Social and Political Advocacy in the Epilepsy Community

Anthony L. “Tony” Coelho

CONGRESSIONAL ADVOCATE FOR DISABILITY RIGHTS,
CHAIR OF THE EPILEPSY FOUNDATION

Interviews conducted by
Ann Lage
in 2004

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Emcee Tony Coelho, Leadership Gala, American Association of People with Disabilities, 2008. Photo by Ralph Alswang, courtesy of AAPD.
ACKNOWLEDGMENTS

The oral history of Tony Coelho was initiated as part of a series of interviews on social and political advocacy in the epilepsy community, funded by a Rennie Grant from the University of California, Berkeley. Additional support came from DBTAC-Pacific ADA, sponsor of a study of “Antecedents, Implementation, and Impact of the Americans with Disabilities Act.”

Thanks are also due to other donors to the Disability Rights and Independent Living Movement project over the years: Dr. Henry Bruyn, June A. Cheit, Claire Louise Englander, Judith Stronach, Raelynne Rein, the Prytanean Society, and the Sol Waxman and Tina P. Waxman Family Foundation. The Bancroft Library’s disability history program was launched with field-initiated research grants in 1996 and 2000 from the National Institute on Disability and Rehabilitation Research [NIDRR], Office of Special Education and Rehabilitative Services, U.S. Department of Education. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agencies.
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Interview History—Anthony L. “Tony” Coelho

The oral history with Tony Coelho was initiated as part of the Social and Political Advocacy in the Epilepsy Community project, an outgrowth of the Regional Oral History Office’s ongoing series of oral histories on the disability rights and independent living movements. Including the perspectives of self advocates, parents, and representatives of epilepsy organizations, the project explores the development of grassroots political activism, changes in the social and political climate surrounding epilepsy, and the role of the epilepsy community in the disability rights movement.

Former Congressman Tony Coelho was the central interview in the epilepsy project. As a youth growing up in a Portuguese-American community in Merced County, California, and a young adult in southern California, he experienced the stigma and discrimination visited on people with epilepsy. Rather than hiding his mostly invisible and highly stigmatized disability when he ran for congressman in 1978, he openly acknowledged it. In Congress, he worked with the civil rights community on a range of disability issues, and in 1988 introduced the first Americans with Disabilities Act [ADA], the major civil rights legislation for people with disabilities.

His oral history discusses his formative experiences of his early years, the development of a fervent commitment to civil rights for people with disabilities, and his embrace of openness regarding his epilepsy. He chronicles his relationship with the Epilepsy Foundation over the years, transitions within the foundation, and his continuing work for education, employment, and medical research for people with epilepsy. A significant section of the oral history deals with his introduction and managing of ADA bills in 1988 and 1989, as majority whip in the House of Representatives, and his continuing work behind the scenes to pass the bill in 1989 and 1990 after resigning from Congress. He discusses his interactions with the leaders of the disability community and others in reworking the original bill and the importance of the grassroots campaign in the passage of the ADA. Throughout he reflects on issues of personal identity as a person with a disability, the importance of public education, and definitions of normality and accommodation.

Mr. Coelho was interviewed during two extensive sessions in September and December, 2004, in a hotel conference room in Fresno, California. The verbatim transcript was sent to him for his review, and he approved it without changes. A short portion was sealed because of privacy concerns. The Social and Political Advocacy in the Epilepsy Community project was funded by a Rennie Grant from the University of California. Additional support for the Coelho oral history came from DBTAC-Pacific ADA, sponsor of a study of “Antecedents, Implementation, and Impact of the Americans with Disabilities Act.” The oral history may be viewed and downloaded from the Disability Rights and Independent Living Movement webpage,
Videotapes of the interview sessions are available for viewing in the Bancroft Library.

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Ann Lage, Interviewer

Berkeley, California

June 30, 2008
Interview with Anthony Coelho

Interview #1: September 30, 2004
[Audio File 1]

1:00:00:01
Lage: Okay; now we're recording and I'll just—

1:00:00:06
Coelho: Good.

1:00:00:06
Lage: —tell us for the future. Today is September 30th 2004 and I'm interviewing Tony Coelho for the Bancroft Library's Disability Rights Project.

1:00:00:17
Coelho: Great.

1:00:00:17
Lage: Particularly the Epilepsy aspect of it. We want to start with your background, your family. I know that you come from a Portuguese heritage. Can you tell me—?

1:00:00:34
Coelho: All four of my grandparents came from the Azores Islands and they came over to California around—around 1910—in that period there and my father's side were fishermen and they went to Monterey and became fishermen there. My mother's side were farmers, and they went to Tulare and then from Tulare to Los Banos, and then eventually to Dos Palos where I was raised.

1:00:01:14
Lage: Okay.

1:00:01:15
Coelho: My mother, her mother came over as a nanny and teenager, at thirteen, something like that, came over as a nanny. Her father came in as a stowaway in a ship, you know, an illegal immigrant, and then my father's family, his mother came over—we call her a blue blood—she came over with money and she was proper and so forth. Maybe she had ten dollars, I don't know, but we kid about it. [Laughs] And his father came over as a fisherman and—

1:00:01:58
Lage: And did they meet here?

1:00:01:59
Coelho: And they all met here; they came separately and didn't know each other, and they came here and they met. And then my father was selling—had the fish catch in a back of a pickup, you know, and he was a door-to-door salesman, in effect. And so what he'd do—he'd take the fish and go from farm to farm and be selling fresh fish from Monterey to all these families in Los Banos and Dos
Palos and so forth. So that's how he met my mother—selling fish at the farm. And then he moved into that family and he became a dairyman, and then I'm the third son and have a sister after me, about fifteen years after. I was born on the dairy farm, at the house on the dairy farm.

Lage: And did they own their own farm?

Coelho: No. Well, my grandfather, my mother's father, owned the farm, and so he moved in and became a worker like everybody else as part of the family. And then he and my uncle, my mother's brother, they then developed a partnership and had this huge dairy operation.

Lage: And so it was a pretty good-size farm?

Coelho: Yeah; a good-size farm and then—

Lage: This is a lot of industriousness.

Coelho: Oh yeah.

Lage: If your grandfather came as a virtually illegal immigrant.

Coelho: Illegal immigrant and a maid and so forth and—and—

Lage: And accumulated enough money to buy land.

Coelho: Right. And basically with this came this real belief in America and about what it's all about. My mother tells the story all the time that the only time her father, who she respected tremendously—he died when he was forty-two of cancer—but she said the only time he ever smacked her was when Roosevelt was on the radio. This was during the Depression and so forth, and Roosevelt was on the radio, and at the house it was absolute dead silence when the president was on. You couldn't speak; you couldn't say anything and she needed to go to the bathroom and was wanting to get permission to go to the bathroom, and she said something and he smacked her, and she didn't go to the bathroom [Laughs] until Roosevelt got through, and—

Lage: You're giving me some idea also of their tie to the Democratic Party?
Oh yes; but what happened is that he—he became—he loved Roosevelt. He just—and here's an immigrant and you know he never voted, but he loved Roosevelt—he loved what Roosevelt did and the hope he provided and that's really what I think politics is all about. A lot of people forget; it's really about hope and can you trust and believe in the person that they really want to make changes. Roosevelt, the reason he won so many times is he was hope; everything about him was hope. And so my uncle and my mother and my father all, you know, were devout Democrats, so that's how I grew up a Democrat, like I grew up a Catholic. You know, there's no choice; that's the way it was. [Laughs]

But then there was a dispute in the family, and there was a split, and so my uncle took his half and had his own dairy, and then my dad took his half and started our dairy. I was in sixth grade at the time, and my brother, who was in the same grade as I was, the two of us did all the milking in the sixth grade, and my oldest brother is the one who fed the cattle, so he didn't do the milking. And then my father worked on the farm, my mother worked on the farm, and it was really a family operation, and—

Lage:

How large was it?

Coelho:

We had 300 dairy cattle; we milked 300, which is a lot of cows, and we had an old-fashioned tail-to-tail barn where you had to carry the milk and take it to the separator and pour it in so that it could then go into the cans and go to the creamery and so forth and so on, and then—

Lage:

Did you have any kind of milking machines?

Coelho:

Oh yeah, we had milking machines. We had the old DeLaval milking machines, where you would manually put them on the teats so the cows—and you'd have to strip the cows. I mean when you finished—the machines would finish, then you had to manually take the rest of the milk out of the udders because if you didn't—that we called mastitis—if milk stayed in the udders, the cow would get infected and so you had to be very careful that you cleaned her out totally. So the machine would do it and then you'd strip—we called it stripping; you would strip her and then you'd release the cow, and then the next one would come in. We'd get up at 2:30 in the morning and milk until 8 o'clock or whatever and quickly clean up—well, we'd milk and clean up and then go in and—and what I used to call, we'd have a Portuguese bath. You take a wash cloth and wash off real quick and eat real quick and drive into school. School started at 9 o'clock; we never got there on time. And the school superintendent was absolutely amazing; he would always make sure that we
had study hall or gym for the first period, and so if we were late it didn't make any difference.

1:00:08:11
Lage: Was that just your family or were there other—?

1:00:08:12
Coelho: Probably did it for others, but I don't know but probably, I assume, others. I don't have any idea. I was very close to this high school superintendent. He became my first real mentor. I had a lot of mentors in my life and he was a real first—he was the first one. When I was in my senior year I was student body president, and he is the one who every day when I got there I had to go to the superintendent's office, and what would happen is that he would then talk to me about what I was going to do next, and he was very concerned that I would not go onto college, because my parents weren't interested in that, and understandably so. For them my hands were what was important. I mean, that was the value. If I left the dairy they would have to replace me with somebody else, and in family farms, family businesses, you don't replace somebody just eight-to-five, because if you're part of the family, you're working, you work twenty hours.

1:00:09:22
Lage: Well, like you said, two in the morning you'd get up.

1:00:09:25
Coelho: Yeah; and so you don't do that with hired hands, so basically you replace somebody with two people or sometimes three people. So it was purely an economic decision, and they were not interested in me leaving and going to college, and he was very determined I go to college. And so every day I'd report in, and it would be five minutes or it would be two hours, and he was pumping me, pumping me, pumping me.

1:00:09:53
Lage: And was it about your studies or about your decision?

1:00:09:55
Coelho: No, not about my studies. No, I was—

1:00:09:58
Lage: Because you were a good student, it sounds like.

1:00:09:58
Coelho: I was a good student. See, like at night we would come back from school; school was out at three. We would start milking at four, so we'd rush home, get cleaned up—I mean change clothes, grab a sandwich. We ate a lot during that—you had to eat a lot just to stay functioning [Laughs]—but we'd have a sandwich and quickly go out to the barn and get ready to milk and try to milk starting at 4:00 or maybe 4:30, which meant we didn't get through until 8:30 at night and then come in and have dinner. And then I studied; so I didn't get to bed until 11:30 most nights and so—
Did your parents support this studying or was this all—

No, I would go in and I'd study in my room and my brothers would be in bed already. We only had—there were three of us and we had one bedroom. I mean, this was the way things were. [Laughs] But I'd go in and with a lamp and undercover, or whatever, I'd be trying to read or do whatever I had to do. And my mother would wake up, because they would go to bed early, and she'd wake up and she would come in and tell me I had to go to sleep, or she'd come up and shut off the light. So it was—it was always the negative because—and this was out of love; I'm not being negative here. She knew I needed sleep in order to function, and they needed me to work, so it wasn't like I had a choice. So from her point of view as a mother, she was more interested in me sleeping than me studying.

But he [the school superintendent] was very determined, and I had the discipline. I knew I wanted to get off the dairy farm; I wanted to do something. So all he did was kept on encouraging me every day, five days a week. And it was interesting, just in regards to him, Donald [Boren ?] is his name, when I went away to college every time I came home I spent time with him; he was sort of pushing me, pumping me to keep going and so forth, and just a wonderful human being.

And you he must have seen something in you that was—?

Yeah, and he didn't do it with a lot of people, so I knew it was special, but we became best friends, and he retired the same year I graduated, and we did a big function for him. And when I got elected to Congress he was very involved, and there was a very personal relationship between he and his wife and myself. His wife was a teacher as well in the high school. She was the study hall teacher, by the way [Laughs]. She used to—well, he died early and I went to, of course, the services and spoke. But she used to say all the time that of all the years—he was in education for thirty-some years—in all those years that I became his favorite, and I don't know if I did, but it was really an obviously very, very, very warm relationship. And as I say, several people mentored me but he was my first—the very first one that took a personal interest and pushed and made me believe in myself, and that's part of what life is—people believing in you; so—.

Well, tell me more about the Portuguese heritage. Were your parents immersed in the Portuguese community there?

Oh yes; we—
Lage: Was there a big Portuguese community?

Coelho: Yeah; it was. It was a large Portuguese community, but percentage-wise in the state it's not that large. But large in that area. Interesting, last night I was just talking about it at this dinner. One of the festivals—we called them festas—these festivals in the Portuguese community. Every community in the Central Valley would have it, and they'd try not to have them on the same Sunday. So they would move it around, so from May through October we would have these pentecostal celebrations. And on Saturday night there would be a free meal for anybody, and it was made up of sopas, which is a Portuguese dish; it's bread—I always find it fascinating—French bread [Laughs] for a Portuguese function, but it was sliced bread and then it was broth that had been cooking for a long time like forty-eight hours or whatever, and it was meat and vegetables and cabbage, but a little bit of meat, a little bit of vegetables, and a little bit of cabbage and lots of water, and then you'd pour it on the bread and let it soak and then serve it that way. And it was basically a tradition going clear back in Portugal where Queen Isabella turned in her jewels to get money to provide food for the people that were starving. I don't know how much real that is but that's tradition. And so this festival is based on that thing, free meals for people so that people didn't starve, and so from April through October nobody in the Valley should ever be hungry, because you had to permit everybody to come—everybody who wanted to come could come.

Lage: So people came from other towns?

Coelho: Yeah; I mean people came from other towns and non-Portuguese of course; anybody who wanted to come it was—let me just stop here. [tape paused]

Lage: Okay. We're on again.

Coelho: So what we were talking about was the festivals.

Lage: The festivals, the feedings.

Coelho: And so every weekend, the Saturday night would be a free dinner and a dance, and it's where I learned how to jitterbug and do all that stuff because that was a big thing with the Portuguese community, and so we'd dance all night long and then go home and get ready to milk again the next day [Laughs]. Then on Sunday—we'd have a parade where girls would compete for queen, and then on Sunday the local queen would then march down the street of the Dos Palos, Los Banos, Gustine—wherever it was—Modesto, and she had two side-maids and they'd be in these like bridal gowns, and they had a big cape that seemed
huge. It may not have been [laughs], but a six-foot cape or eight-foot cape, and then there were cape holders, and I was a cape holder as a little boy. I can still remember going to all these—because if the queen was from Los Banos or Dos Palos then she went to all the other communities on this Sunday, so you would have twenty, twenty-five different queens from all these different communities marching in the parade with her side-maids and the cape holders, you know.

1:00:17:56
Lage: Were they religious?

1:00:17:58
Coelho: Oh yes, all very religious; it was the Pentecostal parade, and so there were a lot of statues that were carried in the parade.

1:00:18:06
Lage: Like you see in Europe?

1:00:18:08
Coelho: Yeah; like you see in Europe and—and they carried—the statues were life-sized, and they were on a platform, and four guys would be carrying it, one on each corner. I would say generally in most parades there were about five statues and then people praying, and you'd march from the pentecostal hall, which was the Portuguese hall, from the pentecostal hall to the church. Now the church could be several miles or it could be just two blocks, but wherever it was you marched to the church, and then you had a mass there when the queen was crowned during the mass and so forth. And the parade to the church and from the church back to the hall was put on by the queen's family. They had to pay for the flowers, and it was a big deal; so it was sort of like—

1:00:19:13
Lage: The queen had to have some substance.

1:00:19:15
Coelho: Yeah; they had to have some, or what would happen is that others would help pay, but it was the day for this family and most of the time the young girl didn't know what the heck was going on, and it was the family's thing, and it was really the mother of the queen; it was her day. That was the whole thing. It was a very Portuguese thing. And so then you'd go to the church, and you'd have this mass. While people were at church then you had people now from all these different communities. You had people from thirty different towns there for the parade, so you would have hundreds of people in and then you'd have starting when the mass would start you'd have these free feedings, and you'd go through two, three, four feedings where you'd give them sopas again. Then when the parade came back then you had singing and so forth and the meals, and then people would go ahead and go back and do their milking. And then that night you'd come back for another meal; so now we're on our third meal see, so you'd come back for another meal and a dance, and it's the queen's dance. This is the whole big thing on a Sunday night, and people
would stay up until midnight or 1 o'clock, and then just go home and start milking.

1:00:21:00:46
Lage: Start milking before going to school?

1:00:21:00:47
Coelho: Yeah, you didn't go to bed. I mean that was sort of the thing you did. So these festivals were really wonderful, and I can remember as a teenager my brothers and I getting in our pickup and going to Gustine and Newman and Modesto, Los Banos, wherever, and going to these Portuguese dances. I mean we were not interested in the food; we were interested in the dances, and we went all over. It was really kind of—it was a fun, fun, very much a part the culture of the Valley and the Portuguese community are still very much identified and do a lot of things.

1:00:21:30
Lage: Very cohesive.

1:00:21:31
Coelho: Very cohesive; the interesting thing—right at this very day, assuming that Jim Costa gets elected in November to the Congress, which he overwhelmingly will, I don't think there's anywhere else in the United States that this is true—the Central Valley is represented in four contiguous congressional districts, starting in San Joaquin County to Bakersfield, by four Portuguese American young men. And it's all contiguous districts.

1:00:22:06
Lage: Now were you the first—?

1:00:22:08
Coelho: I was the first—the first Portuguese American [congressman] in the United States.

1:00:22:12
Lage: So it wasn't a tradition for you to do public service?

1:00:22:13
Coelho: No, no, no. Well, as a matter of fact it was a negative because the Portuguese people felt politics was dirty because they were used to benevolent dictators, and you know, politics were people that were getting paid to do things and so forth. And so when I ran the first time I didn't really have the support of the Portuguese community because they felt that it was a dirty thing, and you shouldn't be running, and I didn't get a lot of support. I'm sure I got their votes, those who voted, but they didn't vote that much, and so on.

1:00:22:47
Lage: So—
But then it got to be very much of a pride thing after I got there, and then a lot of young Portuguese guys, in particular, got involved in politics; it became a big thing and now we have in California, and some other states as well but particularly in California, a lot of Portuguese Americans are involved—men and women—involved in politics, which is wonderful. But anyway, we'd have these festivals, and I did this the whole time I was in junior high and high school in particular.

That must have been the main social—?

Well, the main social—and of course high school. In high school it was every Friday night and then Saturday night and Sunday night was the Portuguese dances.

Was high school largely Portuguese?

No, no; the—

It was public school?

It was a public school, and it was made up of about one-third what I would call white—whatever—everybody, about one-third Hispanic, and about one-third African American, and—

And Hispanic includes Portuguese, are you saying?

No.

No, okay.

Well, it ultimately did, but in those days it was primarily Mexican American, but could have been people from other parts of Latin America but—

But the Portuguese didn't identify—?

Oh no, no; when—see I take the view that if you're Portuguese you're Hispanic, because you're from the Iberian Peninsula and that's what Hispanic is. So when I was in the Congress I joined the Hispanic caucus, which was
very controversial. When the Portuguese community—because there was a lot of negativism towards those Mexicans, in effect, and I always found it fascinating that people discriminated that way but they did. But I joined the Hispanic caucus because I—first off I said I was Hispanic, and I felt strongly about it, and the Hispanic caucus wanted me to be a part of it. And so I did. And secondly I got amendments through the Congress making sure that for SBA [Small Business Administration] loans and different loans where it said the qualifier was Hispanic that it included Portuguese Americans, and so I really pushed it hard. Dennis Cardozo, who just got elected to the Congress two years ago, followed in my footsteps announcing that he was going to join the Hispanic caucus. Well, the Republican Portuguese community really made it into a big issue, and he wasn't sure that he had made the right decision, but ultimately he realized that most of the Portuguese community thought it was positive, but it became an interesting political issue and it's—.

Lage:

Now, weren't Portuguese themselves sort of stigmatized or discriminated against?

Coelho:

Oh yeah; I tell the story all the time. When I was in the Congress is when the Hmongs came from the mountains in Vietnam and Cambodia, and I assume you guys don't need the history of that, but basically they were the mountain people from the Vietnam war. They were our intelligence force, and we made a commitment to them that if we ever left Vietnam that we would give them full citizenship rights, for being our spies. And so sure enough when we left then there's all these mountain folks and they came over; we kept our commitment and they came over by the thousands, and Carter was president and they designated certain areas of the United States for the Hmongs to go to. One of the areas was Merced, California.

Lage:

Did you have anything to do with that happening?

Coelho:

Oh yeah; I'm very pro of that and I will tell you in a moment, I was very involved with the Hmong community. One was Merced, one was Fresno, one was in Michigan, another was in Louisiana and so forth. And when they came to Merced they had no language, no written language, and so there was nothing to help in regards to translation and so forth. So these folks come over; there was total immersion. They just had to learn English, period. Secondly they lived in, you know, huts and so forth; they didn't understand stoves and refrigerators and so on, and they didn't understand you had a bedroom and a separate living room and a kitchen and my God, three families could live in those three rooms. And so they would come in and they'd have families, in a one-family apartment, they'd have three or four families. It was an assimilation into a whole different culture, but the land of opportunity in which they were excited about.
And so they came and they became excellent students, but they started—you
know, dogs and cats weren't pets in Cambodia and Vietnam; it was food. And
so what they started doing was, if there was a stray cat or dog they killed it
and ate it and [Laughs] that caused a little bit of an uproar in Merced. And the
Mayor of Merced, Melvin—whew, I can't think of his name now—but he was
a Republican but he was very upset with the Hmongs because they were
disrupting the culture and so forth, and they became very controversial in the
community. And so he calls me one day and wants me to come out and speak
to the community regarding the Hmongs, because I'm very pro-Hmong so I
got to speak to it.

So—Melvin Wells—Mayor Wells wants me to come out, so I come out. And
I'll never forget it; I was irritated that the community was discriminating, and
they weren't receptive because I was born and raised in this area and I know
what I went through as a Portuguese American, and so forth. And so I get in
the room, and he introduces me with a question, a very curt introduction. He
says, basically, you're a big advocate and they're disruptive and so forth, and
we want you to explain why you're for the Hmongs.

So I got up—and I don't remember the exact names, but I got up and I just
looked at the audience. There were about 100 or 300, I can't remember—and
this was about 1982 or something like that. And I looked at the audience, and
I said, for instance, [Mano?], I can't believe you're here. I remember growing
up with you, when you hated being called Portagee; you hated being called a
Green Horn; you hated all the negative stigmatism that people . . . And Joe, I
can't believe you're here. You hated being called a Spic; you hated being
called the Wet Back; you really resented the way people treated you. And
Sam, it's shocking that you're here. You hate the word Nigger and you hated
people when they called you that. And here we are, here today, and you're part
of an effort doing the very same thing to another group of people that was
done to you, and you're participating in it. I don't understand it; I don't see
why we're not welcoming—they want to be Americans. [Cell Phone] They
want to be Americans, and they want to be part of our system. They want to
participate in our society like you have; that's all they want. They want to
work, so I don't understand why we're here. I don't understand what the
purpose of this is. And I sat down. And there was dead silence for a moment.
[Laughs] And then all of a sudden a few people stood up and started clapping,
and everybody then gave me an ovation.

Lage:
So that really struck a cord, huh?

Coelho:
Mayor Wells never talked to me again. [Laughs] And it just, it just punched
the thing, which is I think what needed to be done. But I would come out, and
I would go and visit and I'd do interviews with them, and I'll never forget. One
time a little girl was—came up to me, a little Hmong girl and she was all
excited to meet me and so forth, and so I asked her if she was in school. And she said, “Yes.” And I said, “Do you like school?” She said, “Oh, I love school.” I said, “Why do you like school?” She said, “Well, here you go to school free.” She said, “Where I came from you had to pay when you went to school every day and we couldn't afford it, so I didn't go to school. Here you go every day and it's free,” and her eyes were big and lit up. It was just so refreshing to see that all over again. I was disappointed in our community here.

1:00:33:01  
Lage: Back in high school, were there tensions?

1:00:33:03  
Coelho: Oh yeah; there was—

1:00:33:04  
Lage: Were you—did you relate to the other groups?

1:00:33:07  
Coelho: Well, it was interesting. I was student body president in high school, and I was very active in government. And I had a lot of support from the black community, but not from the Mexican American community, and so it was white and black versus the Hispanics. Now, I had some from the Hispanic, of course, but the point is that it was interesting to watch the division that was taking place at that time. It was the motorcycle gangs at that point and—

1:00:33:38  
Lage: These are the fifties, right?

1:00:33:40  
Coelho: The fifties, yeah; these are the fifties. I graduated in 1960, so these are the late fifties, and you had the motorcycle gangs with the bike chains, and all the kids would come to school dressed like they were part of the motorcycle gangs and all that stuff. But it was an interesting time, and it was interesting for me—I didn't realize what was happening; I just was part of it—the divisions and the gives and the takes, and I had some wonderful friends. Because the high school was so diverse I had wonderful friends in the Mexican community and in the black community, and I never thought about the, you know, the discrimination. I mean it just—it didn’t—it wasn’t part of me; I just didn’t think that way.

And my family was not that way. My family—I guess it had a lot to do with my grandfather, but my family felt very sorry for poor people, you know, and they would give the shirt off their back to help somebody who was poor. And it was a sin to let somebody go without eating; I mean that was just wrong to have people not eat and be sick and so forth. And I grew up with that culture. I mean that was part of what I was taught and what I believed and so forth, and it’s very much a part of the Portuguese culture. But it was a wonderful life to be part of, and also it ended up being the thing that stabbed me pretty hard
later with my epilepsy. But you felt the warmth there; you felt the—sort of the cocoonishness; it was sort of they put you in this cocoon and protected you.

1:00:35:27
Lage: But it wasn't an exclusive thing, excluding others?

Coelho: No; it wasn't excluding others but it was very much—

1:00:35:36
Lage: Keeping you in your place?

1:00:35:37
Coelho: Yeah; keeping you and loving you to death, as the old saying goes. But it was very much—it was very, very family. I mean we never had baby-sitters. Growing up, never had a baby-sitter. If you couldn't take your kids, they didn't go. I mean if it was a wedding or if it was a party, you just didn't go someplace if you couldn't take your kids.

Also during certain parts of this time, they would take the Pentecostal statue—it’s a crown and it's basically symbolic of the Trinity in the Catholic Church, of God, the Holy Spirit and Jesus—and you would take this crown, and you'd have it at a home for one week. It would start on a Sunday, and Sunday night people from the area would all come over, and you'd have drinks—not hard—well, you had a little bit of hard drink but mainly it was soft drinks and Portuguese wine, and you had cookies and donuts or whatever. So it wasn't a meal; it was just snacks. And then you would pray the rosary. And you'd go through all five decades; you'd say the rosary and the priest would be there and lead in the rosary. And when the rosary was over with you'd have these snacks, and then people would go home. And so a family would do that for a whole week, starting Sunday all the way through, and every night the people would come in and so on.

It was a big thing; growing up, the whole Portuguese culture and the reflection of what it meant to be a part of a family—your own family but a bigger family—was something that was embedded in me going way back then. And you always felt like you were part of this community, and it was a very protective community, and in politics later they were very protective of me. So it was kind of an interesting thing to watch and to be part of, and of course I had no idea of the importance of it at the time; I was just part of it. But reflecting back it was a very interesting time.

1:00:38:15
Lage: And was the school principal Portuguese?

1:00:38:18
Coelho: No. No, the name was [Borne], Donald [Borne], so I imagine he was—he was European, I guess, but probably Scandinavian, I would think, yeah.
Lage: Did you yourself have dreams about what you wanted to be, as a kid or—?

Coelho: I just knew I wanted to go to college and I'd always believed that I could do something. I mean I just was a true believer in that, you know, what I say today—the American dream—but I really believed that I could do something. In my family nobody had been to college. It just was unheard of because it was the work ethic and to work with your hands. But I always wanted to go to college, and so that was when I went to junior high that's where I was oriented, and in high school the superintendent really pushed me on it, and I felt I could do it and so on, and then he advocated to me that I had to go away from home. He didn't want me to go to Fresno State; he didn't want me to go to UC Berkeley or anything like that; he wanted me to go to Los Angeles, at least. And the reason was—it was interesting listening to him; he said if you go to Fresno every weekend you're coming home and milking cows, and you're not going to get out of the culture. If you go to Berkeley it probably will be the same thing. What you need to do is to break so that you can develop your own personality and so forth, and you have a lot of potential but you're never going to realize it if you don't make the total break. So I trusted him and believed him and went to Los Angeles and visited Loyola University and I loved the campus. It was small, which is what I needed a little bit; I was a little afraid to go to a huge campus. And I applied and got in and it was a great—I mean it was like a fish to water; I mean it was a wonderful place to go to.

Lage: How about financially?

Coelho: It was interesting. My parents didn't have a lot of money. As a matter of fact they went bankrupt during my college years. The university—I worked during the summers and the university basically subsidized me the last two years.

Lage: So you got scholarships?

Coelho: Yeah; and I was a student body president, and they just paid for everything then—.

Lage: Isn't that nice.

Coelho: So it was a lot of nice things that happened to me as a result of—and I didn't really struggle with the financial problems that they were having because I didn't know it. Maybe it was sort of like, my life went on. It was not—
Lage: You didn't take it on—

Coelho: Personally.

Lage: —personally that you left, and they lost their work-horse.

Coelho: I didn't—and I took the view that my father couldn't adjust to, basically, me leaving, and my two oldest brothers both got married and left as well because his whole attitude was that you were slave labor. I don't mean that in the negative sense, but that was sort of the family thing, you know. You're a part of it. And when the wives wanted to buy clothes or buy food, they had to come to my mother and get the money. There was no salary. Well, these women that came into the family didn't like that, and I don't blame them, but it was a real tough cultural thing to move into a—bringing other people in as part of the family, who had legal rights and so on, and to be treating them in a different way as opposed to “we control everything”—money and time and—.

Lage: So it was really a generational—

Coelho: Oh it was a real tough thing and as a result they had to hire a lot of people to come in, and the people have a different attitude, and they went bankrupt. It was kind of sad, and I never felt guilty about it because I couldn't do anything about it. I mean it's something that my father and mother had to adjust to, couldn't, and eventually did, and they were fine. But they had a hard time; it was a real difficult time and that's true with a lot of these families during that period. They wanted their kids to stay, and it's true with family farming period.

Lage: Did your brothers marry Portuguese women?

Coelho: My oldest brother married a Portuguese lady; she herself was from Portugal so she came over with her family, a wonderful woman. They divorced. And my brother between the two; he married a—I don't know—what you'd call a Heinz 57 you know. I don't know what nationality she is—Canadian and different—different languages—different cultures and they only were married a few years, and then he married a Portuguese gal and—and—

Lage: And they didn't go onto higher education?

Coelho: No, none of them did.
Lage: Did your sister—your younger sister?

Coelho: My younger sister got pregnant in her senior year. I was pushing her to go to college, and she would have gone but got pregnant and married the fellow—a Portuguese fellow. The marriage dissolved in about six months—they were high school kids—and then she married a Portuguese guy, and she never went to college. So nobody else in the family went ultimately. She would have gone, and she would have been a big success in college. She is very, very bright and still is—she runs a newspaper and a printing company now in Newman, California, and very capable lady and better politically than I am and she's really—

Lage: That's saying a lot.

Coelho: Well, I think I'm decent, but she is very good. I mean she's very, very political and very, very good—gets along great with people and so on. So and I'm sad that she didn't get her chance to go to college, but that was it.

Lage: Let's talk about—about the epilepsy—the reason we're here for that [Laughts], but I'm really glad we got that background because it all—

Coelho: Well, it will help because as we go into the other part—it's important.

Lage: Yeah; so tell me about when you first had—

Coelho: Well, what happened is that on the dairy farm one day I was with this hired hand we had—Walt is his name, I just remember; I had forgotten his name. But Walt was driving, and we were going down the canal bank, and he was speeding. It was gravel, of course, on the canal bank, and he was speeding, and we were going around a curve and he over-reacted, over-corrected and the pickup flipped and went into the canal. All I can remember—I hit my head on the windshield. and I remember the passenger side window was open and when the pickup went down the passenger side was up and I floated out that window—I had a severe headache. But we both were alive, and I had this headache, and he didn't get hurt. So we got out and the headache lasted a long time, and I always joke about I wasn't worried about that end of my anatomy; it was the other end, because we totaled the pickup and I knew what that meant.

And nothing happened; we didn't go to the doctor. You didn't do those things. And the headache went away in a day or so, and then a year later, about my junior year, I think, in high school—I was sixteen at the time or seventeen—I
was in the barn milking in the afternoon about 5 o'clock, 6 o'clock, and the next thing I remember—at that point we had a parlor barn, which meant that instead of tail-to-tail there were eight-cow Surge power, it was called, and four cows on each side and they'd walk up this ramp, and so instead of bending over to milk, the cows were now at your level, and you stood up and you put on the machines, and it was all automatic, and the milk would go through pipes and go into the separators so you didn't have to carry the milk then. It was a Cadillac! My God, it was easy then.

But we didn't have automatic feeders in those days; eventually they did, and they do. But you had to reach down in a big wastepaper can, and you'd pick up a scoop of food, grain, and put it in the bin for the cow to eat while you're milking her. And I remember going down, and that's all I remember. And what happened is I just passed out in the grain can. My brother was in the barn milking at the same time, of course and he noticed me go in, and he started screaming and picked me up and carried me. The house was on the other side of the road. It was a county road that went between the house and the barn, and he carried me to the house and my mother—I'm out, so I don't know anything about this.

My mother called the doctor and the thing I remember—so I had to be out—we lived about twelve, fifteen miles out of town, so the next thing I know I'm waking up and a doctor is sitting on me. I thought that was rather strange. But I was having a seizure—I had a seizure—having convulsions, and so the doctor was sitting on me. When I came to, he got up and I felt suffocated and I was exhausted and I didn't know—I asked what had happened, and so they told me I had just passed out. And obviously because I was tired, you know. Now what I didn't know is that the doctor wanted me to come in, which I did go in the next day, but the doctor had told them that he thought that I had an epileptic seizure.

Lage: Uh-hm; so he told them right from the beginning?

Coelho: Yeah, and of course they didn't tell me that. And so the next day I went in for the test, and the tests supposedly were inconclusive, which they weren't. They said I had it and [Cell Phone Rings]—let me just take this; it's my wife.

Lage: Sure.

Coelho: The phone may keep ringing, so I'm sorry.

Lage: Okay; well we'll just deal with it. Okay; we're back on here.
Coelho: So I had the seizure, and the next day the doctor had confirmed what it was and—

Lage: But—

Coelho: —they didn't tell me; and the reason they didn't, which I found out later, was that they believed that if you had epilepsy it meant that you were possessed by the devil. It's a cultural thing, and it's something that people in a lot of different cultures still believe. For example, the Hmongs that I talked about earlier, in a book about a little girl who had epilepsy, I'm mentioned in there. The reason I am is because the Hmongs came to me and wanted to pray for me to get rid of the evil spirits. They have a real problem with that. And in the Asian culture it's a big thing. It's a big thing in the black culture—the same thing—evil spirits.

Lage: And is it a Catholic cultural thing also?

Coelho: It's very much in the Catholic, because the Catholic Church—and this plays a big role in my life—the Catholic Church in 400 AD adopted as part of canon law that if you had epilepsy or were possessed by the devil, you couldn't be a priest, and over the years people put those two together, so that if you were possessed it meant you had epilepsy. So the—so the two became one for a lot of different cultures; so—.

Lage: Has that changed in the Catholic Church?

Coelho: Well, [Laughs] it's an interesting story. In 1987 I'm whip in the House, and I make my first official foreign trip, and you get to designate—in those days at least—two locations you want to go to and the State Department designates one. So they wanted me to go to Morocco because the king of Morocco was very engaged with Portugal in regards to the Middle East and the king of Morocco was sort of our moderate in those days. And so they wanted me to go there, because I was Portuguese, because I was going to Portugal and so forth, and help cement in some of these things we were doing. And I wanted to go to Portugal and I also wanted to go to the Vatican, so those were my two parts of the trip, and then to Morocco. So we go from Washington DC directly to Rome and have a private audience with the pope, and it's my whole delegation; it's now Senator Boxer but then Congressman Boxer, and Vic Fazio from Sacramento, and John Dingell from Michigan, and Steny Hoyer

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from Maryland, and I can't remember everybody—Jerry Lewis from Riverside was the ranking Republican. So there were about fifteen of us. And we all meet and have a private audience with the pope.

And when you have these private audiences, whatever you're going to say has to be approved prior to the visit. And so we had to prepare a statement and have them approve it, and then they approved the trip, and all that other stuff, so we did all that. So we get there and we have our audience with the pope, and I'm now going to make my comments to the pope in front of everybody and at the podium there. So I go up to the podium, and I make my statement, and when I get through with my statement I said, “Your Holiness”—and nobody knew I was doing this; my wife didn't know, the delegation didn't know; I didn't tell anybody. I said, “Your Holiness, I cannot live with myself if I didn't bring up a personal issue at this point. As a young man, as a result of an automobile accident I developed epilepsy, and in college I decided I wanted to be a Catholic priest, and I was denied because of my epilepsy, and what shocked me is that canon law says that if you have epilepsy you can't be a priest, and I think that's un-Christian of our church, and I would ask you to look into it.” That's all I said. Now around the room, all of his minions around the room, and they're just apoplectic—[Gestures]. And my delegation is shocked.

1:00:55:40
Lage: Because you spoke out of turn?

1:00:55:40
Coelho: Out of turn, and made it very personal, but I just had to do it, so—

1:00:55:50
Lage: Did he respond?

1:00:55:52
Coelho: Well, it was interesting. I got through, and then he did his response, and his response was very much part of the script. It's what they said he would do, and so it was very nice and ignored my personal comments. So we get through, and we take all these pictures. (The other side note is that you're not allowed to have any cameras in the room, but they have their photographers, and they're all taking these pictures of everybody and so forth, and two hours later you have proofs of them and it's $5 per photo, so it's a great way to make money.) [Laughs] So no pictures allowed but our photographers, and everybody bought a lot of them; I bought I don't know how many of them but we bought a lot of them.

But as we left, my wife and I are walking out, and he is holding her hand and she's a convert, and she didn't quite know what to do, but he's holding her hand. And we go to the door, and as we get to the door he blesses her and then he turns to me and he blesses me, and he said, “Young man, I heard your
comments.” And that was it. And he walked out. The Canon Law has changed.

1:00:57:06
Lage: Oh, it has been changed?

1:00:57:07
Coelho: Now it is up to the pope to give personal dispensation to people who have epilepsy so you can be a priest. I have not seen the actual language, but basically, I'm told, there is no longer the exclusion as such. I don't know how they word it, but the most important thing is that people with epilepsy are now priests, and I think it's great.

1:00:57:34
Lage: Okay; so—okay but have they removed the idea that you are possessed by the devil?

1:00:57:37
Coelho: No, no; that's what is irritating to me. I mean I'm not satisfied, because [Laughs] there is still the discrimination, you know, and what troubles me is that it is the stigma; that's what I have real problems with. And the church is responsible for that. And it caused me a lot of trouble, which I'll get into and you've read about.

1:00:57:59
Lage: Well let's go back to this early point where—

1:00:58:00
Coelho: Yeah.

1:00:58:03
Lage: —you were not told what was the matter with you. How did you deal with it? What did you think?

1:00:58:06
Coelho: No; well the interesting thing with epilepsy, as you know, is you have your seizure, you're exhausted, you sleep, get up and you're fine. So that's what happened.

1:00:58:14
Lage: And maybe you're not so aware of what the seizure—

1:00:58:17
Coelho: No, I don't know what the seizure is. I don't know what people saw; I didn't see it. So it—you know, so I had a headache or whatever it was—not a big thing to me. So when they said we don't know; I was fine. Then I went to other doctors and it—

1:00:58:34
Lage: That your parents took you to?
Coelho: Took me to, because they wanted to cure whatever it was, right.

Lage: But they didn't give you medication, it sounds like, or did they?

Coelho: Well, they gave me all kinds of medicine but I never stayed on it because I went to other people. They gave me prescriptions, but I never really took them or maybe I took them a day or so, but then I'd go to another doctor and the other doctor would say it was a lack of calcium, a lack of this, a lack of that, because we worked hard, and so they could blame it on all these things. And that's what I thought it was; I just thought it was from all the hours of no sleep, you know, and all this different stuff. But I didn't change; I couldn't change. I still had to work. I still had to milk the cows. I still had to do everything and so I continued to have seizures and—

Lage: Would you have them at school?

Coelho: It was an interesting thing. I always say this, you know, God was helping me out because it was always very convenient. It was always in the afternoon when I was milking cows. [Laugh] I never had them at any other time. Throughout my whole life I generally always had them in the late afternoons. So it's kind of—that's what happens but I didn't know at the time.

Lage: So you didn't have a problem with explaining this to schoolmates or—?

Coelho: No, no; I didn't—I didn't have any of those difficulties. So in college I did, but not in high school. And so I continued to go to doctors, and they supposedly didn't know. And then all of a sudden I went to witch doctors. The Portuguese believed in witch doctors.

Lage: Now what—is that what they called them, witch doctors, or is that your term?

Coelho: That's my term [Laugh]; they called them—it was a Portuguese name for them but I can't remember.

Lage: Are they related to the church?

Coelho: No.

Lage: So this is outside the Catholic sphere?
Well, all the priests know about them and then recommend people go to them but—

Oh, they do?

Yeah, but they're not part of the church. No, no; they recommend.

But it's within the circle of the church?

Yeah, yeah. The church believes in getting rid of the spirit, you know. This is part of the church culture, so it's—

So it's sort of an exorcism?

Yeah, oh yeah; the church believes in exorcism, and that's a part of it. Remember the movie *The Exorcist* and everything else.

So what was that like?

Well, you've got to remember now. I'm seventeen, and I'm a good student, and I'm class president or student body president my senior year, so it was happening at that point too. So I'm outward and all of a sudden I go into these poor little homes. The first one I went to was a black woman in Merced, and it was in a real poor part of Merced, and we go up to this house and go in, and it's a real small, poor little house, and—.

Hold on one second; I think we need—

We're back on.

Okay; so a black lady in Merced, California, a poor part of town, a very little home, and I walk in and it's scary to begin with. I had never been in a black person's home, and at school I'm extremely successful academically and socially. Working at home was not an issue with me. I thought that was the way you did things. But going into this real small little house in the black part
of town was a little scary. When I got in there my mother and the woman talked. They didn't know each other but it was recommended by a priest. My mother paid her, and so the woman pulls down all the shades and has me lay down, and she has some candles lit, and then she pours hot oil on my forehead and opens my shirt and pours the hot oil on my chest and gets a candle and puts it on my chest to burn and then starts praying and starts praying in—in strange tongues. And it was scary as hell; I just—that's all I would say. [Laughs] I was frightened about the unknown. I mean that's really what it was; I wasn't frightened of her, but I was just frightened about the unknown—what was this all about? It was just so—

2:00:02:39
Lage:

And why?

2:00:02:40
Coelho:

So contrary to everything I believed in; but all of a sudden to me there was something wrong with me. I mean so I had seizures; I didn't think there was anything wrong with me. I mean I functioned. I milked cows and I danced, I partied, I went to school, I got grades, I was active; I mean I was a normal—normal human being and all of a sudden I'm put in this place and told I'm abnormal—something is wrong with me. And it was a very negative experience for me—a very, very negative experience.

2:00:03:13
Lage:

It sounds like it wasn't much verbalization on the part of your parents to explain to you why they were doing this.

2:00:03:19
Coelho:

Oh no; there was no explanation—none, zero—nothing; it was just—you did it. In Portuguese families in those days, and it may be different today or probably not, the kids are not part of any discussion or decision-making. I mean you're—I don't mean this as harsh as it's going to sound but you're a shadow. You're told what to do, when to do it, how to do it, and you do it. I used to, you know, slave labor is what it was. [Laughs] And so you never thought of questioning, because you couldn't, and they never thought of answering or telling you. You weren't part of a discussion of what was going on or why; that's just the way it was. And I guess it's—today I involve my kids in everything. [Laughs] I think it's a reaction to that, but when it was over with I was very turned off. But I didn't say anything because that's part of what you're supposed to do. Then I was told I had to drink a bunch of teas and junk, and so I did all that. Went back I think twice, but of course the evil spirits were still there. And I didn't know they were evil spirits, but I was still having my problem—whatever my problem was.

2:00:04:56 -

Went to another witch doctor because obviously this one didn't work and went to another witch doctor; that didn't work out well at all because my mother didn't like this witch doctor. Then I went to a third one, and it was a
Portuguese guy, who only spoke Portuguese, and basically the same thing, the candles and—.

2:00:05:21 Lage: Did you speak Portuguese?

2:00:05:22 Coelho: I understand it all but I don't speak—I speak a little bit but not much—but I understood it all. And so the room dark, and you had [Laughs] one witch doctor—I can't remember which one it was now—you had to take a chicken egg and you had to keep it covered and had to rub it and so forth and put it on your chest. And if it turned rotten, then the evil spirits were still there. If it didn't turn rotten then they had left. Well, you know, give me a break; the egg is going to turn rotten. I mean there's no way around it, so the evil spirits never went away. I just thought of that and hadn't remembered that in years.

But anyway [Laughs], I go to this third witch doctor and I was fascinated with him because I thought he was probably the smartest of all three, because when he got through doing his prayers—and it was scary to listen to; he was talking about how I had to get rid of these spirits and all this other stuff. And he spoke in Portuguese as opposed to these other witch doctors, who spoke in strange tongues. I had no idea what the hell they were talking about.

2:00:06:46 Lage: Was it speaking in tongues?

2:00:06:47 Coelho: In tongues, yeah; and I had no idea what they were doing or why. But this guy spoke in Portuguese and so I understood everything he was saying, and it was basically to get rid of these evil spirits and—.

2:00:06:58 Lage: So you began to recognize—?

2:00:07:00 Coelho: All of a sudden I realized sort of what was going on here, and it was that to get this stuff out of me, and all of a sudden I thought geez, they're saying in effect that I'm possessed, you know. So at the end of this session he says to my mother in Portuguese, I can't help him. And she, in Portuguese, she says, “Why?” And he said, “He doesn't believe. And I can't help somebody who doesn't believe.” So that was it. We walk out and get in the car and my mother says, “What's wrong with you?” And I said, “What do you mean?” “How come you don't believe?” I said, “I just don't, and I don't want to ever go back to another one again. I don't believe and I'm not part of this.” And that was it; I never went back to another one.

Interesting thing that happened though during that period of time is that I was excluded from public events a lot. My brothers and I used to show cattle at county fairs. For some reason, my forms were never filled out in time.
2:00:08:14
Lage: Your—by your parents?

2:00:08:15
Coelho: By my mother and it was—"Oh, I forgot; I didn't know you wanted to go. Did you really want to show? I'm sorry; I—I didn't know that." Or just—so all of a sudden, I'm no longer going to public events where I could have a seizure. That was what it was all about.

2:00:08:29
Lage: Oh my.

2:00:08:32
Coelho: And it was just subtle little things, but I was just excluded from social occasions where I could embarrass, because what was happening which I didn't know until much later is that in the Portuguese culture and most cultures, the reason you're possessed is because somebody in the family has committed—not you but somebody in the family has committed some major sin.

2:00:08:59
Lage: Oh, so it's a reflection on the family?

2:00:09:01
Coelho: And it's a reflection on the family, and God has punished this family through the individual—in this case me—for something they did that upset him. And in the Portuguese culture what it was dealt with sex. And in the Portuguese you didn't really talk much about sex. It was really, what the suspicion was—was that somebody in the family had had sex with an animal; and if you think that through—what a burden. My God they—

2:00:09:37
Lage: What your mother's imagination and—?

2:00:09:41
Coelho: Well, look, it didn't have to be my father. It could have been my brothers, or it could have been my uncles or my grandfather—I mean it was somebody in the family, or one of the women, but somebody had sex with an animal. You know that's a hell of a burden for the family to have. And to a great extent I'm the one who's telling everybody that they've had it. I didn't know that, [Laughs] but—and of course, I knew none of this. I had no idea that all this was transpiring with my family, and I can understand why they didn't want me to have a seizure in public. I can understand all this stuff now.

2:00:10:21
And of course people knew because in the Portuguese community the word started moving that I—I was having these spells.

2:00:10:34
Lage: Is that the way they'd be described?
Spells—spells. And so it was an embarrassment for them. I go to college, and of course my mentor comes into play now because he's insisting I go. My family is saying you can't go. Now I understand why they didn't want me to go because again I'm going to be having seizures in public and away from home.

But maybe they also wouldn't have wanted you to go anyway.

They didn't want me to go anyway but now it was, you know, cocoon—keep him in the cocoon and so forth, and it was this extreme love, and look it, they hurt me a lot during this period and further on. And I will reflect on it—today is an interesting day to reflect on it—but I will reflect on it because the scar tissue is still there. But what I learned to appreciate is that they didn't hurt me because they wanted to hurt me. They hurt me out of extreme love; they wanted to protect me. And the only way they knew to protect me was to not let me be exposed, not let me be hurt in public by having a seizure. They didn't know or believe that there was any medication, and there probably wasn't at the time, to help me out. So it was this extreme love, devotion to family, the culture, protection, the cocoon—all these things were at play, and I was fighting that culture and—

In more ways than one?

In more ways than one and it was a whole experience for me—the experience for me was more educational than medical. I thought they were fighting me from pursuing education. Little did I know that that was one of the things, but that wasn't the thing—because I never took my seizures that seriously.

Did you tell people about them?

Yeah; I didn't—I didn't—

Did your mentor know about it?

Well, yeah. I didn't have any trouble. I just—they didn't bother me. I mean I just, you know, “So what?” So I'd pass out and after I'd get up I'd function. I'd normally function. I mean it never became—. The stigma became the thing that hurt me—not the seizures. And so I graduated from high school and went onto college. A lot of dissension; they can't afford it—blah, blah, blah, but a lot of it was dealing with the epilepsy. I continued to have seizures. Now interesting enough I would have them in the late afternoon; so it was after
class, so my roommate—I'd have them with my roommate or if I was out with people I'd have it, and I would tell people that I pass out periodically and everybody would laugh, and I'd laugh—no big deal. And it never stopped me from doing anything. I still had great grades. I was under no medication—great grades. I was active in student government. I ended up being student body president and so forth, and so nothing prevented me from doing what I wanted to do, in my view. And so then I dated and all that stuff.

And then in my junior year my very first traumatic experience was the assassination of John Kennedy. It really affected me; I mean I went into a funk for five days.

Lage: Had you been a follower of politics?

Coelho: No. Well, no. I wasn't political. I just loved John Kennedy—the fact that he was young, the fact that he was Catholic, a Democrat of course, from my grandparents. I didn't think Democrat/Republican; I wasn't into that, but I loved, just loved everything about him. I just loved that he was so articulate, and it made me proud; it just was really an amazing thing. So when he got assassinated I was social chairman at the school, and I remember going in the dean's office, and we of course understood that he was in the hospital, and they were trying to save him. And so the dean and I talked, and we decided to all go into church, and so we had the bells ring, and it was a call to mass in effect. So when the bells ring a 1,000—all the kids were there—and the classes broke of course and everything. And the chapel was full and out onto the street outside and the gardens below and the lawn just—everybody kneeling and praying and all the priests and so forth. And of course we were told he died. I didn't do anything for five days. I just watched TV, as most Americans did. But at the end of it I decided that if he could give up his life for the country, why was I—I wanted to be a lawyer, why was I so monetary? I needed to do something to help people as well. This was greedy and selfish on my part. So after a lot of thought and talking to people and so forth—this is like nine months—I decided to become a Catholic priest. Now I joke at this point when I speak about it that my girlfriend of five years was a little shocked. And my fraternity brothers knew better and so forth.

Lage: Because you had had the normal active social life as a college student?

Coelho: Yeah, but I decided about midway, three-quarters of the way through my senior year that that's what I wanted and I was very—

Lage: Do you think the influence of a priest—Jesuit priests, were they not?
Coelho: Jesuit, yeah.

Lage: Was important, or was it your home church?

Coelho: No, the Jesuits were exciting to me; they were intellectual. They pursued education, and I loved talking to them. They were stimulating; they tried to make you think. They tried to make you develop your own thoughts about what was important, and their whole philosophy was they destroyed everything you were taught growing up, and you had to be forced to find out who you were and develop your own personality, and they did that. They did that with me.

My second mentor came into being then; it was Father Alfred J. Kilp, K-i-l-p, a Jesuit priest. He was the dean of men and a former military chaplain—AJ, I used to call him—beautiful man, blue eyes, had the chiseled face of a German and so forth. He ended up marrying my wife and I, ended up baptizing both of my girls, and became part of our family. I had to—at one point I had to tell him—he used to come and visit us every year at our anniversary. I had to tell him, “You know, that's just not the right time to visit.” [Laughs] But he was great.

We got married three times—in Washington, because that's where we lived and we wanted all our friends to be part of it; that was the official ceremony. Then we got married in California in Hilmar, because my mother couldn't travel; she was sick, so we got married there. And then we got married at Loyola because all my friends at Loyola and Los Angeles, they wanted to be part of it, so we had three different ceremonies, and the interesting thing is that AJ did all three. I mean he was—[Laughs]—he's a fabulous guy. But he was part of that whole process then.

I went through public school. I wasn't as educated as the folks from Loyola High School, which was about 60 percent of the students, and the students from other private schools. The priest would, or the professors would refer to different books I had never heard of, let alone read. But not only had most of these students read them but they had them in classes, so they knew everything about them, so there would be references. I'd have to go back and find the book and read it and find out what the heck he was talking about to catch up with the class, but I loved it. I mean it was intellectually stimulating. I was just—I was fascinated with it. And I didn't have to milk cows, so I had plenty of time to do this. I mean other people, you know, felt school was demanding. I thought it was refreshing; my God I had—I had—

Lage: You didn't have that 2:00 a.m. wake-up?
Coelho: Yeah; I had time to myself, to do things and so I spent that time really learning and—and involved with things, and so forth. So AJ spent a lot of time with me, and he encouraged and he was pushing and so forth, and when I started questioning and wanting to go—he was mentoring me in regards to priesthood and wanted me to go in the priesthood. He knew about my spells, but of course we didn't know what it was, and none of us paid much attention to it. I was an A plus personality, so it was kind of like there can't be anything wrong with you; so—.

Lage: You were energetic.

Coelho: Oh God I was—. [Laughs] And I still am to a degree but anyway; so it was I announced, and the Jesuits were all excited about it, with a public announcement that I was going into the Jesuits and so forth. My family was rejected, which was kind of interesting because they now wanted me to be a lawyer and it was an interesting thing, and didn't—

Lage: They didn't want you back at the dairy farm because it had gone bankrupt.

Coelho: No; it had gone bankrupt and they were now—my mother was working at Banquet Foods, which was a frozen food company in Turlock, and she was working and she really worked like a slave. She was working in what they called the boning room, where they would bring the chickens in and you had to crack the bones. You had to manually crack them in order to make the different parts for Banquet Foods for their frozen turkey dinners. And she became the head forelady; I think it's in my genes I think—politics and leadership—but she became the head forelady, but developed a lot of arthritis, and it was kind of sad as she got older; all these experiences made life really tough for her.

But my dad had to end up—he was a salesman, and had to end up working at a farm equipment company in selling and as a mechanic, going out to farms and fixing things and so forth; so a tremendous blow psychologically to him, but they went through it. They wouldn't go to court; they paid everybody back. It took them years to pay everybody back, but they did and that's part of my culture. I mean, it's wonderful—their beliefs, wonderful beliefs except for this one little thing. [Laughs] And so I learned a lot from them—from those basic things.

Lage: But they wanted you to be a lawyer and didn't really like the idea of the priesthood?
At that point I really didn't care, so I went—I basically—in college, I didn't discuss anything with my family. They didn't want to discuss things, and I didn't want to discuss it with them. I mean we grew apart.

But you also said you hadn't discussed much before.

No, but in those days my mentor in high school, Mr. [Borne ?] discussed everything with me. Then in college, AJ, Father Kilp, discussed it, but all of a sudden I wanted to talk. I wanted to communicate. I wanted to have mentors; I wanted to—to share. I was inquisitive. I call it intellectually curious; I just needed to learn. I mean it was exciting to me to read and find out about things and so forth. And at home I didn't get any of that, and I learned also not to bring up these things at home because there was—my dad one time I came home and we were at dinner and I said something; I forget even what it was. And he yelled at me because I thought I was better than everybody else, so I never brought anything up again. I just compartmentalized, sort of like Bill Clinton I guess, but I compartmentalized, and when I was home I never brought up college, or what I was doing, or what I thought, or anything else.

It's probably not that uncommon with the first-generation college students?

Probably yeah; but I just never brought it up at all, and I learned that I shouldn't, and that I knew that they felt that I felt I was different, and I had to be conscious that I wasn't putting it in their face, so I didn't. So when I graduated [Laughs] my family didn't do anything, and good friends of mine there, this family had a party for me and so on. And I remember a couple weeks later going for my physical to go in the seminary, and it was just a week or so later, and I go into this doctor's office—Dr. John Doyle, Sr., about seventy years-old, and he was the doctor for the Jesuits, for the candidates, I guess. So I go to Dr. Doyle's office, to have a physical—not because anything is wrong with me—just to have a physical, the next phase of my matriculation into the priesthood. So I go there and he checks, and he's doing all these different tests and so forth. He says at one point, “Tony; have you ever had headaches or passing out spells or anything like that?” I said oh yeah, all the time. “Have you ever been to a doctor for them?” I said, oh yeah; I said I went to a lot of doctors and none of them knew what it was, and I told him about the witch doctors and nothing happened there, and he asked about spells and so I described them. He said, “Did anybody ever tell you that you have epilepsy?” I had never heard the word. And I said no; I didn't know what it was. And so he explained to me what it was, and he said, “You have epilepsy.” He said all the tests showed it.
Lage: Oh he actually told from tests that he had given you?

Coelho: Yeah. And he said, “It's very evident that every doctor you went to had to know. Now,” he says, “The witch doctors—it's interesting because what's going on here, and let me tell you what's going on here,” and he told me.

Lage: He told you about the church attitude?

Coelho: Told me about the witchcraft and different cultures and so forth. And so he said, “Let me tell you some good news and some bad news. The good news,” 1964, this is June of '64, “The good news is that you're 4-F, and you can't serve in the military—so Vietnam. The bad news is that you have epilepsy and under canon law established in 400 AD, the Church says that if you have epilepsy you can't be a priest. So you can't go in the seminary. Well, it didn't shock me that much. It's a fact; it wasn't like he was giving an opinion; it was a fact, and I respected him, and I didn't argue it and I didn't—it was not a negative; it was just a fact. So okay; so you leave the doctor's office and you do the next thing whatever it is.

Lage: Were you relieved to have an understanding of what was—?

Coelho: Yeah, we talked about that because now for the first time I knew what it was and he said to me—

Lage: How did he explain it?

Coelho: It was—it was interesting; I loved the explanation. He said—what it is, he said, it's very complicated but he said—this is 1964, so he says, “Do you have an alarm clock that you wind up?” And I said, “Of course.” He said, “Well it's just like that; you know, you wind up the alarm clock and you keep twisting and if you wind it up too much it snaps back. And most people don't over-wind, okay, and what happened is that God created people that had a moderator so that when you wound yourself up it automatically released. In your case, you don't have the regulator, and in effect you get wound up and all of a sudden there has to be a release, and you have a seizure, and that's what it is. And so then you're tired and you start getting wound up again.” He said, “Some people that happens in an hour or some people it happens every day and some people it happens in weeks and your situation it happens every few months.” And so he said, “That's all it is.” And it was an interesting explanation because I understood it immediately. It didn't become, you know, this evil negative. It just—it's mechanical, you know. It's just sort of like, okay.
Lage: It also gives the implication of release of stress or—?

Coelho: Yeah; oh yeah, yeah.

Lage: And you must have been a pretty active—.

Coelho: Oh I was very active and very stressed. I loved doing a lot of things, and so forth.

Lage: That must have made sense to you.

Coelho: Well, what made sense to me is an answer, you know. I didn't care what it was; it's just that it was an answer, and I loved that. I mean I just loved to—okay; so it's epilepsy and I'll find out what all that is and—. And he said, “Now, I'll give you a prescription.” And he said this may or may not work. There's several drugs now, but this is the most common one. Let me give this to you; I think it will work but you come back and you'll need to get your own doctor because this was just for the priesthood. And so I said fine. And so he gave me a prescription; it was phenobarbital and he said I think this will help you. So I've been on phenobarbital since June of 1964.

Lage: No change in all that time?

Coelho: Well, we've changed periodically but it didn't work, so I go back on phenobarbital but basically it's still on phenobarbital which is—

Lage: Did it have any side effects from it?

Coelho: Well it's—it's a tough drug as you know, and supposedly it's a drug that slows you down. And [laughs] my family said, “Geez, what the heck would you be like if you didn't have something that slows you down?” My staff in particular when I was in Congress used to laugh about it because I—I still am very—.

Lage: But did you notice that it slowed you down?

Coelho: Uh-um.

Lage: It didn't seem to affect you that way?
Coelho: No; I didn't—I mean—

Lage: You didn't feel drugged or—?

Coelho: I didn't feel drugged, which is great, and it may be that I was drugged but because I'm so full of energy and so forth that it just moderated it some and probably more normal than I was before. But I still had seizures and I still have seizures, so I still take my phenobarbital.

Lage: Do you have them less frequently?

Coelho: Oh yes, less frequently but they're still, you know—I pass out totally. I do it—I've passed out many times in public. It doesn't bother me; I mean that's who I am. I can't help it. But what happened at that point was interesting. I remember very vividly walking out of the doctor's office thinking. “Okay, so I just go on with my life. I'll find out what it is but nothing has changed really.”

Lage: It didn't devastate you that you couldn't go in the priesthood?

Coelho: Uh-um; no. I mean I was disappointed because it's what I really—I wanted to do—I really wanted to help people. I mean that's all—I now knew what I wanted and it was to help people in some way and I didn't know at that point—it was just too new; I didn't know that I'd have to find another way of doing it. But I remember walking out of the doctor's office and going to my car and thinking that nothing had changed, and what I didn't realize is that at that very moment I hadn't changed, but everything around me had—everything changed. And I had no appreciation for that. And then it started coming at me. I remember getting back to—I had just graduated and I was living in the fraternity house for the summer—getting back to the fraternity house, and I called my parents and said, “I know what my problem is. I went to this doctor and I have epilepsy.” Well, my mother immediately said—I probably just got the words out of my mouth—it wasn't like, “What is epilepsy?” I had no idea that she even knew what it was. She said, “No son of ours has epilepsy.” And it was absolutely just not discussable. It was not how you feeling or—. Just no son of ours has epilepsy. And I of course had no idea about the stigma. I had no idea.

Lage: You didn't know about the beliefs, what it meant?

Coelho: Nothing; I knew nothing about it, for her and for people like her. So I knew—I had no idea what she was going through by me saying that. So I could only
react to what she said—not to what was behind what she said and I deeply resented what she said.

2:00:34:55
Lage: Well, did it make you feel like you're no longer our son?

2:00:34:58
Coelho: Yeah.

2:00:34:58
Lage: That was the implication.

2:00:35:00
Coelho: And for twenty-nine years we never talked about it, and the relationship was very strained for twenty-nine years. And it was something that wasn't discussed in the family at all. So again it was compartmentalized, now a different issue but another compartmentalization with my family; you never discussed it. And it pushed me further away because I had to seek other people for mentoring, for fathering, whatever.

2:00:35:44
Lage: Did you ever talk to your father about it?

2:00:35:45
Coelho: It was the same exact way because my mother ruled the roost. She was the dominant person, and he wasn't strong enough to take her on, nor—I think, to a great extent you know, when you believe that somebody in the family had sex with an animal, I would imagine, though I've never asked them about this, I imagine he felt people were pointing the finger at him, I would think. I don't know. But I've never talked to him about it.

2:00:36:24.
So I remember hanging up the phone, devastated and mad, but I already had grown a little bit apart so I didn't really—I did care but I didn't really care. But then a week later I get a notice in the mail that my driver's license was revoked. I had not been told that that would happen.

2:00:36:55
Lage: The doctor didn't give you the full information?

2:00:36:59
Coelho: And now I had just turned twenty-two and I was told about my epilepsy on my twenty-second birthday, June 15th, as a matter of fact and I remember saying the hell with that; I'm going to drive anyway because it's Los Angeles. You can't get around Los Angeles without a car. So I drove without my license. My insurance was taken away, and all of a sudden I realized there was something going on here—that it was serious. It wasn't just okay; so you take a pill and nothing happened and you can go on with your life.
And it was interesting because all the time that I was a senior and I was student body president and very involved and doing a lot of things, I had people recruit me to go to work after I graduated, all the time, until I made a decision to go in the Jesuits. The recruitment was very aggressive. So I had all these people that wanted me—so I said, well I'll go to them and see if any job makes sense. I knew what I wanted, but I didn't know how to get there, so I went to these folks to pursue going to work for them. All of a sudden, I'd fill out the job application and the word epilepsy was on every job application, which ADA [Americans with Disabilities Act, 1990] now prohibits, but I checked it. The first time I was really kind of amazed that all of a sudden it was like a neon light coming at me. I had never seen the word and all of a sudden it was everywhere—or I thought everywhere. So I checked it, and nobody wanted to talk to me after that. It was interesting; as soon as I'd hand in the application I never got the callback. I never got the callback, and I knew that it was because of the epilepsy. All of a sudden I started realizing it and it really impacted me.

Lage: Did you—was there anyplace to reach out for help on that? Were there any self-help groups, or—?

Coelho: Well, it was interesting. The doctor didn't refer me to anybody. There was a local group or epilepsy foundation affiliate, but not that good, and so I assumed he didn't think they were good, so he didn't. And he didn't do any aftercare; I mean he wasn't interested in my psyche. He just prescribed what it was and gave me a pill and that was the end of it, which was typical medical care in those days.

Lage: You want to take a break here?

Coelho: Yeah. [phone call]

Lage: I wanted to ask you—speaking in terms of a broader disability group, had you had any relationship with people with disabilities as you were growing up?

Coelho: You mean knowing people?

Lage: Knowing people or the attitudes in the community towards people who were physically disabled or—?

Coelho: Well, a Portuguese woman, very close friends of the family, was deaf, and we have word in Portuguese, coitadinha, which means “poor little one.” And that's what my family said all the time, coitadinha. Just two weeks ago—her
son is the police chief in Newman, California, and I just had some fingerprints done for an investment I'm into and I went there, because my sister was there, and had him do the fingerprints, and we were talking about his mother and the whole thing. But “poor little thing” was the attitude towards people with disabilities.

2:00:41:37 Lage: Sort of a pity?

2:00:41:37 Coelho: A pity.

2:00:41:38 Lage: But not the stigma that you saw attached to epilepsy?

2:00:41:42 Coelho: No, because I think—it was *coitadinha* for [a woman] or *coitadinho* for a man—but they felt sorry for people who had disabilities, were sick or whatever, and very caring. The only thing that I found fascinating, with epilepsy, is that this possession of the devil is the issue.

2:00:42:05 Lage: It was a different case.

2:00:42:26 Lage: [Adjusts window blinds] I think that will be fine. Okay; so it was sort of a pity, but not excluded from the community or—?

2:00:42:32 Coelho: No, no, just poor thing type stuff. And I never—I wasn't negative or—I mean I was very much always into anybody who had a disability, the disability wasn't a big thing to me. But anybody who had a disability or whatever, I was very much into, well, let them lead a normal life, you know. Let them do what they can do. It's always been my attitude, and that's what I had then.

But in my situation, going back to the story, at this point with not being able to get a job, all of a sudden I felt that this thing was bigger than I had realized. It was sort of reality setting in, and I started drinking at this point, and I would be drunk by 3 o'clock every day.

2:00:43:40 Lage: Had that ever been a pattern that—?

2:00:43:43 Coelho: No. I mean I was a college kid so I drank, but I never got drunk that much. I mean every once in a while I would, but I thought getting drunk was stupid. I don't think that's such a cool thing. I like to drink, but getting drunk I think is a negative, personally. But I was drunk every day and it was always—I'd go to Griffith Park in Los Angeles.
I remember Griffith Park.

And what I realized, and I'd be drinking on this mountain top—it was actually a little hill; it wasn't a mountain top, but at the time I thought it was a mountain. [Laughs] And I'd be thinking, and it was “woe me,” which was so unusual for me because I don't believe in “woe me,” and I just don't—I'm just not there. But it was “woe me.” God, it was feeling sorry for myself, and what it came to is that I thought that everything I had ever loved in my life had turned against me. My church, I loved my church, and I loved what it symbolized and everything about it. But I thought God and my church had turned against me, and I couldn't understand that. And there was really nobody to talk to; that's what was shocking.

You didn't go back to your mentor in the Jesuits?

Well, actually I did—I did at one point—the head of the Psychology Department—. All the Jesuits were shocked I was not going to be a part—they were all excited about it because they took the view that if you could be a good father or if you could be a good husband you'd be a great priest and they felt I would be a good father and a good husband and they were excited about me coming in because of my leadership abilities. That's what they want; they want strong people in the Jesuits. And I was a class prospect and so they were excited about it. And so all of this sudden there was this huge disappointment and a lot of feeling sorry for me. And so they knew I was going through rejection but I didn't—it was fascinating that Father Kilp tried but he didn't have that skill, which was kind of interesting.

But then there was another priest, the head of the Psychology Department, Father Ed [Markey ?], who I had talked to a little bit when I decided I wanted to go into priesthood, and he helped me during that period of time. He's the one that reached out to me at this point and started trying to help me. But when I felt the rejection of the church and everything about it—God and so on—at the same time I felt the rejection of my family. The rejection of my family all of a sudden became a big thing; all of a sudden realizing that when I really needed them they weren't there. I couldn't call them and talk to them about it. They didn't believe it, didn't want to believe it, didn't accept it; so—

Didn't want to talk about it.

Didn't want to talk about it, so how could I reach out to them? I couldn't. And then the third rejection—I loved to work; I mean I still love to work. [Laughs] I'm just a workaholic; I love to work, and that was part of my culture and being raised and so forth, and I couldn't work. I couldn't find a job. So, boy, I
was really down, and I became suicidal, and Father [Markey] really tried to help me psychologically during that period, but it was the only time in my life that I ever really felt that I was a burden or a negative and that the best thing to do was to do something about it.

Lage: It sounds like you were internalizing the social—?

Coelho: I internalized it all; I mean I just—I never do that, but I did; I just—it just came on me and really strong.

Lage: How do you think the priest, Father [Markey] helped you?

Coelho: Well he—he—

Lage: Did he discuss the epilepsy or the social—?

Coelho: No; he was basically trying to get me to believe in myself again. And he would talk to me about my personal skills and who I was and how important I was. So one day he comes to me and he said, “I think I got you a job.” And I said, “Oh yeah, sure.” And what it was, was working at a liquor store, and so I went because I needed the income, and I quit at the end of the week, and the reason I quit is that I was selling liquor to little old ladies with their social security checks and I—I couldn't do it. I just—I couldn't do it.

Lage: Were you still having a problem with alcohol at this time also?

Coelho: No. Well, I was still having a problem with alcohol, but it wasn't that. I just didn't want to contribute—I mean I knew what they were doing and I just—I wanted to counsel them. I wanted to talk to them and say, “You shouldn't be doing this.” [Laughs] But that isn't what you're supposed to do, right? I told the owner of the liquor store, I said, “Look I'm having trouble with this.” He said, “Well, you can't, this is a business and you can't mix the two.” I was crude and so forth—I mean of course you could mix the two; so you lose a little bit of money on some little old lady. Well, what's wrong with that? But his point was—and he was right—they have a right to do what they want with their money. This is America, you know. This isn't some dictatorship. So it was at the end of the week, and I just told him, I said, “I can't do this. I can't.”

So I'm without a job again. So I explained this all to Father [Markey]. He was intrigued. [Laughs] He knew that what I didn't need was to be reminded that I would be a good priest, but he'd laugh about it. He'd say, “Well, I guess the calling is still there.” So then he came back to me, and it seemed like a week
later but it could have been weeks, but he came back to me later, and he said, “I think I’ve got the perfect job for you.” He was my personal recruitment agent. So he comes back to me and he said, “One of my best friends is a psychiatrist and he works with the Bob Hope family. And they are looking for somebody to live with their family”—and now this stuff—when is it public—when—?

2:00:51:32
Lage: When you want it to be.

2:00:51:31
Coelho: Okay; this part is—this part is very—

2:00:51:33
Lage: You can parts of it. [The following section has been sealed until 2018.]
Okay; we're back on and talking about your relationship with Bob Hope.

So the greatest gift that Hope gave me was identifying my ministry. He would spend a lot of time. He was a wonderful human being, and he would help a lot of people, and the stipulation was is that nobody could talk about it.

About the help he had given them?

Yeah.

So he kind of had a ministry in a way.

Well, this was interesting; so one day we're talking and he knows about my problem. So we're talking, and he said, “You know, Tony.” He said, “You really know ministry but you don't understand what a ministry is. You think that a ministry only can be practiced in a church. And a true ministry is practiced every day.” And he said, “There's a ministry in the entertainment business. There is a ministry in any other type of business. There is a ministry in sports. There is a ministry in entertainment. There is a ministry in the church, but one of the really truly good ones is a ministry in politics, and he said, “You're helping people, you're solving people's problems, you can be really committed to it and so forth, and I think that's where you belong.” I never had been involved in politics.

But you had been in student government?

Yeah; that's why he—

Do you think he—?

That's what he did; he did it from student government, and he said, “You ought to go work for a member of Congress—not the government because that's bureaucracy and that's not what I'm talking about.” He said, “You need to go work for a member of Congress, the House or Senate and—and they solve lots of people problems. That's what it's all about. It's a real ministry and you would love it.”
Had you ever discussed politics with him in terms of Republican and Democrat?

Oh yeah. [Interruption] He—he shared with me during this period of time personal handwritten letters that Barry Goldwater was sending him on the campaign trail. This was '64, and I read these letters and I thought—I was fascinated with Barry Goldwater's values. I mean he was very committed to people and the personal side of things, and what he was against was government being involved, but in those days I was not into government. I just was fascinated with his commitment to helping people and letting people fulfill their—not only their needs but what they could and could not do. And I was fascinated with it.

Ultimately, I voted for Lyndon Johnson because my Democratic roots came back.

Right; were you in—?

We also got letters and we also got phone calls from Lady Bird Johnson and from Lyndon Johnson because Hope was a very major political figure. So we'd get these calls and the call would come in from the president, and he would go, “Oh, here we go again; he's calling. I know what he wants but he's just checking in. Of course he's interested in me.” It was really funny. Then he'd get these letters from Goldwater, and they were just so real. I mean I was fascinated with Goldwater. And so we talked about these techniques, and he knew my interest in—but he would talk about it from the point of view of what you could be doing—what I hadn't thought of—from a public policy point of view and how you could really be helpful. So he's the one who got me into this transition from a ministry into politics and how you could really be helpful.

Were you involved in the issues of the day—the Vietnam war, the civil rights movement?

Well, I read a lot because I was very intellectually stimulated on the stuff, so I was into that but I was intrigued because see Hope, don't forget, was very pro-military—I mean very pro-troops. And I got that from him, because I was there when he went to Vietnam in '64. And I became and—and I'm very pro-military anyway, but I ended up being anti-Vietnam because I thought it was an unfair war and so forth, and we didn't need to be involved—sort of like Iraq. But my position in regards to Vietnam and all that stuff didn't really materialize until later in '65 and so on. But the development of who I was and
what I was interested in was really started with the conversations with him. And he knew about my disability, and that didn't bother him; we talked about that but it was not a big issue. Sort of like ah—so. So one day he says, as I indicated, “You need to go work for a member of Congress.” This was in like January, as I recall, or it may have been December, but January.

In '65? 

'65. So I wrote a letter to my congressman, who I did not know, who knew my uncle. My uncle was very involved in dairy politics—agriculture. And so I wrote a letter to him, and I basically said, “You lucky devil here I am,” you know. All my confidence had come back and I have read that letter since then and said, “Oh, my God.” I talked about my interest in government and helping people and my background and so forth. And [Laughs] so I sent him this letter; I had the help of a college classmate, and I stayed with his family off and on. He was a guy who had studied for the priesthood and had left the priesthood and was at Loyola. And his mother was a nurse, and she became a big mentor of mine helping me through this period when I was so down and so forth. She was wonderful—spent a lot of time with them.

Were you living with the Hopes, though?

Yeah; I was living with the Hopes. Kay Kane was her name—Katherine.

The nurse?

Yeah; and there's one other person I should probably tell you about—remind me—Mrs. Crawford. But I wrote a letter to Mr. Sisk, Congressman Bernie Sisk, who I didn't know, and I said, “You lucky devil,” and that's that. And so then I got a phone call just within like a week; it may have been a little bit longer—from his administrative assistant. It was late January because she said the congressman is going to be in Los Angeles at the Ambassador Hotel for a California delegation function, and he has a few moments, not many, but he has a few moments; he'd like to meet you and talk to you about your letter. Wow; this is fabulous. So I said okay; so I remember I had gone to the doctor and had sort of a tumor removed from the back of my head because we didn't know if that was part of what had caused the epilepsy.

Uh-hm; it was an internal tumor?

Yeah, internal, and I was wearing—the reason I remember this is because I was wearing a big band-aid, bandage back here. So I went into see him; and
we started talking, and I found my next mentor. He only had a half hour. An hour and half later we were still talking, and I just—I felt I know this guy and he's just a wonderful human being. At the end of the meeting, he said, “I have to work out something, but I’d really like for you to come to work for us, so it's not a commitment. Let me try to work this out.” What I didn't know was that [there was] another guy they had been recruiting to try to go to work for them, but I was younger, and he was more interested in getting somebody younger. The other guy eventually came in as replacing the administrative assistant who called me, this guy came in later to replace him. But the guy turned it down because he was more interested in doing something with the Peace Corps, and so he turned it down and I got the job.

But I remember walking away from that, going back to the Hopes’ home. And Bob Hope was at the Bing Crosby Golf Tournament in Pebble Beach—he and Mrs. Hope were up there. And I called him to say I just had an interview and had a job offer. And he said, “Whoa, why didn't you tell me that you were—?” I said, “Well, I just took your advice.” He didn't realize he had given me advice—that I should do it immediately. He just thought this is what you ought to be doing, but I took the advice immediately and followed through. So he said, “Well, don't do anything until I get back and then let's get together.” So I said okay, and I said, “Well, I haven't gotten the final offer but you know, I'm going to get the job.”

3:00:11:57
Lage: You were confident?

3:00:11:58
Coelho: Oh, my confidence came back in just spades. Sure enough, a couple weeks later I get the letter and the offer with all the stipulations. I'll never forget it was $6,000 a year. So I go down to Palm Springs and meet with Mr. Hope and— [Interruption]

3:00:12:32
Lage: We're still on here.

3:00:12:39
Coelho: So I go to Palm Springs and meet with Mr. Hope, and he thought it was a great idea. He said he was shocked that I had gone to work for somebody who nobody knew.

3:00:13:00
Lage: Uh-hm; and a Democrat at that.

3:00:13:02
Coelho: And then he came out with that later and said, “I could have got you in with somebody who is famous and somebody who is powerful. This guy—nobody knows him.” And I said, “But he's my congressman, and that's what I like, you know.” So he said, “And a Democrat; why would you go with a Democrat?” He had no idea, because we hadn't discussed what I was, and I didn't think in
those terms in those days. I mean it was not—so he said, “Why did you go
group with a Democrat?” He said, “Stu Symington and I are great friends. You
could be working with Stu Symington.” I said, “No; I like Bernie Sisk.” So then he
asked me—said “I hope you would never write or talk about your experience
here because confidentiality is so important.” He was concerned obviously
with people writing exposes of famous people, and he was considered one of
the famous, of course. And I really, I knew he was but I didn't think of him in
those terms. He was somebody I worked for and I—I didn't think about
Kelly's [inaudible]. He then asked me—he said not to write about it and I
agreed, and I kept that commitment, which later he chastised me for but—but
he then says, “Well, you need some money to get started. Let me give you
some money.” I said, “No, I don't want any money from you.” And he said,
“Well, let me loan you some.” I said, “No. You've done a lot for me and
I've”—you know, over the months I was there, I saw so many people take
advantage of them and just steal—family and so forth—steal from the house
and food and liquor. I reported it to them one time about it going on—

[Microphone replaced, sound quality improves]

Lage:

Okay; we're back on after our microphone problem.

3:00:15:34

Coelho:

And so he said, “Well, how are you going to get established? You've got to
get an apartment; you've got to, you know.” And I said, “I don't know. I'll just
do it.” And he said, “I'll tell you what. Why don't you get a loan from the bank
and I'll sign for it. It means you owe the bank the money—not me; you owe
the bank money.” Now little did I know [Laughs]—nowadays I know what he
was doing, I mean he signed, personally signed, for it which meant if I had
reneged he had to pay it. But I didn't think of that. And so I said fine. So he
said, “Go see”—I forget the guy's name—“Go see Joe Schmoe at Bank of
America.” I knew it was the Bank of America branch in North Hollywood and
he'll take care of it. I said okay.

So I left and it was a wonderful conversation, and so I left and the next day I
go see, or the day after, go see Joe Schmoe and I'll never—this was a
wonderful experience. I walk in and I tell the secretary that I'm here to see
him. And she said, “Well, I can ask you what it's about” And I said “I'm
borrowing some money from the bank.” And she said, “Well, you should go
to the loan officer.” I said, “All I know is I was supposed to see Joe Schmoe
because Bob Hope—” “Mr. Hope,” she said, “Oh, just a minute—just a
minute.” And again I had no idea what that meant.

3:00:17:17

So then of course he brought me into his office immediately and he said, “I
understand you're going to Washington.” Yeah. And he said, “How much are
you interested in borrowing?” And I said, “Well, I haven't got anything.” He
said, “That's all right, but how much do you want to borrow?” And I said, “Let me think, $1,000.” And he said, “$1,000?” And I'm thinking, Oh my God; you asked for too much. Geez, you blew it. And he said, “Do you realize Mr. Hope has signed this?” And I said, “Yeah, he said he would sign it.” And I'm thinking—He said, “Okay, you know that's what I meant by signing it. He said you can borrow as much as you want.” And I said, “Well, I haven't got anything.” He said, “That doesn't make a difference. He says you're okay and he's going to sign it, so you can borrow as much as you want. He says you need money to get started.” I said, “No, no, $1,000 is all I want because $1,000 is a lot to me.

You'd have to pay it back. [Laughs]

Yeah; and so he got me a check immediately for $1,000, and I paid it back monthly, and I kept the card with the signature on it for the co-signing and so on, but it was a great experience because I had no idea about what I was dealing with. It was kind of—I was just sort of in this world.

And I then went to Washington. But the experience with him, a very devoted family guy, committed to helping people—I mean he was an entertainer but he used to—I mean he had the Bob Hope Comedy Hour during that period, and I went to the filming of it and all that other stuff. He was doing the movies and so forth, but what he was really interested in was doing these tours to Vietnam and so forth and how committed—he was personally involved in who was going to be invited and who wasn't and President Johnson thanking him for doing it and—but he loved this. He loved—and he talked to me about what it meant to him that these soldiers and sailors and airmen were so thankful to him for being there and so on. And it was his ministry. It was just—it was obvious what was going on here, and I loved it. I just thought he was fascinating with this stuff.

So then my family, I told them that I was going to Washington; they were happy about it. I didn't really talk much to them about it. I don't really remember leaving home to be honest with you. I just—it was a non-event.

Well, you had left home?

I had left home and to a great extent I was legally and every other way a part of the family but not emotionally, and—

Did you talk to your siblings about this at all?
Coelho: Yeah; they—my sister was young at that point. She was fifteen years younger, so she was too young. But my brother basically felt that I should leave things alone. Now obviously, he probably felt some of the same things. I mean that's—but he didn't—he just—just don't push it; don't say anything. So that's when I then went to Washington and worked for Mr. Sisk and started my political career.

Lage: And did Mr. Sisk know [about your epilepsy]? 

Coelho: All about it.

Lage: —all about it and had no problem with it? (I'm going to ask you to move in just a little bit. Thank you. All of a sudden the—the little flicks of light coming in from the window, cross your face.”  
[adjusts window blinds]

Coelho: Is that better, okay? I had seizures—even though I was on medication I had seizures in front of him—nothing bothered him. They just didn't. As a matter of fact, one time the guy who took over as administrative assistant was jealous of me because Sisk and I developed a father/son relationship—very, very close relationship. He and his wife were like father and mother to me and father and mother to my wife and grandparents to my kids. Phyllis and I had dinner with him—he and his wife—I would say at least four nights a week for years and when the kids came along, the same thing. We'd do vacations together; Christmases were fabulous. We always got these—he knew money was an issue with us and he always gave us a big check and—but we did everything together, birthdays. We celebrated our birthdays with them, their birthdays we were there; I gave the eulogy at his funeral and gave the eulogy at hers and I was best man—she died first and he remarried, and I was best man at his wedding, so it was just really a wonderful—my next mentor, because he was a wonderful human being.

And going to Washington—oh, I was going to say; the person who took over as the next administrative assistant was jealous of this relationship, and it was—Sisk wanted me to review the mail and approve the mail and I didn't have to put it through the AA which was, looking back on it, was part of the problem—obviously was part of the problem. But one day he confronted me about this and wanted Sisk to fire me. And I had a seizure when—the guy wrote me a memo, a long memo and carbon copied Sisk and then talked to Sisk. But I got the memo before he talked to Sisk and I thought, “Oh my God, here we go again.” I was married and had both kids then, I guess. But I'm thinking, Oh my God, here's my whole ministry, everything I've believed in is going to be out the window.
Lage: Was he using the epilepsy as a—?

Coelho: No; he was—

Lage: As a reason?

Coelho: Basically it was the—he didn't feel that I was strong enough, capable enough, and was just—he was a very bright guy, excellent writer, and he thought I was insubordinate to him. So he made a confrontation. It was either—basically what he said was it's either he or I in charge of the office and that you let Tony do too much and it's got to be one or the other. And so I get the memo, a long memo; he was a newspaper reporter, used to be, and so I get this long memo prior to Sisk getting in. So I'm thinking it's over, and I have a seizure. Well, Sisk finds out about it, reads the memo, and he asked the guy for his resignation. It was just a boomerang, totally [Laughs] and so I take over as administrative assistant at a young age. Now the administrative assistants are all young, but in those days they weren't, and I took over, and it elevated my career even more. But it was his confidence in me; it was just really a wonderful reassuring building thing for me. And he's the one that after a bit said, "I don't want you to leave. I'm going to retire and I want you to take my place." And that was seven years later, but [Laughs]

Lage: Well, you were with him for quite a while?

Coelho: Fourteen years—yeah, fourteen years; but it was—

Lage: But then seven years he was grooming you to take—?

Coelho: He was grooming me, and what he did was—it was interesting; he would go out to the district, and he'd say, "Well, I'll have Tony look into that," and publicly—I mean just all the time and it was basically handing over the baton but gradually and slowly without people really realizing what's going on. So we'd go through an election, and they'd always ask him, "Are you thinking of retiring?" and the first time he did it he said, "No, but when I do I want Tony to take my place." So this was in the newspapers, so it's—. So he kept dribbling it out, and of course I was now at this point foaming at the bit. When are you going to leave, you know? I'm ready to take over. He set the stage so that when he did leave it was automatic. Now, if he had left too early I would have never won. Now, I didn't know that of course, but—
Lage: He was just sharp politically?

Coelho: He was very sharp politically—knew exactly what he was doing.

Lage: Now what was happening in these years in terms of your being open about your epilepsy?

Coelho: I was very open.

Lage: Out, shall we say?

Coelho: I didn't think I was open; it was just me. I was who I was, and I didn't hide it, think of hiding it. I called the Epilepsy Foundation and said I'd like to be helpful. They—they didn't, you know—typical of a lot of these groups. If you had the disorder or the disease you couldn't be helpful because other people had to take care of you. That was the attitude.

Lage: Oh so that was the attitude in those days?

Coelho: Oh, oh my God; it was the Jerry—the Jerry Lewis syndrome.

Lage: Would you talk a little bit about that?

Coelho: —is what I call it.

Lage: Back then, who would—?

Coelho: I don't remember the name of the guy.

Lage: But I mean what—?

Coelho: But they were basically doctors, and parents of [children with epilepsy], and drug companies. I mean they were the ones that controlled the Epilepsy Foundation. And I'll get into that later with you.

Lage: Yeah; I'd like you to talk about that when it's time.
Yeah, but they never came back to me because I'm one of them, as opposed to one of us.

So they didn't feel you could help them, as a person who had epilepsy?

No, they knew best, of course.

And how did you feel about that?

I never got, they never called me back, and that's all it was. I mean, they didn't tell me that; they just never called me back, so I realized—I realized much later what was going on. I thought then that they just weren't interested for whatever reason, and I was irritated by it, but you know—.

There were some issues during those years having to do with disability rights, Reagan's attitude—

I was in office when Reagan was there.

Oh that's right; that was later. Well, were there things during the Sisk years—the Rehab Act and—?

The Rehab Act and so forth; there were things and Sisk was very supportive. He was very openly supportive, and he talked to me about it and so forth.

Did you see an identity there with those—?

Yes; but I didn't—I didn't know how to—who to reach out to. There wasn't a movement in Congress among members of Congress that I was aware of or an association that I could go to, and I had tried the Epilepsy Foundation a couple times, and there was nothing there. But it was interesting because Sisk would talk to me about it, and what he would do is he would let me do the research, and he'd let me talk to the people, the lobbyists and others who came in and make the recommendation to them and so forth on all disability issues. So I got engaged at that point because it was interesting the way he handled things. It was never condescending. It was never well, you know more about this than I do—no; so it was mine.

I guess I'm trying to get at when you began, or maybe you always did, to see the correspondence between the problems of someone with epilepsy and the
problems of somebody who can't get into a building because they're in a wheelchair or—?

Well, that—that's an interesting discussion because the visual or the hidden disabilities, as you know, I had no idea that there was a split, or that there was a, a lack of appreciation and so forth, and discrimination within the community as such. I didn't know anything about it at that time. I didn't pay attention to it, wasn't engaged with it, and so forth. I didn't really get into it until my campaign, and the issue came up then, and then after I was elected all the groups then started coming to me to speak on the floor about the issue, or to do “dear colleagues,” or—because I was just, you know, there was nothing. I was never open; it was just _me_.

It was interesting because they felt I was—Ralph Neas came to me with a housing amendment, a civil rights and disabilities—and I became a big advocate for it, and Ralph came to me on anything in this area. And I became very involved with the civil rights movement because of it. My boss, Bernie Sisk, was from Texas, and he's a southerner who believed in civil rights, and John Kennedy and Sam Rayburn put him on the House Rules Committee to break the deadlock that was there to get civil rights bills. See, all the civil rights bills got killed in the Rules Committee because of Judge Smith, who was the chairman, and the southerners on the Rules Committee, and so they loaded the Rules Committee from twelve to fifteen members, added three members. H. Allen Smith from California was the Republican they put on, and they put on Sisk, and they put on a guy by the name of, I think it was Charlie Hagen from Georgia as the three new members. Smith voted for civil rights and so did the other two.

Was this '65, the voting—?

This was '64.

Sixty-four—before you [joined Sisk’s staff]?

Oh, before me. I bet it was '62, a result of the elections of '62. I bet it was, so it started in '63, I guess, or maybe '60, '61, but it was when Kennedy was there so it had to be in '62 when they did it. And so then they moved through the first civil rights bill, and they moved things through, and Sisk was part of that. Now, in all these things I started to equate disability with civil rights.

Oh you did—very early on?
Coelho: Yeah, and I believed in that basically, you know, our rights were being denied, and I felt that it was part of it and started talking to people about it, and when I got elected I was very much into that already. I got elected in '78, and that's when I started dealing with the whole issue of our rights, and it was housing, and it was different things and amendments we got added onto different things, disabilities as opposed to just epilepsy. And I made the—I don't know who told me or how I actually came to it, but I just came immediately to the fact that I had a disability, and I was part of the disability movement.

Lage: Hmm; for some people that takes some time.

Coelho: Oh that—yeah.

Lage: To identify with—

Coelho: See I've never, I've never ever—I've been, I'm proud of my epilepsy. And the reason I'm proud of it is because I think it helped define me, and I think, you know, God played a role. I didn't know who I was, and I was forced to get to know me and forced to deal with me. I know who I am; I know what I'm capable of, and since I was suicidal nobody can ever get me depressed. I mean nobody ever can—can take me down. I mean I had to find out who I was then; I had to reach in and deal with it, and so I thank God for that because I would have never been, in my view, half as successful as I've been if it weren't for my epilepsy. And the Post did a huge article, which you may have seen, about epilepsy being the thing that's been a common thing throughout my adult life. And it's true, and if it weren't for epilepsy I would not have done half the things I've done.

Lage: Well, when you were in a position to make changes, did you look to make changes in law specifically relating to epilepsy?

Coelho: Yes; I got very involved in making sure that—for instance I had a big fight with Henry Waxman in regards to generic drugs. I take the view that with epilepsy we have to have a very specific drug. A lot of them don't work, and you have to have a very specific drug in order to maintain our situation.

Lage: Each one individually?

Coelho: Each one and it's very—if you don't get the right drug, the right dose, and so forth it can't help you. So I was very much opposed to generic drugs because
of our particular [needs], and I took the view that for some people generic drugs would be fine, but with most people it wouldn't be, and with Medicare and Medicaid it would be awful to do that. So I took Henry on privately and publicly and we won, and I was prepared to go battle on the House floor and talk about my [epilepsy], and it wasn't that I'm going to reveal or be open. It's just that I know what it's like, and I'm not going to let you hurt other people because of this. I remember that was a huge fight, and the drug companies started to realize that I was a great advocate for their cause, and I was an advocate in these types of things, but I wasn't an advocate on other issues. So they realized I wasn't controllable.

But I got very involved in that stuff, and I loved playing a role, and one day I basically decided that part of my ministry was this, was being able not only to help people, but it was really to deal with disabilities as my ministry. And I felt I could make a difference. And I also felt very strongly that I had the use of a podium, and that I had to take advantage of it. I couldn't waste it. And so—

3:00:37:55
Lage: So this was all very conscious and when you—?

3:00:37:58
Coelho: Oh yeah.

3:00:38:00
Lage: This isn't in retrospect?

3:00:38:01
Coelho: No, no; no, I knew that—I felt that I had a podium. I should use it. When I was campaign chair I knew I had a bigger podium and that people would have to listen to me, and—

3:00:38:15
Lage: So you could use some of that power?

3:00:38:17
Coelho: Absolutely, and I knew when I was whip I had even more power, and that I could really do certain things, and that's when I did ADA. But I knew very consciously that I could transfer that power into my ministry and to get some things done and I did it. I have no reservations about it; I was open about it, felt strongly about it, and still do. I mean whatever influence I have today I still use it in my ministry in regards to disabilities.

3:00:38:47
Lage: Interesting; then you decided to run for Congress; you did run for Congress; and did you have to handle the question of epilepsy then?

3:00:38:54
Coelho: Yeah; the Republicans convinced a great young guy—he was the head of the Thunderbirds, which is the Air Force I think, the Air Force acrobatic pilots.
They do all the information, the somersaults and the twists and all that other stuff, and he was a Greek fellow from Modesto, married to a Mexican-American, a beautiful woman, guitar player and so forth—in the Air Force, a career person; they convinced him to leave the Air Force and to run against me—the odds of him winning were remote in that district. But they really felt they had an opportunity to break loose here. He's running and gave up his career, which is sad, and in September, it's pretty obvious then that I'm going to win rather easily. And he's at a function in Madera County. As I remember it was in Coarsegold, but I'm not sure, and he's at dinner, and he's speaking and he says—and this is a very conservative part of the district—he said to the people there, “I don't know if you know it or not but Tony is a very sick man. Now, what would you think if he went to the White House and arguing an issue like water and had a seizure?”

Well, that's all he said. He didn't say anything else about epilepsy, or whatever, but that's what he said. Well, several people at dinner were appalled that he would do this. Because I was—I didn't hide it; it wasn't like I—I talked about it.

3:00:40:49
Lage: It wasn't news.

3:00:40:50
Coelho: And it wasn't news; I mean I was open as part of just who I am. I mean I wasn't—I didn't wear it with a neon light, but it was who I was. It didn't bother me. So because I used to talk about that I wanted to be a priest and that I ended up not going into the priesthood because of my epilepsy. So it was part of my introductory story to every group I met, so I thought it was silly. But anyway he talked about my having these seizures.

So a reporter calls me the next day and says, “I understand that your opponent last night said X. And what's your reaction to it?” And not being that clever generally, but that day I felt, you know, God was with me, but I said, “You know, over the fourteen years that I've staffed here in Washington, I knew a lot of people who went to the White House and had fits, and I said, “At least I'd have an excuse.” And the reporter loved it; man, the reporter laughed. [Laughs] And it's never been used against me since.

3:00:42:09
Lage: Hmm; that diffused anything.

3:00:42:11
Coelho: Yeah; and it was a sincere comment; I didn't have a handler or consultant tell me what to say to diffuse it. But it's the way I really felt, and I thought it was—I was irritated as hell that he would say it, but I thought it was kind of dumb. That's my attitude about a lot of these things is that, how dumb are you to think that will work?, because I just think people have a tendency to be very fair. And it worked against him just tremendously. I mean, there was a Greek
TV studio he had gone to, and he supposedly had done an ad dealing with my illness. The Republican Greek owner of the studio calls me and tells me; he said, “I think this is ridiculous what’s going on here. He’s being advised to do this, and he was in my studio,” and he said, “I resent it and I told him that.” They never did use the ad because the story kind of just diffused. But it tells you about the depth of negativism that can be out there.

3:00:43:21
Lage: What about in the Portuguese community, though? Do they—did those feelings still persist?

3:00:43:27
Coelho: Well, it was interesting; I'm in Congress many years. People would come up to me on the street, Portuguese ladies in particular, and say, “Tony, we love you, what you do and all that stuff, but please don't mention your epilepsy.” And my reaction always was the same; my reaction was, “You know the only reason I mention it? Because of your comment.” I said, “I'll always mention it because it's who I am. That's why I do it.” And it is why I do it, because when people say that, I don't dislike them for raising it, but I dislike the fact that they think they have to raise it. “Don't pity me; just don't, stop it. You know, criticize me; yell at me for doing something wrong but don't pity me because I have a disability.” I resent it.

3:00:44:27
Lage: It's interesting that you say “it's who I am” because I have heard people talk about a disability identity and a kind of a world view from having grown up with a disability. Is this something similar?

3:00:44:39
Coelho: Well, it is who I am. I mean, I don't take it as something that's over there. It's here; every day I have it. Every day I may have a seizure, and I think about it. I know that I'm prone to it, and if I don't watch my diet, if I don't exercise, so forth, the odds are that I'll have it, but I'll have it for any type of stressful—emotional stressful situation, and I know that. So it's not like it is something I can dismiss; it is who I am. And it impacts what I do and how I say things and—and so forth.

3:00:45:26
Lage: But does the actual illness—if we can call it that; I don't know if you consider it an illness, or a condition—that impacts you, or people's responses to it?

3:00:45:36
Coelho: Well, I know that if I have a seizure in the middle of something critically important that what I'm trying to do could be affected negatively. And so you've got to be conscious of that because if it's—I'm a businessman now and in a business deal, it could affect the deal. Well, I don't care if it does, but if afterwards it does, because I am who I am. If I had a seizure, I had a seizure; that's the way it is. But do I want it to happen? No, of course not, I don't want it to happen, and I don't want the deal to be blown apart because of it or
whatever, so you're conscious of not having one. But I never resent having one, and I've never said, “Oh, woe me, this is awful that I had one.

Lage: You don't like the pity?

Coelho: I don't like the pity, and it is who I am, and if you don't like it, the hell with you.

Lage: It's having a stigma too.

Coelho: Yeah; I really am very tough about this, and I set a very stern example for others in that I don't want people to feel sorry for me, because I don't feel sorry for me and I am who I am. I have epilepsy. I consider myself an epileptic. It's a big dispute in the community, as you know, that you're not an epileptic; you're a person with epilepsy.

Lage: Oh yes.

Coelho: And I laugh about it, and I say, “Yeah, that's fine for you to think that way, but you know, I'm an epileptic. If you don't like it, that's the way it is.” Because I don't want people to think I'm embarrassed by it by saying I'm a person with epilepsy. Wait a minute; what's that mean? I'm an epileptic. You know, there isn't—every day I have to take medication. Every day I think about it. Every day when I get an aura I think I'm going to have a seizure. I mean it's who I am. It's not—

Lage: Do you get an aura sometimes and not have a seizure?

Coelho: Oh yeah, oh yeah; and you don't know if it's because you're getting ready to have one, you don't know if it's just psychological; you don't know what it is but it's who you are. It's every day.

Lage: Is there anything special about the kind of consciousness that the aura or—I mean—

Coelho: Well, for me it's a claustrophobic feeling; it's a closing in—things closing in on you.

Lage: An unpleasant feeling?
An unpleasant feeling and it's always—I feel blackness and it's like I'm getting ready to faint, you know. But it's always claustrophobic, and then closing in, and it may be seconds, or it may be minutes. And I don't know because you never know. I've never timed it.

Or it might pass?

And it does pass; it has passed many times. I mean I have more of them pass, but I don't know what I'm doing at the time I go through that, because I have no idea if I'm communicating with somebody or not, because it can be like that. [Finger Snaps] You just don't know; that's the thing about it.

Yeah; that is—

But it's interesting, the debate about if you're a person with or if you are one. It's an interesting debate, because, see, I take the view and other people argue with me and that's fine with me. And I really don't care what you think, if you want to be one or if you want to be a person with, I think it's playing with [words]—it's immaterial to me. But I think that the most important thing is for me not to feel that I'm inferior to anybody. I don't feel inferior to anybody. I think I've been very successful in all kinds of things. And when I was on Wall Street I was very successful there. I had seizures. My bosses knew it. I got promoted; I was in charge of—I mean, I think a lot of it has to do with my attitude as opposed to my disability. I think people who are in a [wheel]chair, people with cerebral palsy or people with anything, if they have the right attitude people look through the disability. But if you have a hang-up about the disability, all of a sudden the disability becomes the barrier to being accepted. I want people to see me as someone who can do certain things and do them effectively, not—

But do you think that some of this legislation you've had a hand in has removed the barrier so that people can rely on their own abilities?

I think what I feel strongly about, and it's my culture and it's my belief and so forth, I want people to treat people with disabilities for what they can do as opposed to what they can't do. There's certain things I can't do. I can't fly an airplane. I accept that. I'm not supposed to carry a hand gun—I hunt, but I'm not supposed to. I'm not supposed to drive a police car or fire engine. Fine, I don't have any trouble with that. And I know that I fight discrimination in general in regards to people with disabilities saying that all of us can't do certain things. I said, “Well, as an individual I might be able to do it, so you should give me a shot.”
I don't want you to put me in a position where I can kill somebody else. I don't have that right. And so I'm very firm; I drive, and I'm careful about it because I know that vehicle is a dangerous thing that I can kill other people, and I don't have a right to kill anybody else. I have a right to kill myself if I want to, I guess, but not to kill somebody else. In counseling people with disabilities and counseling people with epilepsy, in particular, particularly young people, I say okay, I do care but I really don't care what you want to do with yourself, but you do not have a right to put somebody else's life in danger. You do not have that right, and I will argue against you. I'll fight you; I'll do whatever to prevent you from having that. So if you need to have your driver's license removed because you are having too many seizures and you can't [drive safely], I'm going to be there; I'm going to say absolutely you shouldn't because you're a danger. And then you need to get around somehow, and you should be able to function without it, but I'm not going to let you kill other people as a result of your disability.

3:00:52:31
Lage: Is that the way the driver's license is handled mainly now?

3:00:52:35
Coelho: Yeah; well, there's a big problem. You know, we finally have—working on some legislation here in the state legislature to get California to change. California [law] basically is that when a doctor reports, it's automatic—bang, you can't have—

3:00:52:53
Lage: Hmm; just as it was?

3:00:52:55
Coelho: Yeah; it's been for years and in my view is that with medication and everything else you should let a doctor determine whether or not somebody is capable of driving or not driving, and if a doctor says that they aren't then they aren't. I don't have any reservations, but I don't think it should be up to some bureaucrat in Sacramento who decides if you can drive or not drive. I think that's ridiculous. But anyway we're getting that modified, and I think we're going to win that this year—we're right in the middle of it.

3:00:53:26
Lage: Let me just point out that our time is coming to an end.

3:00:53:28
Coelho: Twelve-fifteen yeah. I have to be out front at 12:15. What time is it now?

3:00:53:35
Lage: It's five after twelve.

3:00:53:39
Coelho: Yeah; okay.
Interview #2: December 17, 2004

Today is Friday, December 17th, 2004, in Fresno, California.

At the Piccadilly Inn Hotel.

In the Piccadilly Inn Hotel in Room 102.

Right; and it's the second interview with Tony Coelho on the epilepsy portion of our Disability Rights Project. I'll take off these earphones so I can—

Converse?

I can feel I'm with you. I wanted to just go off a few things from last time. We talked about family and work and everything leading up to your election. But I realized that in talking about your time with Bernie Sisk there are a few things that we didn't cover and one was your marriage. I know that's part of the story.

Yes, right.

Do you want to just tell about that, in particular in relation to your epilepsy.

Sure; when I started dating Phyllis—it's an interesting story. She was a staffer on the Hill from Indiana, worked for an Indiana congressman. I was a staffer working for Congressman Bernie Sisk of Fresno. An individual who is now my corporate attorney, by the way, but an individual in Sisk's office, who was an intern, was dating an individual in Andy Jacobs' office, congressman from Indiana, an intern in that office. Those two decided that Phyllis and I should get together, so we met as a blind date for lunch, and we fell in love and dated and got married. And I remember the first time that I decided it was serious, and she threw a birthday party for me. I had never had a birthday party. And she had a birthday party and—and I basically got drunk. And the reason I did was because I figured that she along with everybody else I had ever loved would turn against me once she found out that I had epilepsy.

And you hadn't mentioned it to her?
No; I hadn't mentioned it to her. So I was drunk, and she was upset that I drank too much—when I say drunk, I mean I had drunk too much. So she asked me why, and so I told her. I just—it was very emotional and I said, “You know, I need to be honest with you. It's obvious we're getting serious, and you need to know that I have epilepsy, and my history has been that everybody has turned against me once they found out about it.” And she said, “It doesn't make any difference. I just don't care; it doesn't make any difference at all. And it's not even an issue.” I mean, her attitude was really believable. It was kind of like, you know, you're kind of stupid for thinking that, and I felt bad that I was so stupid about it. [Laughs]

Had she had experience with epilepsy or—?

No; she's not the type who is prejudicial. That isn't the way she is, and so it was interesting. I mean she's been around me with seizures. As a matter of fact, she still has a scar on her finger where I was having a seizure at a restaurant and she braced my fall so I didn't hit my head on the sidewalk as I walked outside of the restaurant. And she put her finger in my mouth to try to prevent me from swallowing my tongue. Of course, the myth; and I clamped down and created a scar, and she still has a scar. But she's been around me with seizures—never been an issue. And she was extremely supportive and it just made my decision so much easier because it was obvious that this was somebody who, you know, it wasn't because she had been exposed to people with disabilities; it was just that it didn't matter. And it's sort of what I believe about disabilities. [Laughs] You shouldn't be looking at somebody's disability to decide whether or not you like them or not, or you want to hire them. It's whether or not they're a person that you happen to like or the person that has ability or whatever.

Yeah; but you needed to be told that too, it sounds like?

Oh, I needed to be told that. Oh boy, did I need to be told that, and it was a huge lesson for me. It was a wonderful lesson for me because I was so emotional about the way I felt at my church, and my parents, and business opportunities that had turned against me that I just I had a scar that was very big, and I just knew that this was another continuation of the scar.

Had you told Congressman Sisk, by the way?

Yes, yes.

And he had been fine?
Coelho: He didn't care; he didn't care, and he was around me when I had seizures, and he was absolutely wonderful. And I had seizures in front of—we were trying to get major league baseball back to Washington. He was a big baseball nut, and so I had been gathering petitions, and he and I and the mayor of Washington DC and three or four other members of Congress, the owner of the Washington Post, the owner of the Washington Star and some other prominent business people took a private jet from Washington out to Arizona for a major league baseball meeting. I was just exhausted from collecting the signatures and putting—in those days you didn't have everything automatic, so you had to go through all kinds of rigmarole. [Laughs] And I was totally exhausted, and I got on the airplane, and I had a seizure. And Sisk's attitude was—he was so calm. Everybody else was panicked, and he said, “Just let him be.” I could hear him, but I couldn't say anything.

Lage: But you were aware?

Coelho: Well, sometimes I am and other times I'm not, you know, and when I came out of it—we were in this private little plane, well, jet. It's not little but a private jet, and we were packed with everybody. And they had moved people aside, and people were sitting on top of each other to give me room on one of the couches and so forth [Laughs], and they were all watching me and when I came to I could see them all hovering around me. And I heard Mr. Sisk say, “Just let him be; he's fine; just let him be. So when I came out of it we got to Arizona and they were all panicky, and I got to Arizona and we had to have a meeting right then with the commissioner. And the boss just took me in the meeting, and I had to conduct the business like I was before, and it was great [Laughs] because it's what I wanted to do, and it was the way I should have been treated. But he was amazing about that; I mean he was just wonderful. He was like—he was really the father I never had. He was such a wonderful, wonderful person. But my whole marriage, and the way the kids were, they all knew from an early age I had seizures, saw me have seizures, and it was never considered a negative in any way, which is beautiful, and that's a lot to do with Phyllis more than anything else. And so that was a wonderful experience.

I might say that yesterday morning, the 16th of December, I went to Four Seasons Hotel restaurant in Washington DC to have breakfast with Dick Gephardt, who is deciding to leave the Congress or has decided to leave the Congress, and I was advising him on what to do and so forth, and he's been going through a whole series of things. And he was going to report to me on where he is, and so I sit down at the table, and it's sort of like a power place for breakfast in the morning in Washington DC. And so I sit down there and I'm sort of feeling weak, so I was a little concerned, so I started drinking ice water and trying to convince myself I didn't have time for a seizure.
And the next thing I know I was on the floor waking up, and looking right at me was this guy Mike Berman, who was an assistant to Mondale, and others. I could see Mike telling everybody around there, “Don't worry. He has epilepsy, and he's just having a seizure, and he'll be fine; don't worry about it.” Well, here I am in this fancy restaurant and they've called 911, and the firemen are there and the police are coming, you know, and they want to take me away on a stretcher. When you come to, you slowly come to, and your body has really gone into a frenzy. I mean, all your muscles get worked real quickly, and that's what a seizure is—is basically a release of all this. And so I'm flushed, and I'm exhausted, and I'm sweating. I'm just really sweating, and I can hear and I can say a few things but I can't say a lot, and so it looks like maybe something happened to me, so they're all saying stuff like, maybe he hit his head, or maybe he did this or whatever. So having Mike there was great because he calmed them down.

When I was able to start talking, they wanted to take me away on a stretcher, and I said, “Don't you dare.” And they said, “Well, we need to take you to the hospital,” and I said, “Don't you dare.” I said, “Look, I've had seizures for forty years; I know what it's like, and I don't want to be treated in an inappropriate way, and you're trying to treat me in an inappropriate way.” Well, they backed off when I started talking like—. And I just had to sign a release form, which is fine. And they left, and I continued on with my business.

4:00:11:01
Lage: And you were able to go on and have your breakfast meeting and—?

4:00:11:03
Coelho: I just went on. Yeah, it was sort of a forty-five minute interruption, but I went on and—which my doctor will get upset with—but I finished the meeting in an hour and a half, so 9:30, so this was forty-five minutes later, I guess, and I got in my car and drove back to my condo, which my doctor will not like and DMV won't like, but no problem, and I knew I wouldn't have any problems. It's not like—

4:00:11:35
Lage: It's not like it happens again immediately?

4:00:11:36
Coelho: No, and it's not like I knew I was putting myself in danger or anybody else in danger. I knew that I was fine; once I came through it I was fine and I got back to my condo, and got on a conference call for an hour, and then a car picked me up and I went to Dulles Airport and flew out to California last night.

4:00:11:59
Lage: I keep waiting for you to say you had a nap.
Coelho: [Laughs] And then I came out on the airplane, and I just read all the way out. I mean I was back to my normal self. But—

Lage: What would your doctor—this is not really what we're here to talk about, but what would your doctor have wanted you to do—rest or—?

Coelho: Be normal.

Lage: He wouldn't have minded, really?

Coelho: No, as a matter of fact, my doctor feels that it's unfair that you're supposed to report into him, because what he has to do is he has to notify the Department of Motor Vehicles, and then they have to take away your license, and it's ridiculous. It's just doesn't leave any discretion to a doctor, and my doctor knows that once I get through with my seizure I'm fine. And so the thing is if I sense it coming on I shouldn't be driving; I should stop immediately, which I would do normally. And once I have my seizure—once I come all the way through it, I shouldn't do anything before I'm through, but once I come out of it totally I function normally.

Lage: By now you know yourself?

Coelho: Yeah, I know myself well, and my doctor knows me, and so his advice to me was, “Don't tell me when you have a seizure. You know, tell me later. Tell me a week later or something so I know maybe I should check medicine or so on, but if you come to me and you've had the seizure and you're functioning I don't feel I have to report you in.” So I don't tell him; I just don't call. [Laughs] So anyway—

Lage: That's that.

Coelho: That's where we are.

Lage: Okay.

Coelho: I mean the reason I tell you that is because when I speak around the country I have a lot of people who say, “Tony, that's fine that you had epilepsy and you had seizures, but you're fine today.”
Lage: They want to believe that.

Coelho: And I always have to say, “Look, I still take my medication and I still have seizures,” and they don't believe me, they just don't, and so one of the things yesterday when I came out of my seizure I said [Laughs], “Look, for all those people who doubt that I still have seizures, here's the proof. [Laughs]

Lage: Now, another question I had—we talked a little bit about Sisk being interested in civil rights and involved with the Civil Rights Act, and that somehow this got you thinking along those lines.

Coelho: Yeah.

Lage: Even though the Civil Rights Act was before you.

Coelho: Yeah, I started working for him in April of '65, and he had just voted to open up the Civil Rights Act as a result of Sam Rayburn loading up the Rules Committee with John Kennedy in '62. And they had loaded up the—or '63 I guess—loaded up the Rules Committee and passed the Civil Rights Act over Judge Smith's objections—Judge Smith from Virginia. They increased the Rules Committee from twelve to fifteen.

Lage: I'm just curious how—what—.

Coelho: And his whole attitude—he was from Texas, he was Southern, and he thought it was totally unfair to treat people differently be they black, be they gay, be they—he was a member of the Church of Christ, so not necessarily a liberal church but he just thought it was extremely unfair that people were treated differently and thought it was—he was insulted when he went to Washington in 1954 and you had rooms—men, women, and colored—that you had the water fountains colored and no signs.

Lage: But he was from Texas.

Coelho: [Coughing, tape interruption] Where he was in West Texas—small areas—and they really didn't discriminate in these small rural areas. He came out to California during the “grapes of wrath,” and he came out and he had to—his family owned cotton gins, and he came out and ended up picking nectarines and grapes, and got elected to Congress as a tire salesman. So he went through all that—you're an Oakie and, you know, you're a transient, and he resented
the way people treated he and his family. And I think that sense of unfairness is what carried into his congressional days. And on disabilities he thought it was wrong; he thought it was wrong to treat people—and he ended up with a granddaughter with a disability.

4:00:17:07
Lage: Oh, he did?

4:00:17:08
Coelho: Yes, I think it's cerebral palsy, I'm not sure. And so he was very sensitive about the whole thing.

4:00:17:21
Lage: And did you see—it seems to me it was a very slow-growing awareness among people with disabilities that it was a civil right that they be treated—?

4:00:17:30
Coelho: Yeah; see what—what happened—

4:00:17:31
Lage: How did that happen with you?

4:00:17:31
Coelho: What happened with me is that when I was there with him, when issues came up about disabilities, he made sure that I knew about it. And things were passed. But when they did the Civil Rights Act they never included disabilities, and so then what they started doing was amending housing bills and different things, as you know, and starting to deal with disabilities, but it was sort of bringing these people in, in certain provisions, but it was only certain provisions and it was “those folks.” So it wasn't a whole class making them full citizens; it was sort of “in this area we probably shouldn't treat those people that way.”

4:00:18:15
Lage: Well the Rehab Act—'73, Section 504—

4:00:18:20
Coelho: Yeah; Section 504 is—the language is that way. It's very paternalistic; it isn't, you know, basically giving full rights and so forth. It was what I call the Jerry Lewis syndrome. It was basically patting you on the head and saying let me take care of you. The curb cuts were part of that; the curb cuts were to help you get on—and so forth—so that there was a lot of things like this where the people were sympathetic, as opposed to your civil rights. When I was going through all this, and when I first got elected, I was very involved in all the discussions on these things. And we were successful in getting some of the amendments through. I got elected in '78, so in '79 to '85 there were several different pieces of legislation that came up, which we amended, and I was involved in some of those things. But what I found was that it wasn't dealing with me as a person. It was dealing with these little things that weren't fair,
and so there was a movement with Ronald Reagan and the Council on Disabilities, or whatever it's called; I can't remember.

Lage: The National Council—

Coelho: Yeah; the National Council on Disability, and there was a woman who was chairman of it, Sandy Parrino from Connecticut, and the vice chair was Roxanne Vierra from Colorado. They came up with some legislation and—

Lage: Were you aware of what they were doing?

Coelho: I was aware that they were doing something, but first off, they're Reagan appointees, so that doesn't have much credibility, right? And secondly, they're Reagan appointees, so they're paternalistic, right? They aren't the type that I'm sort of into, you know, raving idiots: “We want everything now.” And so I knew what they were doing, but I wasn't interested because I didn't think I'd be interested.

And then one day Roxanne brings Sandy by to meet me, and Roxanne's husband I are very close friends. He's Portuguese, Fred Vierra, and he's in the cable business, and I was close to the people in the cable business. And Fred had done some things politically with me, and he was a right-wing Republican [Laughs], as he says. And Roxanne is more conservative than he is, by the way. And so she walks in and brings Sandy with her and says to me, “Look, we're putting together this Bill. Lowell Weicker has agreed to sponsor it, and we would like you to consider being the House sponsor.”

Well, I had never considered it, and so I listened to them and listened to what they wanted, and I knew it wasn't what the disability community wanted. A lot of people in the disability community want quotas and so forth, to correct the problems. And so I said to them—I said, “Look it, let me look at it. I know it's going to be controversial within the community, but if you're really committed to it, let me look at it because maybe this is a beginning. Maybe this is something we need to use as a step to bring people together, and having Lowell as the Republican sponsor on the Senate side makes sense with me, and I'd really like to do something in this area, because this is something I really strongly believe in. And if you think you can bring—” [ Interruption]. And I said, “If you really think you can bring some Republican support, I'm interested. I'm just interested in the concept, but I want to make sure I read the bill and so forth.”

My staff assistant, a person by the name of Heidi Hicks, said to me, “Tony; you know the community is going to go bananas. They're just going to think you're crazy to be part of this.” I said, “Well, they maybe wrong. You're never
going to get through what they want, so maybe I start somewhere in the middle with this stuff.” So I went through it and talked to some people in the community. They didn't want me to do it, but I talked, and I talked to Lowell, and he was totally committed to it. This was 1986 or '85—.

4:00:23:20
Lage: No; it was later. It was—

4:00:23:23
Coelho: No; it was '86, I think it was the end of '86, because I think Lowell got defeated in '86.

4:00:23:31
Lage: No, no; you're off by two years.

4:00:23:31
Coelho: Did he get defeated in '88?

4:00:23:34
Lage: Yeah; if this—maybe it was '87. Let's see, you actually first introduced it in April of '88, the first bill introduced April '88.

4:00:23:54
Coelho: And was Lowell my sponsor in the Senate?

4:00:23:56
Lage: Uh-hm.

4:00:23:56
Coelho: Really?

4:00:23:56
Lage: And then the next year he's—

4:00:23:59
Coelho: He's defeated?

4:00:24:01
Lage: Yeah.

4:00:24:01
Coelho: So geez we moved it in three years, whoa.

4:00:24:04
Lage: You moved it very fast. Before we go into details on that, I want to go back and finish your thought.

4:00:24:08
Coelho: Okay, okay; so whenever it was I decided to go ahead and put it in, and I did it primarily because I loved the idea that it was a Reagan group advocating, that the commitment was there from Sandy, and I love Roxanne. I'm very, very fond of her, and she's very conservative, and she would be supportive. I said,
“Look, if we move this I want testimony, I want involvement; I don't think we can move something that's partisan so I really want engagement,” and they both assured me they would. And Lowell was totally committed, and he said he would get co-sponsors and so forth on the Republican side. And so I put it in and the community was unhappy.

Lage: Can we stop right there?

Coelho: Sure.

Lage: I just want to back up and fill in the big space between when you came to Congress and—.

Coelho: Oh okay, yeah.

Lage: And how you got to know the disability community. Who was the disability community?

Coelho: Well, when I first came to Congress, now, as a staffer, I didn't know there was a, quote, “disability community.”

Lage: Maybe there wasn't one.

Coelho: Because there wasn't—because I came in '65.

Lage: The movement was just kind of—

Coelho: Just getting started, and it was diversified. Easter Seals did their thing, and cerebral palsy did their thing, and epilepsy wasn't really engaged in those days. And when I got elected in '78—well, prior to '78 I called the Epilepsy Foundation, which wasn't very old, and asked if they wanted some help; I'd love to be involved. And they were very dismissive. And they didn't even respond back, and so forth, and I talked to the executive director.

Lage: And he was dismissive right to your face?

Coelho: Yeah, on the phone, and you know, “who are you” type thing? I only had epilepsy, but of course, “who are you?” And then when I got elected I tried again, and they were to some extent the same thing. The Epilepsy Foundation
in the beginning was controlled by doctors and drug companies and parents, and parents were the minority, but there was nobody with epilepsy involved in the board or engaged in the deal, because again it was that whole attitude of paternalism—that we know best and you're the one with the disability. Obviously, you don't know what's good for you.

Lage: And maybe you shouldn't admit you have it anyway?

Coelho: Oh yeah; first off, you don't admit you have it. You know that's not a good thing. And so what I did when I was elected, I would speak very openly. I mean I'd just say I have epilepsy, and I would say why, and I'd be lobbying for amendments, and I'd be saying why I was for the amendment, and so forth. And it's when I met the civil rights movement at that time, because what they decided to do was that in civil rights legislation at that point in the late seventies, early eighties they started including disabilities because they could pick up a few more votes on civil rights legislation. And so the civil rights community started bringing us in as a political ally. Then as I became campaign chair it wasn't just a political ally; it was somebody with power and somebody with strength that could help out in the civil rights legislation, which included the disability amendment. And so all of a sudden I became a factor politically for civil rights because my civil rights were violated. And so that's perfect; I mean it's exactly the right thing to do. And Bob Dole was very involved in the whole civil rights movement and the same issue.

Lage: On the disability side?

Coelho: On anything dealing with civil rights, he was basically very pro, and because of his disability he was included the same way. And so what developed was Bob and I became very, very close friends, and we were sort of poster children in the Congress in regards to disability issues as it pertained to civil rights. And then when Lowell got defeated, Bob then became the principal with me in regards to ADA. But we had both been involved with other civil rights issues that dealt with disabilities moving along.

Lage: I'm trying to think what they were. The ones I have written down, which weren't necessarily civil rights—Social Security amendment regarding work disincentives.

Coelho: It's anything dealing with across the board that was not basically civil rights, our civil rights, but anything dealing with a health issue, with—there was a rent issue. I forget what—
Lage: Fair Housing?

Coelho: Fair Housing, yeah.

Lage: That would have been one though.

Coelho: Yeah; and I forget what year that was.

Lage: That was '88.

Coelho: Okay; and I was very involved in that issue.


Coelho: Okay, and I was involved in that; so it was those times when they brought me in to help and as campaign chair, you know, I was very successful in '82 and so all of a sudden I become the fifth-ranking Democrat in the House and had more power, and it was obvious I was going to move into leadership.

Lage: You have mentioned that your power as chair and then as whip helped you get these things going; would you just kind of give a picture of where is that power? What is that power?

Coelho: Well, I've always considered my epilepsy as part of Tony Coelho.

Lage: Yeah, but I mean as campaign chair, what kind of power do you have? That's what I want to get at.

Coelho: First off, members of Congress, Democrats, need you for money purposes for their re-elect.

Lage: Because you're raising funds for them?

Coelho: I'm raising the funds and providing and targeting their races, as to whether or not unions and political action committees contribute to their races and so forth. And I also then identified candidates for open seats or candidates to run against Republicans. And that was my job, so I could then be very helpful to
incumbents or people running for Congress. So to them, if I wanted something on disabilities, that's not a big issue.

4:00:31:39
Lage:
Small price to pay?

4:00:31:41
Coelho:
Small price to pay for what I was doing for them. And I used it all the time; I have no reservations in saying it because it's what's important to me.

4:00:31:50
Lage:
Were there other issues for you—we're just talking about disability and I don't want to get into detail [on other issues]—but was disability the only—

4:00:31:57
Coelho:
Of course, in regards to my district, agriculture and water were critical issues. It was anything dealing with my district and then disabilities; nothing else mattered as far as I was concerned. There was no national issue I was passionate about or felt I had a ministry for. You know, I was involved in every piece of legislation that went through the House from 1981 through 1989, so for eight years every piece of legislation I was involved in.

4:00:32:27
Lage:
When did you become whip?

4:00:32:28
Coelho:
I became whip in '87.

4:00:32:34
Lage:
And then what did that involve?

4:00:32:35
Coelho:
Well, at that time I'm counting the votes for every amendment, every bill, that goes through the House, and so every committee chair has to deal with me, every subcommittee chair has to deal with me because they have to come to me to get the votes. The majority leader would schedule the bill, but if I said we didn't have the votes it would come off the schedule. So I played a big role in whatever they were personally involved with and engaged in. So when—

4:00:33:07
Lage:
You also knew how everything works.

4:00:33:09
Coelho:
And I knew how everything worked, and so people had to deal with me just in a legislative way, and as long as I was liked, and I was fairly well liked, whatever was important to me became an easy thing for them to help me with. I was willing to use the podium, I was willing to use my disability to get ahead for other people. I felt strongly about it, and I was not bashful about it. I said it very openly. And it also worked with Republicans because Republicans knew that if they were big advocates of mine on disabilities that I would have
a tendency to lay off of them politically, and so why not, and I didn't care. If they wanted to help me on disabilities I'd work with them; that wasn't an issue. And I think that it was sort of a natural progression that because of who I am, a person with a disability, and in the leadership with power and moving up—I would end up being speaker if I wanted to and everybody knew that—so people took care of whatever was important to you. And so whenever I wanted something to be included on disabilities it generally was.

4:00:34:44
Lage: Can you think of any specifics or is this too long ago to—?

4:00:34:46
Coelho: I can't remember going way back, but—I can't remember. I mean for example, I do know that when I put out the “Dear Colleague” letter asking for co-sponsors for the ADA that I had people who came out to me not knowing what was in the bill at all saying, “Look, on your disability bill put me down as a co-sponsor.” And I knew that they knew nothing about it. Some of them had mothers, fathers, wives, husbands, sons, daughters, aunts, uncles, best friends with a disability, and that's why they went on. Others did it just because they knew this would be something that I would like, and I got a lot of Republicans on as well. It was an interesting piece of legislation, and I was at the peak of my power at that point. And we got a lot of people engaged. And then I left the Congress in April—no June of '89, and I asked Steny Hoyer to lead the effort for me, and I still lobbied on the phone, and I came to the Hill when it passed in the House.

4:00:36:05
Lage: I'm going to make you do much more detail.

4:00:36:07
Coelho: No problem; but I parted with a lot of good friendships and a lot of great relationships. So people still wanted to help, but it was a battle to get it through the House. Getting it through the Senate was not as tough but getting it through the House was a real—we had to go through five committees. The speaker at the time was Tom Foley, and he decided that it wouldn't go through one committee; it would go through five separate committees, which meant it should easily be killed along the way.

4:00:36:53
Lage: Now that was an important choice then?

4:00:36:56
Coelho: Yes; and I was—

4:00:36:56
Lage: And that was made while you were still—?

4:00:36:58
Coelho: No; I was out.
Lage: Oh you were out then?

Coelho: Yeah; and I was very, very irritated.

Lage: Okay.

Coelho: Because Foley felt—he told me that he thought this was like the—what was the bill dealing with seniors that the public got so upset at they had to—they were demonstrating and throwing things at Rostenkowski’s car and—?

Lage: Was it a Medicare reform?

Coelho: It was a Medicare reform, some type of reform dealing with Medicare, and they had to repeal it because it was so unpopular. So Foley said this is going to be like this bill—whatever this bill was—and we're going to end up having to repealing it because it's going to be so unpopular.

Lage: Unpopular with business?

Coelho: With business, and I told him I didn't care. And he said, “Well, he had to do the five committees. But this was a personal meeting with him, and I said, “That's fine; we're still going to win.” And he really didn't help me out at all, which really troubled me a lot.

Lage: Had you not had a close relationship with him prior?

Coelho: No, I did. I had a very good relationship. He was just a weak speaker. And that's ultimately why he lost; he lost his House seat and lost his speakership, and the House went Republican and so forth. And Tom and I were very close friends. When I decided to leave, he begged me not to leave. He said that he couldn't handle Newt Gingrich, and he needed me to handle Newt, and begged me to stay, and I said I didn't want to.

But so in that spirit of things we ended up with the five committees and what we did, even though I was out, orchestrated how it should be handled and we decided to go to Education and Labor first.

Lage: Now, who is we?
It was Steny Hoyer, Pat Wright, who is with—

With DREDF [Disability Rights Education and Defense Fund].

DREDF, and oh, I forget her name—the Epilepsy Foundation.

Liz Savage?

Liz Savage, yeah.

Who I spoke to when I was [in Washington].

And Liz was—and see—

So you'd sit around with the advocates for the bill from the disability community?

Yeah; and Liz—see the Epilepsy Foundation was never involved in a major civil rights or—

Right; that's part of the story I want you to tell me.

Yeah, it [the Epilepsy Foundation] was never involved in a major civil rights or disabilities issue, and I brought them in front and center right in the middle of it all.

Now, how did you—should we back up and talk about how you did that?

We can do that; that's easy because—

Because the last story we have from you now is that they really didn’t want anything to do with you. So how do you—?

What happened—they didn't want anything to do with me, and then they finally asked me if I would go on the board. I did.

After you got elected [to Congress]?
Coelho: After I got elected, and then I started Yes I Can Foundation, and I raised—I think it was $3,000,000 or $5,000,000—I can't remember now totally, but I raised this money for a foundation based on my life experiences; this was before ADA. And the purpose of the foundation was to give money to have these puppets all across the country. If Phyllis and I had a boy we'd have named him Brian, so we named the puppet Brian, who had epilepsy.

Lage: To teach children about epilepsy?

Coelho: To teach children about epilepsy, and Brian would have a seizure, and there was a girl—and this is not negative to women—but there was a girl who was a yackety broad, who would make fun of his seizure and so forth and so on, and between the two of them they educated people about epilepsy and whenever—

Lage: People in general? Not just people—

Coelho: No, well kids—no, kids without epilepsy—kids without epilepsy.

Lage: And how did you come up with this idea? Did you—

Coelho: I saw—I saw the puppet—a woman in Maryland had the puppet and I said I want to adopt it. And then we gave a lot of money to have him all over the country and—

Lage: Was she doing an epilepsy education—?

Coelho: She was doing an epilepsy education thing.

Lage: Okay; so you wanted to make her—?

Coelho: So I just wanted to make it national.

Lage: Uh-hm; and you raised these—?

Coelho: Yeah; and I raised the money for it, and it's still in existence. There's still puppets across country, and it's great. I dealt with education. I had a job—we called it a jobs corps for people with epilepsy, to get them jobs.
And this was while you're a board member?

This is this *Yes I Can Foundation*.

Oh, this is all *Yes I Can*?

*Yes I Can*, and then I wanted money for research, pediatric research surgery, $1,000,000 chair to one of the schools. And the story is interesting because I raised this money. I have Heidi Hicks handling the foundation, and I realized that the administrative cost is just tremendous; it's just ridiculous. So I go to Bill Macklin who was the executive director of the Epilepsy Foundation then and a great friend. This is a new guy now. But he's fabulous, and he's really pro in getting me involved and getting me to do things, and so I go to Bill and I said, “Bill, I have this $3,000,000 or $5,000,000,” whatever, and I said, “I just want to give it to the Epilepsy Foundation, and I want to get out of all the administrative stuff. I want to make it a gift, but here's what I want. I want the puppets, which I've started, and I want jobs,” and they had a jobs thing they were working on and this would be perfect for them, and they would call it the Coelho Job Center. And then I said I want $1,000,000 to go to UCLA, because I have checked around and that's where I want to go.

For the medical—?

For the surgery; it was research on pediatric surgery, and UCLA was doing some surgery where they cut off even 50 percent of the brain of a young baby, and it was like *[Finger Snaps]* a sponge, and if it was in the right area the brain would grow back, and the child then would have no seizures and so forth, and I wanted that explored and developed and so forth. So I wanted $1,000,000 to go there.

The Professional Advisory Board for the Epilepsy Foundation decided that I couldn't dictate where the money went. So I said fine; give me back my $3,000,000, so I took it back. And that caused a big brouhaha, and I got off the board and took it. And then I gave the $1,000,000 to UCLA, and it's still going on; it's an endowed chair, and we've got a great professor from Germany there who is doing some wonderful things in the pediatric research. And then after a period of time I cooled off, gave the rest of the money back to the foundation, and then they did the jobs deal and so forth. But I was really turned off of the foundation and then after I left the Congress, I'd say maybe six years ago I got back on the board and I now am chair elect and will be chair in May of next year.
So my involvement with the Epilepsy Foundation has been a rather interesting one. When I'm on the board I take on the doctors who set up the Professional Advisory Board, for obvious reasons, and I say that they—they take all the research money that we raise—we go out and raise—and they take all the research money, and they decide where it goes. Those of us on the board, including those of us with disability—with epilepsy—get no choice. We don't decide where it goes and for what purpose; we have no role, because, of course, the doctors know what's best for us. So it's that whole paternalistic thing again, and so I moved that we amend the bylaws to say that the docs can recommend, but the board votes. Well, they were furious, and some docs left the Professional Advisory Board and so on and so forth.

Lage: I would think legally the board should have that role.

Coelho: Of course, but now it does, of course, and now people that are not doctors are on the Professional Advisory Board. We have nurses; we have technicians; we have other people, and it works perfectly now. The drug companies were totally opposed to things we were doing. They didn't want the ketogenic diet; they didn't want devices—Cyberonics and so forth.

Lage: I saw that diet is now right on the front of the [Epilepsy Foundation] web page.

Coelho: Oh, yeah. Now what we do—so we got into a huge fight there, and I then got an amendment passed at the board that said everybody on the board had to reveal any conflicts. A lot of docs get a lot of money from drug companies, and they go out and represent and do speeches or whatever for drug companies, and they get a lot of money. I mean, what do they prescribe to people with epilepsy if they have a seizure? Oh my God; it just happens to be that drug from that drug company; geez, no conflict though; it's the best drug. Sure it is. So anyway, we forced disclosure, which made people mad. Then we pushed to recognize the ketogenic diet—not saying it's the solution but it is a solution, and we then pushed to recognize devices such as the Cyberonics VNS vagus nerve stimulation]

Lage: Is that—

Coelho: The vagus nerves, which is implanted here and connects to the vagus nerve, and it reduces the severity of [seizures] and reduces the amount of drugs that are needed. It doesn't cure, doesn't claim any of that stuff, but it does the reduce the severity of and the frequency of seizures, so your quality of life goes up and to me everything is quality of life. If I have one less seizure, my
quality of life goes up. And so where doctors want to make sure I don't have any severe seizures, sure, but I can't function because they've lowered my quality of life. I'd rather have my quality of life go up and have more seizures than to have my quality of life go way down, where I don't know what I'm doing.

4:00:47:47
Lage: Because the drugs affect you?

4:00:47:49
Coelho: The drugs affect everything I do, and so that whole fight came about and we got the devices recognized and so forth. So the Epilepsy Foundation has gone through a tremendous revolution—

4:00:48:05
Lage: Had you really been the driving power in this?

4:00:48:06
Coelho: I had been a big factor in it. The president that we had prior to the current president, Paulette Maehara, she's the one who pushed a lot of these reforms through, and she and I are great friends.

4:00:48:19
Lage: What's her name again?

4:00:48:21
Coelho: Paulette—Paulette Maehara, and Paulette got fired.

4:00:48:27
Lage: She was the president, a staff person?

4:00:48:31
Coelho: Yeah, yeah; and the current president is Eric Hargis, and he's been there six years, I think.

4:00:48:38
Lage: I think I talked to Paulette's assistant. She gave me a couple of names.

4:00:48:43
Coelho: Paulette was fabulous, and she was the transition person, and she got dismissed. Now she has a huge job. I mean she has a wonderful job.

4:00:48:52
Lage: Dismissed because she was too—too—in her—?

4:00:48:55
Coelho: She was too aggressive, yeah, and people felt she wasn't a team player. Well, you know, she wasn't a team player, because she didn't go along with the crap that they were proposing, and she was fabulous, and we got the changes through, but she lost her job in the process. And it was the people on the board
who controlled the process at the time. Our first person with epilepsy became the chairman of the Epilepsy Foundation.

4:00:49:21
Lage: And when—?

4:00:49:23
Coelho: Jeannie Carpenter—Jeannie was—the current president is two years; the previous is in his second year. The previous president is a parent, a guy—

4:00:49:36
Lage: She's now president or chair?

4:00:49:36
Coelho: Chair and the previous chair was a parent—a woman and then Jeannie was president for two years before that, so she was three, four years ago.

4:00:49:57
Lage: And that was the first chair to—

4:00:49:58
Coelho: The first chair of the Epilepsy Foundation to have epilepsy, and I will be the second.

4:00:50:04
Lage: That is really quite amazing.

4:00:50:04
Coelho: Tell me. Now it tells you about the problems we have. It tells you about, you know, “Go in the closet, we'll take care of you; don't worry. You'll be all right; we know best”—the doctors, the parents, the drug companies—everybody. But Jeannie died last year—seizure-related and so forth, a young person. Just a wonderful lawyer; very, very successful lawyer, but she had seizures regularly and—and—

4:00:50:36
Lage: It couldn't be controlled, apparently.

4:00:50:37
Coelho: Well, she controlled some, you know; it's reduced. Like mine, they're not controlled. I still have seizures but the severity of them are down, and the amount of them are down, and Jeannie was the same way. She had more than I did, but she was extremely well liked and extremely respected, and she loved the fact that I was a fighter. She loved the fact that I was aggressive, and I was a bull dog and still am. I mean I'm not too sympathetic to people who don't want those of us with epilepsy involved.

4:00:51:10
Lage: I interviewed when I was back there, Liz Rivera, Liz Borda she was when she worked for Epilepsy, and she did the Women and Health Initiative.
4:00:51:20
Coelho: I don't know.

4:00:51:21
Lage: She said she left because—she was a lobbyist; well, she ran the initiative—her boss said she was too passionate. She [Rivera] had epilepsy herself. She was too passionate an advocate. [Laughs]

4:00:51:36
Coelho: Oh yeah; well and that is the whole issue and that is the issue still to some extent with the foundation and they get tired of me but they can't do anything about it now because I'm elected—I was chair elect for two years, and I'll take over [as chair] for two years.

4:00:51:51
Lage: Are you elected by the board? Is that the way it works?

4:00:51:53
Coelho: By the board and—and then—

4:00:51:56
Lage: Do you help choose the board also?

4:00:51:58
Coelho: Yes; and I'm bringing in more people with epilepsy now. I mean I don't understand why not. We have very capable people who have epilepsy; they should be involved. They should be engaged. It's all about them; it's not about the drug companies. It's not about the device companies. It's not about the parents. It's about us. And I think it's great that everybody wants to help us. I love that, but it's about us. And so I brought on a lot of people with epilepsy, and they're all vocal; they're all passionate. And we don't have a majority of the board, but we just a got a doctor on who has epilepsy now which is—he's fabulous—just joined, just got elected to the board.

4:00:52:39
Lage: That's a nice combination to have.

4:00:52:39
Coelho: Oh yeah; it's wonderful. I mean, he's wonderful. I really like him but we're making—and now everybody knows that with me becoming chair and I'll be the former chair for two years, so I'll be chair of the Nominating Committee after I'm chair [of the board].

4:00:52:59
Lage: I see; that's the way it works.

4:00:53:01
Coelho: Yeah; so I'm going to be bringing more and more people on with epilepsy who have the skills to be a board member. I don't want somebody on there that doesn't have the skills to be a board member. That doesn't make any sense; that hurts the cause but people have the skills to be a board member,
yes, definitely. We have young people with epilepsy who are on the board and it's exciting. And so—

Changes the nature of this organization.

Oh, it changes the nature of the organization, and it changes the passion. And our priorities are different. We look at things differently. It's like, you know, white men trying to decide what's best for women. I say, look, if you're not a woman how do you know? And women being elected to Congress has changed the dynamics of the Congress. I mean it's amazing to see what—women have different priorities than me. Well, you know, that's natural. But shouldn't we consider those priorities from their point of view as opposed to just white men deciding? It's like white men and women deciding what's best for black Americans. They have a different point of view and that's what's great about the United States. If we would sort of get beyond the prejudices that we have. But the Epilepsy Foundation has made a tremendous transition. We still have a ways to go, but a tremendous transition.

A lot of the funding, I think you told me or I read, comes from or came from the drug companies.

Right.

Are they less enthused about finding you more passionate leadership?

No, because I want them engaged. I want them involved but I don't want them telling me what my priorities are, and I understand if they have control they're going to do it because their priorities are their bottom line. I don't have any trouble with that, but I don't want it to be the controlling factor. I want to be able to have a voice. I don't mind them saying what their priorities are; I think that's great. But I want to make sure those of us with epilepsy have an equal voice at the table. And if we're passionate, and if we speak out we'll—we'll win because they can't afford to be against us.

But they're still willing to give funding? They're funding part of the organization?

And they help, and now we have these dinners that they help sponsor, and we're into bequests and so forth. We just got a $9,000,000 gift, which was unusual for our foundation, because it's small and young basically but we're getting there. I mean it's really kind of exciting to see it happen. When I first got engaged, the Congress in appropriating money for the National Institute of
Health—the National Institute of Health never wanted money set aside for epilepsy. Now you could for cancer; you could for diabetes; you could for blindness, heart, yes, and AIDS, of course; but epilepsy—no, no, no. We don't want any money for that. So I got heavily engaged with Hoyer, whose wife had epilepsy, died several years ago now; I put Judy on the board. She was fabulous, passionate, which is what I love. [Laughs]

4:00:56:15
Lage: Judy Hoyer this is?

4:00:56:17
Coelho: Judy Hoyer, but she died, and Steny has become one of our biggest advocates. So on the [House] Appropriations Committee he serves, and he is the ranking Democrat on the Health Subcommittee, and so all of a sudden we started getting money designated for epilepsy, and they were furious—no, no, way; we can't let that happen—and some of the senators fought it, because you're not supposed to designate, but if it's for cancer it's okay; if it's for this, but not epilepsy. Well, now we've got that changed; and so we now, since, I want to say 2000-2002, somewhere in there, we've now started every year, we now get more and more money appropriated, and it's not just NIH but it's Defense Department and it's other groups. And it's for a legitimate cause. I mean, we have a need—we have 3,000,000 people with epilepsy, that identify. Now there's more, obviously, but that's a lot of people; that's a lot more than most other disorders or diseases.

4:00:57:28
Lage: When you say identified—you mean they identify, or they have been identified?

4:00:57:34
Coelho: They have been identified.

4:00:57:34
Lage: Been identified as having epilepsy.

4:00:57:36
Coelho: But a lot of people are still in the closet; parents won't let them come out, and they don't want people to know. The doctors don't tell because we still have doctors that say, “Don't tell people you have seizures. [Whispers] Don't say that; they don't need to know,” and it's sad. It's sad what goes on today. So we know we have 3,000,000; that's a lot. And for others to get help to solve the disease, the disorder—whatever it is—why shouldn't our disorder get some attention? So we now are—

4:00:58:09
Lage: So you work in many ways?

4:00:58:08
Coelho: Many ways.
Lage: The Congress—

Coelho: Yeah, and I think it's exciting. I think that's what's really neat about it, and bringing in Liz Savage on the ADA was really helpful because all of a sudden the Epilepsy Foundation is in the middle of everything on disabilities, and we weren't even heard of before.

Lage: I'm going to stop you right there because I have to change the tape.

Coelho: Okay.

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Coelho: I haven't decided where it's [Coelho’s papers] going to go but more than likely Loyola University, Loyola Marymount University, is going to probably deal with something where I'll do an institute over there, which I probably will name and provide a lot of money and have a public policy institute which will deal with national political issues and so forth. And I might put disability in that, or I might go someplace else and deal with something, because I want an aggressive involvement on disabilities in the political process. And so I may do some other school that I think can help really aggressively politically. But I think that's what it's all about, and so I want to help, but I'm not going to be hindered by some school's interest in controlling and so forth. But I was meeting with Fresno State the other day and started giving some stories about Bernie Sisk, and they were funny and they were true; they're all funny. And they're saying, We've got to do the oral history on Sisk.” And I said, “I'm fine; I'm willing to do that. I will,” so now we're going to start doing that. They were going to think of doing it today, but we'll do ours and then the next time I'm in town we'll do Fresno State.

Lage: So we were going to go back to how—part of your vision must have been a more aggressive lobbying program.

Coelho: Oh yeah; I mean, part of what I wanted to do—see, I've said it to you before, I've said it publicly many times, that when I got elected I decided that the podium—you don't get very often. And as an elected person to the Congress of the United States I have a podium and as chairman of the Democratic Congressional Campaign Committee I have a bigger podium. As whip my podium is bigger, and I decided that I wanted to use that podium to help my
district—no doubt about that, because you've got to take care of them first or I don't get there and I don't get the podium, so I've got to have the podium. And I believed in that; so that's not an issue. But number two was that there was only one thing that was my ministry and that's disabilities, and so every chance I had I used the podium to help out in disabilities. And to this day I still believe in that; I'm still an advocate; I'm still aggressive; I still have a ministry; I'm still trying to make things happen. I mean, I don't know if I ever told you the story about the Pope. Did I tell you the story about the Pope?

5:00:02:30
Lage: You did—you did; we got that last time.

5:00:02:34
Coelho: Okay; well but that's—here I'm going to the Vatican to do an official visit with the Pope, a delegation, and I mean it's an official US visit. But in that situation I felt I had the podium, and I thought it was the misuse of what God gave me not to take advantage of that opportunity to try to lobby to get the church to turn itself around. I just believed that strongly, like today I don't mind telling you that Anthem Blue Cross/Blue Shield bought/merged with Well Point Blue Cross/Blue Shield, and John Garamendi had vetoed it, and eight States approved it, and the Governor of California approved it; John Garamendi disapproved it, so it's dead. It's a $20 billion deal. And so they come to me ultimately, because I'm a close friend of John Garamendi and say would you deal with John—?

5:00:03:43
Lage: Blue Cross/Blue Shield?

5:00:03:45
Coelho: I said okay. Yeah; and I said, “Look, I'm willing to deal with John because I know him very well, I like him and he likes me,” but I said, “There's only one—I'm not interested in money. What I'm interested in—your attitude towards disabilities.” And I said, “I want to know what your policy is towards people with disabilities and your insurance policies, but I also want to know what your work policy is. Do you employ people with disabilities? Are you aggressively out there doing it and what I'd like to do is I'll work for you on your whole disability policy—working with you on your disability policy and if you're willing to do that I'm willing to help you with any problem you have—with Garamendi or whoever, wherever—anywhere in the country but I want you as the largest health company in the world which you'll end up being—I want you to lead the area in regards to disability policy.” You know, their attitude was, “Tony, whatever you want.” [Laughs]

5:00:04:36
Lage: Was this—

5:00:04:37
Coelho: And it just happened. It just got approved November 30th.
Lage: The merger?

Coelho: The merger.

Lage: Now, how is the reform of Blue Cross/Blue Shield going?

Coelho: I am now heavily involved with them in regards to disability policy, and I think it's great.

Lage: Working with them on their insurance policies?

Coelho: Yeah; I'm going to be working with them on a continuous basis for a long-term, dealing with disabilities and its overall attitude towards disabilities and employing people with disabilities. That, to me—as you know, I've been passionate about that—is really the bottom line, our ability to get a job, because people with disabilities, our employment rate is 35 percent. That means there's 65 percent of us who have skills and want to work who can't get a job. That just is discriminatory; that is just unfair. I think it's immoral, and so I am determined to try and do something about it.

So here is an opportunity to do something about it, so it's my same attitude like dealing with the Pope. Some people felt that was disrespectful; I didn't think it was. I mean he's a man; I mean he's not anything other than that—he's a man. He's a holy man, but he's a man, and he runs a church that was discriminating, and I think it was unfair for me not to try to get him to change, which he did. As a result of that, there are people now who have epilepsy who are priests. I think that's what I'm here for; I think that's what it's all about. And if I can get Anthem to be a model employer for people with disabilities, I think that's wonderful. I don't have any trouble with that, and that is a continuation of my policy in regards to when I was whip, when I was campaign chair, and how people would change things or vote for me because they felt that would do favor—that's fine; do it. I don't care; it's all right and here's—. [Interruption, Coelho staff member Bren Forhan enters]

Lage: Let's see, you were telling me about Blue Shield and John Garamendi, and I think you finished that story.

Coelho: Yeah.

Lage: How you use your abilities—your power. But this came out of talking about getting the Epilepsy Foundation more involved in lobbying and bringing Liz
Savage on. Now Liz gave me the impression when I talked to her that you were behind her being hired. She was hired in '85.

Coelho: Yes; I was.

Lage: So tell me about that.

Coelho: I don't remember the details. I wanted to get somebody that the Epilepsy Foundation could really basically assign to me to work on disability issues and ADA being part of it.

Lage: ADA really wasn't started yet.

Coelho: Wasn't there yet, yeah; but it was the whole issue about—and Bill Macklin was the executive director, and Bill hired Liz and—

Lage: Did you point Liz—she had the impression you sent her resume over. [laughs]

Coelho: Yeah, I did.

Lage: Do you remember that?

Coelho: Yeah, yeah, I did talk to Bill, and said I wanted her hired, and he was fine, you know.

Lage: How did you know her; do you remember?

Coelho: I don't remember. Liz Savage—I don't remember. I've known her forever. I just don't remember how I did. I mean she became part of, like, my family, you know, so I don't remember—I don't remember what she was doing before she did the ADA.

Lage: She worked on the [Geraldine] Ferraro Campaign.

Coelho: Well, then that would be it because I was very big with Ferraro.

Lage: Maybe that was how—
Coelho: Maybe that was how I met her; I can't remember. I can't remember.

Lage: But was this a new kind of lobbying for them [the Epilepsy Foundation] then?

Coelho: Yes; it was. Well, they did things but they didn't lobby aggressively and basically it was an effort to get us engaged in public policy in a big way. I felt that with my position as campaign chair and my position in the party that I could do a lot for epilepsy, but I didn't have the time to do all the leg work and the research. I had to have somebody who would do that; I'd open up the doors, create the opportunity, and turn it over and let them follow-through. And I told Bill that, and he was great, and that's of course what he wanted, and Liz was tremendous. I mean Liz became one of the leading people in the disability movement who just happened to represent the Epilepsy Foundation.

Lage: And had another disability herself.

Coelho: Yes; absolutely, and Liz is driven, you know, which is great and to a great extent the Epilepsy Foundation wasn't aggressive enough for her and she left and she went to Janet Reno, and she was fabulous with Reno as attorney general, and she basically did a lot of the disability stuff in the Justice Department. Then when Clinton left, she then went to work for UCP. She works at United Cerebral Palsy and is involved in their health and housing area or something; I can't remember the exact title. But the thing that's exciting there is that United Cerebral Palsy is leading the major effort in regards to disabilities now, which I'm involved with, and what we're going to try to do is to change the whole way that people with epilepsy—people with disabilities are looked at—that we just want to be Americans just like everybody else.

Lage: Uh-hm; is this a public education initiative or a lobbying—?

Coelho: It's everything—everything.

Lage: Talk just a little bit more about that since you—

Coelho: We're not going to talk about it because it isn't public yet.

Lage: Okay, okay.
5:00:10:34
Coelho: But we are in the process of developing it right now or raising some money to do the basic research on how we—it's going to be a political campaign. It's going to be a PR campaign. Last weekend I was in North Hollywood, and we met with three different actors/actresses all with some involvement family-wise or one who you probably know is a character actor. He’s gotten some Emmy’s and so forth for the role he's played in regards to a person with a disability.

5:00:11:18
Lage: Uh-hm; and he has a disability himself?

5:00:11:21
Coelho: No; and he's just a big advocate, and he's going to play a major role in this whole thing. And these two actresses, one has a nephew who has a disability and the other has a son who has a disability, and they're prominent actresses and they're going to play a role and a young fellow who is on a very popular TV show now, his father is very famous—he plays the role of a disabled person on TV. And he is going to play a role in this as well. And we've got some writers and so forth, but it isn't going to be Hollywood driven. It's going to be something that we're looking in a big way—sort of what happened with AIDS, in that at one point if you brought up AIDS it was kind of like, oh my God you don't bring that up; that's nasty, that's dirty, and all of the sudden it came out of the box, and then everybody wanted to contribute, everybody wanted to help and everything you wanted to believe—

5:00:12:30
Lage: And people went up in front, saying they had AIDS.

5:00:12:32
Coelho: Yeah; and then basically you provided an opportunity to develop a cure; we're not there yet, but we've made great progress, and we've had some regression because people not practicing safe conditions, but basically we've had tremendous progress in this whole area of AIDS. I want the same thing in regards to disabilities; I want basically for us to all be out of the closet. I want us to have people look at us for our ability and for us to be treated as Americans just like anybody else. And so it's bigger than civil rights; civil rights was our legal rights—jobs, or our opportunity to be fired like anybody else, but this is just as human beings.

5:00:13:27
Lage: Attitudinal changes.

5:00:13:28
Coelho: Attitudinal—that's the whole thing; it's the whole attitudinal change. And we're going to aggressively go after it. It's going to take a lot of money, and we're in the process of raising it, and it's fun. It's going to be exciting.
Lage: Are you working with groups that I associate with the independent living movement or—?

Coelho: I can't talk about it; there's—there's—

Lage: I'm sorry; we're not even interviewing about that. You've piqued my curiosity.

Coelho: You'll hear about it.

Lage: Okay; so I think one of the interesting things you've already said about Liz, that she was lobbying for this disability rights law that the foundation hadn't really shown a lot of interest in.

Coelho: None.

Lage: And so many of the provisions didn't relate to people with epilepsy and a lot of the key things they thought about—like transportation and AIDS.

Coelho: See, I feel very strongly that we shouldn't be exclusionary. We all have disabilities and to say that we should do X for people who are sight impaired or we should do X for somebody who has epilepsy—that's unfair. That's discriminatory in itself, so I just think what we ought to be doing is helping everybody. And so if you look at the ADA, basically the ADA covers the broad scope; that's what it was supposed to do until the Supreme Court got involved. The Supreme Court got involved, and the Supreme Court is trying to screw it up. But basically as you know, I mean it's kind of ridiculous; I helped write it, I was the principal author of it, and now the Supreme Court says the Congress did not intend to cover people with epilepsy.

Lage: Yeah, isn't that ironic?

Coelho: I mean, I'm stupid, I guess is what they're trying to say. I mean, I didn't know what the hell I was doing, and so we're going to try to correct that—because, as a matter of fact, which is kind of exciting—the National Council on Disability, appointed by Bush, they just came out with a recommendation to correct all these Supreme Court decisions including the one on epilepsy, and we have Republican senators who are willing to lead the effort, so you may see in the next Congress a whole effort on ADA restoration, which is something I've been working on for the last two years. But anyhow—
Lage: It's interesting that again you have a Bush in the White House, a Republican is what I'm saying, and a Republican-appointed NCD.

Coelho: Yeah, and that's important because if we can't make it bipartisan we can't get there.

Lage: Uh-hm; I know that was one of the things I saw you quoted as saying.

Coelho: Yeah, yeah; you've got to be bipartisan and having a Republican in the White House really helps us because if we can get that president to be for us then it takes away the sting of the right-wing or the business community that this is bad for business or bad for Republicans or whatever. If it's Democrats advocating, then the Republicans can get away with it. So it’s not like I wanted to see Bush win, but maybe this will be one of the good things that come out of it over the next four years.

Lage: Let's talk a little bit about this tension between the [disability] community that maybe wanted a stronger ADA—

Coelho: Yeah.

Lage: — and how it actually ended up being written, and one of the first things that was dropped was insurance.

Coelho: Right.

Lage: Were you in on those discussions?

Coelho: Yeah.

Lage: And what did you—?

Coelho: We knew that there were certain things we had to do. For insurance, we had to drop it because we couldn't win. We just couldn't get the votes. The other thing we did is like on transportation; we permitted buses to take twenty years to get full compliance, and we only won in the Public Works and Transportation Committee in the House by one vote on that issue. So our compromise, if we hadn't compromised, we would have lost—our compromise was just right because we only won by one vote, but we gave
them—we gave Greyhound twenty years to comply, which is ridiculous, but it was the only way we could get there and we didn't want to do without transportation. We could do it without insurance, because there's healthcare and a lot of other deals dealing with insurance, but we had to have transportation in the ADA bill. And so we made compromises there [for] which the community was very upset with us. I mean I got criticized severely for supporting, even though I wasn't in the Congress, but I was part of the deal making in that, and that we needed to get a compromise where I could get the votes and—

5:00:18:09  Lage:
Did you work with Greyhound also?

5:00:18:12  Coelho:
Oh yeah, they threatened me and threatened all kinds of things, and I will never forget one time they—one of my biggest supporters, a guy from Merced here, Ken Riggs, and Kenny Riggs was a big Sisk supporter and a big supporter of mine. They owned the ambulance company for Merced County, and they also owned buses for schools and for a lot of other stuff. So they had developed a wonderful transportation business and were successful, and they did tours to Yosemite and a lot of stuff. So they moved from just ambulance to a big transportation company. So in the middle of the whole transportation fight, I get a call from Pat who says that the transportation people want to meet with me to see if we can't reach a compromise, and so what do they do before the meeting? They have Ken Riggs call me, and I'm not even a member of Congress. I'm just an outsider. So they have Ken Riggs call me to put pressure on me to come their way. So I tell Kenny what was going on; I said look—we're giving them twenty years and basically in my view in twenty years you'll come up with all kinds of fancy things to take care of people getting on and off a bus.

Now, you know, the buses rock and roll. The air goes out of them and they go way down on the suspension, and they go back up and all kinds of stuff. What they have found is that it's not only economically feasible, but buses that provide access for not only people with disabilities but for the elderly and for a lot of others is economically advantageous. Well, if it's economically advantageous it's great; but if it helps the disabled—oh that's not so good. But anyhow, now they've moved ahead on this area, Greyhound being one of the last, and they went bankrupt, and I don't have any regrets on that, and it had nothing to do with disabilities because they didn't have to comply at that point—just had bad management.

5:00:20:22  Lage:
They went bankrupt before the twenty years?
Coelho: Before the twenty years, and so it was bad management, but basically we had to make compromises across the board on different issues or we could have never gotten there. And people in the community got very upset.

Lage: Tell me specifically.

Coelho: We made compromises in regards to telephone and so—in communications.

Lage: What kind of telephone—for the hearing impaired?

Coelho: Yeah; and I can't remember the details now, but it had to do—because see in those days cell phones were just coming on, and so it had something to do with that, and I can't remember the details. Liz would know; she was heavily involved. But it was—

Lage: Which aspects of the community were so upset, because I also have read that you worked with Pat Wright closely?

Coelho: Oh yeah; see Pat—Pat and I were chums. I mean she would—she would—

Lage: Did she get upset?

Coelho: —publicly beat the hell out of me and privately work out the agreements. [Laughs]

Lage: Tell me about Pat Wright.

Coelho: Oh I love Pat Wright. She would, she'd publicly beat the hell out of me and say I was caving in and so forth and so on, and then she would tell me I was right to do X, Y, and Z and she worked—At first Pat and I were enemies, because she was beating the hell out of me for putting in the bill because she thought it was wrong for me—

Lage: Oh she didn't want the bill at all?

Coelho: She didn't want the bill in because they were working on a different bill and so forth. And the bill I put on became too liberal. We had to compromise on that bill. So if we had—
Lage: Right; the first bill—

Coelho: Yeah; so if we had put in the bill they wanted we would never have gotten anywhere. We wouldn't have gotten an ADA. But anyhow, Pat was wonderful. Pat got very engaged and with Liz and we—Pat worked with the Reagan White House and the Bush White House, and she would go behind the doors and work out compromises and come out and say those damn Republicans; they're doing X, Y, and Z. But it was the only way we could get there to get the community moving along. But Pat was very, very shrewd; she is very, very good.

Lage: Good strategist?

Coelho: Good strategist—a wonderful strategist.

Lage: That's what I've always heard about her.

Coelho: So she's—she's good.

Lage: So despite the fact she was beating you up, you think she had understood the reality?

Coelho: Oh yeah; no, she understood the reality—yeah. And once she understood what I was willing to do, she was willing to play totally, and like she's been engaged in the Restoration Act now and the strategy of having to work with Republicans and so forth. Pat is very shrewd and it's what—and let me be honest; it is important that we have the radical advocates in the disability community. I mean they need to call me a sell-out and so forth because that's the only way I can become credible with other folks, if people are saying I'm a sell-out. So you need to have the real passionate aggressive advocates, and let them think I'm not as passionate as they are, but in order to be effective you've got to have both sides and then you can sort of go in the middle. So I encouraged the people to beat up on me in those days. I thought it was great. You know, go for it. And that just makes you more credible inside, so I think that's fine.

Lage: Tell me more about working with the Republicans. I know you've got Newt Gingrich on board.
What I did was I worked hard to—people were surprised that I worked so aggressively with Bob Dole and Papa Bush and then in the House when Steny was pushing through I was openly, aggressively, complimentary of [Joe] Barton from Texas and —

He's a Republican?

Republican and Orrin Hatch in the Senate, who was spectacular; we could not have done it without Orrin.

Now why was Orrin Hatch spectacular?

He's Mormon, and he told me one day—I testified before the Senate; it was an emotional testimony.

Was this the testimony everybody talks about?

Yeah, and so when I got through Orrin was on the podium along with Bob Dole and Ted Kennedy and some others, and Orrin came out to me, and he had tears in his eyes, and he said, “Tony; I just want you to know that in the Mormon Church we feel that the disabled are special children of God, and I will do anything you want.” I said, “I'll take you up on it.”

Even though there was that kind of paternalistic—

Well, it was a different attitude towards those of us—but when he heard my story about what the Church had done and so forth, he understood right away that there needed to be some changes. And he was extremely supportive and still is, still is.

But didn't he want to put in his own bill or make some compromises?

I don't remember, to be honest. Yeah, he probably wanted to do compromises that were—were something that I—we didn't want but what helped us there is that he and Bob Dole were very, very close, and he and Ted Kennedy, extremely close, and so we had trouble with Tom Harkin at times would get way too liberal, and Hatch would get upset and he would call me and say, “Look, if you can't cool him down I'm going to back out.” So I'd call Ted Kennedy and say, “Will you cool down Tom Harkin?” and so forth and so on. [Laughs]
Lage: These were on specific issues?

Coelho: On specific issues yeah; but it was—it was fun working on it. In the House, we had people like—we decided the strategy would be to go to—well, when Foley said it had to go to five committees, I finally said, “Okay, but I want to designate the committees and the order that they go to.” And he said, “That's fine.” That was a mistake.

Lage: On his part?

Coelho: On his part, because if he wanted to kill it, which I suspect that he did, he did the wrong thing. So we started off with Education and Labor, which we knew we could win big.

Lage: Just because you knew who was on it?

Coelho: The makeup of the committee and so forth and what the issues were going to be before Labor, and so we won big on that. Then after Education and Labor we went to—there were five committees and I'm forgetting the fifth. Oh, the Rules committee was the last one. So the second committee was Judiciary, and Jack Brooks from Texas was opposed. Now I was very close to Jack, and I periodically had to call him and cash in every chit I had to—

Lage: Did you have chits with him?

Coelho: Yeah; I mean look I helped him out a lot when I was campaign chair and when I was whip, and so forth. And I was just very aggressive with him and Steny ended up becoming an enemy of his as part of this. It was not the most pleasant thing, but he voted for us, and we got it out of there with a decent vote. I mean there was not—I knew if we could bring it to a vote we'd be fine. The issue was bringing it to a vote, and I pressed and pressed and finally got him to agree to give us a vote. He knew once he gave it a vote it was out, but the way he did things is he killed legislation by not bringing it to a vote, and that's what he was trying to do to us, but I got him to give it a vote, and it got out. And I think he voted for it, as I remember; I'm not sure. I didn't care because we—

Lage: You had the votes?
Then the third committee was Commerce and that was telecommunications and that was health, and so forth and so on, and that was [John] Dingell. And Dingell and I had an interesting mixed relationship but I could press Dingell, and I did. And Henry Waxman was one of the subcommittee chairs, and he was a big advocate. Dingell ultimately, his first wife had depression and so forth, and so I was able to aggressively work that and get that done. The Public Works was the hardest; that was the last—well, Rules Committee was the last one, but that one was rather easy to get done. But Public Works, we went before that committee and the chairman of the committee was a congressman from Long Beach, and he was a great friend, and the bus industry was very close to him, and he said to me one day—Glenn Anderson, who used to be lieutenant governor of California at one point. And Glenn said to me one day; he said, “Tony,” he said, “They're really putting a lot of pressure on me.” And I said, “Glenn, there's nothing more important to me—nothing.” And when Glenn's son wanted to run for mayor in Long Beach, I had raised money for him and helped him. And I said, “Look, I was there when you needed me. I want you here now,” and he said, “Fine”.

And this was after you had left?

After I had left Congress, yeah. And he said yes. And then we still had Norm Mineta to go to, and Norm Mineta was the congressman from San Jose.

And was he chairman of a subcommittee?

He was chairman of the—the subcommittee—the Transportation Subcommittee. Glenn was chairman of the full committee, and Norm was chairman of the subcommittee, and Norm was close to the bus industry, and Norm was basically opposed. And what I did with Norm was, you know, my aggressive, tough way. When the Japanese Reparations Act was before the Congress on the House floor, the majority leader, Jim Wright—we had it scheduled and there was opposition from, I would say, some racists, in effect. I would say it—I said it, and they convinced Jim that it would boomerang on us if we put through this “Jap” bill. This was an awful bill. So Norm was a deputy whip, and he had supported Jim Wright for leader and so forth and his was a critical vote; Jim Wright had won by one vote. So Jim calls up Norm and says, “You know, I don’t think we should schedule that bill; I don’t think we have the votes for it, and you don’t want to lose it. So let’s schedule it for next week or the week after?” So Norm said, “Let me think about it.”

So Norm came and saw me on the House floor and said, “Jim tells me that we don’t have the votes.” Now I’m the vote counter as the whip, and so he says we don’t have the votes, and he wants to pull it. I said, “Norm, it’s your
decision. Obviously, it's your bill and if you want to pull it you can pull it. But I guarantee you I have the votes. And I guarantee you if you pull it, it won't get rescheduled. So you're going to have to trust me; I have the votes. I can get it through today. If you reschedule it for next week or the week after I don't know what will happen then. Keep it going; we've got the pressure. The fact that he wants to withdraw it means we have the votes—not that we don't have the votes. So let's do it.” So he did. He went along, and we scheduled it, and we won.

5:00:32:28
Lage:
By very much?

5:00:32:29
Coelho:
I can't remember what it was. It was not that close, maybe we won by seven, eight, ten votes; I don't remember what it was, but it wasn't one or two. I mean it was—I had the votes. And I never lost a vote in the House when I was whip. We never lost a vote; we had everything counted right to the nth degree, and if I didn't have the votes on an amendment I'd pull the amendment; I'd pull the bill, and until I got the votes or we changed the bill I wouldn't let it go back. I didn't believe that as a majority party you bring something to the floor when you don't have the votes for it. I mean, it didn't make sense and you don't have to win by thirty votes; you need to win by five, that's all. And you say, “Okay, if you vote for me on this bill I'll let you vote against me on this bill,” and we did that all the time. I mean it's running a business; that's what it all is. So I told him, I said, “I have the votes,” so he said okay. So he went back to Jim, and he said, “I want to chance it. I'm going to take the chance. I think we have the votes and I'm going to do it.” So we brought it up, and Jim was not happy at all. And we had the votes, and we won. So Norm—Norm was always thankful to me for it.

5:00:33:36
Lage:
[Laughs] Just like that?
Coelho: Yeah, and we won by one vote. And once we got it through there, then the Rules Committee was next, and that was easy.

Lage: What kind of pressure does—where is the power that Greyhound has that's so strong?

Coelho: Money.

Lage: Money for a campaign?

Coelho: And just over the years being aggressively involved politically. They were a very effective political operation, very effective. And they were friendly, and they really worked that committee hard.

Lage: And they gave them money for their campaigns?

Coelho: They gave them money for their campaigns—

Lage: Would they target—like you hear the NRA does—target somebody to defeat?

Coelho: Oh yeah, yeah, sure, and they were aggressive about it, and I don't—look, in Public Works and Transportation what you deal with is a lot of transportation issues, and maybe Greyhound supported some stuff that Norm really wanted in some areas that didn't mean a lot to Greyhound but meant something to Norm—that's fine. I don't know why people vote differently. A lot of it is because of political operation, a lot of it is because—I don't care. If it's something I really believe strongly I'm going to try to convince you not to vote that way, and that's what's important to me. But I can't second-guess other people why they vote differently, and I can't be judgmental and say they're right and I'm wrong, but on this issue I knew I was right. And it meant something to me and that's what's important here because it wasn't just HR1236; this was my civil rights and as he felt strongly about the reparations for the Japanese Americans and their recognition by the federal government that we had messed up, that we had violated their civil rights, I wanted him to do the same thing for those of us with disabilities—say that the government had violated our civil rights, and we needed the correction. I didn't see it any different.

Lage: Did he get it?
Coelho: Yes, he got it.

Lage: It wasn't just a personal [favor]?

Coelho: No; he got it.

Lage: What about the Black Caucus? Did they—

Coelho: The Black Caucus was wonderful. They were supportive from day one. Major Owens was the chairman of the Labor Subcommittee, and he was a huge advocate. John Conyers was on the Judiciary Committee, number two on the Judiciary Committee. He was a huge advocate for me. And I just had tremendous support from the black community.

Lage: Did they understand this as a civil rights issue?

Coelho: Oh yeah, totally, totally, and I was aggressively there for all civil rights issues, so it was, you know, I say payback time. I don't mean it in that way but I do mean it in that I worked my ass off for something I believed in, which is their civil rights, and I think they owe it to me to pay attention to my civil rights.

Lage: But I wonder if they get it.

Coelho: Oh yeah.

Lage: I know that some of it—I've heard from some of the disability advocates that a lot of the African American civil rights leaders or scholars don't really accept that the disability rights is comparable.

Coelho: Well it's included in all the civil rights bills, so the leadership does, but do people in the black community across the board understand disabilities? No. Do white people understand it? No. Do Japanese Americans? No. Do Hispanic Americans? No.

Lage: That's why you're doing this new initiative?

Coelho: That's why we're doing this. I mean, my God, why should black Americans be any different than anybody else? They don't understand it; they think if you
have epilepsy you're possessed by the devil; you should be in the closet. Well, you know, I don't begrudge them that, but I have an obligation to try to educate them, to turn them around, but I'm not negative to black folks that feel that way. I mean, if I did I'd be negative towards everybody. So you've got to just work to turn people around. So I think that it's unfair to say that the Black Caucus or the black leadership is not supportive—they are; they've been very supportive and if it weren't for them we wouldn't have been included in stuff. And they worked hard on the ADA; they were very supportive of the ADA, and on ADA restoration they're with us. So I don't accept that at all.

Lage: Hmm; was it important that so many people in Congress did have a family member [with a disability]?

Coelho: Yeah, we just did a poll on some other issue and asked questions on disabilities and 14 percent of Americans polled self-identified a disability. What does that mean number-wise? I mean, think about how many millions self-identified.

Lage: They want the parking place. [Laughs]

Coelho: Yeah; that's what it is. [Laughs] Well, I don't get a parking space because it's different. But the point is that they self-identified.

Lage: Yeah, that's very important.

Coelho: And people say, you know, that ADA hasn't really done much. Bull; that's just so unfair. I mean, you think about all the different things that have happened but the fact that 14 percent are now self-identifying with a disability, that's huge progress. That's a huge turnaround among the attitude of people with disabilities. I say all the time, “Look, it isn't those people without disabilities that are a problem. It's those of us with disabilities. Our attitude, our willingness to be subjected to the abuse that we're subjected to, our attitude to be willing to have our head patted, and say, ‘Oh, it's okay; you stay in the closet, and we'll take care of you.’ I mean our willingness to go through this. We're the problem. We don't stand up. We're not vocal. We're not aggressive. We're not passionate about our civil rights and what we need and we don't need. We need to be more so.”

And so when you get 14 percent to self-identify we've made huge progress—huge progress. And this just occurred in the last year, the last six months. And so I get excited about that because that tells me that, you know, we say that there's 20 percent of people with disabilities. Well, there's got to be more than 20 percent if 14 percent self-identify. So it's a huge number out there, and the
more people understand that, it will happen that attitudes will change because where it's already starting to happen is in businesses. Businesses don't want to discriminate against those of us with disabilities because we have money now; we have buying power. And we make decisions. ADA brought a lot of that about.

And as we get jobs and as we have more money we'll get more changes because we have more money to spend, and we won't spend money with people who discriminate against us. Why are people permitting gays to have benefits? Why are companies doing that? Because they have money, because they have jobs; so they won't discriminate, and it's the same thing. Why are people not discriminating against women and so forth anymore? Because they have money; they make choices; they make decisions. It all comes down to economics. That causes attitudes to change, and so that's why I still am so passionate and I have such a mission in regards to getting people jobs, because economics change attitudes, and the reason that you need to do civil rights is to give an opportunity for us to file suits and to get that in the courts, and the reason we try to change attitudes is in order to get the jobs and so forth. But these go hand in hand; the real power is economics. The real power is economics; people understand money.

You know the movie, *Where is the Green*, or whatever in the hell that—the—what's the saying about—*Follow the Money*, or *Show Me the Money; Show Me the Money; Follow the Money; Show Me the Money*—that's what it is; that's what that whole movie was about show me where the money is and I'll show you what is going on. We're involved in this conflict with terrorism. Show me the money; show me where these terrorists are getting the money, and we can solve the problem. What we recognize is maybe Saudi Arabia is the one supplying the money and yet they supply us our oil, so we got to be careful how we handle the Saudis, but there's the answer right there. They are supplying the money to terrorism. They're supplying the schools and so forth. Well, it's the same thing in regards to the disability movement—if we have money we can change attitudes, but if we don't have jobs we don't have money, and if we don't have our civil rights we can't get our jobs. So all these things fit—

So the ADA—

Is critical.

—is on the highway?

Is on the highway to changing attitudes, to getting money.
Lage: Yeah; let me ask you a couple more things about ADA, and then we'll go off on some of these other things. You described the testimony in the Senate. Liz Savage said, “Have Tony tell you [laughs] about the testimony”—your testimony—the scene and—.

Coelho: Well, it was in the Senate chambers; it was in the Judiciary Committee and—

Lage: You were lead-off?

Coelho: I was the lead-off, and it was televised, and I was the first member of Congress to publicly talk about my disability in the way I talked about it. And I was very passionate, very emotional about what I went through and talked about suicide, talked about what my parents put me through, talked about the Church, and what it did to me as a person and the scar tissue that developed. But I was not deterred; I was determined not to let this scar tissue stop me. And that I was determined to let the scar tissue drive me to be the thing that forced me to try to make changes. And in my testimony I shared all that, and I was very open, and people were crying in the audience and—

Lage: So it wasn't a story they had heard?

Coelho: No.

Lage: Well, some of it had been in the papers.

Coelho: Some had been in the papers, but they never heard it, and it's different reading it than seeing it. And when Ted Kennedy was crying, and Orrin Hatch was crying, and Bob Dole; it was a very emotional impact. It was a very emotional impact for ADA. It also reinforced what I believed in, that honesty is very emotional if you're willing to be honest, and that you can really have an impact if you're willing to share the hurt. You have to be willing to share the hurt, though; it has to show and it has to come out. And I did that day, and people give that a lot of credit for creating the momentum to get going. And I think it did, but I think that to a great extent I was the culmination of a lot of grassroots, the people here in California, to my view, started it. You know, their willingness to demonstrate, their willingness to put their chairs in the way of commerce and do things, set a tone for those of us with disabilities to have pride in ourselves, to speak out. But if you're not willing to show the hurt, if you're not willing to be honest about what you've been through, people don't understand it—don't appreciate it. And if you are willing, you can make a difference and that's my attitude about things. And that hearing was very emotional for me.
5:00:47:47
Lage: And you think it did—?

5:00:47:49
Coelho: Yeah; and I think what it did was to—it created among some of the leaders in the Senate an emotion that they dealt with as opposed to just another story that they dealt with and the civil rights movement or the disability rights movement was in the room—it was packed and it also gave them a public figure that was willing to show the scars and gave them an emotion to push even harder, because to a great extent if you don't have somebody who has some stature or whatever who is willing to be vulnerable and willing to be real you're not going to get there. But you have to be vulnerable, and I think that's what I did that day. And a lot of people talk about it to this day.

5:00:49:01
Lage: Yeah, they still talk about it. And if I have my chronology right it was the previous year when they had people from the community give personal testimony in Congress.

5:00:49:11
Coelho: Yes; right.

5:00:49:12
Lage: Which was the first time that had happened.

5:00:49:14
Coelho: The first time that it happened and Justin Dart had conducted these hearings all across the country on the whole issue, and they were putting together a bill; that was the whole issue here. They were putting together a bill, and Sandy Parino and her group put together a bill in spite of what they were doing.

5:00:49:31
Lage: Oh I see; it was sort of—

5:00:49:31
Coelho: Yeah; so the two groups were coming together. And I pre-empted the communities bill by putting in the Reagan bill, and that's what—

5:00:49:43
Lage: I haven't heard it called the Reagan bill before.

5:00:49:46
Coelho: It's never been called the Reagan bill. [Laughs] But in fairness it was; it was—it came from them.

5:00:49:56
Lage: But it was really a radical bill.

5:00:49:58
Coelho: It was a radical bill.
Lage: I mean more radical than what got passed.

Coelho: Yeah, and it was more radical than what got passed, and it was because of Sandy and —

Lage: Roxanne?

Coelho: Roxanne Vierra having family members with disabilities that they were passionate about.

Lage: And then there are a lot of people with disabilities that were on that, Bob Burgdorf, Lex Frieden.

Coelho: Oh yeah; absolutely. Lex Frieden; Lex is now chairman, and so this new proposal is coming from Lex. And, of course, he reminded people that he was on the old commission that basically started the ADA. And I think that commission—I don't think Reagan knew what they did—but that commission did start it, and that meeting that we had was an important meeting in that they were having trouble getting a Democrat to join.

Lage: Oh I see; so they got Weicker, but they needed a Democrat specifically?

Coelho: They needed a Democrat, and they couldn't get a Democrat in the Senate, and so Roxanne suggested me, and as the campaign chair I was a very public figure, and so that's when they came to me.

Lage: I see. Now, talking about Republicans, let's talk about the first President Bush. I know you had some phone calls back and forth and tell me in general your relationship with him and how you see—.

Coelho: A great man, great man; he—

Lage: In every aspect or—?

Coelho: Yes; I mean I—I love him.

Lage: Okay.
In 1988, I decided that the only way we could ever get this into law was to make it a campaign issue. And so it was Dukakis who I was very close to, and Dukakis publicly announced that if he was president he would sign it. And Pat did her magic with the Bush people, in the Reagan White House but with the Bush people, to get the vice president—candidate for president—get him to say that if he got elected he would sign it; he said it on the campaign trail. Now, most of his people didn't know what the hell that meant and didn't pay attention. But Bush did; Bush was very sympathetic to disabilities. He had a daughter who died of a disability, and he was emotional about it and felt strongly about it.

So he gets elected; I'm in the leadership. I meet at the White House every other week with he and the other leaders in the Congress, and in one of the meetings I talked to him personally about the ADA and that if we were having some trouble with some people in his administration—and he said, “Tony, let me just tell you something. He said there will be people in the White House in my administration who will oppose it. Any time you have a problem, you just pick up the phone and call me; it's that simple.”

Hmm, he wasn't concerned about specific measures within the bill?

He said you just call me. I said okay. So John Sununu, who was chief of staff, and I were very friendly because we debated—in '88 we debated a lot, and we got to be very friendly and so he becomes chief of staff, and so we were friendly after he became the chief of staff and so forth.

Now, what does it mean, being friendly?

We talked a lot and—

You'd go out for dinner or—?

Yeah, we'd go out to dinner but we were very friendly—just really, good guy, and when I would go to the White House for the leadership meetings, of course, he was always in the room, and we'd joke and so forth and so on. So the bill is—we're trying to get the White House, the government, to basically endorse the bill. So it's going through their process, and it gets bogged down in the White House, and Pat was helping to try to get it through. And Boyden Gray, yeah, Boyden Gray was the White House counsel and Boyden was very pro-ADA. But he was having trouble internally with the domestic advisor, and I can't remember the name of the domestic advisor.
Roger Porter.

Coelho: Roger Porter, very good; and Roger was opposed, and so they go to Sununu, and Sununu is opposed, because it would hurt business. So I call up John, and I said, “John, you know”—and he said, “Yeah, I know; this is going to hurt business.” And I said, “John, this is important to me,” and I gave my personal—he didn't care.

Lage: Did you think it would hurt business? I mean, could you counter that?

Coelho: No; of course. I'd told him what I felt, “Look, we have put language in here that all accommodations have to be economically feasible. There is no business going to go out of business unless it's poor management, but it's not going to do anything to do with disabilities,” and of course he didn't buy that. And so he thought it was an intrusion—that the federal government shouldn't be involved in this whole area, which is of course the paternalistic thing, and we'll take care of it. And so John said that he opposed it. And I said, “John, I'm going to call the president.” And he said, “I know you have the relationship with the president, and you'll call him, and he'll tell me to put it through. But I'm not going to do it unless he tells me.” I said, “Well, I'm going to call him.” He said, “I know you will.” So I did.

Lage: It's almost an invitation.

Coelho: Yeah; so I did. I called the president. The president said, “Tony, I know what your problem is; I will take care of it,” and he did. As a matter of fact, he had to do it twice, two different issues, but he had to do it twice and he did, and John in both cases said, “I know what you're going to do. But I'm going to make you do it and he's going to have to tell me. I'm not going to do unless he tells me. If he tells me, he's the boss.” I said okay; so on both occasions he did and—

Lage: And you thought that Bush really got it, or just—?

Coelho: Oh yeah; no, he got it.

Lage: Like the 14 percent who might vote for him or—? [Laughs]
No, no; he got it. He believed it, still does; he's a wonderful, wonderful human being, very emotional about the issue. That's why I always am fascinated that his son doesn't understand it.

Oh, you don't think his son does?

I don't think he really does. I have never talked to him, and if we do restoration, if we get it moving, I'm going to probably meet with Cheney, who I am very friendly with and probably meet with the president about it. And I don't know where I'll get, but I've thought about going to Papa Bush and saying, “Look, I know you don't lobby your son but on this one you should and I would like you to.” So I don't know; I'm undecided. We're not there yet, but at some point we have to lobby the president, and I'm not sure how to do it, but we'll do it.

Or whether you have another Boyden Gray [in the White House].

Or—or yeah.

Which would be helpful.

Yeah, which would be helpful. Boyden told me—he said, “Look it, if you can get it there—my problem is that I don't think the White House staff, we don't have a person like me there today that is supportive.” Now I did talk to Andy Card, the chief of staff, and Andy and I have been friends for a long time because of Papa Bush, and Andy was the Secretary of Transportation under Papa Bush. Andy said, I explained it to him one day, and he said, “Look, don't go off half-cocked. Before you do anything come meet with me because we might be able to work something out on this.” So the timing isn't right there yet, but at the right time I might call Andy. But I might call Papa Bush and say, “Look, I don't want you to do anything. I just need advice. What's the best way of doing it?” And Doro Bush [Dorothy Bush Koch] is a huge advocate of ours.

Now tell me—

Doro is the only daughter, and she is married to my former administrative assistant and—

Who is?
Coelho: Bobby Koch, K-o-c-h, and I've gotten her very involved in disabilities issues. She's a wonderful person, and what I've thought of doing—

Lage: You don't hear much about her.

Coelho: She—actually, you've seen a lot of photos. She's very close to W; she's the apple of her father's eye—very, very close to her father, but I've thought about she and I going to visit her father is what I'd do probably. I'm not sure; I haven't figured it out. [Laughs]

Forhan: [Coelho staff member, Bren Forhan, listening to latter part of the interview] Just knowing connections is amazing. I'm finding this quite illuminating, and fascinating. I mean I know some of the parts from—but some of the details—

Coelho: But I think there's a lot of ways to do this yet; so we have to kind of get our way—you can be premature, and I don't think it's time to do the presidential thing yet, but it's getting there.

Lage: I want to think a little bit more about ADA. Were there places where you were not willing to compromise? I know a lot of compromises were offered and that the community stood, the lobbyists like Liz, you know, stood firm against certain things, like leaving AIDS restaurant workers—.

Coelho: I was adamant about the AIDS issue and that became—we were very concerned with that because there was a congressman from Texas who offered an amendment on the House floor to take it out because, of course, even though they would wear gloves, they would contaminate the food. So it became a big scare tactic. I helped this guy get elected, and I was on the House floor even though I wasn't a member; the speaker had invited me to come to the House floor as the bill was being passed, and when he offered his amendment, or I heard he was going to offer his amendment—you're not supposed to lobby as a former member; you're not supposed to lobby on the floor. You can lobby outside. And I'm not a lobbyist but—

Lage: Well, you were on this instance, it sounds like.

Coelho: In this instance I was—big time. And so I went up to him, and I said, “You know what; I can't believe you're doing this to me. I just can't believe you of all people.” I helped this guy; I helped this guy get elected. I knew him well. It was pandering to a constituency, as opposed to what he knew was right, and it really irritated me, but we beat him, barely—but we beat him.
Lage: I would think it would be a hard one to argue among conservatives, especially because AIDS was a very, you know—I mean it still is, but even more so then—people were a little more fearful.

Coelho: It was more then, it was more then, but we had such strong support going into it that a lot of people felt strongly about ADA that they were willing to go through with this.

Lage: Do you think it was because people stood firm and said we won't—

Coelho: Compromise yeah.

Lage: —compromise on this?

Coelho: Yeah, and I don't think a lot of the members knew what we were doing.

Lage: Stop right there; that's a good place to—.

[Audio File 6]

Coelho: [Begins with a discussion of Coelho’s memory for his congressional years, with his staff member, Bren Forhan and the interviewer] Disabilities, I know the minutia, but water, I have no idea. I mean I need to have what's her name in the room with me.

Forhan: Kim Schnoor—

Coelho: Kim Schnoor.

Forhan: Yeah, and [Jean-Marie]?

Coelho: And [Jean-Marie], all my water experts.

Forhan: Mary [Dickman]?
Coelho: [Dickman], yeah, I need all these people because I have no idea.

Lage: This is important to put on. I think in an oral history you want to talk a little bit about memory.

Coelho: Yeah, well, anything to deal with—I mean, I say all the time and people I don't think appreciate, my ministry is disability. I believe it, firmly, and I know minutia, things I did and said and why and what people did to me and so on. I mean, I know detail about it. Now, if you asked me about, what did I do in regards to the Contras? It was a huge fight, and I led part of the issue. I have no idea what the issues were; I have no—you know, it was money, and they were doing it undercover, and we were trying to stop it; I know all that, but I don't remember the minutia on it. I don't remember who offered what or whatever. Agricultural issues—my most important issue—and water being the most emotional issue for my congressional district, and heavy fights. I was the leader on those issues aggressively.

Lage: And you had to construct compromises?

Coelho: Oh, you had to come up with strategies, and I'd know some of the stuff—some interesting stories about things that I did, where I out-maneuvered George Miller and out-maneuvered Cecil Andres, the secretary of Interior, and President Carter kept commitments to me and so forth, and what I did to get those commitments. I know a lot of that stuff, but the minutia on the actual legislation, I don't remember. I just don't; it's not important to me. I mean it was important at the time, but it's really not what I find fascinating because it's still real to me. I mean I'm still living the disability stuff; it's me. It's who I am. And there's still things to do in this, and on the other issues people have replaced me. They're making the decisions, and they're in the fights, and I'm not, and I shouldn't be.

Lage: It was the keeping-care-of-your-district issues?

Coelho: Yeah, as opposed to keeping care of me, and disability is keeping-care-of-me, so it's a big issue.

Lage: Right; but you did say, just now—did we get it on the tape? Yes; we did—that a lot of these congressmen didn't know what they were voting for.

Coelho: Yeah, we got that right at the end [of the last tape].
I have said it repeatedly, I've said it on the tape to you—they'd come up to me and they'd say, “You know on that disability bill that you got in, you know, my mother, my father, my sister, my brother, my aunt, my uncle, my wife, and my husband, my child, or my son or daughter or my next-door neighbor or my best friend have such and such, and I want to do this for them. They had no idea what it meant; they never read it. They had no idea how controversial it could be. And we kid Roxanne Vierra all the time because she admits being this right-wing, rock-ribbed Republican, conservative from Colorado, and yet she was the advocate of this liberal civil rights legislation to cut through and do something. She's proud of it; she loves it, and she loves being on all this stuff because of this but you know, she and I disagree totally on 99 percent of all the other things that are going on. [Laughs] And a lot of—

It did go through all the hearings, and—

Yeah, but they don't pay attention. They've got too many other things that are important to them. I understand that; I'm not being negative. It's just that, , if—

They didn't know how far-reaching it would be?

They didn't know how far-reaching it would be, and they knew they were doing something for somebody that they loved, and that was important to them. And a lot of members vote for things [when] they don't know what's really in it because they vote for it because the party wants them to, because some friend wants them to; there's no way humanly possible that every member can read every single bill and know every issue in every bill. It's just not possible. I don't care how smart you think you are, and if you say you do you're lying. There's just no way. And so you have to rely on something to either support or vote against legislation or amendments. So a lot of these members—I did at times—a lot of these members voted for ADA because of the emotional side of it, because of what it meant to somebody. And when we brought this bill to the House floor—on the Senate floor I think we had six members or four members vote against it out of one hundred. We brought it to the House floor, and there's all these tight votes in committee, and [people thought] you know, we're going to lose it, and when we brought it to the House floor, we won overwhelmingly. I can't remember what the vote was, but it was less than one hundred voted against it, as I remember; and everybody was happy and proud and so forth. But the last key hurdle was this AIDS amendment, and I was nervous as hell because we had won everything
else, and I knew we'd win it, and we had gone through all the battles, but all of a sudden this guy brings up this amendment on the House floor.

6:00:05:28
Lage: The Chapman Amendment was that?

6:00:05:29
Coelho: Chapman—Jim Chapman of Texas—of Dallas, outside of Dallas, and I was furious with him, and as a result it impaired our relationship. I've never been friends with him since, and I don't intend to be.

6:00:05:42
Lage: Hmm; there's a lot of personalizing of this in Congress, at least from your point of view.

6:00:05:48
Coelho: Absolutely.

6:00:05:48
Lage: I mean do you think it became this personal, about Tony Coelho?

6:00:05:51
Coelho: Probably.

6:00:05:52
Lage: With a lot of people?

6:00:05:54
Coelho: Yeah, probably yeah. I meant it to be personal, because it is personal. Look it, I went through a lot as a result of my disability, and it changed my life for the better. I acknowledge that. And so I always thank God for it; it made me a better person. But I went through a lot, and I've always made this very personal, and people have been critical of me for making it personal. But you know, it's me; it isn't somebody else; it's me. It's who I am, and if I can't use every ounce of my energy and every ounce of my emotion and passion to try to prevent other people from going through what I went through, then why in the hell am I here?

I really sincerely believe that God put you on earth for a reason. Bob Hope said to me when I was struggling, he said one day, “You know, you think you have a ministry but you think it only can be done in a church, and that's where you're wrong. A ministry is great in entertainment and in sports and in business, but it's most effective in politics if practiced correctly. And you can change the lives of millions of people.” And I think back on that, and he's a wonderful human being and so wonderful to me, and I just think back on what he said and how much it was real.

You know, I could have been a priest, and I may have been a fooling-around priest, or could have been an effective priest, or I could have been challenging the pope for leadership, or who knows what the hell I would have done, but I
wouldn't have affected that many lives, quite honestly. And Hope is right in
that ADA has impacted millions of people here in the United States, but it's
been adopted in eighteen different countries. The UN is considering it as part
of its charter today. The impact of that, millions of people all across this
country, the ripple effect of that—Bob Hope was absolutely totally correct.
And why do I think it's had an impact—yeah, because I've been obnoxious
and because I've been passionate and because I've been emotional. But you
know what? If I hadn't been, I'm not sure it would have impacted the millions
of people that it has.

And I think God gave me my epilepsy for that purpose—to use it, to do
something with it—not to sit around and bemoan it and feel sorry for myself. I
mean, look; when I had my seizure yesterday morning I could have felt sorry
for myself and gone to the hospital and not continued with my meeting and
not flown out here yesterday and so forth and so on, and you know, woe me.
That's stupid—use it, you know. I got up and I walked around the restaurant
and made my point that, yeah, I had a seizure. I want people to know that I
still have seizures. I don't want people to think that, yeah, he talks about it but
it doesn't really affect him.

I have seizures; I'm impacted by it every day because I don't know. When I
wake up in the morning I don't know if I'm going to have a seizure. And then I
go to bed at night thanking God that I didn't have one, but I have no idea—at
any moment I may have one. And what's it going to do? What are people
going to think, and if I'm driving am I going to hurt somebody, or am I going
to kill myself, or whatever? It's with me all the time; it's who I am. And
shouldn't I try to change the attitude of the way people treat me and other
people with epilepsy or other people with disabilities? You're damn right I
should, and I think it's a sin if I don't. And so when people say I'm obnoxious,
I say, “Damn right I am!”

6:00:10:06
Lage:
Well, I didn't know they had said that.

6:00:10:07
Coelho:
They do.

6:00:10:09
Lage:
Let's see; I have a few things here I want to be sure to get. How important do
you think the grassroots campaign was, and things like demonstrations on the
capitol steps?

6:00:10:22
Coelho:
Well, look; I thank God for Justin, because Justin Dart took advantage of the
movement here in California and organized a movement nationally and
became the emotion for it. People like me took advantage of what Justin had
done. If there hadn't been a grassroots movement, ADA would have never
happened. There's no doubt about that; if it hadn't been for people like me and
a few others we would have never gotten ADA. I recognize that too, but it all comes together. It's all part—it's an endless seam; it all comes together, and it works, and you know, somebody is doing this.

6:00:11:08  Lage:

Did you get the feedback—well, go ahead and finish that point.

6:00:11:10  Coelho:

Well, somebody is doing this. It isn't me that's doing this. It isn't Justin. Somebody—I don't know who in the hell is pulling the strings—but somebody is bringing this together and making it happen, and it just doesn't happen out of thin cloth. There's something, there's a reason that it's moving forward. There's a reason that it happened. The demonstration on the Senate side of the Capitol was spectacular. We had the votes in the Senate; that wasn't the issue. We knew we had the votes; we couldn't get it scheduled. We couldn't bring it to a vote and the reason was that the leadership in the Senate was the same as the leadership in the House. “Let's not get these people upset, but let's not schedule it either [Whispers]; they'll never know.”

And so we knew we had to create emotion; we had to create hostility; we had to get people mad. And so they formed a ring around the Capitol steps and the entrance to the Capitol, on the Senate side. So these senators had to crawl over wheelchairs, had to pick up their $3,000 slacks and actually not get caught in the spokes of the wheels and so forth and so on, and they were mad. And our friends, those who supported us, were the worst; they were disgusted that we would demonstrate this way. It worked, because it showed commitment on our part. These people who were there showed their commitment.

It's no different than when Martin Luther King had people demonstrate. Even though they had batons beating them up and busting their heads open and people getting killed and so forth, they had to show commitment, and once you show commitment you create emotion. You create a reaction, and when people are negative, when people think they're hurting you, they're actually helping you, because when they show their negativism other people look at that and say, “That's not fair; that's not right. There is something wrong here.” And so in every movement like this you need to have commitment.

The people in the AIDS community when they showed commitment, when they showed they're dying and what they were struggling with, and showed the emotion of what they were going through, people reacted and said, “There is something wrong with this picture. We've got to change it.” Well, we did the same thing; we basically made people go around us and deal with this; walk over us and—

6:00:13:40  Lage:

And then people were crawling up the steps is what I've heard.
People were crawling up the steps.

And that was sort of an extreme--

And it was extremely emotional because it showed that we had no access to the Capitol. It's sort of like what we just went through in this case before the Supreme Court where the gentleman was charged with a crime, and he was told that he had to go to the court in Tennessee, and they wouldn't give him a stay or anything else; he had to be there. And they told him he could crawl up the steps. Well, the first time he crawled up the steps; the second time he wouldn't do it. So they of course convicted him, and the Supreme Court State of Tennessee agreed that he had to crawl up the steps or have somebody carry him up the steps—that he had no right to access to justice.

And the judicial system in the United States finally—we had pluses and minuses, but the Supreme Court finally took it on, and on a five-to-four vote, Sandra Day O'Connor being the key, Sandra Day O'Connor in effect said, “The right to justice is a key right, and the states do not have a right to deny somebody access to justice.” Now, the fact that she's a judge, maybe that's a little prejudicial, and she's been against us on other issues, but on this one thank God she was with us, because it means a lot, and maybe it sets a stage for some other issues. But how despicable that people would say that just because we have a disability we don't have a right to justice just like everybody else. Well, the Court—the Supreme Court has ruled now we do. So that's—

By five to four?

By five to four.

That brings up something else. Wasn't it an issue about whether or not Congress itself would be included under the purview of the ADA?

Oh yeah.

How did that work?

It's always an issue because—and I understand it constitutionally but basically it's an issue that you have three co-equal branches of government, the judicial, the legislative, and the executive, and basically the labor laws do not apply to Congress because that means the executive would have to enforce the labor
laws. And they don't apply to the Supreme Court, because that would mean the executive would have a right to enforce it or that Congress would have a right to legislate it. Now, I understand that because that is separations and that's a tough issue, but we can voluntarily do it if we want to and that's what we forced to happen.

Lage: Is that the way it was written?

Coelho: Yeah, and so we voluntarily have to have an ADA—. And again Steny Hoyer was involved; we got an appropriation through last year that basically permits ten people—ten—to be hired on the House side—the Senate wouldn't go along—to be hired on the House side for the House management, meaning for the sergeant at arms, the clerk, and just the House officers. These ten people all have disabilities, severe disabilities, and they are full-time employees, and they are specifically hired, and we will increase that number each year. Hopefully we will then get it into each office, because each member of Congress has basically a small business. Each office is like a small business, and they have their own hiring practices and so forth. They can discriminate, but they don't have to.

Lage: And what about accessibility?

Coelho: Oh, accessibility, we are getting there big time. It's hard to take an old building and make it accessible, but we've done that. The Senate had to because you had the senator from—

Lage: Strom Thurman must have been in a wheelchair.

Coelho: No, and it was before [Max] Cleland. It was, I want to say, the Republican from Alabama, or somebody, was in a wheelchair. It was an acquired disability, and so they provided for accessibility. Frank Church actually was involved going back and making the Senate accessible for visitors and so forth, but we had a big issue in the Senate in regards to a blind person who was a senior staffer to a senator. Senior staffers can go on the floor; when the bill that that member is handling [is being considered] he can take a senior staffer on the floor. Well, a blind lady had a seeing-eye dog, and there was no allowance for animals to be on the Senate floor, and a senator objected to her bringing her seeing-eye dog on the floor. It became a huge issue, and of course it was reversed. And it was permitted. Unfortunately, it was a Democrat who objected—Bob Byrd of West Virginia.

Lage: Oh my; so—
But it was reversed, and then when Max Cleland was elected then they really made everything accessible, and the Senate is very accessible. The House was made accessible with certain people, but it was really made accessible now with the congressman from Rhode Island who is in an electric wheelchair and disabled from the neck down as a result of—he was a cop scout, as an eighteen year-old—I forget what the name is but they work with the policemen and so forth, and he got shot and paralyzed from the neck down. He became secretary of state in Rhode Island and then got elected to Congress, and so the House is now accessible because of him.

Lage: Will he be likely to work on your [civil rights] restoration bill?

Coelho: Yeah.

Lage: [Laughs] I know you're not giving anything away on that. Now has the ADA helped people with epilepsy, in particular? I know there has been some disappointment in the way it's been interpreted.

Coelho: Well, disappointment in regards to the Supreme Court, but we still have the right to file suit in different cases and do different things. And we'll get it restored. I'm not—I think it's a temporary setback and I'm disappointed, but that's happened with the black community, it's happened with women, it's happened with others; so I don't think we're any better than anybody else. I think we have to go through the trials and tribulations of getting our basic rights just like any other group.

Lage: It takes time?

Coelho: It takes time and it takes education and you know I don't believe people are prejudiced. I just believe that people are uneducated, and who educates? Do we have an obligation to educate? You're damn right we do. Do we have a right to sit back and critique people who are not educated? No, we have an obligation to educate. We have an obligation to be honest, be straightforward about what our disability is and what we need and what we want and why we want it and why we need it and educate people. But if we sit back and demand it they're not going to give it to us, and that is not the way the system works, when you demand.

Lage: Is there anything else about the ADA in particular that you think we've missed?
Coelho: Not that I know of.

Lage: I think we've pretty well covered the ADA.

Coelho: Yeah, I do too.

Lage: Do you have energy left to look at what you've done since? I'm thinking of the President's Committee.

Coelho: Yeah.

Lage: I have until about five, and then I should go.

Coelho: Yeah, no problem.

Lage: The President's Committee on Employment of People with Disabilities—

Coelho: When I quit the Congress my commitment to disabilities was just as strong and Justin was chairman of the President's Committee. And he came to me one day and he said, “Tony, I can't do it any longer. I just don't have the physical energy.” He did it for Bush, and he said, “I want you to do it under President Clinton.” So he recommended me, and I got the appointment, and I guess Justin did it for about a couple of years under Clinton, and then I did it for six years. Basically what I did was—it was no longer an advocacy group because we already had the ADA, and so what I wanted was it to be an effective implementation tool in that I wanted to create jobs. So we took high school high tech, which was a sleepy little thing where you take young high school kids with disabilities and get them exposed to NASA and get them exposed to different job opportunities and so forth, and we grew that and now we have hundreds of high school high tech programs all across the country.

We started a Business Leadership Network, where I got the the president of the Chamber of Commerce, Tom Donahue, who became the national chairman of the Business Leadership Network, and we set up chapters in different cities. They're all over the country now, where basically we take businesses that hire people with disabilities and go out to other businesses and get them to hire people with disabilities and they become the example. “Here's what the benefits are,” and we have these meetings and so forth. And as we did this I spoke all around the country and tried with my story to get people motivated and so forth. And it was exciting, and today the organization still goes on, and it's a national organization that keeps moving.
We did some stuff aggressively in the technology area when the Communications Act was up and some provisions dealing with—instead of providing for accommodations [later], that the accommodation should be in the actual design of communication tools instead of additive, after the device is manufactured. And so we did a lot of work in there.

I did away with the leadership conference that we had because it was just a social thing and it was a waste of money and so forth.

6:00:24:43 Lage: Was that controversial?

6:00:24:45 Coelho: Oh very controversial.

6:00:24:45 Lage: In the community?

6:00:24:47 Coelho: In the community, though one of the good things we did—I went to the first one, and it was people from all over the country, but it was, you know, people in the disability community, and we’d get together and have these conferences. And it wasn't creating jobs. It was just social greet and meet, and that's important; I don't deny that, but the amount of funds that the government gave us was limited, and so I didn't have the funds to have staffers spend all year putting together a conference. I mean that's what it was. I didn't mind, because you'd charge and you could get certain—that's fine, but some people, that's all they did all year long was to put together an annual conference, a waste in my view.

6:00:25:26 Lage: Talking to each other?

6:00:25:26 Coelho: Talking to each other. So we eliminated that, and we used the money to do some other things, but I made a commitment to President Clinton. I said, "Look, let me tell you something. At the end of six years I will be honest with you and tell you if I don't think the President's Committee is effective, I will tell you so, and I will publicly advocate that you do away with it. Now in reverse, I expect something. If it is effective, and I can show you that it's effective, I expect you to make it part of the Department of Labor, and I want an assistant secretaryship out of it.” He said, “Fine.” So at the end of the six years he issued an executive order and there is now an assistant secretary of labor for disability policy and important—

6:00:26:22 Lage: And did that—
Oh yeah, it's in law now. I mean it's part of the—and the current administration hired the first one, because Clinton did it going out and so the Bush Administration appointed the first assistant secretary for employment policy and employment—I forget the exact name. And it's Roy—and I can't think of his last name, but he's from Virginia and is sight impaired, and actually what I'm excited about it—what I wanted—I don't agree with what they do and I think they could do much more with it, but what I wanted was a position at the table so that we could be part of decision-making, and I wanted an annual budget. Instead of the President's Committee where we had to beg each year and nobody knew who we were and we had to go through hoops, and they'd cut the percentage across the board, and they didn't care what they cut. And it meant a lot to us.

And we did some Job Accommodation Network, where if you had a disability you could call a number, or if you were a company and you were trying to comply with ADA and you wanted to know honestly what you could and could not do without violating the law or calling the Justice Department or calling an attorney or calling somebody who would get you in trouble, we started Job Accommodation Network. And it is still in effect; it's a huge operation run out of West Virginia—the University of West Virginia.

But this organization now, this assistant secretaryship keeps getting more money every year, and one of these days Democrats will get back to the White House and we'll use it the way it's supposed to be used. But if it was the President's Committee on Employment of People with Disabilities they would be without any money probably today. So I like what we did; I'm just sad that we don't have a person or the president with the desire to do something.

Now I have to be honest with you; Bill Clinton, when he fell down the steps in Florida, or whatever he was doing, and ended up in a wheelchair, they had to roll up the rugs in the White House, and he was on TV in the media, bitching about having to take a shower in the wheelchair, and how much trouble, and this and that, so I called him up one day, and I said, “Hey, there are people for the rest of their lives that are in a wheelchair, the rest of their lives they have to take a shower this way, and you're going to be in it for a couple—stop, stop, don't ever bring it up again.” “I understand.” He never mentioned it again. [laughs]

It should have been an opportunity for him to have some sense of what was—?

Yeah, but he did. He understood; at first, of course, it was an inconvenience for him, and that's all he paid attention to—woe me. And I tried to force him to say whoa, wait a minute; I understand what other people are going through, and he did. I mean he—he [Finger Snaps]—he's very smart.
He was good at feeling their pain.

Yeah, and he came quickly to it, and he was fine. And then I asked him in the State of Union—his last State of the Union—if he would do something like creating 100,000 jobs over a five-year period for the federal government, 100,000 people over a five-year period hired by the federal government—people with disabilities. And he said it in the State of the Union over the objections of his chief of staff, his communications director, and so forth, because “this is too mundane; you don't want to mention something as petty as this. Petty? For us, that's not petty. And Clinton said, “Don't worry about it; it will be in there.” And Becky Ogle—I don't know if you've talked to Becky Ogle, but Becky was the one who was the executive director of the Task Force on Employment of Adults with Disabilities, which is the second committee, the second one that was all made up of cabinet officers, and I was vice chair, and I was the only non-cabinet officer on the task force.

I didn't know this was a task force.

Yeah, it was all cabinet level.

Now who created that?

Clinton, and Alexis Herman was my co-chair, and she was the secretary of labor and—

And how did that all come about?

That was all something we advocated.

Through the committee.

Clinton agreed and set it up and he started—Clinton in the last four years, three years, two years became very aggressive on disabilities and was wonderful. I mean he was really—it's too bad we didn't get it started earlier because you could have done a lot more.

Because you just had two years right?

But we only had two years with the commission.
Lage: Did it—

Coelho: Oh yeah, and Becky can tell you all the different things we did, but the 100,000 jobs was part of it, in the State of the Union, which is a breakthrough because disabilities had never been mentioned in a State of the Union and not even ADA. Creating an executive order for 100,000 jobs was part of that. Creating the assistant secretary position was part of the task force. There is a lot of things that we did, and I've forgotten them all, as a result of that task force.

Lage: It would be a matter of record?

Coelho: Oh yeah, we've issued all kinds of publications on it, yeah.

Lage: Maybe—I think we can finish today.

Coelho: Good—go.

Lage: I want to get your comment on the things that come up with some of our interviewees who are thinking about issues of life and death. Have you gotten involved in issues about sterilization—well, of course that's a no-brainer but people with epilepsy have suffered from sterilization, limiting the right to marriage, and now we have assisted suicide.

Coelho: Yeah, don't forget. The state of Missouri in 1976—no, I was in Congress, so it seems like '78, '80, '82, somewhere in there—was the last state finally to say that people with epilepsy could get married. Prior to that we couldn't get married in the state of Missouri, but every state had their prohibition. It took time to get it changed. And people with epilepsy in Japan and Portugal were immediately put in mental institutions, if you had epilepsy, so I wonder where they got the possession by the devil from? But the ostracization, sterilization—in effect, all that same thing, in effect has happened to those of us with disability over the years. So that's an easy one for me; I just don't buy it at all.

Secondly the ability to live in society, I think, is a huge issue, and I'm aggressively supportive, and that's a no-brainer for me. I mean, I just—that's an easy one. The right to suicide is a tough one. I'm a devout Catholic; people always question how I could be, but I am. I take the view that the white men in Rome don't necessarily reflect my religion. And I believe strongly my religion, and these men who decide the rules of my church, you know, make mistakes like people made mistakes in passing laws of the United States too.
So I don't get hung up on that, but I don't think—I'm very devout, and I have a problem with the taking of life, but I do think when there's a situation that—well, let me back up a minute. Life support—I think I have the right to pull the plug if I don't exist, in effect—if I'm a vegetable, I think I have the right to ask people to pull the plug, and I have no trouble with it.

On suicide I have a problem, because I'm still functioning. My situation is that with every seizure I have I learn something. With every pain I go through, I learn something, and I question whether or not suicide is the right way out. I have trouble with it; I'm not—you know, in Oregon they have it as law. Would I try to repeal it? No. I think the voters have a right to vote for it if they—I'd probably vote against it if I were there, but—

6:00:35:26
Lage: Do you think it presents dangers for people with disabilities? Slippery slope sort of things?

6:00:35:28
Coelho: Yeah, what I get nervous about is who decides if I shouldn't live anymore? I—you know—

6:00:35:44
Lage: If your life is worth living?

6:00:35:45
Coelho: Yeah, and some people, their life is worth living like [Stephen] Hawking, you know, like Hawking. You know some people would say why is Hawking still alive, or why is Bob Williams still alive? Why don't they take their lives? It's got to be a miserable life. No, it isn't; their brain is working. They are creative; they're wonderful human beings. They're—you know, Bob Williams is very involved in this whole new thing I'm doing on disabilities, and he's wonderful. He writes beautifully and so forth. Hawking is considered one of the brightest men in the world. You know, so who decides if they live or not?

6:00:36:24
Lage: And the same thing about genetic screening?

6:00:36:26
Coelho: Yeah, and I have trouble with this whole thing. I'm not sure, I am not harsh with people who decide that that's what they have to do, because to a great extent I take the view that you have a right to kill yourself if you want to. I think it's wrong, but I think you have a right to it. I just don't want you to hurt somebody else in the process; that's all I don't want. But I don't think a doctor has a right to kill you, and that's where I really struggle with this one.

6:00:37:00
Lage: They're very difficult issues.

6:00:37:01
Coelho: This is a hard one; this is a very hard one for me.
Lage: I love the name of the organization—Not Dead Yet. They raise issues among people without disabilities and make you think in other ways.

Coelho: Yeah, yeah, and I think it's a good discussion. I don't have any trouble with the discussion. I just worry about—I don't want to give people the right to say that I'm different so I shouldn't be alive. The Germans did that, and there are other people who feel that. People used to say to me, “Tony, you know I love you. I think you're great, but please don't talk about your disability.” [Sighs] I think, well, you know I talk about it because you said that! Geez, how stupid can you be? And that's what the whole issue is; you're not wanting me to talk about it is why I talk about it! And so I don't want people to put me into a closet because I'm not normal. And I think, you know—I mean I always joke and I say that my Republican friends think I'm possessed, and they know I'm possessed. That's fine; let them think that, but you know, I don't really think I'm possessed. They think I'm possessed in a friendly political way, but I don't want people to make judgments as to whether or not I'm “normal.” I don't know what normal is.

Lage: That—that's really what this whole thing is questioning—what is normal?

Coelho: I don't know what normal is. I don't think God created a category of normal. And if he did I don't know who they are, because I think everybody is different and everybody is strange in their own different way, and we all have disabilities; we all can't do certain things and so forth. It's just that as a society we pay attention to certain ones, and we don't pay attention to others.

I mean I went to a group one time in Canada, and I was advocating the ADA, and so they were talking about accommodations, and I said, “Okay.” There were twelve of them. I looked around the room, and I said, “You know, I look around this room, and I see eight of you with disabilities.” And I said, “You wear an accommodation just like I do,” and they immediately [Finger Snaps] picked up. And I said, “You know, we've grown accustomed that these stupid glasses can be a beauty item. You've got them in different colors, you've got lenses that change the color of your eyes, and my God it's kind of cool to wear glasses. Well, it's an accommodation; it's a disability and it is all right to wear them. You can drive with that accommodation. You can't without it; well, you know what's different?”

And it was interesting; after I discussed that with them they immediately changed. They said, “You know, I never thought of it that way.” I said, “Of course, it's just what is acceptable. Being sight-impaired is acceptable as long as it's not too sight impaired.” But I said, “You know, if you wear glasses, it's okay; if you wear lenses, it's okay; I don't understand that.” So I mean I don't
want somebody to say it's okay if you wear lenses but if you wear bifocals—
nah, you're not normal.

6:00:40:29
Lage: There is the line. [Laughs]

6:00:40:29
Coelho: Yeah, there's the line. You're not normal. [Laughs]

6:00:40:34
Lage: Well, that's a good way to end.

6:00:40:34
Coelho: Good.

6:00:40:35
Lage: And only because of time. I could go on a little bit more but no this is great.
Thank you.

[End of Interview]