WHEN BILLY BROKE HIS HEAD...
AND OTHER TALES OF WONDER
(DAY ONE, AFTERNOON)
A FILM BY BILLY GOLFUS & DAVID E. SIMPSON
TRANSCRIBED BY JUDITH MACBRINE, THE MIRROR GROUP

Unless otherwise indicated, Billy Golfus is the voice of the Narrator throughout the film.

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(View out front windshield driving down a freeway in cloudy weather.)

NARRATOR: It feels just incredible to be on the road again.

(View of Billy’s face while driving alternating with views of passing landscape and rain on the windshield)

NARRATOR: I’ve been pretty isolated since this car crunched me. Too busy just trying to survive. I went from being so brain damaged that I couldn’t count change to finishing a master’s degree. But this ain’t exactly your inspirational cripple story. Part of the fun of being brain damaged is you’re constantly having to argue that there is, in fact, something wrong. People see the limp but they don’t see: the loss of memory, the “judgment” problems, the going to the bathroom 37 times a night, the difficulty swallowing, the abandonment and isolation. Here I’m going to Chicago for this gathering of disabled people. There are 43 million
of us in this country, but we’re as invisible as Casper the Ghost. I’d only known a few other disabled people in Minnesota.

(City street scene. People moving metal barricades. Police milling about in the street.)

NARRATOR: So nothing prepared me for what I was about to walk into.
(An African-American man using a manual wheelchair zips through the streets trying to get around metal barricades. This view alternates with views of city workers dragging and placing metal barricades.)

COP 1: “No, no, no. You can’t go back there.

MAN IN WHEELCHAIR: I’m just looking for...

COP 1: Yeah, but no, you can’t go back there.

COP 2: personal attendant, nobody else back here.

COP 1: No, for your own safety you can’t go back there.

MAN IN WHEELCHAIR: Why? Why is that?

COP 2: He probably can’t hear you.

COP 1: (Speaking deliberately with pointed finger.) For your own safety. (Cop looks directly at the camera.) For his own safety.

MAN IN WHEELCHAIR: Well, my safety is my choice.

(Different African-American man in wheelchair chanting into a bullhorn. Others, with and without disabilities chanting with him. Camera pans along line of protestors, with and without disabilities.)

PROTESTOR 1: Down with...Nursing homes. Down with...Nursing homes... (repeated)

PROTESTOR 2: Up with attendant care...Down with the nursing homes... Up with attendant care...down with the nursing homes... (Repeated in the background)

NARRATOR: Like everybody else, I thought disabled folks were supposed to act tragic but brave or else cute and inspirational.
(Man in wheelchair pulls up to curb and gets out of chair onto sidewalk.)

**NARRATOR:** But these folks weren’t sticking to the script.

(Police pull man in chair off sidewalk toward street. They grab him by the legs. In the background chanting of protestors continues. Camera pans bystanders without disabilities and protestors with disabilities.)

**NARRATOR:** The people watching were shocked that these kids were sooooo angry. But that was how come I knew we were in the same club.

(Four protestors getting out of wheelchairs and lay on the sidewalk.)

**PROTESTORS:** The people...united...will never be defeated...The people...united...will never be defeated.

(Camera pans back to Billy watching the scene.)

**NARRATOR:** Chicago was the first time I knew I wasn’t alone.

(Cut to live music of a benefit concert in the background. Picture of a stop light changing from green to yellow to red.) Picture of Billy sitting on a red parked scooter.

**NARRATOR:** I stopped my scooter at a stop sign and the car behind me didn’t.

(Someone throwing tarot cards.)

**NARRATOR:** Threw me 67 feet.

(Picture of the death card fading into a picture of Billy on his back on the ground, shirt open, eyes closed, unconscious.)

**NARRATOR:** It’s a good thing I had a helmet in the trunk in case I needed it.

(View of band members playing alternating with views of people attending the benefit concert.)

**MALE FRIEND 1:** Hope you can feel what’s happening here tonight Billy. It’s for you. We love you.

(Female Friend with sign that says, “Say “hi” to Billy!”)

**NARRATOR:** So I’m lyin’ in the hospital, unconscious, when they decide to have this big benefit for me. It was a sellout.
FEMALE FRIEND 2: We love you.

FEMALE FRIEND 3: We miss you. Get well soon.

(Picture of Billy in sunglasses before the accident.)

NARRATOR: I’d been on the radio with a rock and roll show that walks and kills.

(Pre-accident home movies and photographs of Billy in his daily life.)

NARRATOR: I’d been on the scene for years, so the benefit’s jammed with 15 hundred people all telling me I’m their best friend.

BEEG: It’s Beeg. Wake up, will ya?

FEMALE FRIEND 4: I feel like I’m the only person in Minneapolis who hasn’t met you yet.

(Pre-accident home movies and photographs of Billy in his daily life.)

NARRATOR: You think all I’ve got to do is wake up from the coma and everything is cool, right? WRONG!

(Black screen.)

(Shot of legs down walking with a limp – down stairs and along a sidewalk.)

NARRATOR: When I came home from the hospital, my body and spirit were broken.

(Shot of hand opening car door. Still photos of Billy in hospital going through rehabilitation.)

NARRATOR: I was brain damaged and I’d lost partial use of my left arm and leg. The doctors were talking to Mom about a nursing home for the rest of my life.

(Getting into car, driving. Photos of Billy sitting in wheelchair.)

NARRATOR: I went from gallons of people around me to nobody there in a couple of months.

The best job I could think of was selling pencils at the bus station. Things did not look good for the home team.

(Billy backing out of driveway, driving, scenery out the windows.)

(Movie Title: “WHEN BILLY BROKE HIS HEAD... AND OTHER TALES OF WONDER.”)
MUSIC: (Blues beat continuing in background.) “I’ve had my fun...If I don’t get well no more.”

NARRATOR: So here you are. You have this accident and you lose a lot of stuff: motor function, friends, income, belonging, getting treated like a worthwhile competent human being with an important contribution to make.

MUSIC: “See my head...is feelin’ kinda funny...lord knows I’m goin’ down slow...”

NARRATOR: You lose your ability to make money, to survive or have any fun. You never get asked anywhere. You never get told anything. You lose stuff you can’t even count or can’t even name. The things that gave your life stability and meaning.

MUSIC: Lorrrrd....somebody please write my mother....tell her the shape I’m in...

NARRATOR: I only knew one disabled guy whose coat I could pull.

(Cut to a bedroom. A Hispanic American Attendant dresses a white man with quadriplegia.)

NARRATOR: A quadriplegic named Larry Kegan, who I’d run into on the music scene.

(Camera moves between views of Larry and views of Billy talking and listening while Attendant dresses Larry.)

LARRY: How did I break my neck? Ahh, jumped off a wall into the ocean. And ah, landed on my head in two feet of water. Ah, broke my neck, C-5/6 Lesion. Now I’m laying there, doing a dead man’s float, holding my breath. My eyes are open. Seeing the little fish fly by and everything. And I realize that the rest of my life is going to last as long as I can hold my breath. I hear this breathing.

(Larry makes breathing sounds.)

LARRY: But I don’t feel...I don’t feel anything. I look back and it’s this friend that I was diving with who had swam in and turned me over. He thought I was kidding!

(Attendant zips up Larry’s boots, puts on his pants. View of Larry breathing. He has a trachea opening. Attendant applies deodorant, puts Larry into a long sleeve shirt. Tugs Larry from bed into his wheelchair.)

LARRY: Oh man.
(Attendant belts Larry’s feet in place on the footrests of the wheelchair. One of Larry’s feet has the tremors. Attendant inserts air tube attachment into Larry’s trachea opening. Beeping as Attendant hooks up air tube to machine. Beeping stops when air tube is attached to Larry’s trachea opening. Larry takes a deep breath.)

LARRY: Ohhh! Oh man. That gave me a deep breath...I really don’t have to do that, but...I did it so fast for you guys...this morning that I, ah...got out of breath. Ohh.

BILLY: You keep making faces like you’re in pain.

LARRY: Oh. Do I?

BILLY: You know what I mean. Like that. Are you in pain?


BILLY: Just what?

LARRY: Breathin’ on this machine is all.

BILLY: You do it all the time. You do it when you’re not on the machine, you know. You make...I don’t see it anymore because I’ve known you so long, but you keep making faces....

LARRY: Oh, yeah, really?

BILLY: ...like you’re in pain. You’re not in pain?

LARRY: Only between my ears.

(Billy and Larry laugh.)

(Cut to Attendant pulling Larry into a sitting position in his wheelchair. He is wearing a headset with an attached bite tube.)

LARRY: Oh man....

NARRATOR: Life as a quad is a hard row to hoe. And Kegan’s been there since he was a teenager.

LARRY: So here’s how I write.

(Camera shifts from computer screen with words to Larry with bite tube operating the computer.)
NARRATOR: He’s tough and I’m always amazed by him. He types on a computer by biting on a tube in his mouth. Years ago Larry starting a resort for disabled vets that was depicted in “Born on the Fourth of July.”

LARRY: See.

NARRATOR: Now he’s writing a book about his life.

(Billy and Larry looking at the computer screen.)

BILLY: I type with one hand and I think it’s, it’s hard. You know what I mean?

LARRY: I can only type with one head.

BILLY: I understand.

(Pats Larry on the back.)

LARRY: Look at this! Look at this! Look at this!

NARRATOR: Larry’s also a musician.

(View of Larry’s manuscript, “Some Get the Chair.”)

NARRATOR: And I guess he’s kinda good at it since he’s played front act for some guys he knows like Bob Dylan, Neil Young and Eric Clapton.

(Larry on stage in his wheelchair, singing with a guitarist and harmonica player without disabilities.)

MUSIC: “Broken Down in Mexico...and I’m burning up inside...no place I can run to...no place I can hide... Broken Down in Mexico... and I can’t get up and leave...I gotta find some peace of mind with every breath I breathe... “

(Harmonica.)

(Billy driving. Street scene out the windshield.)

NARRATOR: I hate to paint him as inspirational, but I figured if Larry could do what he wants with his life, I could too. Before the accident I’d made these radio documentaries that ended up on National Public Radio. As I recovered, I tried to put together support for a radio program about the brain damage.
NARRATOR: I had experience. A wall full of awards. I had the injury. I figured it would be a way to get working again.

NARRATOR: It was a good idea. But I think it needed a lot more sex and violence, because nobody was buying. I asked the do-gooders of the State Department of Rehabilitation Services to help get me work. They give you all these tests to finger out what you want to be. Why the hell didn’t they just ask me? They never got me one job interview in eight years. My brain damaged friend, Janey, says, “As long as you don’t have a job, then they’ve got a job.” After years of not helping, they tried to close my case as “rehabilitated.” It took four levels of appeals to get them to provide... not a job...not even interviews, but more schooling.

NARRATOR: I went back to the university to get my master’s degree. But with the brain damage and a memory bangin’ on one cylinder, it’s like climbing Mount Everest with your fingernails.

BILLY: One more time.

INSTRUCTOR: One more time.

NARRATOR: I was studying things like Japanese to bring my brain back and Voc Rehab wanted me to do something practical or learn how to polish lenses for four dollars an hour. (In Japanese) “Karera wa wakarimasen deshta...

(Translation: “They didn’t understand.”)

NARRATOR: They’re civil servants and not know for their imagination or vision.

NARRATOR: I figured if nothing else a piece of paper might help me get work.
(Billy boxing the bag again.)

**NARRATOR**: But with the experience, awards, a grad degree, and a good grade point average, I still couldn’t get a job. Maybe I’ve got a bad attitude or something.

(Garage door opens. Billy walks in past the parked car and into his father’s house.

**NARRATOR**: That’s certainly what my father thinks. Dad doesn’t get how hard it is to convince someone to hire you when you’ve got a disability. He figures some disabled people are just too gimped out to work, and the rest of us are lazy.

(Sitting around a desk in his father’s office with his father.)

**BILLY**: Do you know that 76 percent of disabled people are out of work?

**DAD**: Well, I wouldn’t be surprised.

**BILLY**: So you...you...but you’re suggesting that if I would just get the right attitude.

**DAD**: But, but, you’re not that disabled.

**BILLY**: You’re thinkin’ about wheelchairs again. It’s not a matter of degrees. And it’s not a matter of...I mean... the disability is in my head. I got hit in the head. I had brain injury.

**DAD**: Well, you can’t lean on that. You gotta go out...

**BILLY**: I’m not leaning on it. I’m talking to you about it.

**DAD**: Oh.

**BILLY**: I’m not leaning on it. I went back and got a master’s degree. I’m not leaning on it.

**DAD**: So.... It’s a matter of determination. Ah...you showed determination to get your masters’ degree, but you... you fell in love with writing and I felt that you should be...ah...trying to earn a living otherwise, but...

(Billy typing with his right hand at his computer.)

**NARRATOR**: I used the computer to help bring my mind back and got hooked on writing. Professor Christopher Robins says I’m the best writer in America – or the world – I can’t remember which.
(Billy talking with brunette white woman. She is in a wheelchair. She makes the wheelchair extend from a sitting position to a standing position.)

**NARRATOR:** So I’ve started writing this journalism stuff about how the ‘helping systems’ deny you the basics you need to make it. Like Barb Knowlen had to fight Vocational Rehab through four levels of appeals to get a chair that stands her up so she can work and doesn’t land in the hospital with pressure sores.

**BARB:** I got this chair by appealing my case to Vocational Rehabilitation in Kansas nearly all the way to District Court. I got $60,000 in services during my lifetime from Voc Rehab, and I figured out that by working for 25 years and not being on Social Security, raising my three kids, I saved the government two-million dollars. That’s a pretty good trade-off. But I had to appeal and fight for almost two-thirds of those services. They were appropriate. They were reasonable. I should have had them. I talk to people all the time that are in the same boat. They’re being denied services that would enable them to be self-sufficient – enable them to get off this system.

(Piano music in background playing “Love Theme from Romeo and Juliet.” Gray-haired, elderly white woman plays a grand piano in a well-appointed apartment.)

**NARRATOR:** Kay used to play in the Chicago Symphony. When she lost her sight and the money went, she hid it better than anybody I ever met. She lives in an apartment that her brother owns with some furniture from the old days. But I’m surprised she hasn’t turned that piano into kindling wood because she lives on Social Security, and I’ve seen her eat a margarine sandwich for dinner. Medical assistance sends Kay the same 34-page form they send me and I can’t do it without help. But if you don’t dot your “I”s and cross your "T"s they’ll cancel your benefits.

(Kay sitting on a sofa holding her 34-page form.)

**KAY:** I can’t see it! So why would they send all this stuff to a blind person and say, “You get this back by July X or your benefits are cut?” And there isn’t a prayer that I could get it ever back in
my whole lifetime. Now I don’t know what these yellow sheets are. Since they’re yellow, they must be VERY important. I have to have an affidavit stating that, “Yes, I’m legally blind.” Now they have known this for seven years but I still have to verify every year – or every six months that I can’t see. Now it’s never going to get better. My particular condition will never get better. And I cannot read a single word of print, of any kind, of any size. And yet this is my task.

(Billy, typing at his computer.)

NARRATOR: I think I stand a better chance of writing detective novels. Nobody wants to hear about disability. I can guarantee you that.

(Billy’s wall, covered with rejection letters.)

NARRATOR: I’ve been sending out stories for years, and I got a wall full of rejections from some of the best magazines in America.

(Cut to a winter scene. A twenty-something, white woman in a manual wheelchair zips down the sidewalk from her door to her parked van.)

NARRATOR: This is Joy Mincey.

JOY: What... are you gonna... are you gonna film me getting into my car!? (Joy talks while getting into her van and putting the wheelchair in the van.)

JOY: Come here. I was gonna say, that um, most of the time it’s children who are interested in how you...they’re always like, “So how do you get into your car?” and it’s really...so, I’m doing this for the kids, all right? Um.

(Getting into the van)

JOY: Alright, ta-dah. I’m in the car, okay? And...now I proceed to load our wheelchair. Cushion goes first. And in the seat...

(Joy continues loading her wheelchair.)
NARRATOR: By some fluke my video teacher and I got a contract to make the documentary you’re watching. It’s a one shot deal, but it’s the first deal I’ve had in years. So I’m starting to get out and meet some new people. Joy’s one of them.

JOY: That’s it. Bye.  
(Joy slams the car door.)

(Joy in her house with friends, talking to Billy).

JOY: We see ourselves, I think, in the...in the context of our humanity, of ourselves as being, as thoughtful beings, as emotional beings, as spiritual beings, as sexual beings, um...as people who are coming together with thoughts and desires, with relationships, friendships. You know, um...employment, activism, ah, politics, you know, that’s... I think that’s how we are beginning to see ourselves and explore ourselves, whereas the medical community, of course, only focuses on us as flesh, focuses on us as, um...ah...not Joy Mincey the artist and activist, ah...but Joy Mincey as the paraplegic, you know, who experiences, you know, ah...T-12, ah...paralysis and sensation loss.
(Cut to black and white movie footage of white doctor in lab coat lecturing a 1940s group of women.)

MOVIE DOCTOR: Paraplegia is the result of an injury to the spinal cord. That break in the cord causes immediate and lasting paralysis of motion and feeling in the lower body. Most paraplegic patients will at various times suffer all of the following symptoms...

JOY: What they are essentially saying is that there is no possible way for a human to feel positively about disability. That’s, that’s not an option. It’s not an option. Disability is inherently a bad thing. It is inherently something that is just cause for suicidal thoughts.
(Cut to color movie footage of young blonde woman in a nursing home common room, alone, sitting in a wheelchair looking forlorn. Sappy, dramatic music swells in the background.)

MOVIE WOMAN: I’m never gonna walk...
(In a dance studio, Joy, in her wheelchair, dances to harmonic, new-age music with a male dancer and a female dancer without disabilities.)

**NARRATOR:** Crippled people ain’t supposed to do what they want with their lives. They’re supposed to be cheerful and grateful for crumbs, like Tiny Tim, “God bless us every one.” Besides being pretty and smart, Joy’s doing what she wants. And with this job making the documentary, I felt like things were starting to happen for me too. Maybe I could see some light at the end of the tunnel I’d been in for eight years… And then reality reared its ugly head.

(Billy walks into a building, down a hallway where people are sitting and standing.)

**NARRATOR:** It’s called a “spenddown.” And it’s a fancy word the system uses for when they think your life’s getting too cushy and they want something back.

(Billy leans on a counter. There is a sign that says, “Will be Right Back!”)

(Cut to Billy sitting across a desk from a Vocational Rehabilitation staff person.

**BILLY:** I got three notifications in the mail: One cancelling my food stamps. And one asking for a two hundred and some dollar spenddown.

**MR. JENKINS:** Um hm.

**BILLY:** And the other one was something about a 42 dollar something or other.

**MR. JENKINS:** Okay.

**BILLY:** Okay? And it’s like, it’s like, I’ve been trying for eight years since this accident to get something going. You know what I mean?

**MR. JENKINS:** Um hm.

**BILLY:** And I finally get something going. I’ve got $500 a month coming in. It’s not very much money. You know, and you guys are taking away two-thirds of it... You know, is this, I mean it’s like...you hear about disincentives. It’s like this is, ah...it’s like discourage...it’s like you guys are discouraging me from trying to get something...trying to get off the systems, you know. I mean, I don’t understand what this is about.
MR. JENKINS: Okay, well, I’ll explain it to you as best I can, um, explain how your budget is figured.

BILLY: Okay. Please.

(Mr. Jenkins, opens Billy’s file and shows him the document.)

MR. JENKINS: Here’s a copy of the notice that you received saying that, um, your spenddown is now $214 a month. Now what I’m going to show you now is how we arrive at that figure. Okay? We start with your 522, that’s your Social Security. Then, ah, we subtract $20. That’s a disregarded deduction that we give everybody. So that brings your income down to 502. Okay?

BILLY: Okay.

MR. JENKINS: Then we take your earned income which is $500, okay? We subtract $65 from that $500. Ah…again, that’s a deduction that we give everybody on their earned income. Okay. So that brings you down to 435 for your earned income. Which is the number up here. Then we divide that number by two, because we only count half of it.

BILLY: I…I…we gotta stop this because I…because I can handle a couple of numbers but I can’t handle a whole list of…this number from this number, and then we deduct this deduction, then we divide this by two and…I can’t do it. Tell me how, why is $522 a month too much money? I mean, how can you live on… how can you live on $522 a month?!

MR. JENKINS: Um, that’s a, that’s a very good question. But you know there’s really, there’s nothing that I can do to change the numbers.

BILLY: I understand. Mr. Jenkins, could you live on $522 a month?

MR. JENKINS: Ah, well, (exhale) I suppose, ah, I suppose I could. I think it would be extremely difficult. I wouldn’t want to.

BILLY: I mean it feels like it’s kind of a punishment.

MR. JENKINS: Yeah.

BILLY: It’s punishment for having had an accident, having a disability. That’s what it feels like.
MR. JENKINS: Well, I understand how you feel about that. Ah, I’ve got approximately 400 clients and basically, um, they’re all pretty much in the same boat because they’re disabled or...

BILLY: ...old...

MR. JENKINS: ...for, for whatever reason, yes.

BILLY: It’s not very much money.

MR. JENKINS: No, it’s certainly not.

BILLY: Okay.

MR. JENKINS: Okay. So I was explaining your spenddown to you. Okay. Take the 719, subtract, ahh, the 420...

(Billy getting out of a car at the airport. He slams the door. Struggles with his baggage. Walks to the terminal.)

NARRATOR: I don’t know when it dawned on me that it can’t be all my fault. I mean you gotta be a lawyer and an accountant and I don’t know what else to make it through these “helping systems” alive. I got a master’s degree with obstacles thrown in my way. And I’m smarter than the average bear. But when I start to get somewhere, these government systems throw the lead weights on. So what’s the message they’re giving me about getting a job and getting off the system? Millions of disabled people are trapped like me. I thought the Americans with Disabilities Act was supposed to fix all this crap-o-la. That sure was how the television was painting it.

(Cut to the US Capitol Building. A long line of disabled and non-disabled protestors march down the street with the Capitol in the background. You hear them chanting, “The people...united...will never be defeated...”)

NARRATOR: The ADA is official recognition that prejudice exists and it’s supposed to allow us all kinds of access. It sends a clear message to employers that just because we operate
differently, you can’t deal us out of the game. But it ain’t like nobody gave us nothing. I saw pictures of the gimps pushing pretty hard for this one.

(Cut to a security officer behind a White House fence.)

NARRATOR: And when our team scored, Bush called it a freeing of the slaves. But, freedom don’t always mean equal treatment.

(Billy walks down the aisle of an airplane.)

MALE FLIGHT ATTENDANT’S VOICE: Now for takeoff, please put your seat back upright, and lock your tray table in place.

(Cut to recorded flight announcement video. Billy does as instructed. Instructions continue in the background.)

RECORDED FEMALE FLIGHT ATTENDANT’S VOICE: Also, you’ll need to fasten your seatbelt low and tight across your lap. Insert the metal fitting into the buckle and tighten by pulling on the loose end of the strap.

NARRATOR: I’d been hearing about Wade Blank and ADAPT for years. ADAPT had organized that civil disobedience I stumbled onto in Chicago half a year before.

RECORDED MALE FLIGHT ATTENDANT’S VOICE: If needed, an oxygen mask will appear automatically. When you see the mask, please extinguish your cigarette.

(Billy looking out the airplane window. Views of blue skies with white clouds.)

NARRATOR: And so I decided it was time to visit the holy land of the crippled kids. And anyway, I just wanted to touch the hem of Wade’s robe.

(Cut to Billy walking down the street with Wade, a lanky, older white man with long graying blonde hair. The rock and roll song, “Magic Bus” plays in the background.)

WADE: The comparison is Denver who did civil disobedience starting in ’78, has all accessible buses and Chicago who didn’t do civil disobedience now has 600 out of 3,200 accessible, which is less than 50 percent, so if you...
BILLY: And the moral is civil disobedience gives you what you want.

WADE: Right, and ahead of time.

(Cut to a bus traveling on a Denver street. Background music..."Every day I get in the cue....Board the Magic Bus...To get on the bus that takes me to you...Bus, the Magic Bus...” Cut to Wade driving his van with Billy in the passenger seat. Scenes of Denver streets through the windows.)

NARRATOR: In Denver, it was a rush, actually meeting Wade and hearing war stories about how in 1978 the “Gang of 19” blocked city buses to get wheelchair lifts put on ‘em. Like Rosa Parks in Montgomery, those 19 people just wanted to ride the bus like everybody else. So they got out of their wheelchairs and laid in the street and those buses couldn’t move for a day and a half.

WADE: See, that’s the first act of civil disobedience of its kind so the police didn’t know what to do. They called the Mayor. Mayor McNichols said, “I don’t want any disabled people arrested in the City of Denver.” That was his position.

BILLY: Um hm.

WADE: So I said, “All right everybody, we can rape, pillage and plunder!”

(Laughter)

MUSIC: “Magic Bus... I said now I’ve got my magic bus...”

(Cut to the gold topped Denver City Hall. Wade and Billy walk down to a bus stop. A brass plaque on a concrete ankle high stand is surrounded by trash and leaves. Wade has a spray bottle and cloth. He cleans the plaque.)

NARRATOR: A decade and a half later, all of Denver’s buses are accessible.

WADE: Time to clean up.

NARRATOR: So the City erected a plaque to the “Gang of 19.” Wade would clean the pigeon shit and other junk off it.

WADE: Nobody else is gonna do it for you.

BILLY: Wade, you missed a spot there.
WADE: All right!

MUSIC: “I want it...Magic Bus...I want it...Magic Bus (repeats)”

(Cut to the ADAPT headquarters building. Lots of people with disabilities in and out of wheelchairs gather to listen to a speaker. Close-up shots of different individuals.)

NARRATOR: In the fight for civil rights for disabled Americans, these are the foot-soldiers. This is the headquarters of ADAPT, the radical arm of the disability movement. ADAPT pioneered the fight for accessible public transit and they won that puppy for good with the signing of The Americans with Disabilities Act. Their new fight is trying to replace nursing homes with home attendant care.

(A white, bald, bespeckled man speaks into a microphone while ADAPT workers listen.)

SPEAKER: Why are we in this stupid, crazy fight? We know it would all be a lot easier if we didn’t have to run from one city to the other; if we didn’t have to fight with the airlines about our right to be on their damn airplanes. If we didn’t have to be out demonstrating in the hot blistering sun and the driving rain. If we didn’t have to hold those damn vigils all night long while the rest of our brothers and sisters were in jail. If we didn’t have to be arrested and be in jail for several days, life would be so easy. So why the hell do we go through all this? We are in this fight because ADAPT has the dream of freedom for all the inmates of nursing homes.

(Cut to ADAPT workers watching a video of a TV newscast about an ADAPT protest.)

MALE NEWSCASTER: The issue here is very clear. What to do with people who need help but can’t help themselves. And that’s why they’ve come here. Take a look at these pictures, and then we’ll show you exactly what they’re doing here at the State of Illinois Building. They are blocking each and every stairwell, each and every escalator, each and every elevator to stop business as usual here at the State of Illinois Building.

(Cut to video of struggle between a gray-haired white man trying to leave the building and a row of people with disabilities in wheelchairs.)

MAN WITHOUT DISABILITIES: I gotta get out of here!
BLACK PROTESTOR IN A WHEELCHAIR: Talk to the elevator people. Talk to the elevator people. Talk to the elevator people. They won’t let us up. We don’t go up. You don’t go out! (People look at the scene from the floors above. The man struggles and pushes against the people in wheelchairs. A white woman without disabilities comes up to confront the man without disabilities.)

WOMAN WITHOUT DISABILITIES: Shame on you!

MAN WITHOUT DISABILITIES: I just... I got an appointment! I got an appointment!

PROTESTOR IN A WHEELCHAIR: Hold on. Hold on. Sir! Turn loose babe.

(The man without a disability falls down pulling a person in a wheelchair down and out of the wheelchair.)

PROTESTOR IN A WHEELCHAIR Hey wait a minute. Wait a minute you asshole!!

WOMAN WITHOUT DISABILITIES: Is your appointment really worth this to you? Are you crazy?

MAN WITHOUT DISABILITIES: How can I make my appointment?!!

NEWSCASTER LINDA: Channel 7’s Andy Shaw is standing live at the Illinois Center with late details. Andy?

NEWSCASTER ANDY: Linda and Joel, they may be disabled, but make no mistake about it, this has been one of the best organized and most effective demonstrations...

ADAPT VIEWERS: Cheering. All right! Yeah!

(Camera takes in the happy, amused ADAPT workers.)

NARRATOR: Watching videotape of the Chicago Action I’d been at six months earlier, I could dig what the Adaptive Devices were up to. By blocking people’s ability to move freely around a State Building for a couple of hours, they were protesting policies that lock up disabled people and take away their hope so that nursing home owners can make a profit.

(Video shows police lifting stiffened woman with disabilities (possibly cerebral palsy) over and around the metal barricade.)
NARRATOR: The nursing home lobby is powerful. And they have seen to it that more than 80 percent of the Medicaid money for long-term care goes to nursing homes.

NEWSCASTER ANDY: ...loud and clear as they protest cuts in the home care program.

(Cut to Billy walking down the street with gray-haired and bearded white man in a manual wheelchair.)

BOB KAFKA: We’ve organized especially in the physical disabilities...

NARRATOR: Politics is really about money don’t ya think? I learned from Bob Kafka that ADAPT is fighting to get some portion of public money redirected to home care attendant programs; so that disabled people on Medicaid have the choice to stay home which is actually way cheaper instead of being forced to go to a nursing home when they need help.

(Bob and Billy sit at a table in a restaurant.)

BOB: On the national level the American Health Care Association – the nursing home industry – brings in both public and private money – 76 billion dollars. You know, about half of that, somewhere in the neighborhood of 38 billion dollars is, is public money, mostly Medicaid money. You’re talking about an industry that is big bucks, paid for mostly, you know, with public dollars, but it also devastates families who have the money...the ability to pay. You know, the average nursing home cost is now almost up to 40-45,000 dollars a year. Plus you’re a person in the most degrading...you’re taking a person, whether young or old, out of a familiar surroundings, putting them in a warehouse basically. Even if the warehouse looks nice, basically where you’re told when to get up, when to eat, when to go to bed.

(Cut to nursing home. People asleep in their wheelchairs in hallways or rooms. Some walking.)

NARRATOR: Hey, ADAPT isn’t making this up. There’s nearly two million folks in nursing homes in this country, and a big chunk of them are under sixty-five.
(Cut to a man sleeping in a hospital bed. Pan to a man sitting upright and attentive in his motorized wheelchair. He has a trachea opening. Control levers are on either side of his mouth. He motors down the hall.)

**NARRATOR:** Lee Swenson used to be a cop. Always wanted to be a cop. But he got ALS, Lou Gehrig’s disease, and he couldn’t even draw his gun. You get disabled and you get caught in this nether land of rules that won’t let you keep your own home or much of your stuff if you wanna qualify for Medicaid.

(Cut to a large group room. Rows of people in wheelchairs around long tables. Staff nearby.)

**NARRATOR:** Now Lee lives in a nursing home. Not too terrible as nursing homes go. It’s basically clean and tidy but no privacy or freedom of choice. Lee’s mind is sharp as a tack and he could live independently with the help of an attendant for a lot less money than it costs to live in this nursing home.

**LEE:** People...in general...must be...aware...of those of us...with disabilities...that because...our bodies...don’t function...it doesn’t mean...that our minds...don’t function...too...and that we’re not capable...of...doing things...capable...of making...a significant...contribution...

(Cut to stiffened right hand waving inside a van near the roof. Camera pans to a thirty-something white woman with short brown hair, likely with cerebral palsy, driving the van.)

**NARRATOR:** I couldn’t believe that Robin Stephans could drive! Do you think I’d miss a chance to cruise with her?

(Robin drives while Billy talks with her from the back of the van. Views of Robin driving and the city streets going by.)

**BILLY:** Robin, is it hard for you to drive?

**ROBIN:** No, it’s easy.

**BILLY:** It’s easy?

**ROBIN:** Yeah. I learned in two days.

**BILLY:** You learned in two days?
ROBIN: (In halting speech…) Yeah. I had to. I had no choice. It took me about eight years to...to try to tell somebody I could drive. ‘Cause no one believed I could drive. No one believed I could drive. It took me eight, eight years fighting the system, fighting the system, fighting the system, fighting the system.

BILLY: Yeah. I got it.

ROBIN: To get somebody to teach me to drive. But actually I knew how to drive. I just had to do it officially.

BILLY: How about when you had to pass your license test? Tell me about getting the license test.

ROBIN: The first guy was all scared. I didn’t have a chance. Na-ah.

BILLY: Yeah, it must have just freaked him out to see you wanting to take a driver’s test. It cracks me up. Cracks me up.

ROBIN: He was scared shitless.

BILLY: He was scared shitless, yeah. And then so you had to go back a second time?

ROBIN: Yeah.

BILLY: How did you do then?

ROBIN: I did great.

BILLY: You did great?

ROBIN: Yeah, the guy was nicer. That guy was not as scared.

(Cut to Robin unloading a woman in a wheelchair from the van, unloading herself, closing the van up, helping the other woman get her hand on her tray, and together, motoring down the street to the State Capitol building.)

NARRATOR: It turns out that Robin’s only had one minor traffic ticket in nine years of driving. Which is a lot better than most of us can claim. I remember Wade telling me how hard he had to work to steal Robin away from her last job so she could work full time for ADAPT. He wanted her because she’s one tough cookie. Talk about vision. I mean here’s a woman who had to fight for eight years to convince some bureaucratic schmuck to let her take a driver’s test.
Wade looked at Robin and saw only her capacities and power and charm. So I got this flash that the same thing that is throwing obstacles in Robin’s way, and mine as well, is what’s keeping Lee Swenson in that nursing home.

(Cut to Robin and other woman inside the State Capitol, motoring about.)

**NARRATOR**: The physical disabilities are not the problem. The real barriers are the attitudes that see us as sick, incapable, defective, victims of a fate worse than death. It would be a stone oversimplification to say that we get these attitudes from cereal boxes or catch ‘em from toilet seats, or from watching TV.

(Cut to an excerpt from the TV show, *Star Trek: Next Generation*. Commander Riker enters the ship’s hospital where Lt. Worf lies paralyzed on a medical table.)

**LT. WORF**: Dr. Crusher believes my paralysis to be...permanent!

**COMMANDER RIKER**: I’m sorry.

(Dramatic music rises in the background.)

**LT. WORF**: I want you to help me die.

**COMMANDER RIKER**: There must be other options.

**LT. WORF**: No! There are not! I will not live as an object of pity or shame. My life as a Klingon is over!

(Cut to an excerpt from the *Jerry Lewis Muscular Dystrophy Telethon*.)

**VOICE OF ED MCMAHON**: We are here, live in Las Vegas.

**NARRATOR**: It’s a kind of a chicken and egg thing. While movies and TV reflect the attitudes of the culture, they also help create those attitudes.

(Cut to a shot of Jerry Lewis talking to the TV audience.)

**JERRY LEWIS**: My kids cannot go in the workplace. There’s nothing they can do. They’ve been attacked by a vicious killer. I’m begging for their survival.
(Cut to a black and white picture of Jerry talking to a boy in a wheelchair. Lewis is heard singing Rodger’s and Hammerstein’s, “You’ll Never Walk Alone” in the back ground. “When you walk, through a storm, keep your head up high…” Videos of cute or plucky individuals follow.)

NARRATOR: We’re always seen as helpless victims or special inspirations...

(Cut to movie of raging woman in her wheelchair and calm Attendant.)

NARRATOR: ...or we’re shown as sooo full of anger and self pity needing a swift kick from the nearest non-disabled person.

ACTRESS DANA DELANEY IN WHEELCHAIR: When I get stronger, I’ll quit drinking.

ACTRESS ALFEE WOODWARD AS ATTENDANT: If you keep drinking you will not get any stronger.

DANA DELANEY: (Yelling.) You listen to me, I hired you and I want you to do what I tell you!!!

(Cut to black and white video of a nuclear explosion. Then black and white excerpts of a scary man in wheelchair, malevolent little people, amputee...)

NARRATOR: Or else books and movies show us as villains, dark creepy forces and monsters.

MALEVALENT CHARACTER: Mr. Bond, it’s good to see you again.

(Roger Moore as James Bond defends himself against man with threatening prosthetic hand.)

(Cut to a sequence from the black and white version of the movie, “The Hunchback of Notre Dame.” Hunchback is tormenting the public below. He is hopping along a ledge with one foot sticking forward. This transitions into a view of Neil Marcus, hopping on one leg with his foot sticking forward.)

NARRATOR: I suppose you can see playwright and actor, Neil Marcus, as a monster. Because he’s hard to understand and his body is disabled. Packaging is everything. But Neil tells me his whole game is to change the way people look at disability.

NEIL: (Haltingly spoken) I am changing the way that people look at me. I think that is the power of art.
BILLY: You’re changing the way people look at you.

NEIL: Yes!

(Cut to a theatre. Neil is sitting in his chair. Away from him is a “Burger Guy” on the phone taking Neil’s order. There is an Attendant translating the action into sign language.)

BURGER GUY: Are you all right!? 

NEIL: Yeah.

BURGER GUY: Did you just order?

NEIL: Yes.

BURGER GUY: Oh no. Could we try this again, please?

NEIL: I…want…a…cheese…burger.

BURGER GUY: You want a cheeseburger??

NEIL: (Screaming,) Yeeahhhhhh!!!

BURGER GUY: Yes. Yes. He wants a cheeseburger!!!

(Cut to Billy and Professor Longmore walking and talking through the hallways of Stanford University.)

DR. LONGMORE: People with disabilities of all kinds are told, in one way or another, you are defective as you are. You are abnormal. You can never be fully human until or unless you are cured or at least corrected to the point that you arrive at some semblance of normality. Which is to say, you approach as close as possible to being like non-disabled people. There is no positive way within this view of things to be a person with a disability.

NARRATOR: At Stanford University, Paul Longmore teaches a class called, “The History of Human Differences.” He gets his students to consider that disability is not so much a sickness and a chance to get chicken soup as it is a political fact.

(Cut to classroom. Students sitting around a large conference room. Professor Longmore lecturing at the head of the table.)
DR. LONGMORE: You see the problem is when you are defined exclusively as an object of charity; you’re not in a position to demand anything as your right. When you begin to assert yourself as having a right to reasonable accommodations that allow you to operate in the different way in which you operate as a person with a disability, then you initially, at least, will be charged with seeking special privileges, because you’re not supposed to demand these things as a right; these are things that we dispense to you out of our good will.

NARRATOR: The idea that people with disabilities are a political minority and not sick is right and brilliant and perfect. When I started to understand that we’re treated and “dissed” just like any other minority, everything clicked. A gold star for Professor Paul. The day I visited his class they were discussing Jean Stewart’s novel, “The Body’s Memory.”

DR. LONGMORE: There’s a great t-shirt to come out of this book. It’s in the next to the last scene in this story when Kate goes down to the ocean, crawls out of the wheelchair and across the sand, and swims rather awkwardly out into…off shore…and the Greek fisherman spots her. This is the dialogue. He looks down at her, “Are you drowning?” Kate smiled up at him, “No, I’m swimming,” she said. I think that would make a great t-shirt. I told that to one of the disabled students and they said, “Well, nobody’d know what that meant.” And I said, “Yeah, but that’s the point. They wouldn’t know what it meant so they’d say, “What does that mean?” And you’d say, “Well you look at me and you think I’m drowning, but I know that this is the way I swim.”

(Cut to a drums being beaten. A drum circle in the streets of Berkeley, CA.)

NARRATOR: If you’re disabled, Berkeley is the place to be.

(People with a variety of disabilities traveling down the streets freely. A person with a disability gives a handout to a person begging on the street.)

NARRATOR: Disabled people don’t even get stared at here. The Independent Living Movement was born here – a chance to do it ourselves and dodge the do-gooders.

(Cut to Billy walking up a wood ramp and into the home of Ed Roberts.)
NARRATOR: And the undisputed daddy of that movement is this cat named Ed Roberts. Before going back to Minneapolis, I wanted to see Ed. Because I figured if anyone knows about changing attitudes, and making things happen for himself, it’s Special Ed. He’s paralyzed from the neck down, including the muscles around his lungs. So he breathes on a respirator and sleeps in an iron lung. He gets up late, so I knew he’d probably be in “the box” when I got there.

(Cut to views of the iron lung. Breathing sounds in the background.)

ED ROBERTS: Welcome to my humble abode.

(Billy standing next to where Ed’s head exits the iron lung. Ed uses a mirror to see what is to the sides and behind him.)

BILLY: When we talked about it on the phone, it scared me. When I’m here with you in the lung, it doesn’t scare me at all.

ED ROBERTS: It’s funny because your, ah, only your head’s out.

BILLY: (Pointing to Ed’s head.) This is the head?

ED ROBERTS: This is the head, yes. And people think it’s awful. It’s just a breathing mechanism. It works very much like your diaphragm inside your body. It works by air pressure. I affectionately call it my womb with a view. Because it’s very comforting being in here. It’s warm. It’s, ah…I don’t have to hold the respirator hose. I just relax and it breathes for me. And, and that’s a real nice thing.

(Ed’s Attendant separates the two sections of the iron lung and begins to clean and dress Ed.)

ED ROBERTS: This comes out six feet. I have a big room.

(Breathing sounds of Ed using his respirator hose.)

NARRATOR: In the 60s when Ed went to the State Department of Rehab Services for help getting a job, they called him “infeasible.” I mean here’s a vegetable who can’t even breathe for himself.

(Ed lets go of his respirator hose. His Attendant pulls his head through the opening.)

ED ROBERTS: Okay.
NARRATOR: Fourteen years later, Governor Jerry Brown appointed Special Ed the Director of that same State Agency.

ATTENDANT: MMMM. Feels so good. Actually, Ed’s just into bondage, and these are just sex toys.

(Attendant hoists Ed up in a sling-like contraption to move him from the iron lung to his wheelchair.)

ED ROBERTS: But there’s hardly any difference between being tied up and being paralyzed, so....

(Laughter.)

ATTENDANT: That’s not very equitable.

ED ROBERTS: No, so if you have a partner that likes to be tied up, we’re both in trouble.

(Ed let’s go of his respirator tube.)

BILLY: Do you need this?

ATTENDANT: No but if he starts turning blue, call an ambulance.

(Laughter.)

(Cut to Ed talking to Billy from his wheelchair. Ed breaths with a respirator tube and talks between breaths.)

ED ROBERTS: What we have to do...is we have to change the old attitudes that have been there for many years... In order to change the old attitudes, we gotta get out in society...We’ve gotta be seen. We’ve gotta be the neighbors. We gotta be the lovers; we gotta be... the friends. We’ve gotta be seen in a very natural way...Disability’s a part of life. And some of us are gonna have it... And some of us are gonna have it young. And some of us are gonna have it older... But whenever it comes, our job – you and I – is to make sure... that we know that we don’t have to put somebody in an institution... That we can have high expectations of them and their future... And by helping them to begin to take control of their own lives...they can go back to work, or go to work, or do...dream what they want to dream and make their dreams come true like we all do....
NARRATOR: Nowadays, along with folks like Hale Zuckus, another co-founder of the Independent Living Movement, Ed runs the World Institute on Disability.

TONY JOHNSON: Anything that destroys my balance destroys my ability—whether it’s this, a gun or whatever. Right now you should almost begin your sweep.

NARRATOR: Tony Johnson encouraged Ed to do karate.

TONY JOHNSON: If I’m going to stick you, right about here is where you start, because my leg is coming in fast. Yeah, that’s it. That’s it. That’s perfect. Don’t wait too long. Okay. That’s good. Okay. Wait. That’s good. That’s good! Yeah...

NARRATOR: Seeing Special Ed and Berkeley and Professor Longmore’s class, made me come back to Minneapolis wanting to do something to make a difference.

ED ROBERTS: People talk about...some of us are very angry. Of course we’re angry! We’ve been through... the worst kind of atrocities, attitudes toward us that see us as... vegetables; see us as sick and unable, having no future... That’s gotta piss you off. And to me... anger is one of the best things we’ve got going in this movement... Because when you’re angry, it gives you a tremendous... amount of energy.

NARRATOR: You figure anything is gonna start small, but like my dad says, “You’ve gotta try.”

EDDIE FELLINI: This is for Billy Golfus. Billy Golfus is running for Park Board at Large.

CITIZEN: Hi.

EDDIE FELLINI: He’s disabled. He had an accident about seven years ago and ah...
(Cut to another citizen.)

**EDDIE FELLINI:** This is Billy Golfus.

**NARRATOR:** Crazy Eddie Fellini called me, “Chicken.” Told me to put my money where my mouth is and run for Park Board. Seemed like a good idea at the time.

(Cut to Billy standing at a podium, giving a speech to a room full of delegates.)

**BILLY:** My name is Billy Golfus and I’m running for, um, Park Board at Large. And my mission is to tell you that I’m wonderful without actually saying it. The beauty of our parks and lakes distinguish Minneapolis from any other city in the country. And I’m especially concerned about two groups that always get excluded: elderly and disabled people. I’m a disabled guy. Being disabled is as close as you can get to being invisible. For example, right in this very room, we have delegates who are wheelchair users. If you look around, you might see a couple. And today there was a vote on the rules about people having to stand. Now that’s dumb and insensitive.

(Applause.)

**BILLY:** I hate to see…I hate to see disabled people treated that way. We’re the largest minority in America. Wake up. It’s time.

(Cut to Billy getting out of car. Putting on sunglasses. Struggling to get his hat and earphones on.)

**NARRATOR:** I’m 49 years old. I’m brain damaged and hemiplegic. I haven’t had a job or any income to speak of in nearly a decade and they don’t want me on their Park Board.

(Cut to Billy’s Dad busy getting his motorboat ready to go out on a fishing trip.)

**NARRATOR:** My dad’s in his eighties and he wants to go fishing.

**BILLY:** Dad. What time were we gonna go?

**DAD:** You didn’t act like you wanted to go at five o’clock.

**BILLY:** You said five o’clock. You know what time it is right now? Dad, it’s four hours later than you wanted to start. Oh, come on...
DAD: I would do it if you were serious about going....

BILLY: If I was serious. If I was serious. Vay iz mir. (Yiddish. Translation: Woe is me.)

(Cut to Billy's dad driving the car. Views of boat being towed, Billy in passenger seat, passing scenery.)

NARRATOR: J.J. is very, very hard of hearing. But he doesn't think he is disabled. I know that he knows something about prejudice because he hides his age. Mark Twain says, “It’s better to be a young June bug than an old bird of paradise.” I wish Dad could understand that he’s one of what he calls “those disabled people.”

(Cut to boat being put into the water. Billy holds the lines. When on the boat, Dad and Billy eat sandwiches and drink from thermos cups.)

DAD: Not a bad roll.

BILLY: Not bad.

BILLY: I went to a...I went to see some disabled people in a nursing home.

DAD: Hum?

BILLY (speaking louder): I went to see some disabled people in a nursing home!

DAD: What’s keeping them in there? Their disability.

BILLY: Their disability? What do you mean?

DAD: What are you gonna do for these people? You gotta have enough money to take care of them. They don’t have it. You don’t have it. What do you do? You’d have to leave them in a nursing home. I wouldn’t like it any more than they do. But if I don’t have money to go elsewhere, what am I going to do? What is anybody going to do? If the money isn’t there to take them somewhere else...

BILLY: I mean what would happen to you if, like ah, three years from now you had a stroke or something, and, and something serious happened to you?

DAD: I would...what would happen to me?

BILLY: Yeah. I mean, I’m asking you about...

DAD: What would I want?
BILLY: I’m asking about, ahh, it might be necessary to put you in a nursing home.

DAD: I don’t wanna go to a nursing home. And I’m telling you, that if it looks like I... ah... it’s terminal, then I would want to jump off the bridge or do something to end it. There’s no point in living, ahhh, and suffering.

BILLY: What makes you think that being disabled is suffering? What makes you think that being disabled is suffering?

DAD: Well, for me it would be.

(Dad opens the tackle box. Baits a line. Starts fishing. Billy fishes too, struggling to get on the other side of Dad.)

NARRATOR: Dad would rather jump off the bridge than be disabled, and my brothers feel the same way. Dad says, “You could overcome your physical difficulties if you had determination. I would if I were in your place.” Now let me get this straight, they’d jump off the bridge but I need a little determination. Hmmm. They think I’m not okay the way I am. And if I’m still disabled, it must be my own fault. I didn’t wear the lucky charm, or eat my Wheaties, or do whatever to make this embarrassing thing go away. Maybe because I’m brain damaged and Dad’s getting on in years, neither of us remembered to bring the gas line for the boat, so we couldn’t move. Just like some people I know.

(Camera goes to a wide shot of the boat tied against the dock. Billy and his Dad fish from the lakeside.)

NARRATOR: But we had a really special day anyway. I suppose that’s the moral if you think the story needs one.

(Fade to title page. Sounds of water lapping against the boat in the background.)

Title and Dedication Page: When Billy Broke His Head And Other Tales of Wonder...is dedicated to the memory of Reverend Wade Blank.

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(Fade to black.)