with devalued people, driving typical people away, or creating these ghettos of deviants, which is what Wolfy fought to alter.

His ability to articulate these universal practices in such definite and poignant and such precise way. He battled to get more and more clear, in order to really pull out, in an unquestioned way, the breach of expectations, the breach of image, the breach of labeling, of stigmatizing that went on. And it wasn't just to bring people in progress up to zero, which then became a very interesting intellectual and philosophical struggle. The question was to bring people above the norm. The question was, how do you enhance people's status? How do you enhance their image in others eyes? How do you impose value and glamour, and desirability, onto and into a population that has been traditionally been seen as, "yuck, get them away from me."

And there were a number of workers that were all contributing to this spectacular revolution. A man named Mark Gold, for example, that also died terribly young from lymphoma. Mark was the greatest teacher in the world, the greatest teacher of profoundly and severely retarded people alive. He came out of an LA high school and was working in Indiana, in the university there, and developed a technique called "Try Another Way" where he would demonstrate that he could take the most severely involved, mentally retarded, behaviorally-explosive, biting, kicking, killing guy or girl, blind, deaf, didn't matter how totally involved a person was. Mark would take this person and he'd teach them, in front of everybody, in ten minutes, how to do something that nobody watching could do, technically, through his beautiful educational and pedagogical strategy. He completely turned upside down on its head the whole definition of severe retardation, profound retardation.

He showed that the more involved a person was, the more powerful the environment had to be to level the playing field. And to the extent that you defined a person as "profoundly retarded" and allowed them to be profoundly retarded, you demonstrated your unwillingness and inability to apply the necessary resources to neutralize that label and to make that person highly functional and have great social status. If you were going to teach one thing to somebody, and you could only teach one thing, you wouldn't want to teach them to do something that everybody did. You'd want to teach them to do something that nobody could do, which would make them highly valuable and needed in the eyes of the general society.

He would teach people that were psychologically untestable, because—well, that's a whole other issue—to make racquetball rackets and bicycle brakes and electronic form boards, that really required the highest level of technology skills. But Mark broke those tasks down in such a minute way and taught it in such a brilliant, systematic way, that it didn't matter how disabled a person was. He could get them, literally, within a couple of days, into a competitive work force. It was unbelievable. That kind of pedagogy broke the barrier to the attitude that said, we can't do it, or, these people are unhelpable, or some people have to be in institutions!

He would go into the bowels of the worst institutions, take out the guy that was locked in isolation for five years for trashing the whole place and being unmanageable and get them involved in production in seconds in his task. The things he taught and made were so challenging and interesting and his pedagogy was so brilliantly analyzed. Thus, a revolution was taking place in conjunction with the new law, Public Law 94-142 in conjunction with Normalization Theory, in conjunction with these battering-ram moments of achievement, like ENCOR, and a few of the model service system places that were going on, Program Analysis of Service Systems, and the National Institutes on Mental Retardation. Wonderful breakthroughs were coming through other people like Bob Perske, an author, who was writing more and more about the sheer poetry and beauty and wonder and sacrosanctness of the lives of people that everybody saw, traditionally, as absolutely loathing and ugly and unacceptable to have in society.

Bob Perske's wife, Martha, was generating an art form of imaging people with disabilities through pencil drawings. The Federal Post Office adopted her drawing as part of the stamp for the International Year of Disabled Persons. All this stuff was going on at the same time, while I was at Syracuse, and in this era.

Cowan: And you're learning, as well as teaching.

Bronston: Yes. First of all, I was learning PASS from Wolfy, which I had actually learned in a week-long workshop that almost killed me, it was so hard. And what Wolf was doing was running these PASS workshops both in the U.S. and Canada. Since that time, he's changed PASS, and he calls it something else. He calls it Social Role Valorization. He always comes up with language to force a new definition and a new understanding of things. At the time, those of us that were PASS trained were like Samurai warriors, I mean, we strode the country.

Cowan: You went to different programs and showed them how to apply this.

Bronston: I came to California, after this was all over. Remember, this only lasted two years (1973-1975), while I was there. Actually, the first year I spent in the back bedroom of Mark's mother's house in Staten Island, traveling to Syracuse each week and working on whatever I could do to support the struggle at Willowbrook. That was still right up at the top in heat, and writing my book. The only way I could come back to myself was to try and get this stuff on paper. The Center on Human Policy, and Doug Biklen, its head, just hammered me to write a book on the Willowbrook struggle.

So I wrote a manuscript of six hundred pages called *Public Hostage, Public Ransom: Inside Institutional America,* and told the whole story as an insider radical organizer and worker in there, kind of on the model of the great labor histories of the early twentieth century, the *Autobiography of Big Bill Haywood*, and *The History of American Labor* by William Z. Foster. And I kind of posed myself as a model kind of radical worker, working-class, labor organizer, working in human service work contexts. I moved to Syracuse at the end of the first year, 1974, full-time. I moved out of Mark's mother's house and lived in Syracuse in a little lovely place on Westcott Boulevard and really became a full-time staffer in Wolf's Institute for Leadership and Change Agentry. I was commissioned by Burt Blatt to teach a class.

Cowan: What was the name of it? Or what was the subject?

Bronston: The class was called Health Advocacy for Children. There were a dozen lectures that I presented. It was open to everybody in the community, and everybody in the university. It was a kind of a melange of events that I put together, because each class was a piece of theater. Each class was a two to two-and-a-half-hour class and in each class I would recruit theater groups in Syracuse to stage guerilla theater, during the class. Not on stage, but out in the audience. We would somehow create an incident in the audience, through these professional actors, in order to bring the people sitting in the class into the action.

The classes were announced by a huge poster that I had designed either by teens in the community—I went to all the art classes at all the high schools to try to get images based on themes that were coming up in the training—or by the top professional artists in the community. So the class was announced in these two by three-foot full-color posters that were tacked—there were five hundred of them—all over the city of Syracuse in store windows and everywhere.

Cowan: Oh, so it was open to non-students?

Bronston: Yes. The purpose of all that was, of course, to demonstrate and experiment with the new imagery, the new way of touting and using high-end media to convey value on this whole struggle area. Because it really was a cutting-edge civil rights struggle that we were engaged in.

[Tape 11, Side A]

Bronston: Just to kind of focus us, Kathy, we're talking about the years from the end of 1973 to the middle of 1975. In 1975, the middle of 1975, I emigrated back to my home state, to California. So this period was this kind of strange sandwich period of healing and rejuvenation and enormous learning with these two absolutely peerless intellectual and ethical leaders in the world, Burt Blatt and Wolf Wolfensberger. The bulk of my time was spent with Wolfy. Wolfy had a very real contempt for Doug Bicklen, and the Center crowd because they were very unsystematic. They were very mushy. They were very emotional. They were not very scholarly.

Wolf was, if nothing else, a killer scholar. I mean, he was an old-style Germanic scholar, academic. He required a level of work from his students, and a level of understanding and brought an originality to his pedagogy that was unparalleled. I mean, just unparalleled. He really, I tell you, was a Nobel intellectual, were they to give Nobel prizes in human services. His contribution is almost incalculable. I could talk about what he contributed for days. I mean, anything he looked at, he saw with freshness and an incisiveness and a connectedness that I've never seen in another human being.

He's a genius, he sees things that other people don't see. Puts things together that other people don't put together, and studies and looks at data and at history in a rigorous way that is patient and thorough and definitive. And when he's all over, he's got it all, he's got all the information. And somehow, he organizes this stuff into sets of reference-based lists of criteria to make his point, and lays that stuff out there like a machine gun. He's unbelievable. So Wolf was constantly in the process of providing training programs, which he's doing to this day, in order to empower, enable, articulate, a social force in North America, or in the world, to understand a different way of looking at society and at human beings that is predicated upon his "Prophetic Catholicism," his sense of the sacrosanctness of life. He is a rigid, and absolutist in that area. He has a fearless way of indicting the status quo with really malevolent and valid allegations of its misdeeds, mispurposes, malfeasance evil. And to somehow try and figure out how to turn that around, how to build an ethical and principled firewall of human beings, of advocates and change-agents and teachers and human service workers, and always trying to move people more towards a personal epiphany and in his frame of reference, salvation.

So at the beginning of the second year in my time at Syracuse. My first year, I spent most of that year traveling all over the US and Canada with and without Wolf, learning PASS, and applying PASS, and becoming an assistant trainer to Wolfy in these one to five day long training workshops that he was doing. The role I was playing was very interesting. I'm a photographer, and I'm very visual. I spent an enormous amount of time photographing examples of each of the levels of service, of each of the fifty evaluation criteria in the Program Analysis of Service Systems. Wolf would open up a training with two solid days of eight hours a day of just showing a thousand pictures in order to give people a concrete visual example of what the hell he was talking about.

Like, for example, he would have four or five levels at a given program quality rating, from "ideal" to "utterly atrocious," each with a different score. The whole valuing system would score out to a maximum of a thousand points. A human service would get to that thousand points by the amount of points allocated, in a very careful way, to each of these fifty criteria based on levels of quality in each of these criteria demonstrating the competence of a service delivery model. It could be a childcare center, or a school program, or a physical therapy operation, whatever it was.

Cowan: Can you give me an example of a picture from one end to the other?

Bronston: Exactly. So we would go looking at programs and photographing as we would go in order to show, for example, the range from full segregation and dehumanization and the whole humiliation of people, to the most ideal situation, where you had a kid that was exactly the twin of a kid in the mortified situation, in a typical environment with typical clothing and extraordinary equipment. The setting and human service management model created completely changed their image in the eyes of everybody, parents, human service workers, funders and so forth. So we built together this extraordinary physical library of photographs, this slide show, which I worked with him on. Because his pictures were awful. They made the point, but they were technically bad pictures.

I shot good pictures, and so I helped him build this training. We were constantly in dialogue around the application and implication and translation and teaching strategy of each of these aspects, and gathering data from extraordinary travels that we doing around the United States and Canada, giving these training sessions, as my role as an assistant, all the way up to actually doing some of the lead training in this thing, which was an absolute revelation to me. As a radical, as an American radical, and as a Marxist and a Maoist, I was already very deeply embedded with a way of looking at things that was already pretty stress-imposing, in terms of a working-class analysis.

I already understood how things worked, using dialectical materialism kind of ways of looking at things. I added to that, this extraordinary materialist approach to understanding how people create things in society. Wolf's evaluation system exposed the roots, the unconscious belief systems, the prejudices, the distortions, how they creep in, the reinforcers for the distortions that make systems so inhumane, so bizarre, so alienated, especially in this mental retardation service system area. People's incredible efforts to try and attenuate their true antagonistic or fearful feelings towards this devalued community leads to words, images. Like, we walk into a place that is completely inhabited by elders with mental retardation, forty, fifty, sixty, a hundred, in a nursing home, and the walls are completely decorated with Walt Disney characters and little bunny rabbits and things that are totally age-inappropriate and culture-inappropriate.

You walk in and there's this glaring dissonance between who the folks are that you're looking at, how they're dressed, what they're called, and what the environment communicates to you in terms of each of privacy, in terms of culture-inappropriateness, age-inappropriateness. The decor in the room, with all of this infantile media set up, these childlike media, that creates an immediate dissonance, an immediate weirdness. How can you possibly communicate with an eighty-year-old woman in a nursing home, with a Mickey Mouse on her bed, except in a distorted way. These childlike media, defines this person as a child to everyone around, unconciously.

Or vice versa. You have children with mental retardation, with no age separation, seen as eternal children with no hope. The people who are teaching them or caring for them do not have the skills or the capacity to provide the kind of pedagogy to break them out of that status, because they don't understand how to teach in a causal way.

Cowan: So you would take your teaching and assessment to the people who ran these organizations and help them learn it.

Bronston: That's right. We would use PASS as a less than overtly threatening strategy to teach them to see what they were doing differently, if they could tolerate it. The problem was that it was a rigorous evaluation. It took about three days and a team of five-plus people.

It was not economical to do. It was an intellectual challenge of the first order. We would work literally around the clock when we were out in the field.

Cowan: Would people invite you to come?

Bronston: Yes. Or we would somehow rig a way to get them to accept an evaluation and then we would give feedback to them. But you know, we're giving people an insight into their program that they can't even begin to fathom how in the world to comply and raise their score when so many aspects of their program are locked in by law, rule and regulation, financing standards, safety standards, building codes, on and on, worker identification. But you have to start somewhere. Wolfy started with this tool that added new language and a new resolve and a new confidence and a new pride to those professional people.

At first, he chose very carefully who he trained. He had a mixture of people that really were change-agents in their own communities, or in a position to become very strategic influences on larger numbers of people. He would run these classes that had between thirty and fifty or sixty or seventy or eighty people in them, a week at a time, while he was teaching issues of community advocacy and a variety of other technologies that he had invented in his head.

I would go up there and I would be involved in classes that he was teaching, be interacting with him, be interacting with kids of the Center for Human Policy, doing their work. We were all warriors. It was us against the whole world. Because we knew that the whole world was absolutely bitterly in the wrong place and that the work that we were doing was really dealing with changing where the floor was. Everything we were doing had to do with how bad and how low the floor of human tolerance was for human care.

Cowan: How were you thinking you were going to implement this training? Were you thinking you were going to stay at Syracuse?

Bronston: I didn't really know. I went there terribly injured and was so enormously inspired. I grew so much there. It changed my life. For a very long period it made me a really significant national spokesperson. Only because my kind were so rare. I'm not talking about the fact that I was already a self-conscious, self-avowed communist, in terms of all the best things that that implies, but that my training in Wolf's hands, and my association with the Center for Human Policy and that advocacy work, and my immense friendship— I mean, I literally knew every major actor in the country that was involved with the cutting edge of our field, and also had a very keen sense of cross-over into other areas like the disability human rights movement, which was just beginning to grow.

The mental retardation civil rights movement really led the way, because it had its roots in the fifties, and this ignominy of the state institutional barrier which was this ominous, dark planet, death planet kind of reality, in the US body politic. It was just an absolutely incredible opportunity to break a hole in a wall and bring light in.

Thoughts on the need for a civil society

Cowan: And did you see it this way, that this was your opportunity?

Bronston: Oh, absolutely, yes. I was so self-conscious. I was so clear. The thing that really upset me was that there was not other socialist or Marxist activists or organizers, no other radicals, no other political radicals anywhere in the damn field of mental retardation. I was totally alone in the whole country, putting together the larger picture of seeing this as a class struggle arena that carried with it all the most wonderful opportunities and dreams to articulate what a quality of life would look like, what a civil society would really look like, dealing with all the issues, all at once, for a constituency that was demonstrated ground of a socialist, humane society.

Housing, income, jobs, health care, recreation, education, the whole ball of wax, it was all there. My sadness was that I couldn't talk to anybody about the linkages between all these arenas. I wanted to show that the struggle area here, and the opportunities inherent in bringing about reform in the area of service to this constituency, was the absolute most extraordinary model of what a caring and loving and merciful and cooperative and nurturing and progressive society would look and feel like.

Cowan: At some point, did you think about leaving Syracuse and finding a place to go to that you could put all those ideas into?

Bronston: It wasn't quite that rational. What happened was that I ran into a wall at Syracuse. Again, I think that I was growing and integrating at a level that outstripped the locals. The people at the Center for Human Policy really became allergic to me because they couldn't move where I wanted them to move. I wanted us to make very deep connections with the black community, with the organized trade and service union community, with the senior community. I saw instantly the absolute consistency of interest in all those interest group. I wanted to take the struggle to a more inclusive level of relating to more profound social policy questions that were confronting us all.

I understood that you couldn't fix the mental retardation political situation as long as you had the kind of awful political circumstances for the general population in place. I mean, we still didn't have universal health care, we still didn't have—in the education community—individualized, rightful education for typical kids. We had it for kids that were labeled, under the rubric of special education. But that model, in order to survive, had to be adopted and embraced by every kid and every family in the school system. The school system had to be revolutionized!

As long as you could keep that policy initiative contained with special ed, we were doomed to be an island that would ultimately be cast against, in an antagonistic way, the typical school kid. Divide and conquer was being exploited all the time by our adversaries, who would say, "Why put all that money in special interest teachers, requirements and entitlements in the hands of special needs kids? What are we getting for our money?" Just a broken kid that's never going to be president of the United States, or whatever the paradigm is.

So the whole notion of right-wing political strategy of divide and conquer by forcing the schools to fund quality, individualized services at the expense of shifting dollars from typical education to special education was a diabolical and unethical agenda that was consciously waged by the school bureaucracy. Their aim was to isolate us, slow us down, contain us, rather than seeing this as a progressive revolution in the educational process in America and in the world. So I went, over and over again, to explain and convince my colleagues, to try and convince them, that this was a larger struggle, that it required broader alliances, that it required a more universal line that we needed to put out there in order to mobilize new relationships, a new force for social change, and break-through opportunities.

And they just didn't want to go against their university power structures, because their careers were involved. They didn't want to rock the boat because they wanted to be the chairman of this department, and get their professorships in that department and so forth. They were unwilling to travel with me into these new areas of political alliances which really were, for me, part of my heritage.

I always had this profound identity with the black community, and I was much more comfortable in the black community, always, than in the white community, which is a bizarre situation. Because, I'm a carpet-bagger, I don't belong in the black community really. But it was where there was soul. It was where there was a real sense of emotional connectedness between the ideas and reality. White radicals tend to separate what they believe in from how they live and who they make friends with. There's never a sense of bringing the two pieces together in an honest and authentic way of living and advocating, being political in the community.

Through all this turmoil and angst, my ex-wife, the kids' mother, Aram and Darya's mother, decided that she had finally had it with the East Coast. She was still living in New York City, in Staten Island, in our big house. She decided that she was going to move with her new boyfriend, back closer to her mother in San Diego with the kids. So when she decided that she was going to move, I decided that I had to move west also. Plus, I was going nowhere at Syracuse University. I was experiencing more and more strong opposition, and isolation. Not with Wolf, of course. Wolf could take me in spades, you know. He was never threatened. He was just always so ornery and cantankerous, and so much his own kind of fiery Gandalf [laughs], we've always been beloved friends.

Wolf came in for a lot of criticism. He was maligned for being anti-Semitic, and for being too religious, and being anti-university. He was just—he's a giant. All that happened was that mediocre, small people were threatened by his brilliance and by his leadership and by his moral demands on them that challenged their lives. He didn't go along with just running a sermon, metaphorically speaking, and then letting people go. He insisted that they be genuine, that they be authentic, and he was unwavering in that demand. And what was so interesting, was, here I am, I was this Marxist, and he's this Catholic conservative, and I have a whole rigor and belief structure in my world. One day, he gave me a *Little Red Book of Jesus's Quotations* that he put together, like Mao's red book. In return, I gave him this beautiful, very powerful, piece of art, a crucifixion, from a very beloved artist friend of mine, Rico LaBrun, that I'd been friends with—we just loved each other.

There was also an immense love between Burt and I, and immense respect. But I was costing Burt a lot of money, because my class was fairly expensive. He had to shell out three or four thousand dollars to implement all the stuff that I was doing, because it was really unorthodox and very unusual. The classes dealt with the most controversial areas in health advocacy for children. That's what it was called, "Health Advocacy for Children."

Cowan: I wanted to ask you when you mentioned people operating from within the class. Can you give an example of how that was done? You would have someone acting as if they were part of the class?

Bronston: Yes. Nobody knew who was sitting next to them, and we would do a situation, guerilla theater. I would bring in a professional theater company, maybe six or eight actors would come in.

Cowan: And what would they do?

Bronston: They would ask a question and then they would somehow react to me, or they would initiate some kind of a little vignette between them and the audience that led to a tension in the room and a sense that, this thing is getting out of control, and that there are these people that are so passionately concerned or opposed to what's being said—because what we were talking about really required some change of thinking about how things worked.

Cowan: So you would, for example, talk about normalization, and they would stand up and say—

Bronston: Right, they would say, "This is all wrong. You can't do this. I want my kid in the state hospital because that's where they're going to be the safest. I can't have my kid out on the street and have some marauding, pillaging rapist or somebody take advantage of my kid, under no circumstances, and you're just full of shit, Bronston." I mean, they would, you know, do it, right? And it would come in different packages, in different ways, where there might even be a terrific battle in the audience, between two or three actors. All that stuff would be gone through around each of the major topics that was articulated in that particular lecture around Health Advocacy for Children.

The class went on for a whole six months with two presentations a month. It was really a load. I've got to tell you, it was really tough. It was experimental live theater, total learning kind of environment.

Cowan: Well, it must have been very hard for you to think of leaving.

Bronston: Well, it was and it wasn't. It was sort of like, in a funny kind of romantic way, I had to go out and take the message out. I had to do my apostolic work for "normalization." I wound up looking for work in California, in order to follow my ex-wife and kids back. I had no idea... I felt very worn down... I thought, Jesus, who in the world is going to hire me? But on the other hand, I was really good, I mean, I really knew my stuff. I knew more than anybody knew about how to look at a human service delivery system and how to bring about systematic change. I wound up coming back to California on a long visit here, for about two weeks.

California State Department of Health, 1975, medical director and consultant

Bronston: A week of it I spent with my kids, traveling around, just the three of us. We hung out in Catalina and the Central Valley. We just went everywhere together, just the three of us. They must have been five at that time. It was really fabulous. The rest of the time, I used to search for work. The breakthrough of all breakthroughs was that the governor of California, [Edmund G.] Jerry Brown, Jr., had just been elected . Jerry had miraculously and courageously hired a man by the name of Jerome Lackner, a physician, who was Cesar Chavez's physician, to be the director of the California Health Department, which at that time, encompassed all the human service departments in the state of California, under one director.

Jerry [Lackner] was this remarkable, remarkable physician, who I had known when I was a leader in the Student Health Organization. We had hired him to be one of the "preceptors," to provide supervision for our Central Valley, Delano United Farmworkers Children Screening Projects. Because we needed real docs to supervise the medical and dental and nursing students who were doing volunteer work in the Central Valley with the farmworkers, in terms of kid's nutrition and hearing and so on and so forth.

Cowan: Way back when you were a student still?

Bronston: Way back. So all of a sudden, here's this friend of mine who had worked for the Student Health Organization as a preceptor, suddenly becoming the Director of Health! And though I had never met him, or talked with him, he knew I was the leader. I called him and I said, "Jerry, I need a job, and I know this special stuff that could really make a difference in California, if you're willing to stand up and make a difference and to close down the state hospitals and to build true community-based delivery system, change the whole way in which stuff's been going on out there."

[Tape 11, Side B]

Cowan: Did Jerry find a job for you?

Bronston: Yes.

He hired me as a consultant, a senior consultant and medical director, for what was called at that time the "Developmental Disabilities Branch" and the "Mental Health Branch" of a division in the State Health Department that oversaw all social services, all mental health, and all developmental disabilities services in California. Everything was in "Health." So I did not have line administrative authority or employees to supervise, but I was given the programmatic responsibility to be the senior clinical service program advisor to the mental health system and to the developmental disability system.

I worked for a man named Don Miller, who was the division administrator, one of the major divisions, in the Health Department at that time. Then Jerry Lackner, the director of the Health Department, who was a gubernatorial appointee—began to work on developing his agenda to try and improve health under the new Democratic regime, which followed on the Reagan years. So it was an absolute renaissance of the most amazing scope in terms of Governor Brown, and the changes that both brought about, despite the down side of it.

The problem was that Jerry Lackner was not a very courageous or a skilled administrator. He spent most of his time in his office, rather than going out and stumping the state for comprehensive health care. He surrounded himself with the most extraordinary group of progressive leaders in health care delivery imaginable, but never convened them to ever collaborate with one another in order to concentrate their influence and power, because, he was somewhat intimidated by the possibility or the danger of what would happen if we all got together. I'm really convinced about that. Because there was just too much fire power among us, if we ever really began to collaborate—

In those days, in my capacity, I had to figure out ways to artificially, and in an unorthodox way, bring together critical players. I didn't really understand the nature of the bureaucracy. I've been there now for thirty years. I still don't really get how to work it, because I've never been an administrator. There's certain technologies that are central to mastering state-run or large bureaucratic services that have to do with them being intimate with budget and personnel rules and regulations.

So anyway, just to sum up here, I came out in mid-year of 1975, Jerry hired me. I took on this extraordinary, un-blueprinted position as the leading theoretician and consultant in this extraordinary expanse of services that I had no idea about. Other than, I knew about the Developmental Disablity Regional Center system, and the state hospital system, of course. My special area was in developmental disabilities. I began to piece together, simply out of survival, a gigantic network of advisory committees in all the major areas that I wanted to bring about change. I always had to work with existing veteran administrators and state bureaucrats who had been running this system in the old way, forever.

No matter whether they were young or old, there were people, who, essentially, were involved with business as usual and accountability to the legislature and the finance department of California, which governed, controlled, and limited any kind of real change, and kept our service delivery system always at a point of leanest and most fragile survival. It was always a struggle just to keep doing the main thing, as opposed to turning the whole system around.

The regional center system

Cowan: What was the regional center system?

Bronston: The regional center system in California had been established about fifteen years prior, through the work of my original teacher, Richard Koch and Assemblyman Frank Lanterman, who was the head of Assembly Ways and Means [Committee] in the Reagan administration and a wonderful Democratic assemblyman by the name of Jerry Waldie. Very historic characters that played a crucial role in shaping the mental health system, the developmental service system, the regional center system in California and the special education system.

They were the most amazing pair of bipartisan Democrat-Republican allies. Especially Frank. Frank didn't have any kids, was never married, was a roly-poly kind of guy. But he really had an eye for children's services. He made California the greatest children's service delivery state anywhere. Dick Koch worked with Frank in creating a model for serving people with developmental disabilities to get them the hell out of institutions and keep them out, and prevent them from going into the state hospital system. Dick understood the incredible carnivorousness of that system and the lack of any organized alternative. They created under a conservative private Republican model, a strategy to establish non-profit corporations that would divide up the State of California into different regions, "Regional Centers," in order to provide comprehensive, life to death, support services, purchase of service dollars, counseling, and assistance, to anybody that fell under the rubric of developmental disabilities before the National Developmental Disability Act passed at the federal level.

Cowan: And was that working?

Bronston: It was working, you bet it was working. It was an extraordinarily controversial but poignant system. They laid track in terms of delivering testimony to the California legislature, and provided materials that laid out the whole story of what was happening to the children and adults in the state in terms of no case management and mainly state hospitalizations. They documented the incredible cost, the inhumanity of that whole non system of care. Now they didn't have the slightest idea at all about "normalization" in human services, because that came later.

But they had already gotten, through Dick's Child Development Clinic at Children's, this enormous humanity, and this enormous conviction that kids could be taken care of in the community outside of state hospitals, in their homes, if any kind of services or provisions were provided, a reality that was absolutely absent in the state of New York. The reason why the state of New York was in the debacle that it was in, was that there were absolutely no community services in New York. There were only large, congregate, segregated institutional facilities for anybody labeled with these conditions.

So here in California, the state was divided up into twenty-one regions. Each region had a regional center run by a separate non-profit that was contracted to the state department of health. Specifically, the contract was managed by the Developmental Disabilities Branch. I was the clinical advisor to all that, plus all the state hospitals, wherein people with developmental disabilities were still largely incarcerated. All were administered by that same DD branch in the State Health Department. In my influential role, I was able to put together a statewide advocacy group of key bureaucratic leaders across all public children's services, another key group in staff training, another key group in evaluation standards, one in media and public relations and finally, a key group in infectious disease control and management.

I met with each of these statewide committees every month, took the notes, generated the interpretations of what we were dealing with, and personally challenged each of those groups to not only create convergent interest and work together, but also to inculcate, to insinuate a whole new consistent ideology of looking at how to reform and destigmatize human services in California, and how to move towards comprehensive, unified, community-based services.

So my strategy was that if I could influence and define the standards for quality, against which, funding could be matched, and control and define staff training in the state, in the field, I could catch the system between two absolutely invincible pincers. If I could determine what people thought and what they expected, and if I could define what constituted quality and competency and coherency and normalization in human services and build those standards against funding streams, the system would have to change. I didn't have to go against state hospitals, I had to create a new paradigm in the state that would gradually leech the vitality and necessity out of the state hospital system.

Meanwhile, the state hospitals were in a constant battle, because they were shitholes. There was this huge struggle to try and upgrade them because of structural problems for earthquake safety and a whole variety of other considerations that made them even more formidable as a dumping place for state dollars that had to come from someplace. It was clear that more than eighty-five percent of the entire state budget for developmental services, went to service about twenty-one thousand people that were incarcerated in state hospitals, while a hundred and fifty thousand people or two hundred thousand people were on the roster roles with developmental disabilities in the community-based system, which was completely unstabilized because of the lack of public service unions, no institutions, no standards of salary or benefits for workers, no ideological commitment.

In the meantime, remember, titanic lawsuits are being waged around the United States against the states for institutionalization and breach of constitutional amendments related to right to treatment, cruel and unusual punishment, right to due process, on and on, filed by family and professional advocacy movements, supported by the federal civil rights offices and other amicus, led by the most brilliant lawyers in the world, consulted to by a handful of maybe thirty or forty of the most brilliant spokespeople for humane, family-based, community-based, individualized, high-expectation-based, competency-based services. Including people like Gunnar Dybwad, Burton Blatt, all of them. Interestingly, Wolfy never testified in these trials, but that was never his schtick. But these were amazing pieces of theater that were being coordinated and organized, and while all this was happening—federal law is beginning to change.

Cowan: Were changes starting to happen, or did you have to work through the legislature to make changes in these regional centers?

Bronston: I got to tell you that this whole period of struggle was very confusing to me. I was totally hanging out there. I mean, I had something to do two minutes for every one minute of the day that I was operating. I was just in seventh heaven. I was in full-blown struggle against underdevelopment, trying to establish my own credibility, trying to get the deconstitutionalization ideas out there. We captured some training money, and through a contract I produced, an extraordinary six-part monograph book of training, a training manual, for rank and file, community-based, residential service workers and community-based service workers there in order to articulate the normalization principle in very popular and animated form.

I was able to establish a major alliance with the key state-contracted manpower training programs. I brought a colleague with me, Sandy Weiss, from Syracuse and I vested in her the responsibility of developing the whole service system evaluation tool. She created a tool whose acronym was ANDI. It's called A Normalization and Development Instrument. Sandy was able, through a period of about three years or so of relentless committee work and negotiations, to build into the developmental disabilities system, a set of quality evaluation criteria, tied to funding, that would tend to reinforce attention at the more severe disablity end in the community, at the more demanding service end, the more challenging end of service needs in the community.

Now, the system never worked well, but it was an enormous breakthrough, to establish a funding relationship that had some ideological ground to it and some accountability built into it. We were in the process of trying to move this titanic mountain, four or five or six of us, through some strategic relationships at the top of the department's policy structure, generating a variety of small pieces of legislation to help us, and also organizing people. We were involved in very, very concrete, physical, organized struggle against all the inequities of the system that we discovered. I also established kind of a secret group, called the Friends of Developmental Services. We were a mystery group, where I handpicked about fifteen or eighteen of the most progressive activists in the regional center system, in the Governor's Council on Developmental Disabilities, in the Area Board Developmental Disabilities system for the state of California, from the school system, from the bureaucracy to meet, plan and take reform action.

And we would meet in a consistent way and try and anticipate and develop the challenges to the state of California, in order to move the system more expeditiously toward a more progressive kind of course. The group was just a spectacular group of mostly liberals, but again, limited by, in large part, a chauvinism around mental retardation services and not understanding the larger need for taking this thing to a more generic policy level for all society. It was so clear to me that what was good for people, for people with mental retardation, was even better for people without mental retardation. That connection has never, never been made in our movement. The only person that ever really got that was Ed Roberts, the director of the Department of Rehab.

Now, I made one critical political ally that was the most remarkable ally imaginable, named Tony Apolloni. Tony is now a full professor of poly-sci at Sonoma State University. But at the time, Tony was a shoulder-length-long-hair, Peabody University Special Ed Ph.D. graduate with an older sister with very severe mental retardation, living in Santa Rosa, working at Sonoma State University as a young teacher who also was just absolutely a warrior of the first order, pristine, conservative, quiet, tall, physically powerful, brilliant mind, and just an absolute laser beam.

Cowan: How did you make the connection with him?

Bronston: I knew everybody. I simply knew everybody in the state.

Cowan: But he wasn't working for the state.

Bronston: No, he's not working for the state.

Cowan: But he was connected to his sister.

Bronston: And because he was very involved in his Regional Center, in the Santa Rosa area, and because he was working on developing some group home programs for his sister and others, and was very active in the parent movement, as a family member. Tony was just the bravest, and the best possible partner imaginable. That guy, when we had to go to war with the governor because of cuts or whatever, would load two hundred people with mental retardation into buses in Santa Rosa, and park them in the governor's damn office, with signs. I mean, he was just unbelievable.

And there was another thirty people that were of lesser stature, but similar ilk, that were part of our movement. That is, we had a brain trust in the Friends of Developmental Services that met regularly to try and figure out how to combat this relentless strangulation imposed by the state hospital system, in all the many ways that it could constrain and limit, even off the scene, the progressive development and emulation of a community-based delivery system.

Cowan: When you say "our movement," what do you mean? The movement for change in services for the developmentally disabled?

Bronston: Exactly.

Cowan: Could you say again something about what kinds of services regional centers provided?

Bronston: Regional centers were governed by very rigid and strict legal and budgetary constraints and requirements. The regional center system is theoretically an entitlement program, rightfully available to anybody who falls within the rubric of the Federal Law of Developmental Disabilities, autism, mental retardation, cerebral palsy, epilepsy and there's one more, a fifth. It has some area of reading disability, dyslexia. It wasn't the whole learning disability rubric crowd, but it was a fraction of that crowd that was always a problem because the mental retardation families didn't want kids with what they saw as minor learning problems, wiring differences, becoming eligible for a part of a limited budgetary pot that would only reduce and dilute their services, which was historically, always the case, the resource available to the legitimate mental retardation community. Again, we always had to fight the inequity of having parents divided by diagnostic definitions to build unity for service needs.

Cowan: And what services would the regional centers provide? Educational services? Medical services?

Bronston: Yes. Well, the regional center was prohibited by law from providing any direct services of any kind. It was required to be an "advocate" to obtain the services or alter the existing services to meet the needs of their individual clients. So they were, by definition, an advocacy operation that provided counseling, case-management, and had a budget for purchase of services, specifically tied to a formal individual development plan.

I believe the way things worked, that if somebody went to the state hospital, the state hospitals had their own budgets, so the regional centers would not have to pay for anybody going to the state hospitals, which was a major disincentive for utilizing the put-away. On the other hand, there was enormous changes brewing to essentially bottle-up the growth of the state hospital system in California. [Tape interrupted by phone.]

The growing cost of the state hospital system repair needs, in order to utilize them and meet federal standard in order to get Title 19 money were simply prohibitive for the state of California around these accreditation and earthquake safety standards. Plus, there was this growing national realization that there had to be community services. Not that state hospitals shouldn't be there, but that there had to be an expansion and a more adequate grounding of alternative services that the state clearly saw as cheaper, because they didn't have the same labor costs, the same liability costs, and so on and so forth, which was part of the whole Republican strategy to privatize, in an odd way, the human service delivery system, which was one of the deep philosophical underpinnings of the mental retardation design in our state.

So what was interesting from a state system standpoint was that everybody, each major element, was exactly in the wrong place. The regional center system was prohibited by law from providing direct services. The state hospital system was essentially prohibited from taking new people even as a point of last resort which left the third and only other component of the system, and that was the voluntary parent movement, as being the obligatory service providers of last resort. All of a sudden, as a result of the regional center system's design implementation, you have the parents' organization being removed from their vaunted role as advocates, demanding standards of quality and compassion and care, into being the providers of last resort, funded and dependent upon the state of California through the regional center system which suddenly was posed as sort of in loco parentis, and the institutional conscience of the mental retardation movement.

But, the regional centers were nevertheless, a quasi-state bureaucracy, tied to state funding, which was very fickle, and a state hospital system that was soaking up between seventy and eighty-five percent of all dollars for a fraction of the people, essentially off the scene, continuing its awful service. The state hospitals were an awful presence in the ecological system protected by law that required enormous amounts of money going in there and standards that were going in there that would only enhance and strengthen the amount of budgetary allocation to the state hospitals. It was totally crazy.

So the typical decade, twenty, a score of years, that I watched the system, the struggle that goes on, year after year after year, happens between the various community-based service providers, battling the state regional center system and the state department of developmental services for increased rates, paid for service, rather than changing the fundamental model entirely and essentially looking at the critical need for universal healthcare funding, the need for a comprehensive program to fund in-home support services and respite services as the ground zero of the service delivery system and to close all the state hospitals and put them into the archive book of a terrible mistake that was made in a period when we didn't know any better.

The problem also is that, in the state of California, there's no independent advocate in the system, which has always been a brutal problem. The parent movement, as long as it continues to be the provider of last resort, dependent on state funding, is neutralized. The regional center system can't provide services by law, all they can do is hold money out there to purchase what's needed, though they try to define or dictate the quality of that service, or the nature of that service. And so they go fishing with their money and they can pull up and old boot or an old pair of jeans that have been down there or a dead body. But they can't necessarily get what they really want. They can only buy what's available from vendors in the community, who are mostly parent organizations.

The out-of-home residential service system, Title 19 and 20, had created this gigantic cottage industry of poor and oppressed people, mostly people of color around the state, who are relegated to providing humane and human services in the most economical and chiseled-down way, governed by a range of bureaucratic rules and regulations from half a dozen different departments, in order to license them for this program or that program. Paradoxically and cruelly, the system creates requirements and standards for safety that are completely de-normalizing, that create environments that are completely stigmatizing in every way.

And so we have this battle going on for community-based, integrated services that I'm a key spokesperson for, in 1975, 1976, 1977, 1978, 1979, and into 1980, where I'm trying to organize in every conceivable direction, to try and somehow provide a center of conscience, a vision, a vocabulary, a work force, and to support the other progressive activists in the state, of which there are many, many of us, working at different levels and different arenas, but without any kind of centralized organization or centralized support. The parent movement is completely divided, and the changes that are going on are absolutely numbing, in terms of their significance and their complexity, and in some instances, their contradiction.

There's huge changes also happening in educational law and educational opportunity, and the whole working out of the Education for Handicapped Children's Act Public Law 94-142 on a day-to-day basis, as the school systems are challenged to change their ways, is a relentless drum-beat.

[Tape 12, Side A]

Bronston: What happens in all this, and I want to kind of get to some of the history of the situation, was that, at a critical point, Jerry Lackner got into a very serious struggle with the Secretary of Health and Human Services, a man by the name of [Mario] Obledo. The two men did not like each other. Obledo was a patrician kind of guy, a Latino nationalist. He was put into office, really, by Governor Brown, to offset the installation of a more progressive Latino leader in the state of California, who might have been aligned with Cesar Chavez. Brown didn't want to, in any way, be jammed by a more progressive and explicit labor ideology.

So he put this patrician Texas Chicano lawyer in, who became the minister for Health and Welfare, for the state of California. In addition to that, Lackner was very unaccustomed to and had a lot of difficulty in dealing with the legislature and making decisions and being very accountable. So the State Senate Health Committee leader, who was from the Bay Area, got terrifically pissed off, and with Obledo's alliance, concocted a strategy to completely legislatively reorganize, the Department of Health, which would eliminate Lackner's position entirely and split the health department up into eleven separate state departments.

Cowan: Do you know who that was?

Bronston: The senator? Arlen Gregorio. And they accomplished that. The legislation passed. Brown supported it, and Lackner was out. What was even more interesting, besides Lackner being out, who was my patron and my guardian, was that we all of a sudden we had, from my little departmental branch, inside a division, a total free-standing department. I was able to ram home the name for it. Instead of calling it the "developmental disabilities whatever," I forced the installation of a name that reflected what the department did, the "department of developmental services." Because we didn't make developmental disability, we provided developmental services. It was all part of the struggle to turn words and our paradigm around here. I don't fully know what the impact that name change had, but it was an example of the work I was doing, both in front of and behind the scenes.

Cowan: So were you able to stay on?

Bronston: Yes. But more interestingly, I wanted to stay on as the director of the new department. I waged a very relentless campaign to have the governor appoint me as the new director, because I thought, you know, I've gone far enough in this situation, I've got to bite the bullet and give this a shot. But the state hospital parents and the hospital workers union rallied against me and my community bias. They were the big money contributors—and they impelled the governor to appoint a man by the name of David Loberg, who was the state hospital director for one of the Central Valley MR institutions.

David was a psychologist. He came in and first of all, knew that I was his principle antagonist for the job, his principle competition for the job, and set about to really contain me and ultimately get rid of me. Loberg and I never liked each other. It's kind of an understatement. I thought that he was the enemy, and he brought the enemy philosophy to a time when Tony Apolloni and the Friends of Developmental Services, the state DD [Developmental Disabilities] council, even the Regional Center system was really beginning to make some in-roads into developing a community-based service delivery system.

To have a state hospital director with all of the corruptions, intolerances inherent, be put in charge of the entire system, was a catastrophic setback for us. It wasn't as bad as all that, in retrospect, because David only had so much power. But he did delay and derail a lot of stuff, and systematically undid every one of the committees that I had been working with for three years up until that point, and put me in a situation with my supervisor that set me up to be fired. They prohibited me from using the phone, from leaving the building, from—I mean, it was a war.

They just didn't want an independent, community-oriented force which had to have been set up at the governor's level by the key people that influenced the governor in selecting Loberg instead of me. They knew that I was after closing all the state hospitals, and that was just simply not tolerable to them. The only way we were going to see real change in the state was to have the state hospitals close. Otherwise, they would siphon off all the money, all the intention for a small percentage of the population that we had demonstrated nationally, through the federal law suits, could absolutely not only thrive, but do better in community settings, in normalized community and individualized settings than in the state hospital system.

Cowan: Did they manage to get rid of you?

Bronston: What happened was that I was able to hold for a while. At the worst point, my father came to town, just on a visit, at a time when I was just at the end of my rope, about to be fired. My dad found out about it, and he went to talk to the governor and to the state attorney general, and to Obledo, and to key leaders in the state legislature on my behalf. Here comes this world famous movie producer, dapper, camel-coated powerhouse and explains to them that his business was media, and that if anything happens to me, the news is going to be "The son of Samuel Bronston is fired," and he can't afford to have that happen in his business, and so he just wants to share with them that he would have to bring to bear the entire might of his ability and his influence in the media, to correctly produce that story, in a correct way, as to what was really happening and why I was really being targeted.

He presented and defended to all these political leaders my true role in the system, as a progressive change agent, community-based service delivery system. All of a sudden, as a result of an intervention by the secretary, under the impelling influence of the head of the California Senate, I was moved from my department medical director position to become the assistant to Obledo, and to be a senior consultant to the chief deputy of the State Health and Welfare Agency in charge of establishing a brand new governor's council on developmental disabilities in a newly revised and reauthorized version of the Developmental Disabilities Act at the federal level.

So all of a sudden, I was pulled out of the fire and put in a position where I could hand-pick all the members of the state DD council, which were really the chief policy advising structure and citizen oversight structure. This included representation from all the major departments in the state, sitting constitutionally, on that council. So I spent a year with Obledo, in that context, and with a guy named Jim Connors, who was the chief deputy and just a wonderful man.

Ed Roberts; California Department of Rehabilitation

Bronston: And then, things got too hot again, because of my activities, and my outspoken commitment to community-based services and against the congregate and segregated programs. Loberg and the State Hospital forces raised hell. So Obledo transferred me under Ed Roberts in the State Department of Rehab in 1980.

Cowan: Was that good?

Bronston: It was all right. Ed was a perpetual, beloved brother, friend. From the minute I arrived in 1975, I just locked onto Ed, because he was the sunshine. He and I just did some outrageous things.

Cowan: Do you want to say something about Ed's background? Or is this a good time to say what was going on in the independent living movement in California, at the time Ed Roberts was influential?

Bronston: Well, let me get there, let me get to the part, and then we'll talk about Ed, because you asked the question about what was happening with the whole disability rights movement that was starting. When I was in New York, in the struggle with Willowbrook. Remember I was also head of, or played a key role in, this very significant student health professional presence against the war, in connection with what was going on in the civil rights movement in the South, and in the whole reform movement in the city of New York. We were organizing strikes in every hospital in New York, in order to oppose something called the Affiliation Program, which had been set up by the private hospital sector to subvert the agency and the authority of all public city hospitals in New York City.

I was on the street constantly, in the city of New York in demonstrations of every conceivable kind. I was heavily involved with the Black Panther Party, because I was the main physician to the Black Panther Party in that part of eastern New York. I was heavily involved with the new women's movement, led by Gloria Steinem and that whole group. Bill Kunstler was very close to us in a whole variety of legal rights struggles. The whole Vietnam War thing was still very much on the table, and progressively very much involved with the emerging disability rights activists in order to connect them to my anti-Willowbrook and anti-institutional agenda. In that context, I met Judy Heumann and a whole bunch of other spectacular activist lifetime friends.

We were on the streets, militating and getting arrested because of the 504 regulation struggle that was going on. Nixon was the president at that time. So there was this brotherhood, bond between so many of us, between all of us. We were just like this one incredible, loving, family of strangers. Just loved to be on the street, loved to be in demonstrations, and just couldn't lose. The paddy wagons in those days were not accessible, so they couldn't arrest anybody in a wheelchair. It was fabulous! Just fabulous, fabulous. Outrageous things happened. And I remember us getting arrested together on the street in relation to the 504 demonstration, where we were blockading a hotel where Nixon was having a meeting.

So I had a long history with the militants, the young militants in the disability rights movement, and was trying to figure out how to establish rapprochement between the mental retardation movement, which was really a movement not for independence, but for autonomy and normalization, always under the rubric of patronized care. This was very different from what the first kids that grew up in the civil rights movement with disabilities, understood to be their patrimony in terms of really having independent lives where they didn't have to depend upon anybody, particularly their parents. They didn't want to be eternally juvenilized and understood that to be independent was the only way to take their place in society.

And Ed Roberts, of course, was the scion of that movement. He was the first to break into [University of California] UC, and the organizer and originator, with Judy, of the independent living movement at UC Berkeley and the Center for Independent Living. CIL was like this granddaddy of the great peer-support and peer-advocacy organizations of disability rights. And I, of course, was hugely bonded, emotionally bonded, to them at every level, ideologically bonded to them at every level, because you know, we were the same. It didn't matter whether you could walk, talk, see, hear or not, if you understood what was at stake. We were one. We were one. The change had to be to democratize and humanize all of America, that was always the issue.

Now what happened was, that my movement, the mental retardation movement, was allergic to the independent living movement agenda. Because the mental retardation movement was driven by parents who wanted their kids safe and sound and who saw themselves through the organizations, as the active arm of change. Their kids were still in the process of inventing “People First” and their own peer organizations to provide their own voice. A number of people in the country were specializing and working that area, organizing, and giving political voice to people with developmental disabilities, to people with mental retardation, to people with cerebral palsy, who were still not part of the independent living movement.

The independent living movement never welcomed with peer joy, an association with the developmental disability crowd. Because there was always a status pecking order to the disability movement similar to the divisions in the mental retardation and developmental disability movement. The kids with post-polio, the young adults with post-polio, were at the top of the pecking order. They were the elite of the elite, under them were the people with minor cerebral palsy. Associated, off to the side, were people with muscular dystrophy, which weren’t even part of the developmental disability area and had their own mafia kind of related and Jerry Lewis kind of related charities that funded them totally independently.

People with spine injuries and brain injuries from traumatic brain injuries were also a whole other group with its own family defense organization, its own institutions of struggle, its own medical hassles. And then you have people with a whole variety of genetic and inherited diseases that also have their own specialized defense groups. Then you have the blind and the deaf in two separate armies that don’t want to associate with anybody and have their own sense of segregation as a desirable agenda.

Especially people with hearing disabilities, who are extraordinarily isolating among themselves, and unwilling to really be part of a larger disabilities coalition, or to allow programs to be set up that integrate kids that are deaf. They found that discrimination is so relentless and the isolation so terrible for an isolated one or two people with hearing disabilities that are really deaf, that unless those people are in a cultural milieu with their peers, they become culturally retarded, just by virtue of the lack of stimulation and integration and the difficulty that the hearing community has that can’t communicate with that crowd.

So you know, there were all these political and organizational divisions going out there, and I felt totally clear about those problems. The issue is, you have a country with a set of social policies that is just not willing to build a social delivery system predicated upon the realities of the need, a new service agenda governed by an overriding commitment to enhancing the status and lifting the spirit of all people.

So in coming to Ed Roberts and the State Department of Rehab, being transferred there, all of these experiences, all these relationships, come with me. I know everybody. I think I understand and empathize and identify with all the agendas. They all have virtue. But unless they’re brought into convergent relationship with one another, unless mediation can be established in order to take the political struggle to a higher level of unity, the whole thing flounders. And everybody ends up fighting each other, becoming more and more isolated, and more and more dispirited, slowly but surely, and more and more distrustful.

So, when I got under Ed's wing, the first thing that happened, because it was 1980, 1981, the United Nations announced the International Year of Disabled Persons. That was a major turning point in my professional life because the first thing that we did in 1980 was, Tony Apolloni and I, and Ed, with Ed's backing, organized a unique event at the Claremont Hotel in Berkeley, called the "Consumer Unity Conference." What we did was we invited every disability group in the state of California to come together, to meet, to talk about internal unity in the struggle for reform in the country and in the state.

Cowan: What kind of response did you get?

Bronston: It was extraordinary. There were two hundred people there. I have a beautiful book that I'll show you. It was just the beginning of the International Year of 1980-1981. I photographed the whole conference and we produced it. The governor was there, Obledo was there, people were there from the blind community, the deaf community, the physical disability community, the mental health community, the mental retardation community, on and on. Everybody was there. The main speakers were major people looking at the paradigm of full integration and political power. The minister of Glide Memorial Church, the whole black power movement, and black civil rights movement and the heads of key labor unions that were involved and interested in disability rights.

Finally, I had a chance to put on the ground, what I'd been railing about for the last five years in terms of a genuine solidarity movement between the elder community, the black community, organized labor, and the entire spectrum of disability interests, parents, and primary consumer interests. A similar kind of meeting to the monastery meeting that we had about Willowbrook, in terms of getting everybody together. That's my forte, bringing all the disparate community elements together and try to create an environment that creates the synergy, the discovery and the Ah-a! and the sense of comradeship and mutual respect that had to be hammered out in order to change the political balance in the state, in order to advance our interests of health, transportation, and housing, social services, guaranteed minimum wage, etc., etc., all of which we worked to put together.

Out of that meeting came this spectacular book which we distributed everywhere, all over the state. It had photographs without captions, of the faces of the people and everybody, and the full text of Judy Heuman's presentation, Mario Obledo's presentation, Assemblymen Tom Bates, who was the head of the social services committee of the legislature, the governor's statement, my statement, the key lawyers for the feds, from the office of civil rights that had been our critical ally. It's a spectacular book that has in it, all the language, all the ideas to promote unity.

Cowan: And did a unity, an ongoing unity between these groups come out of that?

Bronston: I don't know. You know, I don't know. I'm not as keen an observer as—I mean, I'm always in the thick of the struggle. I'm always talking as opposed to listening. I talk more that I listen. It's a terrible curse that I experience. As much as I try and listen, clearly I get a lot, I wind up having to say more, because if I don't say it, it doesn't get said in what I think is the right way, the way to promote unity, the way to promote breadth, and encircle the whole movement, and to try and put the thing in a context for people who get a gut feeling for what's at stake, and then can sort that out with their own particular politics.

Paradoxically, I stay pretty isolated and have a reputation, I'm not even fully aware of, but I feel I'm sort of a pariah, in general, in the movement, because I just speak my mind and I don't play ball with half solutions. I can't. I can't. I just get too anxious. I can't. I can't postpone, put off, or somehow mute the real issues and the real answers. Just saying the truth, and saying it as clearly as I can, and explaining as clearly as I can, what would really make a difference, and enduring, powerful, deep, difference in our relationship to one another and in our lives, makes me very unpopular in most contexts. I stand up with fury and I think part of my anger and my intensity also causes people initially to draw back.

I haven't learned to be a [Nelson] Mandela, or a Ho Chi Minh, or a [Mahatma] Gandhi, or a Martin Luther King, Jr., I haven't learned how to spin my presentation in a way that draws people in and doesn't intimidate them, that gives them a sense—I mean, I try and speak on behalf of, and through the common interest, but I wind up always feeling I didn't do it right. I didn't say it softly enough, carefully enough to succeed in what I was after. So I wind up never quite knowing, and because the agenda is always so huge, I believe that I play a role in change. I believe that I am another piece in a very complex puzzle, another tiny force of light and inspiration and energy and positivism and I've never changed, not an iota, from day one, what I believe in, what I think ought to happen, how I think it ought to happen, who I think ought to be responsible for it happening.

As I get older, I may get a little more circumspect and pick my struggles a little differently. There's a lot more to talk about here, in terms of what's happened in California in the last twenty years that I've been involved.

Cowan: Did you come out of this conference with a feeling of success?

Bronston: Oh, it was great. It was one of the most extraordinary, it was like, Health Advocacy for Children events in Syracuse. I mean, if I get a chance to produce a political event, it's not an easy thing to do, and the circumstances and the conditions have to be right, for something of this magnitude to happen. But it was really a coup. It was one of the most extraordinary ad hoc political meetings. We did it a decade later around the whole reauthorization of the Federal Rehab Act, Colleen Wick and I. Colleen is the chief executive officer of the Governor's Advisory Council on Developmental Disabilities for the state of Minnesota. She is a genius.

There aren't many of them, but she's one of them. She and I decided that the Rehab Act was just a piece of shit, that just had to be fixed. So she and I single-handedly organized a conference, over two hundred people, in Washington, DC, in order to articulate a more progressive model for the reauthorization of the Rehab Act, which happened that particular year to be a very significant challenge. We were able to bring together simply the entire leadership in disability programming in the United States, in order to look at the Rehab Act, and cause the most profound changes that have ever been made in the Rehab Act up to that time.

Cowan: Do you know what year that was?

Bronston: No, but I can very quickly put my hand on it. I have tons of brochures and literature and stuff on that. I think it was 1992, 1993, 1994, something like that.

Cowan: Back to this conference at the Claremont. Do you feel alliances were made between the disparate disability groups?

Bronston: I don't know. What I do know is this, that Ed was in charge, that Ed got it. Ed had money, he had the position at the head of the state Department of Rehab, and I believe the most historic and significant changes in the century happened in his administration.

Founding the California Institute of Human Services

[Tape 12, Side B]

Cowan: After the Consumer Unity Conference, you're still working for the department of rehab with Ed Roberts, what happened then?

Bronston: Let me try and relate a development associated with grounding the Consumer Unity Conference, which I think led to a very poignant structure. Tony Apolloni was working with Alan Rohrer in Canada. He was very impressed with Alan and they became very close friends, working around the whole question of guardianship. Guardianship is a very thorny question and a very challenging problem in the whole mental retardation political sphere. And as a result of all our work, and as we toiled to try and figure out how to institutionalize the movement and how to provide it with the same kind of extraordinary infrastructure, support, that for example, the Canadians have, with the NIMR, the National Institutes on Mental Retardation.

Tony and I began looking at all the different kinds of models of intellectual and academic structures that could be established to support a radical social reform policy agenda. How do we create a structure that is not like the President's Committee on Mental Retardation with its limitations, the ENCOR office, with its limitations, the National Institute in Canada with its limitations? And we hit upon a model and established a thing called the California Institute on Human Services (CIHS), which Tony arranged to vest, under the President's office of Sonoma State University.

The purpose of the CIHS was to create a think-tank and a funding source and a legitimate agency in the state that would become the instrument for parent militant advocacy. We would challenge, through really unquestionable scholarly studies, the whole premise of budget analysis and budget distribution in the state of California for the developmental service system. With the establishment of this non-profit 501(c)(3) apparatus at the President's office at the university, which Tony ran, we were able to garner lots of commissions from the State DD Council and other critical liberal parent organizations, advocacy organizations, and to do the crucial studies to challenge again and again, to look at all the major issues that we wanted the state to deal with. Our aim was to change the service delivery system from a congregate/segregated one, to an integrated and inclusive one.

We produced the most definitive study on “community living” that had ever been done in the past in terms of defining the model and its total costs, similar to what was going on in ENCOR but taking it a step beyond that. Tony produced the most spectacular study on “respite care” and its ability to essentially be the center piece rather than a marginal piece of the service delivery system in California. CDHS did a whole piece challenging the cost-effectiveness of putting money into the state hospitals for renovation or earthquake standards for safety and so forth, rather than putting them into the community-based service delivery system.

And we used the Institute for a funding source to bring together all the most articulate aggressive spokespeople in our movement, in the United States to provide consultation to the State Developmental Disabilities Council, which I had just formed. I did this work under the aegis of the Health and Services Agency Secretary’s office, in order to combat the institution mongers, and the segregationists. The California Institute on Human Services has radically grown and is one of the most extraordinary existing apparatuses. Tony must have twenty major contracts now, everything from soup to nuts in human services, and continues to play the truth-telling role, but at the time, his focus was on the mental retardation area.

He and I were just inseparably committed to bringing about the kind of respected, national-quality, better than anything the state of California could ever hope to do, intellectual work, and study work, research work, through his staff. I never did any work in the CIHS, never got any money through it or anything like that. But what happened as a result of our establishment, it was almost like creating Soviet Union in the midst of a capitalist world, the State Department of Developmental Services, and Loberg, went after Tony, for three years, in the most relentless witch hunt that I’ve ever seen, ever, in my experience.

They literally did everything they could to try and impugn Tony as some kind of fraudulent, double-dipping, or crooked kind of a guy, in order to somehow expose him. Even the relentless pursuit, to try and investigate him, had its own benefit to them, of discrediting him and raising questions about the safety of even seeking his consultation in this area. It was proof how effective were we in confronting the state department of developmental services and its nefarious efforts to maintain the status quo and to challenge the segregated delivery system and all the missteps of the regional center funding system.

So they sent an investigator after Tony, armed police. He showed people his badge and gun, saying, “Do you know this man?” It was like an FBI kind of witch hunt, trying to track down all of his clients at the university that were commissioning the CIHS to do studies for them. The whole thing crashed and burned, finally. Finally, the very investigator that they sent after him for three years was put in jail for pedophilia.

Cowan: Who was this?

Bronston: It’s not that important. He’s a mercenary guy, a real sleaze bag that was working for the State Department of Developmental Services. He was the State Department of Developmental Services “investigator.” Eventually, of course, the government changes, Loberg was out, a new director was put in, but the aftermath of that witch hunt was so ferocious and Tony’s reputation was so heavily burdened with implied misdoing that it was very difficult for him for a while. In addition, Loberg waged a major campaign to try and break up the Friends of Developmental Services, because it was that think-tank and that alliance of jovial friends, militant friends, that really ate him up.

The guy that was the most marvelous advocate was the chair of the state DD council, a man named Jim Burchell, who was a lawyer in San Francisco and was just absolutely beyond the best. He was just an extraordinary man. He died of cancer and was lost to the struggle. Then a number of very severe attacks were made on Ed Goldman, who was another extraordinary activist in our group, who was at that time, the pending director of the Valley Mountain Region Center, which was the Stockton Region Center. Ed had been working for me for two years, as a consultant.

Even though we were physically promised a budget from my department to work with me for one whole year, they wound up never getting the money and never allocating the money. Ed worked for me for a whole year for free, without a single dime, wound up at the end of that year, challenging the state, suing the state internally, for his salary for that year, and wound up winning the challenge, winning the appeal, from the state personnel board. They went after him and accused him of fraud because there were two days in the whole year, when he had invoiced and gotten paid and was off doing something else. They were going to bring a felony charge against him for two days' error in this 365-day record.

What happened was, he was up for consideration as director of Valley Mountain Regional Center, and by law, anybody with a felony charge against them couldn't be considered. So they were effectively able to block him from, this is Loberg the chair, block him from becoming the executive director. He was actually arrested before he was obviously exonerated because of a bookkeeping error, that occurred. This incredible struggle was going on and it really hurt him.

They wound up offering money or jobs to three or four of the other people in the Friends of Developmental Services group, who were small business-oriented kinds of folks. They who were leaders of agencies, the San Francisco Aid for the Retarded. A guy named Al Bergman, another guy who was an advocacy lawyer, Burns Vick; another, a woman by the name Fran Smith and Lonnie Nolte. There was a batch of people in the group, that were part of our group, the "friends," that were offered money in order to give them consultancy jobs for a year or so, before the money was erased, but to break the group up.

The struggle was getting to the place where these people, the liberals in the circle, were really confronted with the issues of all around consumer accessibility, their relationship to the true non-patronizing empowerment of their own disabilities constituencies, let alone a willingness to make alliances with the physical disability and independent living movement because there had to be a bond. There had to be a larger alliance. They all came to the Consumer Unity Conference in 1980. Part of our struggle was trying to take the relationship to a level of trust and purposeful, concrete project-based collaboration.

All this is really to kind of explain to you, my sense of struggle and frustration in terms of how I was looking at the situation. We all came out of the Consumer Unity Conference, Claremont, that incredible meeting in Berkeley which was really an extraordinary meeting. It was incredibly facilitated by a visual facilitator that was the best of his kind in the country, and all the leadership were there. The question that you ask about what came out of it, was not totally clear to me, because its purpose was to build consciousness, build awareness.

I'm not like a dentist, where you look in the mouth and you see exactly what you've done. My work is more like a psychiatrist, like a psychoanalyst where I'm working with dream-states of people and don't have any idea where the new experience is going to vest itself in terms of the change of their behavior or in relationships with one another. These are all people who were veterans of the movement who came. Interestingly enough, two people with disabilities that were in that room, in that meeting, subsequently became directors of the State Department of Rehab down the line, during the [Governor George] Deukmejian and Pete Wilson regime.

Cowan: Who were they?

Bronston: Bill Taintor was the first, and Brenda Premo was the second. Bill was an independent living director in Southern California, as was Brenda, who ran the San Diego ILC at the time. Everybody was there. Everybody spoke their peace. It was a meeting of historic significance. Maybe its virtue was our ability to articulate the most progressive political unity vision and to host in one room the most respected representatives of these various social constituencies in our community that all had an objective common cause and no political alliance, no common projects.

Ed Roberts understood and subsequently, in his life, made tremendous linkages to the elder movement, to the senior citizen disability community efforts, whereas no one else did. But no real connections were made to the civil rights movement. The irony of it all was that later on, in a very interesting test situation, which arose a decade later, or more, when we struggled to advocate for a heart-lung transplant for Sandra Jenson. Getting the disability movement to line up with the mental retardation movement was not feasible.

Prior to that, in 1994, when we were struggling around Prop 186 and the universal health care initiative in California, getting the disability rights movement to support in the most fierce way, the passage of that crucial piece of legislation, there was a tremendous splintering fragmentation and even outright parochial opposition to 186 even though it was objectively the most progressive and powerful unity policy that we could possibly have put forward that would not only have united the disability movement, behind an absolutely breakthrough material benefit to them, and social benefit, but also establish a profound bridge between the disability community and the mainstream community in America and California.

So the splintering and the self-interest and the parochialism in the disability movement continues well, and areas where there is really bridging and convergence of interest and collaboration between the various different interests at a higher level, at a higher political level that would bring the two groups together, which go beyond the specific minutiae of their particular enabling service systems, by law or program, that has not happened. It does not happen. The movements remain stunted, adolescent in their growth, or geriatric. I'm not really sure what the right indictment is.

They either don't get it, or they're too young to get it, or they don't understand and they've forgotten kind of what the possibilities are. The irony is, here we are, full circle, with all this generation of political activists, now confronted with nursing home care, in the next twenty years, for themselves. And institutionalization on a mass basis because of the lack of universal health care financing in the United States and in California. I'm sure that the next five years, between now and 2008, 2010, the question of universal health care will come as maybe one of the great unifying, saving, politically progressive challenge opportunities to the disability movement. And the only thing that will heal the built-in fragmentation, rifts that exist and trivial and petty areas of competition and disconnection between the various interest groups is going to be the health question, the universal health question.

International Year of Disabled Persons sparks commitment to youth

Bronston: No matter what people call it. National health care, socialized medicine, single-payer medicine, whatever it is. It means a resurgence of a democratization movement of principle based on a profound ground of caring, mutual respect, love of life, sacredness of life, individual choice, economy, all the great challenges. So what happened was, as a result of all that, in 1981, which rolled in, in the International Year of Disabled Persons, it became really clear to me that I needed to try and find and build a political power base that might be able to take a proper position and a proper progressive place in the body politic. The opportunity of the International Year of Disabled Persons, articulated by the United Nations, was absolutely the right invitation and the right challenge. It captured me, since then, for the remainder of my professional life, to organize high school kids.

Cowan: But at the time, this thinking lead you to become disillusioned with the movements?

Bronston: Very much so.

Cowan: But you were still working for rehab.

Bronston: Very much so—

Cowan: So how much longer did you stay with the California department—

Bronston: Well, I'm still with them. I was with the California department because of my politics, on a certain level. I mean, I was there because it was a very pleasant job. I had a tremendous amount of latitude because of my work with the political leadership and with Ed specifically. And in 1981, this is now twenty years ago, I embarked on a strategy that I am still intensely working on, which is still unfolding and still becoming evident to me as I work the game. Because you don't understand anything unless you try and change something. That tells you what you understand and what you don't understand.

So in order to move the agenda—my agenda is always the most at risk, most jeopardized, most dependent, the most vulnerable human being alive. Because I have touched and held and served so many people at that level of disability, that it's sort of like one paradigm in my heart. And whatever I do, the standard of success is the emancipation of that person, of that constituency in American society. If we can make things right for people that can't talk, see, walk, hear, think, then we got it right for everybody. If we can't make it right for that individual and that individual's family, then we have work to do, day and night. Because the danger is, excluding or diminishing that person's standing in society, creates the ground of fascist extermination.

Cowan: Was project interdependence part of your new thinking?

Bronston: Yes. It was all of my new thinking. What happened was the United Nations put out the call to celebrate International Year of Disabled Persons, That's what they called it. And it was articulated for the year of 1981. I went to Ed Roberts, the Director of Rehab, and I said to him, "Hey, I need to do this. I want to try and do something." Because we just came out of 1980, the International Year of the Child, and a beloved coworker of mine, Dr. Ed Melia, had been sort of the point person for the Department of Health and the whole children's health movement. He was a long-term colleague a cofounder of mine with the Student Health Organization a million years before that, and had been running California's International Year of the Child celebration in 1980.

In my opinion, it was a disaster. They exercised so much effort and time, pulled together a single conference that was complicated like a clock, a watch, in terms of getting all sorts of people together. I knew what the limits of the conference were. It wasn't going to change anything. What needed to really be done, was to build a new action-based constituency that was willing to immediately put into practice, a new way of behaving, and working. Ed Melia's leadership of that Year of the Child conference, although brilliant, and incredibly laborous, made no lasting change whatsoever. At the end of the International Year, all we had was one giant blasted conference.

I had done a major conference earlier when I was still in the Department of Developmental Services, under the aegis of the governor, I invited Sven Olaf-Brattgard to come from Sweden, who was the head of a thing called the Focus Society and was the most advanced model of empowered people with disabilities anywhere in the world. I used his coming to the state of California as an excuse to establish a governor's conference on disability. Getting Jerry Brown to take the credit for inviting this foreign dignitary to come and do a conference, which resulted in more than two hundred people being in the room, of all the major leadership in the state of California, and the disability and disability rights movement, and the mental retardation movement.

The conference was moderated by Richard Byrne, who was the dean of the USC Annenberg School of Communication at the time. Ed Roberts was on the dais with the governor, and Sven, and Richard. We had this spectacular meeting that looked at summing up the needs and issues of the disability movement, inside state government, and all its tributaries, under the aegis of a governor's conference.

Cowan: Did this conference have a name?

Bronston: It was called the Governor's Conference on Disability. And out of that came a whole other set of pictures, working papers, white papers. It was a spectacular conference. But the point that I'm trying to make here is that organizing a conference is an interesting tactical, political effort. You've got to chose your time, chose your issue, chose your people. You can't do it every time, and to do a good one takes a year to prepare, and takes a year follow-up. If you don't have a follow-up, the conference has been a waste.

What I did was I used that conference. I organized under the aegis of the governor to create a certain authority to put forward an agenda into the state of California that led in many directions after that point. The governor himself was immensely impacted by the brilliance and profundity of Sven's demonstrated leadership in Sweden, in terms of what was happening with disabled people in the general society there. So these strings had been played, It's like working a guitar with six strings on it. There's always been, in the work that I've done, a string that I pluck and play on in relationship to adult services and adult integration and the vocational aspects of the adult achievement in our culture.

There has always been a major string that has to do with the children's movement, per se. And then there's always a cultural and political string, which leads to a certain kind of structural manifestation, organizationally, politically, ideologically, philosophically, theatrically. It was always theater in everything, to create an image, to create an event, like the lecture series in Syracuse, Health Advocacy for Children. Those weren't just classes. Those were pieces of compelling theater, in order to grab people and whack them with some ideas and with a living experience that ups their level of anxiety, increases their sense of, A-ha! I got it! And it links them together in some kind of a—"We shared this together. We can go forward with a different level of intimacy and friendship, trust and interest in one another as a result of having been at this movie, or at this particular show."

So part of it always is to figure out how to get people to hang together, how to get people to work together. Because it's the hardest thing in the world to get any two people, any two people, to goddamn work on something together of social consequence, apart from just earning a salary and doing what they do from an employee mentality, rather than moving as an electric force of change.

Project Interdependence

Cowan: After this 1980 conference, after the International Year of the Child conference, you went to Ed Roberts.

Bronston: With Project Interdependence. What happened was that within a matter of about three weeks, with a colleague of mine by the name of Bill Campagna, who was a coworker and friend in the Department of Rehab, one of the few really progressive activists in the department, and free of the constraints of the department's employee mentality. We proposed an idea to organize all the high school kids that we could in California, into an integration project that had a vocational payoff, so that it would be legitimate within the frame of the Department of Rehab's mission.

[Tape 13, Side A]

Cowan: Continue with your thought about Project Interdependence.

Bronston: Well, what happened was, that I had this idea, you know. I mean, I had so many experiences to draw on, and they all go into this pond, and out of the pond comes the creature of the lagoon, out of my head. What I tried to do was to find a locus of engagement with the youth community and the state that would be totally inspiring, totally relevant to them, shaping to them, and would influence the whole cultural paradigm in the state of California, through this opportunity to talk about integration and its true meaning, its true consequence, which the fundamental humanization, democratization, empowerment, socialization of everyday life for everybody. That's the big picture, right?

Cowan: That is the big picture. [Phone rings, interrupts tape.]

Bronston: So what we did was, a group of us got together with a very dear friend from the state Department of Education, and I proposed an ideological agenda around which we needed to create a program. And we were laughingly trying to deal with this thing, and we start off by saying, what kids would really respond to would be "sex, drugs, and rock and roll." And that became sort of a reminder for us, as silly as it was, it was ground zero. It was heartfelt ground zero. If we could compete with sex, drugs, and rock and roll, we could make a great program.

So I also wanted to try and build in, every drop of understanding I had of normalization in practice, plus my sense of what it would take to build an enlightened, heartfelt organization among kids, and to really do something that was haunting me all along. That was, that it was my growing impression that young people in the culture were becoming more and more alienated and isolated from any kind of intimate understanding of what they could and should and wanted to be when they got into the world of work, when they grew up.

When I was a kid, you could be a nurse, or a doctor, or a teacher or a policeman or a fireman—there were about eight professions that you could sort of tick off. That was it in the world! The fact was that things had gotten wholly more complicated, wholly more transparent, and people couldn't even name the kinds of jobs emerging—and plus, the fact that the country never invited its children to take up moral arms to advance the mission of the culture apart from going to war and getting killed. There was no need for the children of America, in any way—we had a terrible impasse and the kids were demoralized and didn't have the vocabulary or the vision or the heart spark or the heros to find themselves in terms of where they wanted to go in their lives.

So I formulated five goals around which we built our model for the International Year of Disabled Persons. It was clear to me that I was using the disability integration issue, which was the commission of the UN, and the lionization, the valorization of people with disabilities in the culture, as a synthetic spear-head, as a beach-head, as an entre into articulating a more profound dynamic that could be operationalized. The first idea was to "show the contribution that everyone made to our lives." Show the contribution that everyone made to our lives. That was aimed at being able to say, the least should be first, at some level. I mean, as cliche as that sounds.

If we could show, show the contribution that everyone makes to our lives through programs, through media, whatever, that would go a long way into validating human life in all its various forms. The second one was "to remove barriers and stereotyping."

That meant for everybody. The third one was to create "new pathways to success." Because we had to create more ways for people to figure out how to make achievement happen in their lives. The fourth was to "build up school and community projects." Because one of the things that needed to happen was we needed to bridge, and needed to break down the chasm between what was happening in our school system, our high school system, and what community life was all about.

Cowan: So these goals are the five goals of Project Interdependence that you authored for Ed Roberts.

Bronston: Right, that I proposed to Ed. And the fifth spearhead was to "cultivate student cooperative learning." Now, within those five goals, was a lifetime's opportunity, a lifetime's work. None of these things were explicitly focused around disability but the issue of disability and integration and liquidating the impact of disability was implied. The whole campaign was aimed at high school kids, purely and exclusively. It was proposed, at its time, as a major demonstration of a commitment to promote public-private partnerships, because Ed didn't have a budget.

All that Ed could give me in the Department of Rehab was staff and a special office. We needed to cross over to the Department of Ed [Education] because that's where the children were. Because the Department of Rehab was not interested in kids and I always had to fight the fight and one of the reasons the program was ultimately sabotaged in 1985, four or five years later, was because the Department of Rehab was not interested in children. They didn't want to wait in order to convert a case into a job placement while the kid was still in school.

So we had to create an inter-agency agreement which was an explicit document creating a commitment from the leadership of the Department of Ed, Wilson Riles, and Ed Roberts, the Department of Rehab, in order to establish this thing which I named Project Interdependence. And I took a lot of heat, because people said, interdependence, That's a big name, That's not a pretty word. But I was a Wolfensberger child, so I figured, big word, unusual word, They're going to have to come to grips with a new thing. At the time, interdependence was just coming into its use at lots of different levels.

And as people understood it, it was really ground zero. Because what it did, it cut between the service delivery model for people with mental retardation and the independent living movement of the disability community. There had to be a middle ground that was at a higher level to show that we needed each other. There needed to be mutual empowerment of different constituencies.

Cowan: So how did you implement that? You went to high schools in California? All of California?

Bronston: What we did was that we identified twenty-five school districts in the state of California that had been operating under a decade-old memo of understanding, and an agreement between the state Department of Education and the state Department of Rehabilitation to share resources and to collaborate. There were only twenty-five school districts in the entire state of California that had that contractual relationship between the two state departments to help each other. Then we identified, in those school districts, the flagship high school, and began to develop the idea.

First of all, the program had more to it. It was a very beautifully codified concept that we worked out at a retreat. Tony Apolloni was there, Bill Campagna was there, I mean there was a bunch of us I got involved in this thing. People from the state Department of Rehab that we had brought in that were interested in volunteering to work on this project. Ultimately, there were seven full-time positions that were given to this project by Ed. Then I was responsible for raising private money, for anything that costs any money, I had to raise it privately.

So it was a very interesting opportunity that I was totally elated about, about being a state-paid worker, going to the private corporate sector, pan-handling dollars in order to create this idea, which had the governor of california, and the superintendent of public instruction on the board. I created a board, a total theatrical board, that had everybody possible that was anybody interesting in the state of California. I had my beloved friend, Jim Burchell, who was the head of the state DD Council, and who had been my colleague all along, be the legal counsel for the board.

Then I wound up recruiting Marvin Davis, who was the head of Twentieth Century Fox, as a movie mogul, Don Gwin, who at the time, was the head of Pacific Telesis, the CEO and chair of Pacific Telesis. I got the head of the California Community College System, a guy by the name of Jerry Haywood, and another extraordinary Republican, a business executive by the name of Charlie Lynch, who was the head of a company called Saga Corporation. Saga was the largest food service company in the world at the time, subsequently bought by Marriott. Beverly Sassoon, Vidal's wife. And then California State Senator Diane Watson, who was always my bodyguard, ever since I began operating and organizing, for the last thirty years. So here was this amazing board that had these amazing people on it with Brown and Riles on my first board. When the Brown administration went out, two years later, I was able to get Governor Deukmejian and Superintendent Bill Honig to replace them. It was just miraculous, but I had them. I put together all these sponsors.

All these people were on a piece of stationery. So when we wrote to somebody to ask for money—first of all, the people we wrote to were the two-hundred-plus-dollar donors, given to me by the governor's office. Because the governor was on the stationery. Now how they ever gave me their names and how I got away with this, I tell you, to this day, I'm still awed. In addition to all these, I had a group of sponsors on the stationery that included all the people who I wanted to try and create an image about and with about what we were all about.

So I brought all the elements about capacity and glamour and political power and influence that I could, into connection with this operation Project Interdependence which was unique in the country. There was nothing like this going on of the scope, anywhere. So I had Linda Boles who was a deaf actress, who had just done *Children of a Lesser God* and gotten a Tony. Mayor Tom Bradley was a sponsor, Claire Bergner, who was a congressman, extremely right-wing congressman, who had a son with a disability who was run over by a train and killed and was always a very major advocate for disabled persons, although he was an extreme right-wing politician. Senator John Garamendi, Senator Jim Neelson, who was the Speaker of the Senate, Goldie Hawn was involved. Linus Pauling was involved, Stevie Wonder and Itzak Perlman were on my sponsorship list. Of course, Ed was sitting there, Wilma Rudolph, the athlete, was involved. Senator Art Torres, who was a major leader in the Democratic Party. It was just amazing.

Cowan: So you didn't have any trouble raising the money.

Bronston: Not true. You always have trouble raising money. But what I was able to do, by the creation of this mythical structure, this theatrical structure, was to keep the bureaucracy off my back and be able to execute outrageous activity, outrageous activities, for a state worker, in a state department.

Cowan: What would be an outrageous activity?

Bronston: We, first of all were able to go and market, to the general corporate community about what we were doing, and to support what we were doing, which, in and of itself, was not a normal state duty for a state ordinary damn worker, and especially not a doctor.

First of all, we had to create this program. The program was built around a whole package of the most beautifully artistically created materials that I was able to develop in conjunction with a graphic arts company in LA, and particularly a Chinese artist who was completely deaf. An extraordinary artist. This guy worked with us for about six months and we developed a package of color materials to die for. The program was set up like this: what I wanted to do was to simplify and make emotionally recognizable, a limited number of career pathways that called what we would become the "spearheads" of the project.

Those pathways, of course, started with "awareness." We needed to be able to build awareness into kids about the difference between disability, nondisability, able-bodied, and all the stereotypes, in terms of them understanding that they had a role to play that applied to their lives. Whether they were the football star, or in special ed, back of the room kind of throw-away in a school, that they were all affected by the existence of this demeaning set of labels and identities and statuses in their school lives.

The second thing was that we definitely wanted to make careers a fundamental agenda for the whole involvement in Project Interdependence. In the career arena, we identified four career pathways—science, recreation, sports, and arts—and figured that those four areas were absolutely ground zero in the state of California as the four growth industries. Three of them were curricularized in the school: art, science, sports. Recreation was the other part of the day. And that each one of those industries could contain anything you wanted to be in the world, in that one industry. So our task was to articulate this pathway vision and present them in meaningful ways, to children, high school children, young people.

Cowan: Did you go to the high school and present?

Bronston: Let's just say, in general. We organized a model opportunity to become part of a state-wide membership organization, whose task it would be to generate a set of activities and projects to replicate an outdoors training experience that we provided to an initial charter participating group of kids. We went and invented, out of nothing, our first training event that would be held for seven days and nights for the first hundred kids, selected from among these twenty-five school districts, in critical mass enough that when we finished, we would send the kids back and there would be enough of them in any given site, to begin to mobilize and build the structure in their own schools and school districts.

In the first year, we identified ten school districts from the twenty-five, that we invited to send ten kids each, to Half Moon Bay to the California coastal mountains, to a YMCA camp, in order to train them in what we called "Discover Interdependence."

Cowan: Kids with disabilities?

Bronston: Half and half. Each school was asked to send five kids with labels and five kids without labels. And it became a major event that was held in the fall. Unfortunately, it rained about four out of the seven days that we held the first event. So creative, and so innovative, and so moving was the whole design of the seven days that we invented—I mean, every minute of every day was filled with activities to build into these kids: one, a sense of their own power and their own virtue and their own integrity, regardless of how they came. Secondly, to teach them about the inequity and the insanity of "we-they," to teach them new language, theory of normalization.

And after we built up, through very concrete behavioral activities that were incredible fun—we slept overnight, outside, even in the rain, we had a whole bunch of activities called "new games," which were beautifully invented games and projects that were non-competitive. We created various kinds of outdoor challenges that placed kids that were deaf, blind, or in a wheelchair at an advantage over other kids. We did team-building activities which are now very well-understood and now known—but in those days, they were cutting-edge kinds of things, like "ropes" courses, that were really incredible.

Of course, we photographed and videoed the whole operation, and required the kids to essentially be conscious of all these four pathway spearheads. That is, we had sports activities going on, we had recreation activities going on, we had arts activities going on, and we had science activities going on. We had, for example, all the rehab engineering crowd, from the Department of Rehab, come up in their big demo trailer, with a whole demonstration and exhibit, of all the new kinds of disability adaptive and facilitative equipment that we were using. We had people doing Tai Chi with the kids. We had just, we had the most extraordinary experts in working with young people in the outdoors to teach them about the environment, and ecology.

They were broken down into ten teams. And each team was doing something different with a different pair of adult mentors, the whole time. Five kids with, five kids without disabilities, all mixed from ten different schools. Then, in the middle of the week, we regrouped everybody by school and began intensively training each of the school groups, with their teachers, who came up and were part of the operation, and with rehab counselors, who came from those districts in the Rehab/Education cooperative to learn how to do community organizing.

Cowan: The intent was for them to go back to their schools and do it.

Bronston: Exactly, how to do community resource surveys, how to do speaking presentations, how to use the photographs and the slides that were built up in the event, how to propose integration ideas, how to do planning seminars, how to handle a group—in seven days and nights, day and night. At night time, we would have these fantastic arts and theatrical events, culminating at the end in the kids putting on their own talent show. I had the top rock and roll musicians, the top—I mean, we had the most interesting people in the state of California, from the entertainment industry, coming and putting on these incredible concerts and dances of all sorts, every night, in order to add and demonstrate the role and the power of the arts.

During the day, we had these recreation activities, sports activities, science activities, and the whole thing was aimed around discovering careers. We made very explicit, the role of all the adults, of any the adults, the people that ran the camps, the people that handled the school buses, everybody demonstrated a job. We wanted to teach the kids about the universe of jobs, and connect them. So we had press people there from the newspapers, covering the event. There were big articles in San Diego and so forth. Bree Walker, who ultimately became the main news anchor for CBS television and the LA market, who is just this incredible woman who doesn't have articulated fingers and toes because she has a dominant genetic condition of syndactalyism.

It was incredible. So involved. There were somewhere in the vicinity of sixty-five or more staff and faculty, maybe as many as eighty, and a hundred high school kids, with and without disabilities, from ten different school districts, that came to our first event in 1981.

Cowan: It was hugely successful.

Bronston: More than that. It was magical. It blew us all away. It was so powerful, so compelling, I'm telling you, kids that couldn't walk, walked, kids that never talked, talked. It was miraculous. What happened was that, in the context of these larger-than-life expectations of accomplishment and in a context of full respect and non-judgmental expectations, and of "anything's worth trying," given the incredible barrier-breaking impact of the ropes course which really takes you through something, like you think you're going to die. And when you don't, you're in a whole other place of self-confidence and comradery. Every kid went, and the whole thing was aimed at supporting every single kid with their team, in the most loving way.

Cowan: Not just kids with disabilities—

Bronston: Fantastic—I mean, you don't have to be scared of heights, because you're in a wheelchair. I mean, on the contrary. The kids that were involved with disabilities, once they were on their own, tended to make the risk-taking move with less apprehension than the typical kids that were more careful about themselves.

Cowan: Was this ongoing? Did it happen year after year? Is it still going?

Bronston: Yes, yes, and no. Well, in a couple of places in the state, actually, I think it's still happening. But what happened was that we were inventing something so new and so unusual, so amazing, and so out of keeping with the department, that it was only Ed's leadership of the department that protected this rare and marvelous thing. And we're operating in 360 degrees. We're using the advent of the activity as a way of influencing schools, teachers, rehab counselors and workers, the corporate community, the political community, the media community, and kids. And after each training event I have seven full-time workers going into each of these schools and working with these counselors, keeping the kids together. Because they develop a sense of capacity and collaboration that is stunning when they go back home.

Cowan: Was the second year even more successful?

Bronston: The second year was even more successful. Out of the second year came a forty-eight minute film called "Discover Interdependence" that was narrated by Bree Walker, and by Edward James Olmos, that is really a masterpiece. It's the most unique documentary. I've never seen anything like it in the disability area—where the kids speak for themselves. I had a friend of mine put together a twenty-two piece symphony orchestra and write a brand-new piece of music for the background music for the piece. It is awesome. It's so moving. The guilelessness and the authenticity and the genuineness of these kids' transformation which happens right in front of your eyes. You see them coming out like turtles and becoming eagles in seven days.

Cowan: When did it start to diminish? What happened? Was it the change of administration, and you lost the support? Tell me how it ended. Or did it end because you left?

Bronston: No, no. We were crushed. What happened was that the minister of the secretary of Health and Welfare, under the Deukmejian regime, was extremely hostile to us, despite the fact that we had the governor on the board; despite that we had Congressman Claire Bergner who was a close friend of this minister. This was a Reagan kitchen cabinet guy who came from Washington, DC. His name was David Swope. He basically hated the fact that this was going on. I don't think he cared anything about human beings at all. He was just there as a mercenary for the Deukmejian regime to kind of protect the Republican interests in the state and the reactionary political interests in the state.

He essentially hated the fact that I had direct access to the governor's office through a very wonderful friend of mine, a man named Sal Russo, who was actually the head of the Deukmejian campaign, and helped me arrange to get Deukmejian to accept a position on the WIF Board after Jerry Brown was in. I remember during the Brown administration, with Ed Roberts at the head of the Department of Rehab, we were flying high, and we were able to do anything. What happened, subsequently, just to insinuate one more model, was that, the Department of Education, dug in its heals and didn't want to go beyond the idea of this fantastic training camp, we called "Discover Interdependence" in order to build awareness. I was interested, primarily, in developing this extraordinarily innovative model to demonstrate each of the four career areas beyond the disability awareness experience.

I wanted to have a separate training event, each year, two for awareness, like we did for Project Interdependence, with Discovering Interdependence, and then two in the area of each of the career areas. So I had to try and define, what was the nature and the scope of each of these career pathways, of the sports industry, the science industry, and so forth. It took me about two and a half years to invent and craft the first one against tremendous opposition, even from my own staff, who just didn't believe it could be done, called "Win Interdependence" which was the sports industry model, which I wanted to create in order to show the bankruptcy of Special Olympics.

[Tape 13, Side B]

Cowan: Could you say something about the implications and the outcomes of this program, and how long it lasted?

Bronston: Well, the program lasted for five years. We moved about 2,500 kids through the operation. We ultimately connected with all twenty-five school districts that had a memo of understanding with DR. What we were doing, I just can't emphasize enough, was just so out of the box, and so different. It was such an innovative public-private partnership. I was able to raise thousands of dollars, not in big chunks, but enough to be able to handle what we needed to do, and to generate the media. Creating beautiful media about something, not only printed material, but video and photographic material, this was before the Internet, was absolutely ground zero to me. Because the question here was, what remains? After you have these events, these spectacular events, and everybody is just blown away, what remains, and how does it translate? And if we couldn't go back into the schools and replicate the event at a local level in the school district, then the project wasn't doing what it was doing.

Cowan: Did that ever happen?

Bronston: You know, we were able to ground the thing long term in a self-repeating model in two school districts in Southern California. One in Santa Barbara and one just outside of Los Angeles, so powerful was the impact on the lead teacher. The key to it was that we converted a lead teacher who became the anchor and was able to replicate the program in the context of his own school.

In addition, as I mentioned, I was able to mount the sports event, and the sports event, Win Interdependence, was the most complicated thing I think I've ever done. There were eighty-five kids there, drawn from kids that had already been to one of the discover training events, who we handpicked in order to be part of the sports event which was held at Pepperdine College in Malibu.

Cowan: What was the point of the sports event?

Bronston: In order to demonstrate a different paradigm of a sports competition activity involving kids with disabilities, and to show again, as I was saying, the bankruptcy of the segregated Special Olympics. Win Interdependence was a normalization-based, strategic, sports career-aimed, theatrical event of seven days and nights that showed kids, the notion that it was fitness that was the ground zero of convergent interests between kids with and without labels, not "winning." Win Interdependence, not win first place. So everybody fit on the continuum of fitness. We had Richard, what's his name, the guy on television, the exercise guy—Richard. [Richard Simmons]. We had his crowd in there doing a whole set of projects with our youth.

We had every major Olympic and world-class athletic star come to Malibu in order to demonstrate their sport with and without disabilities. We had demonstration games in tennis between the disabled and nondisabled tennis leadership in the country; track and field; canoeing and kayaking; volleyball; basketball; archery. We had the most spectacular—it took me almost three years to put this damn thing together and to get it funded. Only eighty-five kids, we had a hundred and twenty-five faculty. And each day, for four of the seven days, we featured a career area in sports. Sports media, one day, sports organizing, another day, sports health and fitness, another day, and sports manufacturing, another day.

On the manufacturing day, we had ten major corporations, as we had in each of the other days, demonstrating, in a circular set of touring visits on the campus, what they did, and the magnitude of their particular industry. So we had the largest archery manufacturing company in the world there, that was one of our sponsors. We had one of the greatest rehab engineering people from Stanford coming and talking about adaptive equipment. We had the largest manufacturer, out of Alabama, of sports clothing in the United States, come, that did all the blanks, that they then put the labels like Puma and Nike and so forth.

Cowan: The point was to show that there were jobs in every one of these areas?

Bronston: Millions, millions of jobs in manufacturing, millions of jobs in sports organizing. We had the professional sports organization, the woman's Olympic top team, the woman who was one of the top people on the—we had everybody. Wilma Rudolph. We had everybody. And every night, we would then have a theatrical event in relationship to sports, arts or sports theater, something like that. And ultimately, a talent show at the end again, which was our signature design.

During the week, we had opportunities for kids, regardless of their disability, to participate and learn about, each of a variety of world-class sports activities that involved world-class people with disabilities. Track and field, weight-lifting, kayaking and canoeing, basketball, tennis. It was spectacular. We had the world, the world's best, most known athletes come to Malibu. It was all covered by the newspapers. However, the Department of Rehab, at that time, that was in 1985, not a single person came from the state Department of Rehab to see this historic and spectacular event.

So for example, we had a day of journalism, where we had sports writing, that was *Sports Illustrated*, sports photography, *LA Times*, sports television, ABC Sports, sports filming, Twentieth Century Fox, and one other sports area that came from another newspaper. On the last day, we had a "pentathlon," where we broke the kids up into ten teams and each member of each team played a different role in each of the five competition events. Each kid in each team had to be the journalist or photographer or media recorder in each event. So let's say we had a major run, we had a one k [kilometer] run or a two k run, I'm not sure what it was, as part of the pentathlon.

There was a kid with a disability and kid without a disability competing, and the other three kids on the five-person team, of the ten teams that were competing, had to play a role of manager, coach, mediator. And then in the next event, they would switch roles. There would be two other kids competing, the other three would take up these other roles. At the end, they had to produce a media project describing what they were doing, all of which were skills and strategies that had to be taken back to their schools. So a kid had to know all the different aspects. They had to know, conceptually, what went into a whole sports event, issues related to careers, issues related to personal fitness, issues related to celebration of the arts.

Cowan: And communicate that in some way to their student body.

Bronston: Exactly.

Cowan: I see. Why did people from Department of Rehab not support this?

Bronston: They hated what we were doing. We were so eccentric. They were so resentful. The Republican administration of the department hated us beyond hatred, and were doing everything they could to discredit us. I had seven full-time people in my unit, working in the main office downstairs on the first floor, the Department of Rehab, and we were having so much fun. This was so creative and so glamorous, and so fabulous, they hated it. They hated it. They hated that we were having fun. And then the Minister, the Secretary, Dave Swope, really just couldn't stand—I mean, he insisted that anytime we wanted to do something, we would have to come up by asking the chain of command in the bureaucracy.

I would have to ask my supervisor, it had to go to the chief deputy director of my department, it had to go to the director of my department, it had to go to the contact person, the liaison, the assistant deputy secretary in the secretary's office, it had to go to the secretary, had to go to the governor's liaison with the Health and Welfare Agency and then get to the governor. Normally, I could pick up the phone and go straight to the governor's office, if I needed something. And Swope hated it. Hated it!

And so at a certain point, they finally figured out a way to do a personnel audit on my position because I was defined in state service as a "medical consultant" with a specific job description of acting as a sawbones within my department. So they were able, very simply, through the bureaucracy, to show that I was working out of class, and be able to say to me, "You're working out of class. We can't have you work out of class. We're going to have to replace you with somebody in the class of the position that you're assuming, which was a senior manager." Which had a different job description that did the kind of stupid things that I was doing, which was making phone calls, managing staff, having a secretary.

Once they pulled me out, through this technocratic personnel ploy, which of course we blew in the newspapers—I went to the legislature. We even went and generated a piece of legislation in order to physically move us from the Department of Rehab, to the Community College Chancellor's Office, who was sitting on my board, which was theoretically a welcomed move. We would have worked from the community college standpoint, rather than the Department of Rehab, which was very painful struggle. We had to try and figure out the validity of all that, because we were constantly forced to battle at the federal level to get us an exception from the rules that governed what was within the meaning of the Rehab Act to fund such as integration, youth and non-client beneficiaries as a prevention strategy.

What was happening was that the Department of Rehab and their bureaucracy were challenging the legitimacy of what we were doing by virtue of the fact that the enabling legislation for federal rehab dollars would be considered an audit exception. Were an auditor to come down and look at what we were doing, they might say, "Why is the rehab department spending this money on Project Interdependence," through our salaries, because they were not putting in any cash dollars. This was strictly my salary money, Bill Campagna's money, Brian's money, Jack's money. The people were part of my team. They contended we were illegally doing this project, as the project didn't fit into anything imagined before.

And in order to get the federal dollars, to be legitimately applied through our salaries and our time, there would have to be a "federal waiver." Well, we sent forward a federal waiver letter, but the department sabotaged it because they didn't want it to happen. So we tried to put together a piece of legislation to move us out of Rehab at the end. The legislation passed with no opposing votes, in both the Senate and the Assembly, to validate this thing. But the secretary of Health and Welfare hated us so much that despite our good offices with the governor, that the governor was forced to veto it with pressure from the director of finance, whom the director of the Health and Welfare Agency cut a deal with and said, either Bronston goes, or I go. That wasn't even an issue. That's how badly they wanted me out of there and to kill the operation.

Once the legislation was vetoed, we lost our ticket out and into a separate, another authority, the community college authority. We were dead—they pulled me out of the project. I was sent to hell, to the local county district field office, where I am working now, a supernumerary physician. Once I was out of there, my secretary, who had a high civil service status, also fell out. I had three clericals, because of my station, because as a physician, I could hold a certain level of infrastructure in the civil service system. The whole thing crumbled. Miraculously, Bill Campagna stayed with the program. They put another of their chief mercenaries in, to essentially make the program go away gradually. Because we had to much press coverage, and there was such a big to-do about it, so many significant people wrote support letters, so many calls went to the Governor's office. It was just too hot, it was too hot to kill immediately.

Cowan: So they had to let it dribble away.

Bronston: They purposely made it dribble away. In the meantime, Bill ran the program, maintained his position there, and fought them for about another two years. But quietly. But ultimately, they liquidated the program. So between 1985, when I was moved from that state-wide position as the chief medical consulting office for the department at a central level, running Project Interdependence, until 1991, I was put into the district, county-based office of Sacramento with virtually nothing to do. I wound up bringing in another $250,000 grant in order to create and organize a major project locally in vocational area.

Cowan: Disabled adults?

Bronston: Yes. Adults with disabilities. Right. So Project Interdependence kind of went into the archives and was not resurrected again until 1991 through a federal grant of national significance we got.

Cowan: You were still involved.

Bronston: Yes. I became involved. Bill Taintor was the rehab director at the time, this is all under Pete Wilson's Republican administration. I was able to engineer, making my application to the federal Department of Developmental Disabilities in Washington, DC, a proviso that gave me approved fifty percent time, to apply to the national project while still under the aegis of my assignment as a local county district medical consult position under the definition of "doctor" in the personnel system for the Department of Rehab. And in the meantime, Project Interdependence, I mean, I was completely severed from Project Interdependence. Bill was terribly, terribly injured by this fracture. Because he had been banking on this as a lifetime evolutionary job. This project was magical.

Cowan: This is Bill Campagna.

Bronston: Bill Campagna, C-A-M-P-A-G-N-A. He just did an incredible job. Just did an incredible job working on the project. Yet he didn't have the firepower like I did, or the support, or the ability to just go into offices and just deal with the politics. I mean, he has always been a more within the box kind of a guy.

Cowan: Even when it was resurrected?

Bronston: By that time, I took the project, essentially to three states. I took it to Minnesota, I took it to New Mexico, and I took it to Pennsylvania. We had profound relationships in each of those states. And in each state, did something entirely, spectacularly different. In Pennsylvania, we were connected with one of the most progressive and revolutionary black organizers and activists in Philadelphia, Shafik Tahir. He was building a program there among teen youth from the ghetto, that he was essentially educating and empowering. This man had a mortal case of bone cancer that he had been living with for almost eighteen years. He was the longest living person in the United States with this killer disease that normally would have killed him in two years. We had this amazing discovery of each other. I don't even remember exactly how I met him at first, but he was a saint of saints. We did a whole series of workshops with him, and worked on developing the project in his framework, in the city of Phildelphia.

Cowan: Still with youth with disabilities as well as—

Bronston: Both, mixed. But then he died, and with his death, everything kind of went down the drain. In Minnesota, I was working with Colleen Wick, who is the steel backbone for the most progressive changes in Minnesota. They have closed all their state hospitals, as a result of her leadership. She has been running the most innovative, profoundly impactful, cadre-building, leadership-building, people-empowering, training, organizing, set of projects in the world, in my opinion, in her state. And out of that, she and I began working together, in order to fundamentally transform the evolution of the work that she was doing there, towards developing a consolidated approach to spending their DD council annual federal dollars, in a single objective, built around a Project Interdependence model. Because the key to this thing was to build youth-empowerment, and stable youth organization, and new leadership based among high school kids.

Cowan: What would you say the impact of this Project Interdependence has been? It's been at least three states and California. Do you see that it has an ongoing role? Does it have an impact on people at all?

Bronston: I'm still not sure. I may be wrong. There's this huge consequence in Minnesota, where the principles, and the spirit, and the elegance of the all-in-one model is operational. Where you have a leader that's stable, and continues to be able to operate and doesn't get shot out of the water. You have ongoing programming. Everything, everything turns upon people leadership. And we were only able, in the most limited way, to spin out, or clone, leaders—we didn't create the leaders, we were able to instill the model, and the inspiration of the complexity of the model in a few people. But Minnesota is moving forward with an enormous youth agenda. It's not like Project Interdependence. They have a huge, elegant, extraordinary project around this whole issue of integration and inclusion that Colleen directs.

In New Mexico, we worked for three years. It was absolutely a tour de force, an operation that created a secondary non-profit corporation, the World Interdependence Fund of New Mexico, as its locus. We organized another spectacular showcase board and advisory committee in New Mexico to try and pull together the education community, the rehab community, the Native American community, the Hispanic community, the black community, and the arts community in New Mexico.

Cowan: How could you do that as an employee of the California Department of Rehab?

Bronston: That's an extraordinarily good question. What happened was that nobody knew what I was doing, nobody watched me, nobody supervised me. Nobody gave a shit about me. They wanted me to die or disappear. So I was going back and forth to New Mexico using my fifty percent sanctioned time. Nobody was checking anything. I would go and come as I pleased. I had this federal grant of national significance to work on for three years. It was only one hundred thousand a year, a pittance. Other than that, a full-time office, and a full-time co-worker Billie Shawl. Others were mostly volunteer. I paid Billie a little bit. She worked with me for about five years on this whole apparatus. We prosecuted and promulgated this policy agenda in order to organize kids with and without disabilities, in the arts community, in the school community, around creative projects to change people's paradigm and their viewing and thinking and definition of opportunity and integration for people with special needs in the culture in general.

In California, Bill Campagna, who helped me manage P.I. kept working the California scene. We had a couple of very major evaluations that were done by independent agencies as attempts to kill us by Rehab. But the evaluations came back extraordinarily glowing about the impact on kids. The whole questionable character of the organizational design of P.I. and its legitimacy, was their preoccupation and to play that card against us ultimately. And so while we operated there came a whole wave of art imagery, a whole language, five years of the most amazing training, which had to have had an impact on hundreds of kids that were just moved to the core.

Cowan: Was there ever any tracking of participants?

Bronston: No. There was never any funding, because nobody wanted to know what mattered, whether it worked or not. Because, God forbid, they would have to deal with the fact that it worked.

Cowan: Have you ever, personally, gotten any information from someone who said "I was a part of that?"

Bronston: Certainly, we have that, but that's too anecdotal. I'm interested in looking at four hundred of the kids that went through there to see where they went. We know a score of kids that keep calling Bill and are connected to him. Because I was not really—I didn't have relationships with the youth the way Bill did. Bill actually was the operational person. I was on the phone. I was the "producer." He was the "director." I put the ideas together, the model. I put the resources together. I ran interference. He operationalized the program and made it work, made it accountable, made it programmatic, put it into writing. What came out of it was—first of all, we have the film shot in 1982 which has got to be one of the most beautiful things ever. It's selling today, out of a major company that markets films in education focused on developing children with disabilities.

Cowan: The Project Interdependence movie?

Bronston: The "Discover Interdependence" movie. And in the meantime I was able to take this model and everywhere I went—and we have all this art. The emblem of this model, which is the International Year of the Disabled Persons central figure with our six spearheads, and the word interdependence, these gorgeous materials that went into thousands of places, everywhere we went—and everything was described. We had printed pages that talk about the meaning of the arts industry, the meaning of the sports industry. We did the Win Interdependence event once to address the sports industry, which had a profound impact. I'm sure, on every single—I mean, the impact we had on the faculty grown-ups, and the world-class athletes that came, was really astronomical.

Cowan: Do you have any final thoughts on Project Interdependence?

Bronston: Project Interdependence really is just another chapter in my struggle to figure out an intelligent and compelling way to address changing society. And as is the case in all the stuff that I do, I never really know how much it works, how well it works. I do know that the models are overwhelmingly complicated, overwhelmingly beautiful, overwhelmingly impactful, in the short term, and absolutely sadly undocumented in terms of their consequence or meaning. In each of these instances, the struggle in Kansas, the struggle at Willowbrook, the struggle in my Department of Developmental Services when I was trying to regroup and organize everybody—I have to feel very doubtful and self-critical at some level.

I hope I'm doing good, but I've never been able to know that what I've done has any perpetuity to it, at any level that I'm interested in seeing sustained. Changes do happen. Influence does happen. But whether or not it makes a goddamn bit of difference always, always undoes me. I feel completely frustrated and saddened, depressed by how complicated and hard and dedicated the work is, and how I never can look people straight in the face, and say, well, it made a real difference. Every day that we worked—I worked sixteen, eighteen hours a day, on the phone, in peoples' faces, out in the community, with the kids, with school people, with industrial people, with politicians—and the work is always awesome. Awesome looking, awesome functioning.

Cowan: But it didn't spread to the rest of California as you had hoped.

Bronston: No. We didn't have enough time and we didn't have enough departmental or political support. If we had been able to go another five years—this was a project of such complex magnitude—I was still in the process of designing the science career piece. I was struggling to find a major national corporation in each of these four spearhead career areas that would be willing to develop a set of career materials, imaged with kids with and without disabilities, in the imagery of the package, that could be sent to every high school in the United States to assist in career counseling in the area of food service, in the area of energy, in the area of sports, in the area of recreation, in the area of civic infrastructure development. I became very thoughtful and creative about defining those irreducible areas of work in the world down to about ten major careers that encompass everything that you could be in the world, and trying to see if I could figure out some way to provide tools for young people to feel secure and confident about making a choice, early on, in terms they wanted to be and do in life, because we were able to talk about specifically, what it meant, what it looked like, what it felt like, what the relationships were, what the payoffs were—

Cowan: But without adequate funding, without support from the state—

Bronston: Right, these began to feel like they were gigantic masturbatory activities. I just don't know what to say about them. Again, somebody on the outside, historically, has to come and judge what all of this was about. Is it all about keeping me afloat, so that I can continue to run my mouth and continue to be some sort of a conscience, or some kind of a peripatetic prophet? Or some kind of a visiting visionary? Is the purpose of this thing to create organization? To transform peers, to generate a confidence and energy out there and advocacy? I don't see any evidence of any of those things happening. I see the people around me not excelling, not breaking through, not having the kind of courage and militancy and getting worn down little by little as they get older.

The only thing I can hope is that our investment in these kids made a set of kids out there who, at somebody's level, are more loving and more caring and more sensitive and more confident and more successful. And I have no doubt that kids that have been through the program, if you compare them with kids that didn't have access to this kind of encouragement and this kind of nurture, are just completely more accomplished in their family lives and in their work lives. But who knows? It remains a mystery to me, and a source of tremendous pain, of not being able to know at this point.

V. REFLECTIONS ON A LIFETIME OF ACTIVISM IN HEALTH CARE AND HUMAN RIGHTS ISSUES

The Governor's Invitational Forum on Services to Californians with Severe Disabilities, 1977

[Interview 5: February 7, 2002] [Tape 14, Side A]

Cowan: Bill, let's start with an event from 1977—it's going back a ways—to the Governor's Invitational Forum on Services to Californians with Severe Disabilities. How did that conference come up?

Bronston: Well, remember, I had just really begun my work here in California after the New York stint in mid-1975. So as I began to try and get a grip on California, I was bringing with me a strategy and a perspective on radical reconstruction of the service delivery system that was at least anti-institutional and integration-oriented, and focused rigorously and relentlessly on elevating the status, the social, economic, and cultural role of people with disabilities. I needed to shape culture, both for the disability constituency's emancipation and empowerment, and for fundamental transformation of everyday life in this country, in California, in American culture. Because I believed profoundly that as we figure out creative ways to individualize the resource system, the social service delivery system, the cultural and value-based system and the economy in the country to integrate everybody; everybody benefits. Everybody benefits!

That was always the fundamental burning spear in my sense of understanding of these issues. You make schools appropriate for the most significantly difficult-to-teach kid, you will fundamentally enhance the easiest-to-teach kid. If you make transportation available for everybody, everybody gets better transportation. Housing, jobs, daycare, income, the whole nine yards.

Cowan: Was this state conference your idea? Was it part of those goals?

Bronston: Yes. I was always looking to try and figure out how to generate a certain kind of synergy by bringing key, unanticipated forces, structures, and resources together, that would absolutely be an A-ha! experience for people and would shift their paradigm.

Remember, Wolf always taught that you have to go to the absolutely original, to the redefined, to the newly defined, to new language, to new ways of shocking people out of their sleep-set to jolt business as usual and habitual thinking about everything and anything. And I was an agitator and an organizer. My whole joy was creating these moments of consciousness and awareness and celebration and ecstasy in understanding, you know, how to make life better.

Cowan: Did you go to Ed with these ideas?

Bronston: Certainly. Ed was my accomplice in everything until the day he died. We were bonded brothers. We just shared a sense of outrageous boldness about everything. I mean, nothing was impossible. And I talked to him about this whole idea. What I had decided to do was try and figure out how in the world we could get all the major bureaucracy leadership together in California to talk about something that applied to each and every one of them, that related to health and well-being, that related to housing, that related to education, social services, mobility, employment, and advocacy. Which became the interest groups in this ultimate meeting. What we did was create a human projection of a problem-solving convocation amongst the entire power structure, in and outside of the California governmental system.

Cowan: You invited people from other places?

Bronston: Half the people came from the advocacy community-based structure. That was crucial. You could not leave the apparatus of change in the hands of the state bureaucracy. You had to create circumstances where the force came from general public consciousness, and organized awareness. So the purpose was to create a series of events that would lead up to and co-opt the governor in his newly established position of leadership. As a result of his appointment of Ed Roberts, to the head of the Department of Rehab in California, Jerry Brown needed to confirm, to affirm, to engineer, to authorize all of his government in California, which was like a world government, in my mind, to begin to develop and integrate all of the concepts of normalization in human services, full integration, paradigm change.

Cowan: Was this going to be a conference of speakers, or workshops?

Bronston: Both. What we had was an enormous number of key people that would be essentially organized to make presentations, by a genius leader communicator, whose name was Richard Byrne. He was the dean of the Annenberg School of Communication at USC [University of Southern California]. Richard and I were bonded together, I mean, we were incredible friends. I just loved him. He was the most brilliant, the most amazing, the most humor-filled—he was a genius, an absolute genius. He architected the entire communication studies system and architected the building even for Annenberg, at USC.

Richard had two daughters with autism that he had adopted as babies, as infants—he didn't realize that they had autism. The fact that they did completely locked his whole life. As a result, he became a major Dybwad Fellow, studying mental retardation all over Europe, when he was a younger man, after the girls began to grow up. Megan and Heather were their names. Richard and I plotted—you know. I had a samurai team, I had a group of "seven samurai"—I tell you, the best in the world, between Ed and

Richard and a half a dozen other key people, we were able to conceptualize the theater of pulling this meeting together.

Because we weren't sure we could grab the governor, and we had to grab the governor in order to give unity and propulsion to the meeting. In order to get the bureaucrats to do what had to be done, we had to have the governor's imprimatur on this meeting. And we had to have his damn body sitting there in a chair with Sven Olaf-Brattgard, who was sort of the trigger for this thing. He was the excuse for the meeting. I was going to bring a visiting pooh-bah from the universe—from Sweden, who was like the world's leading advocate, and the leading proof-positive of the full commitment of a nation, Sweden, to comprehensive integration, and normalization of life, and whole industry of inclusion, in Sweden—to California.

Cowan: So the goal was to implement some of those programs here in California.

Bronston: Exactly. Not only implement the programs, but to enshrine the ideology, to drive any program in the right direction that would fundamentally make transportation accessible, make housing accessible, make schools competent, make health programs encompassing and comprehensive. And to create a social stir in California that would change the way in which people thought about the problem of disability. This is not an issue of throwing dimes through United Way or March of Dimes or any other pity-image, tokenizing, colonizing, disability, charity organization. This was a question of rightfulness. This was a question of technological development. This was a question of ubiquitous access. This was an issue of changing the whole approach of looking at disability as a problem in society to a universal opportunity for modernizing and fundamentally transforming everyday life for everybody, that would be totally inclusive.

Cowan: So you needed to get the governor, and members of the legislature, you were hoping for legislation to come.

Bronston: Absolutely.

Cowan: And did legislation come along?

Bronston: Absolutely. It was an extraordinary blast. Well, first of all, what happened was that the way the theater of the event worked—now remember that we're working on this thing for a year ahead of time. And Ed Roberts allocated a couple, three of his staff. I was still working in the state Health Department, under Jerome Lackner. Ed headed a department inside Health. The whole system was administered by the Secretary of Health and Welfare, a guy named Mario Obledo.

What I was looking for was instrumental change, as opposed to advocacy political unity. So I went to Ed as the Health department's liaison, I was the medical director of the Developmental Service System, which at the time was called the Developmental Disabilities Branch, in order to hook this Brattgard meeting together. I had already hooked up a whole bunch of other horizontal interdepartmental structures together around children's services, comprehensive adult services, and so forth, that we've talked about earlier, in our interview.

This was one of those events that was part of what I consider my art of figuring out how to get an idea out there, how to get it into the hands of scores and scores of relevant people, how to force convergence of interest, confluence of effort. And so we decided that we would invited Sven Olaf Brattgard, who I had met actually, as a speaker, out there in the world. I mean, the Willowbrook thing put me in a place where I met everybody, talked to everybody, knew everybody, practically in the world, at that time, because the political explosion was so extraordinary that it drew people from all over.

And by the time I came to California, I had a very significant set of friends. Then having met Ed, Ed brought in another whole phalanx of extraordinary intellectuals and change agents and organizers from all over the world, into California. Because Ed was unique. He was unique. He was the sunshine, he was the magnet. He was the sun that generated the gravity for everything, he was unbelievable.

Cowan: So he was the right person to approach.

Bronston: Exactly. And he was very excited about it too, because he and I both knew, that we were going to walk this state, we were going to make this state really move. Because we were both here, we both had this kind of indomitable commitment and passion for the empowerment agenda. There were scores of others, but he was a mentor to me—anyway, so we went and got Brattgard to agree to come here, to be the statesman that would bring the development of the Scandinavian countries in terms of disability services, programs, manufacture and rights, to the state of California, to give to our governor a platform position. And to provide a context in which our governor could communicate with California constituencies as a real hero.

Cowan: And this was Jerry Brown.

Bronston: Brown got it. He got it, he got the picture, we were able to make it happen. And he came. I don't know if he came super-gladly, but he came brilliantly, because Brown, if nothing, was a brilliant guy. And he could lock into an issue and really make something happen with it. So, of course, Ed was his appointee, and he kind of owed it to Ed, kind of by virtue of having appointed him. So, first thing that we did was we got Sven here.

Cowan: And this was in Sacramento?

Bronston: This was in Sacramento. The meeting took place, in one of the big auditoriums of the bureaucracy, in the Health Department. And we toured Sven for about two weeks, prior, all over California, into the most interesting clinical and program places, to let him see what our state of the art was. We took him to Rancho Los Amigos, to let him look at a major medical-model rehab institution, in Los Angeles. We took him to Santa Barbara, to look at the most current research going on in "talking" wheelchairs. We took him to Stanford, to the rehab engineering and robotics center at Stanford. We took him all over the state.

Cowan: What was his impression of how California was doing?

Bronston: He was fantastically interested. It wasn't a black and white, yes or no, kind of situation. He was the most brilliant engineer, doctor, social scientist, maybe in the world, in his field, because he had more leeway to implement than any other political leader in the world at the time. I mean, he had a whole heritage of development in Scandinavian countries and specifically in Sweden, from the University of Gothenberg, which was his home base. Sven was in a wheelchair, and he was a physician.

He got into a wheelchair because he had a meningioma of the spine. In the old days, and before they knew what they were doing, they x-rayed this meningioma to knock it out, with so much radiation that it took his lower spine with it. There was nothing left in front of the ray-gun. So he wound up with paraplegia, and in a wheelchair. He was this incredibly graceful, incredibly elegant, incredibly brilliant scientist and physician, and the head of a thing called the FOCUS Society in Sweden, which was the adult peer organization of people with disabilities in Sweden.

Cowan: Did he feel that California was so far behind that it would be impossible to change?

Bronston: No question. He knew everything was on a developmental road. He knew that this was a pioneering time. He was a pioneer, and with Ed's installation as the director of the State Department of Rehabilitation, that this was going to be a real renaissance. A real Mecca situation.

Cowan: And he had already agreed to speak at the conference?

Bronston: Oh, yes. We were friends, we were all a beloved family of worldwide advocates and change agents. People from Cerebral Palsy Association in England—we had connections everywhere, through Ed. Ed was this enfant terrible, this young prince, who being the director of the seventh largest economy in the world, with resources beyond imagination, the first time that a major person with disability, who was a true agent of change, was put into a position of authority, by a governor. So anyway, we put this visit together, and this incredible conference together in Sacramento, on October eighteenth and nineteenth, in 1977, at the Sacramento Convention and Community Center, and approximately two hundred and fifty people came. The people who we invited represented all the state departments, all the major private agencies that were involved with disability that we could find. In the state, consumers and consumer organization leaders, private researchers, educators, legislative staff that had interest in the field, and responsibility and authority in the human service field in general in the state of California.

We had six major agendas that we wanted to kind of lay out there. One of them was to demonstrate Brown's personal interest in the international advances in services for people with severe disabilities. This conference was focused on people with severe disabilities. People who really had been excluded from society and whose return or invitation to come into society would fundamentally change everything.

Cowan: Did you have a definition for "severe disabilities"?

Bronston: People pretty much had a notion. It was people that required essentially mobility device assistance in moving. It required significant special programming and education. It required fundamental job, employment adaptation, and accommodation technologies, that didn't exist at the time. It required new communication systems to make sure that people with hearing disabilities, visual disabilities, were completely integrated in all of the public systems. It involved people with blindness and deafness, with mental retardation, with every conceivable kind of condition that handicapped them.

We understood by definition that people were handicapped by the circumstances. What we wanted to do was shift the concept of handicapped, from people to situations. That was one of the big paradigm shifts. People were only handicapped to the extent that the environment was not designed on a level playing field that enhanced their capacity through whatever differences that they possessed, to participate fully in everyday life, in the economy, the social community and the culture.

Cowan: How did the conference proceed to effect this shift?

Bronston: We had people there from the transportation department, from the housing department, from the economic development departments, from all the human service systems, in the room. That two hundred and fifty people were the most carefully selected people with responsibility, and their boss, the governor, sat up there, saying, this is how we're going to go, this is what my administration is going to be committed to. It was a spectacular conference. Richard Byrne was the moderator of the conference, Sven was sitting up there, Ed was sitting up there at the dais, and the governor was sitting up there at the dais.

Bang, there are the four leaders! The international conscience, the king of California, the lead intellectual in California, and the lead advocate in California, were all talking about how we're going to look at this issue from a future standpoint. There were workshops that were affinity interest workshops, all throughout the two days, that identified critical agendas and issues, policy issues, that would fundamentally be implemented, state department by state department—in human services, in infrastructure, in economy, in culture, the arts, everything, in order to bring about this idea and service change. These were all linked to new manpower training strategies, new standards of integration, human rights, and access strategies. It was an absolute concatenation of interest in the state, with the head of the state there, and the entire state authority, moving with these agreements.

No real study was ever done to show the change, to document the extent that these agreements were actually carried out—but Ed's administration of his eight years, and now. He's only a year-and-a-half in, here, was accelerated astoundingly, because it gave him a podium of recognition, influence, and access to these other departments. Ed needed to be able to get into the housing department, more seriously with the governor's support, in order to insist on issues of architectural access. This required changes, of such magnitude, in rules, regulations, that determine how wide a damn door is, what bathrooms ought to look like, what kind of handle-bars had to be everywhere—

What we wanted to do was, to square off and take this whole state in one chomp. And this meeting was a technique of doing that, and what made the difference between meetings that happened like this, more or less all the time, where people come together and come apart, was we were killers, we meant business. This meeting was organized by change agents, not by liberals. Not by good will.

This was put together in order to give us authority to do what we knew had to be done, and to create a context in which we could bring people along. Most of these officials had no bearing. They had no North Star of their own. But they were in key positions to deny the North Star forever, unless we could get them clear that the cloud-cover was gone, and that we knew where we were going, and that we were going to navigate to a policy resolution that would fundamentally change life in this state and thereby, in the world, for people with severe disabilities.

Cowan: And one of the goals was to make independent living possible?

Bronston: Absolutely.

Cowan: And were you thinking of the basis of this as that there was a right to these things? The civil rights issue?

Bronston: Absolutely, that wasn't even an issue. That was our in-going—we had all the independent living leadership there in the room. We had all the developmental disability people there in the room. We had consumers, people with disabilities in the room. The room was like United Nations of interest in disability rights, disabilities empowerment and societal transformation, architectural, intellectual, ideological, programmatic, financial change.

Cowan: We have the program for this, with the list of attendees.

Bronston: Attendees, and the purposes. We wanted to focus attention on programs of common responsibility and concern where different departments, despite the fact that they were separated with vertical administrations, had jurisdiction over similar kinds of things like housing, social services, transportation and education. We wanted to spark a lot of interagency collaboration and new ideas and new projects to improve the quality of life, and to create that context within an international set of standards.

What we were really interested in was smashing the isolated parochialism of California and its self-satisfied, navel-studying kind of posture, to look out into the world and to become part of an international community with international standards of achievement. There were places that were far beyond us and places in the underdeveloped countries that were far behind us, but needed different kinds of solutions. It sprung, it was like a hand grenade. That was probably not the right word for it, like the Big Bang, hurled out from this meeting. God knows how many different kinds of individualized projects, individualized agendas, individualized trajectories in order to create a new set of planets, a new set of universal body relationships in California government.

And Ed's administration, if nothing, absolutely was the greatest single transformation of state government policies in every imaginable corner of possible activity. This conference was a strategic way in which we tried to harness human capacity, human leadership, human purpose, that would give us a check list of what the hell we were going to do for the next eight years, and eight years after that, and eight years after that. The policy statements set forth in here, addressed everything from how dollars were going to be spent, what dollars were going to be called—

For example, we wanted to provide an insurance system, in order to create fair and equitable rates for people with special needs. In one of those issues, in mobility, we wanted to create a comprehensive, multi-mobile transportation system, that provided all sorts of different ways. Within a certain period of years, we wanted to create barrier-free housing, with appropriate services for all disabled citizens in the state. I mean, we're talking about the big pieces of the puzzle. We have about a hundred such big pieces that were articulated in sharp stone, with the governor's imprimatur. And then we decided that we would take the next step, and we would do a repeat of this on a gigantic satellite conference about six months later, with the governor, Richard, and Sven—I mean, Sven participated from where he was, in Sweden, but the governor already knew him.

Cowan: By satellite conference.

Bronston: It was a broadcast system that could be sent out, at that time, to the whole world downlink system. There was a teleconference on comprehensive and universal inclusion and services of people with severe disabilities, with Governor Brown and the dean from Annenberg School of Communication, and Sven being part of this agenda with questions being sent in and called in to this teleconference.

Plus the rest of the world—six months later. We have transcripts of all of that information, of course, we have extensive documentation, both visual and documentary, of all that event. It was really one of the, I think, one of the most important organizational stepping-stones, in terms of my work and the kind of style that I used to make my contribution to the disability rights movement, both here and around the world, whenever possible.

Cowan: Did some specific things result? For example, where there already architectural standards that improved? Or were there no architectural standards and some were developed from this conference?

Bronston: I think that this meeting was the most significant point of impetus, to bring all that work that was beginning—I mean, remember that we're dealing with a time—first of all, Ed himself was an absolute material phenomenon. Nobody had ever seen anybody this physically disabled with so much authority and power and executive responsibility for scores of millions of public service dollars, in order to help people get back to work, people with disabilities. And Ed's role in the administration was really to be the spirit, the leader, for everybody else.

[Tape 14, Side B]

Cowan: Well, can you say what specifically came out of this conference? Did, for example, things change in transportation, but didn't change in health services? Or was there some effect of the conference that you could say yes, in black and white, this happened?

Bronston: No, I can't give you that kind of easy answer. But remember, the problem was that, you know, we could start the avalanche, but we were at the top of the hill, we never could see—I mean, I never could tell you. If Ed were alive today, he could. Ed knew because he was administratively responsible for carrying through all of these relationships. But real legal and programmatic opportunities and projects were specifically launched, or reinforced, or changed direction as a result of this conference.

In my opinion, this was a pure strategy policy conference, that brought into the light fifty agendas that needed to be worked on. I can guarantee you that radical change happened within the next five to six years, in almost every area as a result of the impetus of this conference. The purpose of the conference was to take from the shadows, an atomized, uncoordinated, unfocused, unarticulated agenda of empowerment, enfranchisement, and liberation of a unique constituency in our state, in California, and bring it into a focus, with focused leadership, focused responsibility.

People were designated within days, weeks, months, to deliver certain outcomes from this conference, and be accountable within their own bureaucracies. Interagency agreements were generated and driven as a result of this conference. And I can tell you, that if you look at what happened to street curb-cuts alone, what happened to door widths alone, what happened to public access bathrooms, alone, just that, it was extraordinary. Now the big one would be, did the employment sector change? Were more people with disabilities hired? One thing for sure, was that there was a new commitment on the part of the governor to integrate people with disabilities to work in every state department.

That was one of the contextual foci of the conference, to get the governor to be more sensitive and aware as a point of checking his head whenever he was dealing with anything. And, to give Ed more access to the budget, to give Ed more access to the legislature, to essentially multiply and escalate Ed's influence. Because these things happen, at least in this period of time, through a new kind of enlightened leadership. They didn't happen, really, in terms of mass-based movement, from below, although that was growing. It's sort of like a dialectical relationship.

You have a mass movement. A leader begins to happen. The leader creates circumstances that magnify and multiply that mass movement. That mass movement begins to peter out, a new leader has to come, you know. And so what we were having at that time was the beginning of a renaissance in California. My feeling was that it took a conference like that, an event like that, which was a pure organizing strategy. It was not meant as window-dressing, it was not meant just to discharge the energy of the movement. It was meant to bring into sharp focus, with specific agenda items, which are spelled out in the summary report from the event, a half a dozen policy initiatives in each area of every aspect of social, economic, cultural, programmatic life, that the government has a relationship to.

Cowan: Can you think of any legislation that came out of that?

Bronston: No, I can't. I would have to go back to the materials, because it's been, what, twenty, thirty, it's been almost twenty-five years now.

Cowan: Also, when you said the movement was growing, can you think of what you mean?

Bronston: Well, independent living was booming. I'm not sure, but I bet you that Berkeley Assemblyman Tom Bates, and the whole independent living legislation emerged from that event, I'm pretty sure. I mean, there was change everywhere. It gave us legitimacy. I mean, here we are out there, kind of crying in the wind for justice, crying in the wind for integration, crying in the wind for individualization, crying in the wind for full-inclusion of people with severe disabilities. Because we knew that there was an extraordinary virtue in integrating everybody into society for the people with disabilities. We knew that the real beneficiaries of any major paradigm shift, and any major integration agenda was a fundamental platform for the enhancement of life for every single body in society.

You cannot have a just and functional and ebullient culture without including all human beings in it. People with disabilities brought a set of issues, agendas, challenges, opportunities, sensitivities, that created such a contribution to the richness of everyday life. It's a continuous miracle; it's a continuous unfolding of discovery; it's a continuous stretching of the human paradigm. Because people come in such extraordinarily different shapes, sizes, and structures, and with such needs, to the extent that we, as creatures that can mold our environment and can create a transcendental value system, are pressed to do that. We fundamentally keep building our tower of Babel closer and closer to heaven.

Cowan: Well, after this conference, and its successful feeling, you went on to do Project Interdependence, and after that—

Bronston: Well, yes. What was going on, of course, was that I was in full steam working in every conceivable context that I could to drive new awareness, new relationships, new programs, day in and day out. I was free from administrative obligations and responsibilities to drive ideas, to create contexts in which people could share their work, to elicit, from every conceivable corner of government that we could find ideas, agreements on community of interests, agreements on collaborations, ways to redefine everything. My particular focus was the developmental disability program system, which was later became defined as the Department of Developmental Services.

Cowan: So you were still director.

Bronston: I was at that point, the medical consultant to the Developmental Disabilities Branch and the mental health system, and a consultant to rehab and social services. I worked in the State Department of Health, and was Jerry Lackner's principle policy voice of program direction for people with disabilities, people with developmental disabilities, children, specifically. My shtick was primarily kids and youth. Not explicitly articulated, but that was my interest, because that's who the "developmental disability" constituency was, people would have a disability of certain types that occurred from birth to twenty-one.

Cowan: So Project Interdependence, was youth-oriented, though not confined to developmental—

Bronston: The reason, of course, that I mentioned, that I invented Project Interdependence was because of the IYDP, International Year of Disabled Persons, and because I was really frustrated at trying to get the adult disability interest organizations, the advocacy groups, or the bureaucracy, to do something really breakthrough. The breakthrough was to get out of the preoccupation with "disability," into a higher order of policy activities, generated by the disability community that triggered broad human-rights agendas, in terms of labor, in terms of economy, in terms of issues of racism, gender justice, environmental issues, and so forth. This meant making alliances with lots of other constituencies in the culture, which the disability movement, has to this day, resisted. Fiercely resisted.

Cowan: So you went on to do EDee [Employment and Disability], what is this? It's after Project Interdependence.

Bronston: This is a totally separate project. We need to kind of make a real cut-line here. What happened was that when I was—when Project Interdependence was crashed, very purposefully crashed by the Republican bureaucracy in the Deukmejian regime, in 1985, I was essentially marginalized to whatever extent the system was able to marginalize me. They could remove me and remove Project Interdependence as a legitimate, effective, creative undertaking.

Anyway, they moved me to the Sacramento district office of the rehab department. Ed was gone from power. Ed set up the World Institute on Disability, in 1984, and I set up the World Interdependence Fund. Ed was on my board, and I was on his board. Ed's was sitting out there in the Bay Area, organizing with Joan Leon, Judy Heumann, and the, in large part, physical disability, sensory disability crowd. And my whole interest is to work with kids with and without disabilities.

I decided that I was going to stop trying to solve problems entirely. I'm going to stop solving problems entirely. I'm going to start creating solutions, and to hell with trying to fix broken things. I'm going to begin to invent new structures, new forces, new relationships, that will show exactly what I want to have happen, rather than trying to get what's going on up to what ought to be happening.

Cowan: And that turned into your non-profit organization, the World Interdependence Fund.

Bronston: Yes, World Interdependence Fund. Which of course was set up three years after the International Year, which was 1981. Remember, in 1980, we did the Consumer Unity Conference in Berkeley, which was another incredible event, and we had beautifully documented it in a gorgeous book called "Consumer Unity," which has photographs that I took and excerpts, central excerpts from every major speaker there. It was another conference like the Governor's Invitational Conference with Brattgard, in fact, the governor was involved in that as well. Brown was still there. And we brought together the entire California movement leadership.

After that period, I needed really to try and do something without having to work through other people. And Ed gave me that privilege, that opportunity to generate "Project Interdependence." We've already talked at some length about that. I cannot tell you the vitality, the originality, the breakthrough stuff that was going on. But it was all invisible, on a certain level. Because the bureaucracy in the state of California was totally uninterested in it.

With Project Interdependence, we were going about our little eccentric, unorthodox agenda. God knows how little it was, how insignificant it was, but we were absolutely intoxicated by the work. And we tried to use big brushstrokes and link hundreds and hundreds of kids from all over the state of California, and to try to create a paradigm. We were well on the way towards doing that when we were stopped. After I was put into the Sacramento district as an extra-numery doctor, I had almost nothing to do. I was put into the medical review process of looking at client cases, which interestingly enough, is still what I'm doing today. I'm still in the same building, in the same office, from 1985, to now 2002. I have been in the same room in my office, and doing my thing since then, and getting my paycheck, since then.

In 1985, after the assassination of Project Interdependence, there I was, sitting there, trying to figure out what the hell to do. I had been completely cut away from my youth organizing thing. I said to myself, you know, I got to stop this dreaming and I got to stop this escape thing, and I got to just try and focus on helping this department, earning my money, and just kind of smoothing my feathers out, and seeing what I can do good in my own community. Instead of trying to solve all the problems of all the kids in the state or whatever—for the time being, anyhow, until I could get my heart back, and my center back, and my footing back.

Employment development for persons with severe disability

So I wound up being able to recruit a very fat little grant of two hundred thousand dollars, I don't remember exactly from a new foundation, called the Sierra Foundation, here in our area. Its purpose was to establish a project called "Employment and Development for Persons with Severe Disabilities." The purpose of that grant was to do everything we could to organize a major agenda in the Sacramento area, to help adults with employment—adults with disabilities.

I was able to hire this wonderful woman, Billie Shawl. She and I began working together to figure out how to get a handle on helping all the people in our community, and to generate our agenda in the process, our emancipation and empowerment agenda. One of the things that we did, was we put together a really unique adult services and referral directory, EDee, which was one of the most interesting projects. The whole thing took about ninety days, from concept to actual printed finale. It was absolutely a tour de force of discovery and insight.

I got Bill Campagna, my old partner, who was pretty burned out, and pretty injured from the destruction of Project Interdependence. It really broke his heart, when this thing was smashed, because he really had put life and soul into PI, as I had, but it hurt him more, it hurt him much more. But anyhow, he agreed to help with EDee.

Cowan: He came onto this project?

Bronston: He came to work with us, to help conceive the design of this thing. The Sierra Grant was complex. There was organizing work that we were doing in the community. We were putting doctors together in various different kinds of programs, where I could use my medical expertise and my status, my standing in the community, to promote awareness of the needs of people with disabilities, in the medical community, and in the social services community in Sacramento. We decided to put together this unique guide, that was a total user-friendly document that could help anybody with any kind of a disability find anything, any help or resource they needed, in order to float, and to get help with employment, or whatever else they needed in the region.

Cowan: You did that in ninety days?

Bronston: We did it in ninety days. When I look back on it and I think, ninety days, I can't believe it. Because the product that we came out with was one of the most sophisticated algorithms of a search tool to help people. Anybody could pick up the Directory notebook that we created, and essentially think through their personal dilemma, comprehensively, using visual prompts, and an indexing and organizing system that linked their information-referral needs, their "home"-base needs, in terms of who would provide them—not home, as home to live in, but a home-base from which to generate an action plan for themselves.

They could search any initiative need such as agency management assistance, health and medical programs, their skills and abilities areas, employment resources, empowerment strategies, and then basic needs of living, like money and food and housing and so forth. And then also, since the book was set up to be used by professionals, as well as consumers, whole strategies of professional development, for anybody working in the field of disabilities to improve their understanding of the field were included.

So what this book was, was essentially an inventory of every single conceivable resource in our community.Within Sacramento County.

Cowan: And surrounding counties?

Bronston: A little bit larger. It was more of a functional metropolitan area than a hard county-line thing. You could open up the book and essentially find anything that you needed to find, in an area, that would systematically explain to you, as somebody in need, exactly what a service was delivering, where they were, whether they were accessible, who to contact, how to deal with the problems of getting into that particular service delivery system— The whole thing was handled through icons and very brief, very accurate, very consistently-defined descriptions of each of these systems.

Now, the county of Sacramento, had for years been producing a guide book for professionals, in order to list and explain all the services in the community. The book was about an inch-and-a-half thick, sold at the local bookstore, and was impenetrable, absolutely impenetrable. From my standpoint, it was unusable for a consumer. But it was the bible for the service delivery professional community, which was one of the reasons why things never worked. The very strategy of the county's planning council guidebook was so confounded, and so obscured, and so subjective. All of the descriptions of what the programs did were written by those programs themselves and sent in. Edited, to some extent, but there was no attempt to tell the truth about what was really going on in those programs and what was really there and what wasn't there.

So we developed a systematic way of talking about, describing, and crediting any given program, agency, or resource in the community, with a consistent, clear, simple, real description. So you could compare anything with anything, and know where this program was in terms of what it really delivered and what it didn't deliver. What it would do and what it wouldn't do regardless of what it said it did. And then we put in a glossary, where we really laid out the true, consistent, normalization-based definition of each program and each service that gave people a consistent vocabulary to define and describe their needs and what they saw out there, from our standpoint.

Cowan: Did you encounter resistance?

Bronston: Yes. There was enormous resistance. First of all, putting such an inventory together, in and of itself, was daunting. And I don't know how we did it. I had about ten volunteers, that were sort of "dialing for dollars," who were calling all these places. We had to look in the Yellow Pages, we had to go through—just the search for resources that lay out there, that nobody knew, or that had never been codified—half of them were not in the social services guide from the Community Services Planning Council, what I was just describing, the county program had done—

The project was—incredible. And that we got it to the printers, and that we got it designed in such a radically useful way, was amazing. Then, I think because we had a fixed amount of money, like a hundred and twenty-five thousand dollars or something. I think we spent about thirty-five thousand dollars, on this particular piece of the grant, to generate this notebook, which we called EDee, which meant "Employment and Disability" is what it stood for.

Cowan: Who came up with the name?

Bronston: I did.

Cowan: It was okay with the department that you got a grant and did this work independently of them.

Bronston: Well, that's an interesting question, because yes and no. Yes, it was okay, because out of sight, out of mind. I was working in Sacramento—what they wanted me was to keep my face out of the newspaper. Because I had just been in a killer battle with them, in the press, about their assassination of Project Interdependence.

Cowan: So you were allowed to do this because they just didn't want to know what you were doing?

Bronston: Right. And because I wasn't in the newspapers. And because I was bringing thousands of dollars into the service of the Sacramento district office, organizing all sorts of meetings. I put together a meeting, for example, with a couple of the largest durable medical equipment companies in order to invite every rehab worker, from Redding, Chico, Sacramento area, and Placer area, to a conference I invented, that I produced—I'm a conference-maker. In order to look at a five to eight-year strategy that would fundamentally improve the way that the department was able to carry out its work in order to service the actual professionals at the ground floor of the rehab system.

Cowan: And that conference was after Project Interdependence.

Bronston: That's right. It was part of the Sierra Foundation grant. Money that I had also gotten from private corporations that I recruited in order to make this happen. Out of that conference came an agenda for me. I was looking for something that was validated by the mass of rehab workers and consumers, in order to give me direction on where to take my horse and my lance and my shield and my pot metal helmet, to do my windmill tilting. Out of that substantive fantastic meeting came essentially, a five-year project for me, which led me, with all the data that I needed, to garner this Sierra Foundation grant, to begin to work on how to support and better understand employment and disability needs among the adult population in my Sacramento district geographic area.

Between 1985 and about 1991, I pursued this strategy with a vengeance and brought in about a quarter of a million private dollars, in order to do this. Now the interesting part is, similar to another story if you remember, when I just came in 1975 and developed this big piece of money in order to do training in normalization, this huge workbook that I generated—this book, EDee, that I created, also met with enormous resistance from the Department of Rehab. The Department of Rehab, once I had the book in hand, was unwilling to really celebrate this as any kind of a useful tool. Partly because it was such a comprehensive challenge to the way in which people thought about, defined, and carried out their work.

This book could have been, had it been really embraced—and I put a copy of the notebook in the hands of every single counselor in my district. About a hundred and twenty copies of the book went into the hands of the counselors. Absolutely current, absolutely accurate, absolutely comprehensive and unprecedented in its problem-solving design. I mean, the algorithm of search that we invented for this book, to really pre-empt the chaos, the potpourri thing that the county was using at the time, and focus just on people with disability. Our purpose was to sensitize both sides of the equation. Not only the workers who were the counselors, looking for how to handle this thing, but also how to sensitize the agencies, in terms of how they fit in the big picture.

Now this thing lead to another major adventure. Because, remember, Ed's still there, out there in space in the East Bay.

Cowan: Well, before you get to that, I want to ask you, did they use it?

Bronston: Minimally. At the time that I had it printed, and was able to hand it out, I spent a lot of time in general conferences with the workers, explaining to them how to use the book. I know some workers used it. The crazy part of it is that this book is still sitting on shelves and still is turned to by some workers. Now, twenty-five years later.

Cowan: Is it in bookstores at all?

Bronston: Oh, no.

Cowan: Never got to general distribution?

Bronston: This book was too expensive. EDee was so elegantly done. I mean, the whole thing was done by graphic computer design. This was a real visual breakthrough. Part of the reason we were able to move this thing so quickly was the whole thing was done on digital disk. I don't remember at the time, I mean, I didn't know anything about high end computers, but we got this thing done, probably on Pagemaker. It's one of the most elegant physical setups I've ever seen, in terms of visual and text integration in a search guide.

[Tape 15, Side A]

Cowan: So in the end, this directory, this useful document was not generally distributed to the community?

Bronston: No. Not to the community. Its primary distribution was to the caseworkers in the department to use, initially.

Cowan: But they didn't really use it?

Bronston: Well, some did, some didn't. But they didn't have administrative direction to use it, or to evaluate it. And the caliber of the workers in the department was so varied. There was so much dead wood, I mean dead wood, that were working in the State Department of Rehab, counseling system at that time, that—I mean, it was my way of trying to heal, objectify, elevate the capacity of my rehab confreres, rehab and counselor confreres, to do their job really well. Because one of the things, I've said before, was that the transition from working in the Developmental Service system to the rehab system was like going from rubies and emeralds to granite—decomposed granite. In terms of the hardness, and the substance, and the value of what was going on.

Cowan: Did you say what year you did this book?

Bronston: The book was actually copyrighted in 1989. The book was essentially designed in 1988. This was my fourth year of being in exile, after Project Interdependence, in the local district office. The second year, and final year, of this beautiful grant that I got from the Sierra Foundation, which then led to a next step.

Had the new director of the department, in any way, been interested or willing to, or open, to looking at our ability to really provide an effective service systematically, systems-wide, or had the district administrator, I think his name was Phil Ladas, who was my immediate administrative supervisor, my boss, had the courage to get the workers under him to really make this work, it would have been extraordinary. But, it would have required an advocacy departmental consciousness. But, by then they were so allergic to me. Anything that I did, they wanted to squash, just by reflex. Secondly, there was no drive to really take a paradigm step up, from the level of professional mediocrity, to the next level up of shareable, accountable, performance, in the department. Had there been caring leadership they would have grabbed this book.

But it saw me, anything I did, and this book, as just far out. And it was. Because it looked at the system as a whole system, from a local perspective. It offered an opportunity to fundamentally begin to put oxygenated blood through their arterial system. EDee and the Sierra grant were just a fundamentally different circulatory concept for them, intellectually, professionally, operationally, and they just couldn't absorb it. It was just too new. It happened too fast. And you know, if you look at it from their standpoint, what is this assault, that comes upon them from this whirling dervish in their midst, who they don't share much with. Because I had come, really, from a very different place. I had always been the enfant terrible of the administration. I had always been privileged, kind of an unorthodox prince of change. A doctor on top of that. I was never really a digestible bureaucratic entity at any time.

Cowan: What were your feelings about that? Were you thinking of throwing up your hands and giving up?

Bronston: You know, by this time already, I was getting used to this kind of confrontation, and kind of exile status. I keep operating, trying to figure out a way to get in, trying to figure out a way to do something significant. And at some level, I was very happy with myself and with what I was doing, because I knew I was doing really good work. The fact that it didn't work is a whole other ethical dimension of the problem in terms of what the hell was I doing.

So anyway, what's going on is that I'm reviewing client charts, and I'm doing rehab work every day in the district. When EDee suddenly came up—the quality of the work was so pristine, so comprehensive, so objective. Through our data gathering, we knew everything in our community about everything that had to do with services, programs, and resources for people with special needs and disabilities, at an adult level. At that point, a situation came up that was keenly interesting.

Robert Wood Johnson Foundation independent living request proposal

Bronston: I don't remember exactly quite how it came up, but Ed Roberts had been working intensely with the Robert Wood Johnson Foundation to try to get Robert Wood Johnson to generate a big national grant for the independent living movement to do some major funding. He was able to nail something like nine or so million dollars of Robert Wood Johnson money. He was on their national advisory board, the chair of the national advisory board of that operation. Immediately after completing EDee, this opportunity came up to make application to Robert Wood Johnson for what essentially was, I'm pretty sure, a four-year grant project. It would have funded the first year for "planning" at the level of about a hundred thousand dollars, in order to ascertain, in every community, a needs assessment and to look at all aspects of a community service delivery system, that would then be translated into a strategy to provide economic sustainability for a local independent living center.

The whole nation of independent living centers applied for this grant. We applied, and I put all the work from the Sierra Foundation project, including EDee, on the table in grant form, and made partnership with the local Resources for Independent Living program here, run by a woman, Frances Gracechild who is one of those anathemas in the disability movement. I had to make partnership with her because, first of all, because I thought she was terrific, at the time, didn't realize what an unethical person she was. I soon learned she was pursuing her own self-interested, self-circumscribed agenda, wholly presents herself as the darling of the disability rights movement. Given the RFP guidelines, I couldn't make application directly but had to go through an ILP.

Cowan: You needed to use a partner—

Bronston: I needed to make an independent living center make application. As luck and reality would have it, we received the grant as the only independent living center in the entire state of California, funded by Robert Wood Johnson because of our Sierra grant work.

The work was so, so extraordinary. The whole first year's work was already done, and we were going to get a hundred thousand dollars to grow on. I was, for the first time, going to have some money, and some kind of a future, in order to lock in Billie Shawl, who was vital to my operation, a crucial staff in this work, and intellectual partner.

Our Robert Wood Johnson grant task was to develop a whole employment strategy, and the whole health services strategy. In partnership with the independent living center was to develop the advocacy strategy and the housing strategy—neither of which were central to the grant, but were things that Frances wanted to do. I assigned her the responsibility of genuinely creating an advocacy-based congress of all Sacramento area disability groups, including people with developmental disabilities, people with visual and hearing disabilities, in the consortium, as a crucial structure in guiding, empowering, and uniting all those folks.

Remember, this is building from the 1981 Consumer Unity Conference. I was continually trying to figure out how to create bonds and bridges between this terribly atomized advocacy movement out here, where parts bounce against each other, rather than creating a coordinated effort to bring about system change in terms of economics, program resources, okay? So we got this Robert Woods Johnson grant. We beat out the CIL in Berkeley, we beat out San Diego ILC, we beat out all the multimillion dollar independent living centers in California. RIL was the smallest independent living center in the state—strictly because we had a handle on the strategy before the big grant existed.

Cowan: With EDee?

Bronston: Yes. On the whole system, that was extraordinary. The catastrophe was that this director, this independent living director, within weeks, essentially decided to grab the whole grant, which was a seven hundred fifty thousand dollar grant, over four years, in order to bend it to her interests, and to apply it to her interests. She essentially got her board to block us from any receipt of any of the dollars.

Cowan: By "us," you mean?

Bronston: The World Interdependence Fund. On paper the deal was a partnership headed by Resources for Independenet Living with World Interdependence Fund as a subcontractor. And here we were, right at the precipice of really translating our work that we had caged into a grant of national significance, where we could have just made the most profound changes in the system in our region. You can't imagine—we were there! We were there. And through greed and narrow interest, and a kind of corruption, the grant was lost. Because within months, because of her abdication of the employment and health piece of the grant, which is what it was all about, Robert Wood Johnson never funded her after the first year.

Cowan: And there was no way you could prevent her from doing this?

Bronston: I tried to go to the Senate Health Committee chair, who was a member of my board, and beloved friend, to appeal to Robert Wood Johnson, and it just didn't work. This was the first of three major, almost million dollar grants that I lost through exactly the same set of disastrous partnerships and alliances, subsequently. It's very interesting. Project

Interdependence, I don't know if I mentioned. In 1996 we received a million dollar grant in partnership with this agency called the Sacramento Community Planning Council.

This particular structure had solicited us with a new idea I developed, the Tower of Youth, to make an alliance. Because they had just gone through five million federal dollars that they had spent to create an anti-drug program in the community. This was the fifth year, and they had to get refunded in order to keep their empire that they had created of office space and furniture and workers that hadn't done anything. They jumped on the my Tower of Youth Project, which I had just documented, put on paper, and the submitted it to the feds. The feds funded them for continuation for three more years, at a million dollars.

They immediately cut us out, pocketed the million, and went on to spend the million over three years, but again, nothing to show. I was again left on the outside with just the idea, and my own capacity to build towards it—which is now very substantial. Still unfunded, but it's fifteen hundred kids, six counties, hundreds of involved agencies and so forth.

Cowan: What was Ed's reaction to this grant thing?

Bronston: Ed was just heartbroken. He was just heartbroken. Everybody around us was heartbroken. They gave us the money, I think, knowing that I could pull it off. But I didn't have the ownership of the grant. And that technicality wiped us out. I lost Billie Shawl, my staff person, as a result of that. It was a terrible blow. So when you say, how did I feel about this EDee publication not rooting in the department—these kinds of experiences kept happening after one or two years of really extraordinary work. I never had the ability to preserve, at the proper level of integrity, these giant projects and ideas. To show the tangible possibility of some really intellectual, programmatic, organizational, interagency, consumer-based transformation.

So that led us into the next pair of major situations. Because, remember, in my rehab district medical consult role, I'm working with—there's no romance in the work that I'm doing. There's no thought in it, there's no payoff in it, in the department, in terms of my medical consulting work. So I was just on fire, trying to figure out some things to do, and, as a physician, I have certain leeway and certain privileges. The momentum from my relationship with Ed, over the years from 1980, and my credibility and credentials in the disability advocacy community, carried me through even the Republican period, where a couple of the major directors appointed by Governor Deukmejian and [Governor Pete] Wilson turn out to be people that helped and assisted in getting their appointments.

Cowan: Did you go on to this next grant from the Federal Developmental Disability System for the Minnesota and New Mexico—?

Bronston: What happened was that this amazing compatriot of mine, Colleen Wick, who is the executive director of the Governor's Advisory Council on Developmental Disabilities in Minnesota, and who's a genius in her own right, also.

Cowan: And is still in that job?

Bronston: Still in that job. Colleen asked me to come to Minnesota to help consult because she was so enormously interested in Project Interdependence, and wanted to somehow try and figure out what to do to apply the idea there. And also, she was very impressed with our discussions about the need for a new youth leadership generation. Colleen was a real power. She was on the National Association of Retarded Citizens advisory committee and board. She was on the Association of Persons with Severe Handicaps board, she was on the American Association for Mental Retardation's board, AAMR. This woman was the most brilliant leader in the nation, of her kind, in the developmental service area, in the developmental disability area.

She ran the Minnesota Governor's Council with the most original and extraordinary leadership capacity. In 1989 and '90, she asked me to come and sit down with her and look at all of the work they had done for ten years, and to advise her and the council as to what they should do now. Were they successful in their work in promoting integration? In advancing the agenda for people with developmental disabilities? I said to her a couple, three things when I looked at her decade work. I said, first of all, that the whole developmental disability council grant pot, which was then part of the federal funding situation to all state councils on developmental disabilities, led to a totally ineffectual waste of dollar. Historically, those grant dollars, under a million in most small states, were given out in a shot-gun fashion, with no purpose, no payoff, and no change in the system.

I suggested that all the federal discretionary grant monies be concentrated in a single agenda. That this single agenda be based on leadership-building, purely. I urged that a whole youth component be part of the underpinning of that leadership training agenda, and that there be a pyramidal building strategy, area by area, county by county, throughout Minnesota. As a result of my written recommendations to Minnesota, which occurred over a period of about four, five, six months of travel there, she presented my proposal to the Minnesota Council. And with her incredible leadership and her ability to sum up the experience of what had happened, and what hadn't happened, was able to get the Council to make a decision to commit a hundred percent of the developmental disability pot to a single ten-year agenda, with a ten-year outcome, that would essentially result in deinstitutionalization of the state, and the establishment of this unique coordinated pyramid of citizen and consumer leaders in the state of Minnesota, to fundamentally build the dream.

The 1992 conference on the reauthorization of the Federal Rehabilitation Act

Bronston: They, the Council, gave her the authority to make that transformation. As a result of that, we had, we built a huge relationship, she and I, over that consulting work. I must have gone there six or seven times, to work with her on the Council, in order to make this strategy change, which was unique in the nation. Out of that came the realization that as the Federal Rehab Act was coming up in 1991, 1992 for reauthorization, that it was an opportunity for us to, just out of sheer arrogance on our part—we were going to say, goddamn it, we're going to push something through that's going to change the Rehab Act—

I was so frustrated with the mediocrity and the tacticalness of the rehab system after having worked in it. I decided, I'm going to change this goddamn law. And she was my partner. We went about developing a strategy to have a meeting, another one of my meetings.

Cowan: A conference.

Bronston: Yeah. That would essentially bring together the leading thinkers in the nation that could bear upon the inadequacies, deficiencies, and opportunities inherent in the reauthorization of the Rehab Act, and try to get the bill to be an entitlement bill; to try and get the bill to focus on careers instead of jobs; try and get the bill to focus on real empowerment and consumer leadership, and to really take the paradigm of the program to a kind of a major strategic level that would really make a difference in terms of the employment and involvement of people with disabilities in the workforce in the nation.

Cowan: So this conference was to be held in Washington, DC, and it was calledB

Bronston: Good question—[laughs]. The title was really important, you know, because it was one of those—ways of really talking about it—I've forgotten the literal title of the damn thing—the acronym was "REARM."

Cowan: We can find it out later.

Bronston: I'll definitely give you all the materials and stuff to put in the archives.

Cowan: It was a conference on the reauthorization of the—

Bronston: It was the 1992 reauthorization of the Federal Rehab Act. And that meeting was partly funded by Apple. I raised about twenty thousand private dollars, in order to put that meeting on the ground.

Cowan: And did you have people from all over the country?

Bronston: All over the country. That meeting was the most amazing confluence of leaders in the disability field in the nation. It had everybody in it.

Cowan: Can you think of a few names?

Bronston: Well, you know—Justin Dart, Jr., was there. The chairman of the EEOC was there, that was really another key player in the ADA, subsequent to that. All the major people from the State Rehab Directors Association. All the independent living movement leaders were there, Ed Robert and Judy Heumann were there. All the major policy leaders were there. There were representatives there from Senator Robert Dole's department, there were representatives there from Madeline Will, the OSERS [Office of Special Education and Rehabilitation Services] Secretary. It was an astounding, astounding gathering of people. And as the meeting became more and more clear and organized, it became, at a certain point, it became the only place for everybody in the country to be, at this meeting.

Because it was such a rump operation in order to establish such a gathering. Of course, Ed was a crucial player in all this thing. We had everybody who had anything to say about rehab in the United States, in the Washington, Hilton Hotel, at this meeting.

Cowan: And that meeting was January third to the fifth in 1991?

Bronston: Yes.

Cowan: The third to the fifth.

Bronston: Yes, the third to the fifth of January, in 1991. It was kind of wintery in Washington, at the time. Again, we set up this whole series of interactive workshops and strategy-planning groups. We had all the professional groups sitting together, all the consumer groups sitting together, all the policy leaders sitting together—it was extraordinary. And out of that, came—well, first of all, the way that people came to this meeting was that Colleen and I co-signed a letter that I wrote, inviting them to come to Washington, in order to make war on this terrible seventy-five year old act that was so creaky and so parochial, and so underserving people with severe disabilities and the independent living movement.

Because, remember in California, that independent living had become, one of the agendas associated with the rehab department, through a state piece of legislation. Ed was constantly moving to make independent living a federal agenda. So independent living became a crucial piece, broadly defined, as the center stone of a new reauthorized rehab act with new authorization capacity. And Dole, who was a very crucial player, was the Republican Senate head, was really a key force. And because of his arm war injury, had set up a foundation, for his own purposes, to advance the interests of people with disabilities.

Cowan: So he was in favor of change?

Bronston: He had to participate in this amazing meeting. As did Kennedy's people. I tell you, Kathy, it was—

Cowan: You mean Ted Kennedy's?

Bronston: Yes. It was simply the most amazing meeting. Out of that meeting came a set of agreements. Colleen and I, essentially forged at the front end, and got ratified at the meeting—I mean, we set the bar, and then asked people to define what that would mean.

Cowan: And what were those agreements?

Bronston: Well, essentially, to radically rewrite the Rehab Act, and not just to reauthorize it in its old form—to focus on real consumer, people with disability, real empowerment in the rehab process of individualized planning, to increase the panorama of opportunities towards career purposes, rather than just job placement in the system. To create the proper kinds of accountability, and advisory structures, driven by the disabled community, in the rehab process, for the rehab system. To interject independent living, and to almost go back and re-tap into that amazing set of agreements and visions that were galvanized in the Brattgard Conference. Almost fifteen years prior, to resurrect the comprehensivity and the humanity and the trajectory of a respectful, integrated, inclusive, effective service delivery system in the Department of Rehab per se.

Cowan: But this rewriting of the Rehab Act, that would have to be done by Congress, right? They take recommendations.

Bronston: Right, exactly. So we issued a document which was distributed to all the Congress, as a result of this meeting, spelling out all the detailed pieces of our recommendation, in terms of human rights, in terms of service process, in terms of service program, in terms of outcomes, in terms of accountability, and in terms of funding this whole system.

[Tape 15, Side B]

Cowan: To continue then, so the outcome of the Washington conference was that Congress did rewrite the Rehab Act.

Bronston: Yes. The most sweeping changes that have ever been put into the act were agreed upon and put into the reauthorized act. I mean, it was an absolute transformation of the act. It placed people with disabilities in an extraordinary guiding role, in terms of respect for their agenda, and their interests, and it put the counselor, the rehab counselor, in a facilitating role rather than in an excluding role. The whole notion of “feasibility” for work, which was the cornerstone for exclusions by lay counselors, of people coming to the department, who couldn’t imagine that they could get somebody a job, was stricken from the new act. That is, the knife, the service cutting knife that had been used for seventy-five years, was removed from the act.

What was put in its stead was another very interesting tool, but concomitant with that tool, which had to do with limiting the budget allocation, if the cost exceeded the state budget, was another extraordinary development, which we drove. That was that people with the most severe disability condition would be served first, not last.

Cowan: Ah, that’s a real change.

Bronston: We turned the entire paradigm exactly upside down. So if there was no money in the budget, the most severely involved people would be served first, not last.

Cowan: That must have felt like an amazingly successful change.

Bronston: It was, it was astounding. Now, obviously, you come to this very rusty kind of a rehab system operation, and you challenge it to be a streamlined rocket ship, that’s going to take some metallurgy, and some new fuels, in order to get this thing launched—but the new policy was there. The requirements were there. And from thenceforth, there has been this enormous struggle to fundamentally change the federal rehab, vocational rehab system in the United States, for better or for worse. And of course, that momentum again continued to lead forward to ADA.

Cowan: Just a question. Didn’t the California Department of Rehab already have that focus under Ed?

Bronston: No. Ed was bound by federal law. Ed couldn't do—

Cowan: He couldn't switch to—

Bronston: No!

Cowan: The most—

Bronston: No! That was absolutely not in the law. that's the problem with these programs. These programs aren't somebody's good idea. Most people think, oh, Health Department is supposed to make health, Rehab Department is supposed to give people jobs— that's true, on some level, but only under the strict and explicit conditions of legislation that strictly control dollar-flow, and strictly control federal accountability. So you might be able to do something extra, but you're going to have to go way out on a limb, and somebody can sue you, that you are moving money from someplace to someplace else, at somebody's expense.

You have to have the law defined, in meticulous detail, the exact design and architecture of your building in the human service delivery public system. This is a hard thing, first of all, to become aware of, that public services are not just somebody's good idea, but that there is an architecture to this whole thing that's rigorous. Just like building a building, two inches here, three inches there, a certain angle here, and if you don't comply with that, then there's a consequence to it, or no consequence, but you can't just go and do the right thing. If law doesn't let you do the right thing, you can't do the right thing. You've got to make new law do the right thing.

Cowan: So this made new law—

Bronston: This made new law.

Cowan: And the emphasis had changed.

Bronston: Radically. In terms of the whole paradigm, and the role of people with disabilities in the program, in terms of the priority of service delivery. In terms of diminution of inhibition for eligibility for the program, so that—I mean, it was a breakthrough of extraordinary consequences. I tell you, it was really Colleen's brilliant command of media and her ability to use her budget. She generated, out of her budget, about fifty thousand brochures. These beautifully designed, technicolor brochures that spelled out the outcome and the agreements of this Washington reauthorization, war-council, this council, meeting, this conference meeting that we organized.

We sent this damn thing to everybody in the nation. I mean, fifty thousand doesn't go very far, but it was a very targeted list of decision-makers. It went to all the Congress, it went to all the leaders of the federal agencies, and departments. It went to all the state directors of rehab services in the states. It went to all the independent living movement leaders, it went to all the advocacy organization leaders in the United States.

We sent out about five or six thousand copies of the proceedings of the meeting in Washington, which were so beautifully laid out. Just like the book that came out of the 1977 Brattgard conference. It laid out policy after policy in every area of the federal act.

And so immensely powerful was the momentum of that meeting, that the opposition to that meeting, which were the old-line rehab people, could not forestall it, could not regain strategic control over what was to happen. And somehow, it passed. It passed!

Cowan: The government works very slowly. Between the end of this conference and all its recommendations and the actual passage in writing—

Bronston: One year. Done.

Cowan: One year! Who would have imagined?

Bronston: Who would have imagined. It didn't make a revolution in a certain level, but it really created a context in which a progressive advocacy agenda could then be mounted, and of course, the next big step was ADA. Out of, I know, out of the exhilaration of communion and community experienced at these great political events, comes the seeds of the next step. The ADA was the next big step that required a few more years of brewing, or whatever. But it was the next step. Because we couldn't get the ADA into—we tried to get the concepts of universal access and nondiscrimination into the rehab act and we had to pull it out. And everybody said, no, we're going to go right on to the next act. We'll separate this piece out.

So Justin Dart, and the rest of the crowd, put the ADA together within another two years, whatever it was, we had it. That was the next big step that was missing in the Rehab Act. Because we couldn't put all that human rights stuff into the act because it would have required a different kind of congressional action. And we wanted to just get the changes in the program first. And we knew that the ADA issues went far beyond the rehab act. The rehab act couldn't impel justice, it couldn't impel housing, it couldn't impel health services, it would only impel employment support and placements.

So we did what we did then, then came the next step. So in a sense, it was like an amazing U.S. soccer game, where the ball gets kicked to different parts of the team in different parts of the country to pick up pieces. So the little piece that Colleen and I demonstrated was the effectiveness of this kind of organizing strategy for policy change in the country, through these grand rump conferences that bring together disparate forces that never would be invited by the establishment into the same room together, precisely because the synergy in such aggregations would always be driven from the community side, from the people side, not from the bureaucracy side. Bureaucracy calls the meeting, bureaucracy dictates the meeting. Community calls the meeting, community dictates the meeting, simply because of the invitation list and who comes to the table.

Cowan: That's a wonderful story about how that all came together. So when you got back to California, you must have been feeling very successful, and looking around for the next thing.

Bronston: Yes. [Laughs] There's always five or six things going on at one time. That thing about the Rehab Act was just an impulse. It was just because we were so full of our own sense of—we've got to do this! We've got to do this! We can't just keep screwing around with second-level solutions. We may not get what we're asking for or demanding, but at least articulate it and have it out there, so that you know you've fallen short, but you've got a great—

Cowan: Goal.

Bronston: —moon to shoot a rocket to, somehow or other. So that was 1991. And then, as a result again of my relationship with Colleen, and with the woman who was the new secretary, the new OSERS secretary.

Cowan: OSERS?

Bronston: Office of Special Education and Rehab Services, in the Republican regime.

Cowan: What was her name?

Bronston: I don't remember her name. We got—Colleen helped us engineer a grant for us, that was a grant of national significance that came through—bear with me a minute, I want to make sure I'm clear with this—no, I think this was not—this was the Commissioner's, not OSERS. This was the Commissioner on Developmental Disability Services in the US Health Department. This was a grant that I somehow engineered with Colleen's help, from an associate. It was a woman who respected her very much who was the Commissioner for Developmental Disabilities in the Republican administration. This was before Bob took over in the Clinton administration. We got this grant.

More on Project Interdependence

Cowan: When you say, we got the grant, by "we" you mean—

Bronston: Well, Colleen acted as my agent. She was able to help me insinuate the grant to the Commissioner for Developmental Disabilities, and this wonderful Republican woman funded Project Interdependence to be emulated in four or five places around the United States. So we got this grant, and that's where the New Mexico, continuation of Minnesota, Pennsylvania kind of initiatives began to take place. And California, of course. We submitted a grant to refurbish Project Interdependence. Now this hiatus had been from 1985 to 1991 when there's been a kind of a quiescence—we were working on all this other stuff, but we built up the connections.

I mean, Colleen was really the strategic trigger for this thing. It was her integrity, and her reputation that allowed her to introduce me to the DD Commission and propose the need for federal funding for our youth leadership strategy, which had been implanted in Minnesota, the year before, through a DD Council grant. So I had this imprimatur from Minnesota. I picked out New Mexico because I was interested in trying to do something in New Mexico, and we had an incredible African American revolutionary organizer leader in Philadelphia that we were able to promise a certain consequence in Philly, to be able to make something extraordinary happen in the inner city—just through our connections. And of course, Colleen sitting in Minneapolis.

And then of course, I had already this big piece of stuff that had been going in California, that we were able to throw into the pot and say, "We'll move California, New Mexico, Minnesota, and Pennsylvania forward." We would pick the states and so forth and run this project that would essentially promote a replication of the Project Interdependence model strategy in these four states.

Cowan: So this was the "World Interdependence Fund."

Bronston: "Of New Mexico," was one of the spin-off consequences of that. Starting in 1991, I spent most of my time in New Mexico, organizing for three years, and in Philadelphia, and in Minnesota, where much of the work was already going on and all that was required was me going there and providing the leadership and the guidance. I had to organize from scratch in New Mexico. The Philadelphia project had this fabulous anchor, my collaborator, Shafik Taffir.

Cowan: So you were still in California?

Bronston: Still in California, in the Sacramento County District Rehab office.

Cowan: And you had the time to—

Bronston: Got the time. Got this fifty percent sign-off to go out and do this work, from Bill Tainter, who was the new departmental director under Pete Wilson. And when that happened, I was home free. Again. I had again escaped the noose, in a sense, and was able to get his approval for applying for this grant, and being able to use official departmental time to do organizing work. You have a bunch of that on tape, earlier.

Cowan: How long did that last?

Bronston: Till 1994. Three years. A hundred thousand dollars a year for three consecutive years, in order to do all this national organizing work. Then, when Clinton came to office and the grant expired, we applied for re-funding of the grant, and were turned down, by the Democrats, interestingly enough.

Cowan: So that was over.

Bronston: Yeah.

Cowan: Did those projects continue on their own at all, in New Mexico and Philadelphia?

Bronston: I don't know. I was never able to really follow up. Shafik died. He had multiple myeloma. What was interesting was that Shafik was so sensitized by our friendship, and by a breakthrough understanding that he had—I mean, he had been living with this terrible, mortal, devastating disease that ultimately killed him, for almost twenty years. And he had never had an intellectual context in which to place the role that his condition played, that he could share in his grassroots, street-organizing work, and integrate it into a larger context of empowerment and revolution, revolutionary awareness, revolutionary society, in the black community in Philly, where he was really a saint, very extraordinarily highly regarded, man of impeccable integrity, a genius street organizer.

Cowan: And so through this project, he —

Bronston: Through this project, he learned a new language, he learned a new paradigm. And he began to become a national trainer in our movement, in the disability movement to bring his issues from the streets of Pennsylvania, from the street of Philly, and the black community, into the consciousness of our national disability community in order to create that linkage, the bridge between black power, black emancipation, revolution, socialism, and the U.S. disability movement. That was one of the extraordinary diamonds that came out of that alliance.

The work that was done in New Mexico had to have had an impact, because we hammered in there for three years. And we had a profound alliance with the chairwoman of the Senate Education Committee, Cynthia Nava, who was the chairman of my WIF board in New Mexico, with the head of the all-Pueblo Indian Nation, the chairman of the Pueblo Indian Nation, Herman Agoyo, was a member of my board. The principal judge of the juvenile justice court in Albuquerque, Tommy Jewell, an African American young jurist, a key organizer from the Sioux Nation, Karen Buller, a key organizer—I mean, I put a board together of the most interesting people in the state of New Mexico, who actually met regularly.

And by this time, since I had so much stuff behind me, from Project Interdependence and so forth, and the work we'd done in terms of employment and the Rehab Act stuff, that—I mean, it was just a free-for-all. It was just an amazing free-for-all in terms of trying to build a program agenda in New Mexico that would link the art and culture ministry, the Indian affairs ministry, the education department, the disability community, kids. All kid agenda. I got a small grant from the National Endowment on the Arts to hold this leadership conference in the state capital, in the legislative chambers.

Cowan: In New Mexico.

Bronston: In New Mexico, in order to bring all these forces together, the black community, the brown community, the Native American community, the Asian community, the arts community, the education community, the political community, in order to try and do another one of my conferences. In order to give me an agenda for the ensuing three-year period, to organize in New Mexico with the imprimatur of all these constituencies, which we accomplished. And another gigantic picture album came out of that, and documentary materials, and I consolidated this board so the work went on. But it was always terribly diluted by the fact that I had to schlep—

Cowan: Back and forth—

Bronston: I could only be there for so long. I could only stay there, you know, I could only do so much when I was there, and I was challenging the New Mexico leaders to look at their situation at a very strategic level. I wanted them to reconstruct their whole rehab system, their whole art economy for the generic community, and their whole youth movement in the state, in terms of community integration. The issue of trying to get people with disabilities from the native community, or the Latino community was the hardest thing I ever tried to do in my life.

Cowan: Why was that so hard?

Bronston: Those communities treat their kids with disabilities in a totally different way that inhibits those kids from ever exiting from the protectiveness, or hiddenness of their cultures, into the general community. No Native American school makes room for kids in wheelchairs, or kids that are blind, or kids that are deaf.

Cowan: In New Mexico.

Bronston: Period.Those kids are made invisible. They are not seen, they do not come out in the open. And I don't know how the families deal with them. They deal with them. They don't kill them. But they don't put them out there into the general community. And to try and use the bridge to those cultures as an additional strategic force, influence in transforming education policy or program was absolutely stonewalled the whole time that I was there, despite the level of influence that I had.

Cowan: And the school district in Albuquerque, or whatever town in New Mexico, can't insist that those children come into their—

Bronston: No.

Cowan: They can be kept isolated?

Bronston: What happens is, they use federal tribal reservation schools. And those kids with disabilities are not in the reservation schools, but you don't see that. Those kids—I mean, you're dealing with a nation within a nation. That's a whole other interesting thing. What was happening was, I became involved in these different states, out here in space, got farther and farther away from the traditional disability movement. First of all, I was no longer working with the developmental service crowd. Because I had long left that, in 1981.

The normal disability rights movement, was totally focused on a very self-conscious, self-interested benefit agenda, and advocacy agenda, became too parochial for me to stay inside their confines. What I was trying to do was to co-opt them into joining with larger social political forces that can bring about the kind of policy issue change and social organizational changes that are so vital for real progress in the country, to democratize, to address issues of quality of life, to challenge mainstream structures of education, housing, health, work, leisure.

Cowan: But that's not happening?

Bronston: I don't know what's happening, but that's what I do. What I do is, I strike that rock, over and over again, with agendas that make me no longer fit or digestible in traditional advocacy interests, by creating these heterogenous, globby things, that I keep doing over and over again, that I continue to do because I believe that we will not make progress without these striking leaps forward in community-building, in new alliances. And I can't—I'm suffocated in contexts that don't see or allow that level of aspiration, that level of program opportunity, that level of social transformation.

Cowan: So back in California—these things are going on in Minnesota and New Mexico. But in California, you're looking for something to do again?

Bronston: Then the money ran out in 1994. I was really—I'm getting older and older, and I keep struggling with this stuff. And it gets to a place where—what was interesting was that throughout this grant of national significance that we got from the Developmental Disability Office in Washington, Billie Shawl was working with me—I was able to hire and pay her. Afterwards she winds up pulling in a grant from the Social Services Administration, a little grant, in order to work with families that have young adult children who have now, on the verge of matriculating from high school, have essentially become candidates for what we call the "black hole." The system lets the majority sitting at home in an easy chair, in front of a television set, for the next fifty years, until they die. Because there's nothing out there for them.

Sandra Jensen and the fight for heart-lung transplant

Cowan: Is this young people with developmental disabilities?

Bronston: Yes, mostly. So Billie hired this marvelous princess, Sandra Jensen, an incredible woman, who was head of People First of California, who had Down's Syndrome, and cyanotic heart disease, of grave substance, to work with us. Sandra worked with us as a part-time employee and spokesperson, who went with Billie, to talk with family groups and consumer groups, People First crowd, around the Sacramento area, in order to assist families in developing a strategy and a plan for transition from school to work. Their goal was to fundamentally attack the low level of expectations, and the black hole experience that most of these families accept for their young adult children, young adults who are no longer children. [laughs]

In 1994 already, let me just double-check the dates—

Cowan: 1995—but we can check that.

Bronston: Billie gets the grant after the grant of national significance, the youth grant of national significance expires, for the following year, two years later comes another one of the pieces of work that I've been responsible for, and that had to do with trying to save Sandra's life.

[Tape 16, Side A]

Cowan: We were talking about Sandra Jensen. She was working for you and became ill?

Bronston: What happened was, Sandra, as I mentioned, had cyanotic heart disease. Which meant that she had a hole in her heart that because of the way in which the pressures of the various chambers of the heart worked, was pumping unoxygenated blood from the right side of her body, which was the return side, to the left side, and pumping it out into her system, inadequately oxygenated. And worse than that, it allowed the enormous pressure of the left side of the heart, to communicate directly with the lungs.

Let me just explain something physiologically, to you. The heart is actually two separate organs, separated by the lungs. Blood comes from the body, and the head and the legs and so forth, back to the right side of the heart, back to the right atrium. It's pumped from the right atrium to the right ventricle. From the right ventricle, it's pumped into the lungs to be oxygenated. Then it comes back through the lung circulatory system to the left atrium, which pumps the blood to the left ventricle, which then pumps the blood out the aorta, to the body, to recirculate again. The lungs are interposed between the two halves of the heart, completely, even though it's one organ, it really is two completely different organs.

So what happens with Sandra was that she had a situation where the blood from her body was pumped across to the left side of her heart, in large part, with inadequate oxygenation, resulting in her appearing blue. He lips were blue, her skin kind of had a blue-ish cast to it. Her fingernails were gigantically, what we call "clubbed", that is, enlarged and misshapen, which were very much a part of longterm experience of inadequately oxygenated blood. And we don't really understand what causes that deformity. Of course, she would run out of steam very quickly.

And as she got older, the danger was, that the pressure from the left side of the heart was transmitted back to the right side of the heart, and thereby directly back to the lungs. The lungs are a low-pressure system, that operate at very low pressure, roughly thirty to forty millimeters of mercury, as opposed to the arterial side, which pumps out at about a hundred and twenty to a hundred and thirty millimeters. As a result of that, damage gradually grows in the lungs, so that the lungs protect themselves by causing constriction of the vessels, narrowing of the vessels, that then can lead, little by little, to what we call pulmonary hypertension.

And once a person has pulmonary hypertension, they're a goner. As the pressure builds up in the lung circulatory system, in defense against the system side pressure, the blood vessels change, and the right heart, which is a thin-walled structure, compared to the left side of the heart, begins to expand, little by little, and ultimately results in what we call congestive heart failure.

Cowan: Which is irreversible.

Bronston: Which is a death sentence, little by little, and it happens over time. A person will ultimately drown in the fluid that is caused by the lungs not being able to pump out all the blood into the other side of the heart. It's a devastating condition, and people usually live maybe into their twenties, maybe into their thirties, with this kind of a problem. But as it progresses, and as failure begins to happen, you get all the evidence of an inadequate ability of the right-sided system to get rid of the fluid to the left side. So that a person's liver gets larger and larger, because the liver is the final organ through which the venous system pours its blood through channels into the right heart. And you begin to get congestion in the lungs, which causes more and more difficulty breathing.

Sandra was beginning to look gray to me. She was spending more and more time in her wheelchair. She had less and less oomph in order to make her presentations, and so forth. And I knew, because I knew medically, what was wrong with her, that there was only one thing that could save or prolong her life, and that was a heart-lung transplant. There was no more medication that was going to be able to make what little function she had in her heart stretch to be able to compensate for the demands that were being made on it. And the problem, of course, was that I also knew that nobody with a severe disability, nobody that had Down's Syndrome had ever gotten a major transplant of the sort.

In the United States, five thousand transplants are done. Only five thousand transplants, despite the fact that at the time, in the mid 1990s, there was about forty-eight thousand people on the waiting list for transplants of all sorts, kidney, skin, heart, lung, liver, whatever. Only seventy people had heart-lung transplants, each year, which is the biggest transplant operation that was being done at that time. Part of the problem was that the supply was extremely limited of heart-lung transplants from the donor system.

And part of the issue that we were struggling with was, if there is inadequate supply, who is going to get the supply? And is the system going to give a heart-lung to a person that has no value in the culture, that is, a person with Down's Syndrome. And another piece of the puzzle, and there are many pieces of the puzzle, is that close to sixty percent or more of people that have Down's Syndrome have congenital heart defects of one sort or another that reach to the most severe level, sort of like Sandra's. Some kids have it so bad that they die at birth because the heart abnormalities are so significant that they're born with. But typical kids are operated at birth, or operated within the first year, depending on their cardiac deformity, in order to fix the problem.

So you had a medical problem here, first of all, of extraordinary sophistication, that would have challenged even the best potential patient to be able to get a solution. In addition to that, you have a strategic issue of the whole transplant system in America, which is governed by law, and even more seriously governed by supply. You have a problem in this particular instance, where in order to get a transferable set of donor organs, lungs and heart, in a block, you've got to have what we call a "head-death", because you can't have somebody mangled, and pull out that heart and that lung and move it.

You've got to have somebody who has their head knocked off, motorcycle accident, gunshot wound, something that kills the person, and be able to capture that individual in time to be able to save their organs, with approval, and only with approval from relevant family—so the supply problem in the country was, is, an intolerable problem. And for a person like Sandra with Down's Syndrome, who is thirty-four years old, to knock on the door and say, I need this to save my life, I knew was going to create a real problem, which, I became more and more intimate with as we propelled the search for Sandra, and as the campaign began to form itself in my head in order to get her operated.

Cowan: But she had a formal refusal.

Bronston: Her doctor was this wonderful doctor by the name of Phillip Bach, B-A-C-H, who is a cardiologist here in Sacramento. Phillip had been taking care of Sandra for ten years. I called him up. That was the first hurdle. I said, Phillip, this woman needs a transplant. He said, I know. I said, there's never been a transplant for anybody with Down's Syndrome. He said, I know. I said, I'm going to get her a cardiac transplant, a heart-lung transplant, but I need your help, are you willing? He said, anything you need. I said, I need you to write me a letter of Sandra's history, and I need you to make recommendation and refer her for transplant. He agreed. I said, be out there. Lay the whole story out there with her, and deal with her as if she were just a regular person, so that the issue of her Down's Syndrome is nothing more than an associated phenomenon, but not an issue with regard to the transplant.

So he wrote this beautiful two-page letter, which he then sent to UCLA and Sandra was then sent to UCLA to be evaluated. UCLA evaluated her, and while they were looking at her to confirm that she was in truth, only salvageable with a transplant operation, I called up the guy, who was a very dear friend of mine, who was the head of the Medi-Cal system in California, to find out how we could get this thing paid for. Because I knew that the pay was going to be one of the real stumbling blocks. His name was George Wilson, he was the head of policy for Medi-Cal for California for years, and an old friend of mine from the Medical Committee for Human Rights when we were involved in the struggle in the South with the Southern Christian Leadership Conference and the civil rights movement. George was now working here, and had been this key officer.

He told me that there was only two hospitals in the state of California, that the state of California would fund in order to operate her, and that in fact, were she to be accepted by either of these two hospitals, the state of California would pay the bill. So the single biggest, wildest hurdle that I thought, the money, was solved, if I could get her in to either the University of California San Diego, or Stanford. So UCLA could not perform the operation because they were not approved by the state of California Medi-Cal system to be reimbursed for this operation. They could do hearts, but they couldn't do heart-lungs. And different hospitals had different certifications with the state of California, to pay for the operation, independent of disability. The Medi-Cal system doesn't discriminate as such.

So we sent her to Stanford, and Stanford didn't even look at her. A resident fellow wrote back a one-page letter, declaring in the most naked honesty that because she had Down's Syndrome, they would not consider even putting her on the list or looking at her. And that letter, essentially, was written post ADA. So it became clear that they were in violation of ADA to begin with. That was the easiest and first insight. We then sent her, simultaneously, to the UC San Diego, and got a very much more sophisticated turn-down from University of San Diego.

It said that yes, in fact, she was in cardiac failure, and that the transplant would be an appropriate solution for her. But because she had a variety of other issues that were crucial for them to put her on the list, they had to demure. That is, she could not understand the significance of the operation. She could not withstand the surgery because of other conditions that she had, unnamed; and she could not understand the self-care obligations because of her mental retardation, that were essential. All three of which are bullshit. Because, for example, babies that get transplanted can't take care of themselves, can't understand the situation, but they transplant babies.

The Regional Center System and the State Department of Developmental Services, who were a managing system for Sandra, as an entitled Regional Center client, with developmental disabilities, under the Developmental Disabilities Act, provided a comprehensive base of services, home-support, whatever she needed, so were she to have been operated, it would have been the responsibility of the Developmental Service

System to cover whatever it cost, and whatever resource service needs that she would need for the rest of her life anyway.

So we were turned down by the only two covered places. Stanford was so arrogant in their letter, so pitilessly arrogant, this transplant fellow, this one guy that wrote this letter, that I wanted to focus on UC San Diego. So I began to put together a campaign to try and get the operation. But what was also interesting to me, was that as I learned more and more about the transplant system, I began, quickly, to get an idea that here was another opportunity to really address the bigger picture. Number one, the disability community was rigorously excluded from transplant opportunities, in general. There was no database in order to document that, but nobody in the disability community had gotten transplants ever, in California.

Cowan: In any disability?

Bronston: Yes, in any disability, that I was able to find. Especially with developmental disabilities, people with mental retardation. Now, remember, I'm working for the State Department of Rehab. I'm working in an essentially neutral to hostile regime, I'm working in a Republican regime now, there's no Ed Roberts there to protect me, you know. Or to support what I'm doing or to initiate what we're doing here. The thing I was concerned about was, how was I to effect Sandra's designation as a legitimate waiting list candidate, let alone getting a heart and lung.

So I began putting together a campaign, not only to represent her need as an opportunity that could really ignite a united front amongst the disability community in relationship to an area that was clearly a flagrant violation of ADA. Not to mention a service urgently needed by that constituency under any circumstances given, even in the Down's Syndrome community, the high percentage of people that have cardiac problems or whatever that may need transplants. But also as a way to insinuate or to project the disability community and their families and supporters as a fundamental lynch-pin to American commitment to caring, and to fundamentally address the insufficiencies and underdevelopment of the transplant system in America—which is administered by a federal agency, by a federal contract agency, a non-profit, non-governmental agency, called the United Network of Organ Sharing. UNOS.

UNOS was the consolidated bureaucracy from two or three organizations, community-based organizations prior to the federal, National Organ Transplant Act that administered the transplant process in the United States. And they were really the key structure that made all the decisions and followed the regulations set up by federal law on how transplants were obtained and distributed, and how they marketed to the American public the commitment to become donors. So it became clear to me that if we were to turn to the disability community with Sandra's story, that it could galvanize a commitment on the part of an enormous number of people to sign up to become donors as a political act of support, a) for the disability community, and b) for the general community, because of the incredible shortage of organs and the incredible loss and suffering that normally occurred because you had a situation, nine to ten-fold of unmet need.

So I proposed the notion of generating "a million new donors" in the United States as the disability community's good-faith commitment to eliciting from the general public, the political support for Sandra to be operated. Now, granted, there was no one-to-one connection between people in the United States wanting Sandra operated, and either Stanford or San Diego doing the operation. they're a whole different struggle, but I saw it as an opportunity, one, to galvanize a relationship between the various disability organizations that were still very divided, and to generate an agenda that again had whole relevance to the generic population, to the general public.

The disability community would be willing to have Sandra go to the bottom of the list, just to get on the list, to take her turn like everybody else. But more importantly, that we would, the disability community would, instigate a campaign for a million family donors to expand the pool of available organs for the general population, and people with disabilities would come on the list just like everybody else, with no preference. So it wasn't an off-set kind of situation. And I entitled that thing, the campaign was called "Fill the Need".

I designed a pin that was the emblem of the campaign, which was a beautiful red cloisonne heart with a hole, a heart with a hole in the center of it, which was the "need" that had to be filled. And proposed that the disability community sell these pins for five dollars a pin; gorgeous gold pin, beautiful thing, as a way of linking each other up around something that I felt was metaphorically heartfelt. A heartfelt campaign around Sandra as the kind of major recipient, beneficiary who couldn't be more of a significant citizen, personality.

Cowan: How was Sandra's health while this campaign was going on? Was it deteriorating rapidly?

Bronston: Awful. Awful. She was in really bad shape. I mean, she was in marginal congestive heart failure that was being held back by medicines, but with less and less effectiveness, and with less and less energy. And the interesting part of that was that Sandra, though she was an adult, was still a competent person. So I was very heavily involved with her mother, whose last name is Demaio. Once her mother realized that Sandra was going to die if we didn't get the transplant, she really joined the struggle with both feet, and was just an extraordinary advocate, an extraordinary woman. Calm, lovely—kind of a heavyset woman in her early fifties, but tremendously cogent, tremendously just. Just an extraordinarily fine woman.

Then I went back to the specific struggle, to isolate the two university transplant hospitals. First of all, I had almost every card that I needed in order to deal with the hospital. I began to initiate a campaign in the press, locally, nationally, and internationally, in order to tell Sandra's story. I built a whole material package with the pin and a beautiful flier that laid out the whole campaign, which I was able to distribute with some minor funding that I got from a few angels like Evan Kemp, to all of the major disability organizations, top get them on board. Everybody was—you know, Sandra was like the angel of the movement.

I was able to get in touch with one of the key members of the board of UC trustees, Claire Bergner, who was an ex-Congressman, who had a son that had mental retardation, who was an extremely conservative Republican, who was a very dear friend from way back, that had been on my board for Project Interdependence.

Cowan: Did this campaign take, how long did it take?

Bronston: It took a year until we were able to turn the corner. But little by little, we developed a strategy to really put incredible public and political pressure on the two universities. I had the head of the Office of Civil Rights in Clinton's administration, the Federal Developmental Disability Commissioner, Bob Williams; Judy Heumann, from OSERS; Ed Roberts; the Protection and Advocacy System, the Independent Living Movement, United Cerebral Palsy, the National Down's Syndrome Society, the National Down's Syndrome Congress, Association for Mental Retardation, TASH, AAMR—every major disability, disability rights, consumer and professional organization that I could get my hands on; I knew all of them intimately. I laid out the situation to them, and got a letter from each of them to support Sandra's operation, a) to the press, and b) to Stanford and UC San Diego.

Finally, Sandra was provisionally approved by UC San Diego, to put her on the waiting list, and then we never heard another word from them! Meanwhile, about six months in, after demonstrations, after speaking tours all over the country, and Sandra would come with me and talk, we began to get more and more television coverage, and began to put together videotapes about Sandra's life, and who she was, and her talking about her situation, and interviews with all the people that were involved. So this stuff was on television, it was front-page news in all the newspapers. The *New York Times* picked it up, the London *Times* picked it up, the Australian *Times* picked it up— I mean, this was the first ever, and it was an incredible thing, because she was just so beautiful. She was just such an articulate, remarkable human being that could speak her own thing.

The turning point came when we forced Stanford to re-look at her. And the same resident fellow wrote back a letter again, saying, "No, we are not going to do the operation—she doesn't qualify." And then Sandra wrote a letter, a handwritten letter, to the chairman of the Stanford transplant department. Which was an incredible letter. His name was Bruce Rietz. She essentially said to him, "You are absolutely, totally, so off-the-wall in terms of your stereotype of me. Do you think I want to die? How do you think I feel about being turned down by you, just because I have Down's Syndrome?"

And within a week, she got a call back from him. At the same time we got a two-page article in *People* magazine that came out that same day, that was done by friends that we had hooked up, and a magnificent article in, in *US News and World Report*, by Joe Shapiro. We really had our hand on the press, and on the federal legal system, and on Protection and Advocacy, who was threatening a lawsuit. Not filing, but threatening, because we couldn't afford to file a lawsuit because that would have been a death-sentence for her, because they would have stalled for three years and she would have died, so we had to get through politically.

An enormous struggle developed, interestingly enough, between the work that I was doing and the traditional disability community advocacy system that really wanted to go to court, and another wing of the movement that was very committed to self-determination, and felt, for better or for worse, that the campaign that I was running with Sandra, and on her behalf, was really "using" her, and preempting her from exercising her role in leadership in this thing. At the same time, she was flat on her back in the hospital, in congestive heart failure, and couldn't say anything to anybody about anything.

Cowan: So this letter was an approval then, that you got from Stanford?

Bronston: Yes, so the chief of the department at Stanford, who had been the aloof pooh-bah in the background, who hadn't even wanted to look at her, and had used his resident system as a screen, was really moved. When he finally met her, he was moved by her, and shamed by the denial of his department, or at least, he was ostensibly shamed, plus the fact that he was out-gunned and out-numbered and surrounded by everything and everybody. By then, it was Stanford against everything on the planet. We had all the federal officials, all the state officials, I mean, the chairwoman of the Senate Health Committee was on my Project Interdependence board. We had the UC board sitting there, we had it all, we had Medicaid with us—I left no stone unturned in terms of every power point being close. Stanford had no allies whatsoever except the body of disability prejudice latent in the public, and the arrogance of the doctors and whether or not they wanted to go to the law and be discredited for this totally discretionary choice that they made to exclude this wonderful, leading woman, this gorgeous, fantastic, citizen-advocate, from staying alive.

Cowan: This was just to get her on the waiting list, not any special treatment.

Bronston: Right.

Cowan: So they put her on the waiting list.

Bronston: Five days later they did the operation.

Cowan: How could that be so quick?

Bronston: Well, for better or for worse, Sandra had type AB blood, which is a rare blood to begin with. And out of nowhere, came a teenage heart-lung block, from a kid that had committed suicide, a girl in Arizona.

[Tape 16, Side B]

Cowan: So, a heart-lung turned up within five days.

Bronston: Right, and she was operated within five days of being listed. She was helicoptered from Sacramento to Stanford, and it was just one of the great victories imaginable. It was an incredible victory, but—there's a "but" to this thing. First of all, Sandra lived for about another year after the operation, but she stayed in the hospital an inordinate amount of time, and was terribly, terribly impacted by the imuno-suppressant medication. On the one hand, she became very physically distorted from the steroids. She just became totally filled with fluid, and rotund, and she never came back to her same energy, and really lived a very fragile life with her mother and friends all around.

And then secondly, which was really unanticipated, and the first would have been tolerable, and would have been fixed over time, had the second circumstance not arisen, and that was, that she developed lymphomas, that were a result of her body's fighting back against the imuno-suppressant medication. The lymphoma that she developed was in a very critical place in her brain, right at the exit of the last ventricle, as it went out into the spinal column, causing a block. She began to develop fluid inside her brain that couldn’t get out, called hydrocephalus. The docs went in, and they removed the tumor from this particular locus, and she suddenly got incredibly better for about twenty-four hours.

Then she lapsed back into semi-coma. It turned out she had a hemorrhage at the site of the operation which acted just like the turnover. The decision had to be made whether to go in and pull out the clot. I had this terrible, heart-wrenching meeting with Sandra’s mother, Kay Demaio, in the hospital. She agreed that we had to go in and get it. They went in to get the clot out, and Sandra never regained consciousness from that operation. She essentially died on the table. That was just a stunning loss. Because she represented such a personal breakthrough in so much.

Not to mention just her own personal heroism, and her conscious involvement at this life-risking situation, to be the first. I mean, she had to ultimately give personal approval, consent, for the operation. She had to demonstrate to the docs that she understood the gravity of what she was consenting to. We had an army of people that essentially had been sensitized and alerted to essentially acknowledge and celebrate and support this journey of hers, on their behalf as much as anything else. In a funny kind of a way it was almost mythical kind of a struggle, because she really took on herself a personal risk that was a terrible sacrifice, in order to move a whole human rights movement forward one notch. And she understood that this was both her life and everybody elses.

She talked about it on film, that it was more than just her own life that was at stake, even though it was a terrible, fearsome thing, and she was scared to death, and didn’t want to die. She did not want to die, she was scared, a lot of the time, about dying, before the operation. But she gave consent at the point of operation, knowing what the stakes were and knowing that she was dying without the operation.

Cowan: But was this a victory in terms of changing the view that people with disabilities were not even considered for transplants?

Bronston: It’s an interesting paradox, Kathy, that is really the most heart-wrenching part of this whole situation—again, to try and explain to a quarter of a million or half a million constituents, the opportunity inherent in this personal breakthrough, that it had nothing to do with transplants, as such. The transplant was just the excuse, it was just the opportunity to take the issue of the sanctity, validity, and substance of the lives of people with special needs to the forefront of the American human rights agenda, that what was really at stake here was everybody’s life. What was really at stake here was challenging the general insufficiencies of the healthcare delivery system, general insufficiencies, gross insufficiencies of the lack of financing for lifesaving medical care.

Because had Sandra not had the medicare benefits that come with having Down’s Syndrome, we wouldn’t have gotten to the point—without raising half a million to a million dollars, which would have sent the campaign in a whole other direction. Furthermore, the struggle that we had, that I had, to convince the disability community, including the National Down’s Syndrome Congress, which was an all-family organization, that they needed to take this opportunity to generate a campaign that would focus on reforming the transplant procedural system and the data being gathered. To this day, to this day today, the system still does not gather data in order for us to be able to ask one intelligent question about whether people with disabilities are getting seen or operated.

I only know of one other child in the United States, since Sandra's death, in 1996, that has had a heart transplant, not a heart-lung. One other kid! You're talking about a population of maybe three hundred thousand, four hundred thousand people with Down's Syndrome in the United States. You're talking about a situation where maybe sixty percent of those people have severe cardiac disabilities. Now one piece that is different here, is that kids with significant cardiac disabilities are operated right now [snaps fingers], like every other kid; a) because of ADA, b) because of advances in the technology, and c) because of their being covered by certain kinds of public coverage because of their disabling conditions.

Nevertheless, the whole barrier-ridden system of knocking on the door, of knocking on the door of the American transplant phenomenon is virtually cut off to all families that have disabilities, the same as it was then, despite national and international coverage sustained for a year, *People Magazine*, *US News and World Report*. I mean, every major newspaper carried Sandra's struggle step-by-step as a result of our ability to move the information out there, put the press releases out there, and notify people.

Cowan: But it didn't change.

Bronston: It didn't change. In the process of all this, the Assistant Secretary of Health, who was another very beloved friend of mine, and friend from medical school, his name was Phillip Lee, who was both the Assistant Secretary under President Johnson and then again under President Clinton, helped me facilitate a meeting under his jurisdiction among the leadership of the federal regulatory bureaucracy that had administered the law and contracted with UNOS in Washington, DC. I brought to that table, twenty of the top leaders of the top organizations in the United States. And met with the chief of the transplant bureaucracy in Washington, under Phillip's jurisdiction, in the US Department of Health.

Cowan: Disability organizations?

Bronston: Twenty national organization leaders. ARC, United Cerebral Palsy, Down's Syndrome Congress. Colleen was there from the Minnesota Governor's Council. We had the A-Team around the table with the top people in the federal Health Department that administered the multi-million dollar transplant system in the United States, to find out that there was not a single person with a disability on any one of about twenty of their advisory committees. There was no data being taken, they could not tell us one word about whether or not people with disabilities were getting any kind of transplants, or applying. There was no down-the-line accountability that would, in any way, facilitate even the application of our constituencies to ask for an evaluation for consideration, given the way in which doctors controlled and deflected access at the access door, at the bottom of the system.

In order for somebody to be considered for transplant, their medical specialist had to refer them to an appropriate transplant center for evaluation. Even that one step, that first step of the family thinking or being told by their generalist, or specialist that a transplant might be indicated or useful, wasn't happening. Most doctors would not, under any circumstances, write that letter like Phillip Bach wrote the letter, with my support and instigation. Although Phillip would have done it, he wouldn't have done it on his own recognizance, without somebody coming and telling him. So here is a system that leans entirely in such an antagonistic, antithetical posture to building any kind of a flow of legitimate inquiry or petition to the medical delivery system to take care of itself.

I immediately saw this as a generic problem in the entire medical system, let alone the transplant system. This was just the most elegant and interesting kind of opportunity that thrust itself out of the water because of its esoteric and interesting technological significance. I could have made the same argument about our dental problem, about getting braces for a kid, for dentistry, or teeth extractions. Same problem in the dental community as there is in this vaunted, elegant, incredibly outrageous transplant bureaucracy.

Cowan: Never gets off the ground. Step one never gets taken.

Bronston: Right. And then step two never gets taken, step three never gets taken, because what happens is that there is such a rarified level, and such a self-serving refusal to provide at the top ends because nobody ever comes through the system with disability, and they've got to knock out ten, I mean, nine out of every ten people that come to them in the first place, have to be knocked out, essentially, or maybe more, maybe ninety-nine out of a hundred get knocked out before they get on the waiting list, because the waiting list is already ten times bigger than the supply. So the justification is who is the right person to get it? Is it going to be the person with blue eyes that gets it? Or maybe the Jew will get it? Or maybe the president will get it.

Or maybe Mickey Mantle will get a liver when somebody else won't get a liver. Mickey Mantle was a chronic alcoholic, who essentially got his liver and then died from other complications. But because he was Mickey Mantle, he got the liver. But the poor guy, maybe the retarded guy, maybe the black guy, maybe the Asian woman, who knows? Who knows, in those subjective, unaccountable contexts, where these individual hospitals, and out of 6,300 hospitals in the United States, 5,000 hospitals don't provide transplants of any kind. There's only 6,300 hospitals in the United States.

Five thousand of the 6,300 don't do transplant operations, period. The other 1,300 that do transplants have a whole variety of different certifications through UNOS. Some may do kidneys, some may do livers, some may do skin, some may do corneas, some may do hearts, some may do heart-lungs. So you're talking about seventy-one operations in 1995-1996 of heart-lung, seventy-one in the entire United States. The demand for heart-lungs was 438, that year that they did seventy, that means that seventy, subtract from 438 died. Died.

And so here we come with this woman, who is seen as less than human, regardless of her attributes, who, I mean, would it not be for having a gunfighter with her, who knew how to play the system and who knew everybody—I knew everybody, from top to bottom, I knew I could get them, like I knew I could get Willowbrook—so who has that kind of firepower with them?

So you have this situation that was begging, begging for recognition, by the Disability Rights movement, to understand the higher and more generic opportunity that existed, for them to make a mark on the American conscience. Not as, oh, we've done something so wonderful for this poor girl with Down's Syndrome, and you've been so wonderful to give her an operation, and this delicious blond angel is now okay and everybody can go back to business as usual. That is exactly the wrong kind of agenda. The agenda had to be that this had to be open for everybody, because if it wasn't open for everybody, it was open for nobody. And nobody had the capacity, short of millions of dollars, short of insider relationships with the chief surgeon, short of being the head of that community or whatever, could be more or less assured of having their life valued enough to potentially be operated, or to potentially have their life prolonged.

Cowan: So that campaign just did not broaden out.

Bronston: Right. The disability movement, again, did not see that this was a viable agenda, didn't see that they had the resources to be able to engage it, because all they could see was the remote and limited relevance of transplant surgery to a remote and limited component of their beleaguered and embattled lives in general, at every level.

Cowan: What could they have done, for example?

Bronston: They could have generated one or two paid positions, placed in Washington, to follow up with the federal bureaucracy to ensure that there was a relentless campaign to study the problem. I wrote a study bill for California at the same time that I passed through to Senator Watson, Diane Watson, who is the chairman of the Senate Health Committee. It was picked up, instead, by one of the Democratic Assembly people that just ran for mayor, Anthony Villaraigosa, who instead put in a human rights bill disallowing discrimination by any transplant program of people with disabilities, which was just a paper kind of thing, because it didn't have anything to do with fixing any of the problems.

<u>Need for universal health care</u>

Bronston: What instead I tried to do with another very dear scholarly friend in Washington, DC, Bob Griss, who runs a think tank program there, was to really create a way of setting up a set of public hearings in the state that would bring people out to talk about the larger issues and connect that to universal health care. Because without universal health care, you were right away dealing with another fractured piece of the population that can afford the operation because of their public subsidy in the first place, like Sandra could. But the majority of people can't. So unless you have a situation where you can look at universal health care as a fundamental right, the question of how to deal with the discrimination and barriers that exist to reach the transplant arena, and the ability to create some impact on the donor scarcity in the country, could not be addressed.

But the disability community would not invest the dollars to hire a staff person. And we had, God knows, half a dozen key people who surfaced in the campaign who could have been put in Washington for a year for twenty or thirty grand—

Cowan: As a lobbyist?

Bronston: As a lobbyist, as a researcher, as a coordinator, as a staff person to be a go-between to try and begin to look at what was happening amongst the membership of the various different disability organizations. We needed to do a study, a survey, amongst the parents of, these parent organizations to find out, did they know about transplant access? Did they ever realize that it was a system available to them? Do they need, do they think they need, some advice about this thing for their kid, who may be three now, but is going to have to have a transplant because of the problem they've got when they're twenty-three?

We never could staff the campaign. We never could ask the right questions. We never could take the system on at a point where we had the drop on them. We had the public relations drop on the federal bureaucracy, and the eye of all the media, on us. And anything we could have done, we could have walked through that system like a hot knife in butter, had the disability community only had the capacity to establish, even for six months, one or two paid people to do the job.

Cowan: Do you think that's because that community itself has no national unity and is itself composed of small pieces that can't unify, or do you have some insight into why it didn't?

Bronston: You know, it takes a certain amount of energy to imagine the problem. And even at my height of energy, I still can't seem to push through my own emotional blinders to try and come up with an answer to why it doesn't work, why in hell the disabled community, as vast as it is, as suffering as it is, doesn't have the capacity to rise above the narrowest, right in front of their nose, self-interest. Why there's such incredible lack of boldness, lack of imagination. I mean, God knows they have enough to deal with, and they do a lot. But I believe things relentlessly get worse if they don't get significantly better. And the key to getting better is generic alliances, not political breakthroughs in a narrow categorical sense.

You can't make things better for the disability community without them getting worse at the same time. Because to the extent that you win concessions, from the system, at the expense, in the minds of the general public, of their resources, you wind up creating a breach. You wind up creating a tug-of-war, so it's a competition between one interest group and another, regardless of the virtue of that interest group against the whole. So I believe that people that really have an legitimate interest that flows from an insufficiency or an inadequacy or a corruption in the general community, have to speak on behalf of the general community and the generic benefit, not just their own parochial payoff.

Cowan: Well, after your effort to save Sandra, and use the crisis as a tool, what's been going on since then in your career in the Department of Rehab? That's 1995 to now?

Bronston: Sandra's death was just a terrible loss to me. I can't even tell you how much that hurt to have her die and to have her die without my sense of feeling that it was a warranted struggle, that the sacrifice was worth it. Because I really didn't know, and didn't have any capacity to influence what was to happen from then on in relationship to either the transplant situation or disability politics, for that matter. It again led to another reason for my painful withdrawal from disability rights politics, and an attempt to try and move to a more general strategy around organizing kids, high school kids, to address some of the social issues that I see, that burn with me.

Summing up: struggle for equality continues

Bronston: I've had very little or no contact with the developmental disability community since then. I found myself really struck by the lack of any significant challenges or breakthroughs that were relevant to the general community at all, since that time, that I was aware of. Certainly, there were lawsuits that were filed, the Coffelt suit, and a number of other major challenges that were challenges that were really thirty years old, fifty years old, sixty years old in terms of their relevance, their political policy relevance in the human rights movement. Ed Robert's death was really another crowning loss.

And without Ed alive to provide the kind of fearless and bold and loving leadership that he did—I mean, there was really nobody to take his place. There was no leader, there was no champion that I knew. Granted, there are, I'm sure, thousands of heroic warriors out there. But the system is set up a way to make those people invisible, and to not allow us to link up or to know about each other's achievements, or struggles, for that matter, in a way that would make them more than just survival battles in a defensive mode, in a situation where everybody's overwhelmed with trying to just keep life and soul together.

So I really lost track with all this stuff. It's sort of like, I don't know whether I can generically talk about my time being passed as a leader in this area, because I certainly have such embedded prejudices and disappointments, in and amongst the achievements. I just don't know where the benefits have flowed from the work that I've done. And I certainly understand, as well or better than anybody that I know, what's at stake. I certainly can make the argument, and I can certainly stand up and express my concern about the odd disassembling of consciousness, of militancy, of organizational integrity.

It's as if, with ADA and 504, and 94-142, and kind of going back and looking at all the lawsuits—the struggles, essentially, have brought about a significant affirmation of people with disabilities in the culture, both physically and culturally. But it seems to me, in an odd way, that we're maybe not even up at the null point, at the line yet, really, to take some creative steps forward. When I look at what's going on right now, for example, in my own department, the whole rehab engineering field, is almost invisible. There were enormous opportunities for adventure and breakthrough and linking people to facilitative strategies to enhance their integration and inclusion in everyday life.

Certainly, the vocational movement, with the new Rehab Act Law changes that occurred in 1992, have had an enormous effect, but it has essentially deprived advocates, in large part, for anything more than tactical or individual attempts to look at the system. And what we've seen in the ensuing twenty years, is the artificial manufacturing of more disabilities than we ever dreamed possible through war in the world. Relentless killing and war. In the Horn of Africa, in Southern Africa, in Northern

Africa, in Latin America, Central America, in the Slavic Bloc—in India, in Pakistan, in Iraq, in Iran.

What you see is the capacity to undo, and promulgate injury and disability that staggers the mind. Here we are, trying to figure out how to get a kid into a mainstream class, how to get an adult into a decent job, how to get a law changed here and there, how to get some funding that would establish some security and integrity to programs being delivered by the state, or the county, or the feds— And we're spending money beyond imagination in corruption areas, like the whole Enron thing, like the whole Savings and Loan system collapse a decade ago, and in war.

[Tape 17, Side A]

Cowan: Well then, looking forward to next steps, next challenges—

Bronston: Right now, in California, something very interesting has happened that is really fascinating to me. And it really was emphasized by the experience I had when I went back to Willowbrook for the twenty-fifth year convocation to commemorate the Willowbrook Consent Decree Ruling. I went back to Staten Island, as I think I talked about earlier, in order to revisit Willowbrook, and the joy of joys, to meet with the many families that had become almost like my family back then when I was there. The thing that struck me was that there was a pervasive sense of sadness at that gathering, two years ago in Staten Island. And it was just so impressive to me, how much struggle these families had had to make in order to fight against this cancerous system of congregate, segregated management of what the system saw as a social problem, handled in a way to benefit it through a commodity, profit-making, bureaucracy-building agenda, which was kind of the response of the system of the challenge.

Cowan: And that's what you see going on in California now?

Bronston: The thing that was so impressive to me there, was that all those families were now in their seventies and their eighties, and their sons and daughters were in their fifties and maybe sixties, and all of a sudden, the irony, the total irony was that not only were the young people, now facing reinstitutionalization in the generic system, but their parents, the warriors against institutions for their kids then, were absolutely candidates for nursing home, warehouse, institutional care, premature death, and exactly the same circumstances that they had fought against, in a different arena, under a different flag, forty years ago, thirty years ago, twenty years ago.

So here we are, 2002, without a drop of progressive change towards fundamentally ending the manufacture, through our funding systems and our policies, of a domestic refugee population that is destined for institutionalization, to rid society and capitalize on its unwanted and burdensome membership. So we've kind of come in that funny full circle. The next major wave, I think, of human rights struggles, are going to be focused around the preservation of meaning and integrity and liberty for elders. And the promulgation of a vision of what dying well, or growing on, past old age, is going to mean and be translated to into service delivery, which is going to require at least two major profound breakthroughs. One, the elimination of profit in human service delivery, and two, the establishment of a comprehensive, universal, healthcare delivery system in the United State and in the rest of the world.

Without those two fundamental breakthroughs, the whole anathema and cancer of institutionalization and alienation of people of questionable value to the mainstream commodity commercial system is a fundamentally centered agenda.

Cowan: What do you think the chances are that that change will happen?

Bronston: It's the same gambit that brought down the Berlin Wall, the same gambit that down Apartheid in South Africa. It's not going to happen by evolution. It's going to happen by a leap, a lurch, a revolution in society, at some level, a breakthrough that will create a crashing change, provided we're ready to take that leap, and provided some work has been done in that direction. For example, right now, there are four things that are going on that are very interesting here in California, that I think could be used catalytically if there was leadership to be able to bring those four things together.

Number one, you have a situation where a piece of legislation has been proposed to capture all the assets in the current state system for serving people with developmental disabilities, read institutional land and buildings, so it doesn't get lost when that stuff is sold off because it's not being used anymore, and go into the general fund. It's supposed to stay in the developmental services system. Now, we're not talking about the disability movement in the physical disability, sensory disability area, but in the developmental disability area, which is again where the opportunity it arising. That piece of legislation is AB 896, that's been created by Assemblywoman Diane Aroner. Where that struggle, where that policy issue is going to wind up, I don't know yet, but at least it's been struck, at this moment.

The bill hasn't passed, it's being held up, the system doesn't want to pass it, but we just had a situation where Agnews State Hospital sold off a little piece of land. They got $176 million and the governor stuck it in the general fund, it could not be retained in the developmental service system at the same time that the system cut $100 million from the developmental service department, and is proposing, this year, three years later, to cut another $52 million from the system, when we're already at a place where people have to not be served.

Number two is that a new lawsuit has been filed by Tom Gilhool, the Sanchez lawsuit, that essentially is challenging the disequity in pay between institution workers who make an average between thirty-five and fifty thousand a year, and community-based workers who make an average of eighteen thousand a year, on the ground that the disequity in pay is a direct barrier to constitutionally guaranteed, rightful services that promote life, liberty, and the pursuit of happiness, and a constitutional violation that has to be corrected through a wage-scale and benefits adjustment.

If that lawsuit succeeds, it challenges the whole question of what we're going to do, where we don't even have a fraction of the people that we need to deal with people with disabilities, read elders, because the real change is no longer the one solution fits all, out-of-home placement for people with disabilities. That's the one solution that fits all, for all of us, us, who are getting older.

Number three, the state is foregoing each year, a billion, five hundred million dollars in unapplied-for waiver money through the HICVA system, and the Medicaid system in the United States, that essentially that would bring back a billion five to the state of

California to pay for alternative, read in-home support service programs, for people with disabilities, read elders, in that equation.

The governor and the state of California has to be challenged for how it can dare yield a billion five every year, this year, next year and every year from now on, that it desperately needs in order to meet the constituency needs in the disability community. So the question is going to be, can we link up with common heart and common vision between the disability community and the elder community, which is everybody? Again, the real challenge is how to take the specific human rights struggles that are so clear and definable in the disability area, and make them as clear and definable for the general populace as a relevant and urgently needed human rights reform, human service delivery and economy transformative challenge.

Then, of course, part of what will make all that stuff begin to come to fruit is the forced closure of the existing big state hospitals because of a billion five requisite for fixing them for health and earthquake standard—architectural criteria in order to continue to get federal dollars. So the state, with its twelve billion deficit today, is not going to look for a billion five to fix and renovate those old properties that are worth ten times, a hundred times that much money to sell off—to solve some of those problems. And there is going to be the question of, who is going to put the gun to the head of the system, in order to prevent that money from being squandered, to be put into the foibles of the mainstream political agenda. Like the energy crisis that's going on that was fabricated by deregulation movements and so forth.

And our movement, the disability movement, doesn't even think about the energy crisis, as a relevant political touchstone. They don't think about the war against terrorism as a relevant political touchstone that is a gross distortion and betrayal of a different kind of a social future, and a different kind of a social paradigm. So again, we're constantly struggling with when and who will wake up. When and who will wake up, in order to make the proper conclusions, to see the proper connections, upon which ride the fate of all the people. People with special needs really reach the precipice first, and have to fight the fight for everybody, first, and get everybody to see the virtue in a victory that is marketed as a competitive consequence that causes dilution of critical resources, between the special interest population, so-called, and the general population, so-called, all of whom have special interest, have everything to gain by class solidarity, class consciousness, in terms of understanding who the real enemy is, where the real attrition of resources are, where the real corruption lies, where the real dream possibilities are, of an almost utopian existence.

Cowan: But for the disabled community to make a connection, to make the general populace understand that it's everybody—

Bronston: It needs new leadership. It needs new leadership. So that's one of the roles that I try and play, at least on a role-modeling basis. I went to this meeting of the California Association of Integrated Communities, last weekend, where Tom Gilhool was. There were six hundred people there, and I take the pluck to stand up in the middle of that big room, without a microphone, and outloud, try and articulate whenever I can in the meeting, what the connections are. Somebody has to speak to the opportunity. Somebody has to speak to the issue. Somebody has to speak to what the prize is here. Somebody has to challenge the parochialness and the tacticalness of our little piece of the universe in the disability area, in order to talk about the incredible possibilities that are inherent in the same struggle, slightly differently vectored. Just aimed a little bit higher, and a little bit more to the left.

And so those kinds of connections have to be made, and leadership has to be there to do that. Now where is that leadership going to come from? Maybe it'll come from unexpected sources, from young people that are growing up, from new parents that are growing up, that only suffer from one vital and critical disability, lack of history, lack of memory, lack of knowing what went on before with a feeling connected to knowing, that gives them a sense of confidence to be able to overcome the fear and inhibition of standing up in front of other people, and articulating, forcefully and compellingly, the real answers, the real forceful solutions that could make or break the next epoch of the human rights movement.

Cowan: Well, in light of that, would you like to say something about the current work you're doing with youth, since that's very likely to be where the new leadership comes from?

Bronston: Well—I've organized about five years ago, six years ago, a thing called the "Tower of Youth," which is sort of my home-spun, homegrown agenda. My impetus for that was that I really believe that if you're going to organize, you've got to reach a million people. Otherwise, what you're doing is really a token kind of a thing, which doesn't have staying power, because the system can kill that many people very quickly. And that's a very real market for me, a very real way of defining the bar. So in order to reach a million people, from a local organizing effort, there has to be a way to multiply outreach. So the sum of my work is with high-school-age kids, that I'm hoping to draw to reinforce their interest in radio, television, film-making, journalism, digital media technology, and Internet technology, and theater.

Cowan: These are not youth with a disability?

Bronston: These are general high school kids, with and without disabilities. However, honestly and truthfully, I must say that I have not seen a single kid in a wheelchair, or a blind kid, or a deaf kid, come to any of the events that I've organized in the last five years in the open community, that involves more that fifteen hundred kids a year, from six counties.

Cowan: Why do you think that is?

Bronston: I think that the disability community is fundamentally broken. I think that it lacks the leadership to be able to take advantage of opportunities to propel its youth, its seed-corn into chambers of social change and opportunity. I think the children with disabilities are more closely held than I ever imagined, as one of the leaders in that movement. I think that they are having their lives sucked out of them by parents and professionals, who fundamentally expect little or nothing from them, and don't see them as civic leaders or as artists that can be insinuated into a larger environs of influence. It is amazing to me, I mean, amazing. I market to seventy high schools, in this area of a hundred and twenty high schools, in my six counties that I work in. I essentially work with very little or no money, money that I raise through corporate sponsorships, that are now up to about forty thousand a year, which is really chicken feed. There's no paid staff. I have no space that I rent. It's all done out of my home, or out of university meeting spaces, where I bring high school kids and teachers.

In all this work, I have not been able to recruit kids with disabilities. And in truth, if a kid that was visually or hearing disabled, to come, I would be in straits, because I don't have the capital to be able to hire interpreters or Braille materials, and make the program accessible, which God knows, I know, what that all means. But I have to try and turn the corner so I have a sustainable financial capability so that I can then begin to pound, once I have the kids that come voluntarily stabilized with some kind of staff support and some kind of regular programming, and some money to be able to apply, to begin to augment and complement the access issues there.

Cowan: But there's nothing keeping kids with disabilities from signing up, they just don't.

Bronston: They don't. Now, why wouldn't they? Why wouldn't they want to do what every other kid wants to do in terms of the glamour and status-enhancing kinds of media arts activities. Every kid wants to be in show business, every kid wants to be part of high technology, every kid wants to be at the cutting edge, every kid wants to be on the in, wants to be cool.

Cowan: And that's what your program does?

Bronston: Yes. It markets "cool." I market "cool," as a way of getting there. And I market pro-active productivity. I don't want my kids sitting around being consumers, I want them being producers. I want to teach kids pro-action. I want to teach them to define the world and see the world of extremely high risk, and that they are the solution, not the problem. And that's every kid. Every kid and any kid. If they're willing to step up to the bat, and see the exciting opportunities of self-discovery, and self-realization, and community service.

Cowan: So you think kids with disabilities are not coming because they're just not—

Bronston: The adult world is prohibiting them from coming. The grown-ups are prohibiting them from coming, passively or actively. The parents are not reaching out, the parents are not projecting their kids into generic contexts. The agencies are not looking around for new solutions, they're staying amongst themselves. It's sort of like an extraordinary cult. It fills me with a sense of anger and frustration and hurt beyond my ability to really give it word. The movement that I have dedicated myself to—consciously, because I believe it is the most noble movement, is to move the culture the farthest and the broadest in terms of its understanding of life and quality of life, and the miracle of human life. But it lacks, for whatever reason, the courage, and the vision, and the leadership to serve the world properly, and continues to operate as a beggar on the corner, holding its hand out, handicapped, still, in 2002.

And that is a terrible, terrible loss to me. That is incalculable, and irreplaceable. I operate alone, without my family, without my interest group, trying to build change that is fundamentally flawed, because of a lack of leading edge involvement, by people whose very being demands the shaping of a utopian society, to which I'm dedicated. Utopian in a secular, contemporary sense of the word, of really being the kind of society that a) we can afford, and b) we got to have, and c) that's totally possible, but only possible with bold, take-no-prisoners human rights agendas, and a tremendous amount of love of the unexpected and chaos.

Cowan: Is that your final thought? Do you want to continue on?

Bronston: No, that’s it for the time being.

Cowan: Well, thank you very much for a wonderful and interesting interview.

Bronston Thank you, Kathy.

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In the 1980s, Kathryn Cowan was a job developer for a disadvantaged youth organization. She developed a program that brought youth together with senior citizens who served as mentors by sharing their personal and work histories. She subsequently served as librarian for HomeBase, the Center for Common Concerns, a public interest law firm that develops and supports policies and programs to reduce and eliminate homelessness.

She has a long-standing interest in political and social change, and followed closely the civil rights, anti-war and women's movements. In the early 1990s she became interested in the disabled persons' independence movement. In 1995 she was diagnosed with multiple sclerosis.

In 1997 she joined the staff of the Regional Oral History Office, The Bancroft Library, University of California, Berkeley, as an interviewer and editor for the Disability Rights and Independent Living Movement oral history series.

Kathryn Cowan has a B.A. in Communications from California State University Hayward.