

# Voices: A Series Of Oral Histories

## 'PLAYING THE CARDS YOU'RE DEALT'

by Jan Schmidt

**John Iversen, interviewed March 19 and 20, 1995. John Iversen is a musician, song-writer and political activist.**

**Jan:** Anything else you want to describe yourself as?

**John:** A recent accident victim.

**What happened?**

Today, I backed at two miles an hour into a Mercedes Benz and loosened the grill. It looks like it could pop right back into place. Since I don't have auto insurance, we asked them to not report it and I would just pay them. They refused to do that. This may result in a year revocation of my license except for driving to the doctor and fines, and the necessity to actually purchase insurance. On SSI, this is difficult. I had agreed to pay them for the damages, which I thought would be somewhat slight, but if I'm going to go through all this, they can inform their insurance company and get their rates raised.

**And we waited for the cops, for an hour?**

An hour and a half.

**One of the hot moments of the whole affair, was when you had the opportunity to answer the question, "why don't you have insurance?"**

Yes, and I answered, BECAUSE I HAVE AIDS AND I'M ON SSI AND INSURANCE IS HARD TO BUY WHEN YOU ONLY GET \$620 A MONTH. That seemed to shock the lovely couple.

**Who continued to call their insurance company.**

Yes, and didn't call the police to say forget it.

**So now you're 46 years old. You were born in the Midwest?**

Yes. A small town in Northern Minnesota was a pretty good place to grow up in. Primarily a working class town. Everyone was unionized. It votes 80 percent Democratic. I still have friends there when I go home. Most of them aren't aware even of my health condition. I get together and have coffee with people. I simply tell them I'm disabled.

**Tell me a story from your childhood, I remember hearing about a fire.**

Oh, we'd start fires in garbage cans. I don't know psychologically what this is a sign of, but I remember once being stopped by the police because four of us drove through a tourist campground at around 11 o'clock honking the horn and yelling at people to 'get up.'

**This is when you were a teenager?**

Yeah, the police were waiting by my parents' garage when we got home.

**Weasel told me about the first time she met you was when you were in a show?**

I portrayed Mrs. Miller in the Winter Frolic Talent Show. I was a



hit.

**What did you sing?**

'A Lover's Concerto.' (singing in a falsetto) 'How gentle is the rain, that falls softly on the meadow.' I had balloons as breasts and a wig and some sort of operatic dress.

**How did this go over in a small town?**

They thought it was a hoot. I had them rolling in the aisles. In fact I wasn't scheduled to be in the night time show, but I was called to do it.

**When you graduated from high school, you went to the University of Chicago. How did you end up doing something like that?**

Three people from my high school had gone to University of Chicago before me, so I was aware that they had a scholarship program for people from small towns. I applied to many schools, including Columbia, with good sociology departments. Chicago gave me a full scholarship, so I went there in 1967. I was put on suspended suspension for political activity during the 1969 sit-in. In fact I spent one third of my time there under suspended suspension. If you were caught doing anything else, like having overdue library books, they would expel you. So this is just a continuation of that. A constant state of suspension. At the U of Chicago you became more political. Was it the times?

Yeah, and it was the Viet Nam War. The war and just the stark

difference of seeing really urban poverty for the first time, and going to school with some of the wealthiest children in the nation. It was a bit of a contradiction.

**How was it, being with some of the wealthiest students? I assume you were not.**

No, nor was I one of the more intelligent ones. I had to work my way through school. I worked 20 to 30 hours a week the whole time, four years. I would be a little resentful coming home from work and there would be the rich kids playing bridge in the common room of the dorm. Some of my friends were rich, but most of them were middle or working class. At least at that time, college student bodies were very diverse, economically.

I got involved in the antiwar movement, something called the People's Peace Treaty, the Black Panther Party Defense Committee. I cooked in a Black Panther children's breakfast program and I tutored underprivileged kids in a very poor area about 10 blocks from the university.

**After you graduated from college where did you go?**

I moved to Albuquerque, NM, with you. It was an odd city, a mini-Los Angeles. There was no housing because it was growing so quickly. Whites were definitely at the top of the power structure with blacks, Chicanos and Indians at the bottom. We had horrible minimum wage paying jobs.

**Where did you work?**

Presbyterian Hospital, in central supply. For one cent above minimum wage. Some friends and I got involved in the underground newspaper called, *Seers Catalogue*. We saw the first issue and four or five of us were working on the second issue. Eventually we put it together in our house. We'd go out to high schools and hand them out, you were with me once when I got arrested at an Air Force Base for handing it out. But we managed to avoid any suspension of driver's licenses for that period of time.

**You worked with the Brown Berets, the Chicano group, in their health center?**

Just basically liberating supplies from the hospital and giving it to them. We helped them to organize one demonstration and march, to get the maximum turnout when the police murdered a couple Brown Berets.

**Then towards the end of that period you came down with this arthritis?**

Reiters Syndrome. It's a form of rheumatoid-arthritis.

**You woke up one day and couldn't walk?**

Yeah. It came on pretty quickly.

**Then you went into the hospital that you worked at?**

Yeah, as someone else who had insurance. Insurance is a recurring theme. It was very interesting, especially when former co-workers would come up to visit me. Eventually, to get out of the hospital, we had to pay the bill anyway.

**That's when Marvin and I left. And you flew home and stayed with your parents?**

For four months. They thought it was some kind of arthritis, so they were treating me with Aspirin and heat.

**In about a year you were walking again without a limp. In that time you moved to Madison, WI. How long did you stay there?**

Two years. I started working with the United Farmworkers as a volunteer. Eventually got hired by them for \$30 a month plus room and board. I met one of the two loves of my life, who I'd have back in a minute. That was Beth.

As you know, Wounded Knee happened. I went there with a group of Indian people, being part Indian myself, Chippewa. Stayed there for seven weeks. It was probably one of the major experiences of my life. You were surrounded by the government, and food eventually became very sparse. But most people were willing to share and those who didn't were publicly shamed.

I was given a desk job in the security office in charge of doling out ammunition to people, because I had the arthritis. I mean, this

is a little scary, 'You can only have five bullets.' But you just do it. We had a little newspaper, so I would print that. I would type it up and copy it on an old mimeo machine. Then we ran out of paper and ink, so that was that.

**So what was the particular thing that caused this?**

There were numerous causes. The Pine Ridge Reservation was run by a goon squad under tribal president, Dick Wilson. There had been many murders on the reservation. About a month earlier, an Indian man named Wesley Badheart Bull about 30 miles away in Nebraska was killed. The trial was a farce. The reservation was basically a police state with people who had sold out, getting government money and attacking more traditional people and those, such as public health nurses, who were really concerned about the community's well-being.

Wounded Knee wouldn't have happened without four elderly Sioux women, putting their feet down, saying we've had enough of this situation on the reservation. These four women invited AIM in. They took over the town and made demands which I thought were quite reasonable: They wanted a change in the local government, to meet with the justice department, and an investigation into treaty rights.

**What response did they get?**

Planes buzzing over them and armored personnel carriers surrounding them. The demands were so reasonable, I'm surprised. Although Nixon was president, they wanted a meeting with Senator Kennedy. Kennedy never did come out there.

**What about it made it so major to you?**

The fact that a group of people can really share and get along with one another under wartime conditions. I did have bullets coming within a foot of me.

I left before it ended. I think the FBI was happy to have anybody leave. You were just harassed. They certainly knew where I lived. Later they did call my parents. Luckily most of the people who went on trial, such as Russell Means and Dennis Banks, were let off, but the story continues. Leonard Peltier is still unjustly jailed due to Wounded Knee aftermath events.

**What was it like with Beth?**

With Beth, it was always so very easy being together. Everything worked, it was never a bad time.

**How did you meet her?**

She volunteered with the Farmworkers.

**What happened with her?**

"IT'S  
A RADICAL  
PROPOSAL,  
SOMEWHAT  
NATIONALIZING  
A CERTAIN SECTION  
OF AIDS RESEARCH.  
IT'S STILL A PITTANCE  
COMPARED TO WHAT IS  
DONE AT THE NIH  
(NATIONAL INSTITUTES  
OF HEALTH). THE  
PHARMACEUTICAL  
COMPANIES HAVE THEIR  
HANDS IN THAT. THEY ARE  
PART OF THE PROBLEM,  
THE OLD BOYS NETWORK  
BETWEEN THE  
PHARMACEUTICAL  
COMPANIES, THE NIH  
AND UNIVERSITY  
RESEARCHERS. IN THE  
'50S, IT WAS THE  
MILITARY-INDUSTRIAL  
COMPLEX. NOW IT'S THE  
NIH-PHARMACEUTICAL  
COMPLEX. C. WRIGHT  
MILLS' THE  
POWER ELITE IS  
STILL  
VALID  
TODAY."

There was another man who was in Boston and she moved to Boston.

**That was a couple years later?**

That was in January of '74. I went to Boston also and lived in the same large communal house she did. I had gone to Boston to study acupuncture and to attempt to reunite with Beth. She ended up years later studying it and becoming an acupuncturist. I lost interest in acupuncture.

I had a lot of crappy jobs. I organized a union at a school for multiply disabled children. We eventually lost a strike on a technicality. It was a school, but they got it classified as a medical facility, and you can't have a walk-out of a medical facility without advance notice.

I got a job working for the welfare department for about two years and then applied to Columbia School of Journalism. I went there for approximately one week and decided there are enough radical journalists, I don't have to do this and I don't want to do this. I had started smoking and drinking a lot of coffee, and I said, I've got friends in California, I've always wanted to live in California, I want to play rock music. I was influenced by Neil Young: 'Rock and roll will never die. Better to burn out than it is to rust.' At the time, I thought I'd rather do social work and play rock and roll, than be a newspaper writer.

I lived in New York three weeks, after five years in Boston. I'd had it with the East Coast big cities.

**So you moved to Berkeley, California. What was your first band?**

The Stickers. Then we changed our name to Dreams Die Hard because we were sick of The Stickers. When we put out a second 45, putting down Oliver North, which got a lot of play on college stations, I got about \$500 in royalties for BMI. We came close. Virgin Records in London called us. We had also been signed by a management company but the guitarist in the band didn't want to have to play when they said play. I was sick of looking for replacements, we were very musically compatible. He would have been hard to replace. So I stopped. Being HIV positive, I knew an AIDS shoe would eventually drop. Working so hard playing live, though very enjoyable, was taking its toll.

**Before that you had a lounge type act with Marie?**

Oh, right. About a year after moving out here, I met Marie in a song writing class. We formed the Rhythm and Sleaze Revue, Sonny and Cher with a Bette Midler mentality.

Our only paying job was at the Sutro Bath house. We'd be competing with sex and people couldn't drink, so they weren't tipsy. It was all so serious.

**You couldn't drink?**

No, there was no drinking in the place, so we were playing to a straight audience competing with sex.

**Your audience could sit there and watch you or watch other people having sex?**

Right. Only one show could people come in off the street. One of our best shows we had about 25 people all sitting there in towels watching us. Men and women. It was a co-ed bath house.

**And what kind of songs did you sing?**

Marie and I clicked because some of the first songs we both wrote were dirty songs. She had this great song called, 'Carrots and Candles' about masturbation. I had one called, 'I've Got My Period,' which I believe you helped me with the subtleties of different ideas to use. Marie happened to find a letterman's sweater with a big red 'P' and red pom-poms and while I was singing she'd go out into the audience and lead the cheer.

**Could you sing a few bars?**

(singing) 'Well, I got up in the morning, jumped out of bed, ran to the shower, wiped myself and it was all red.' I can't remember.

**There was another song about golden showers.**

'Give me a life in a golden shower, pee on me, hour after hour, I'll be your pretty little flower, a salty taste but a little sour. Pee with all

your might. Pee on me make it last all night. Then I've forgotten the words. When I moved once, I lost a lot of old lyrics.

**What a tragedy.**

Not being in a band is what I miss most, from getting arthritis and being ill.

**What was the band like?**

More country rock. Basically at the end, it was like the Ramones meet REM. I liked the slicker sound. Mostly I just sang at the end. The guitarists were far better than I was. When we did the recording, I would do most of the backgrounds, too. Because I had been in choirs and choruses, I could put together parts. Harmony with one voice sounds great.

**At some point you were diagnosed HIV positive.**

January of '86.

**That's when it was the Stickers. When did you first start getting sick?**

The band stuff stopped in about July of '89. It was with the guitarist not wanting to sign a management contract. Virgin Records being interested, but we were breaking up. I didn't have the energy and I thought I'm really playing with time here anyway. I did keep nosing around auditioning for bands. But in December of '90 the arthritis hit hard, caused by an experimental drug. So that was it. My fingers were just mangled at the time, so I couldn't touch a guitar anyway.

**This is the same arthritis that you had in Albuquerque?**

Yeah. Reiter's Syndrome.

**Then you were living in Emeryville.**

Yes. In a loft in the back of a factory. I took it because we could practice there. It was cold and drafty. I went up and down the 17 steps on my butt for approximately four months, I couldn't even use crutches. My friend Martha would help me stand up again at the top or bottom. It was horrible. (laughter)

**So you had people coming around to help you.**

Yeah.

**They'd bring you food. Is this when you got the AIDS diarrhea?**

It was about six months later.

**You were still not walking?**

On crutches. Still in a lot of pain. I switched AIDS doctors at that time, because my doctor was moving to Florida. The new doctor freaked when she saw what the rheumatologist was giving me, because apparently it causes HIV to replicate much faster.

She got me off the drug right away. She sent me to a rheumatologist and they put me on other drugs. I was hospitalized in January and decided I had to leave work in two months earlier, when the diarrhea was bad. I was at work and I couldn't make it to the bathroom.

**What was the job?**

Director of a senior center. I worked there for eight years. While ill, I didn't quit the job, I came in once a week and people would bring me the work, or I'd bring all the paper work home and make calls from home. I was able to minimally do the job, but it wasn't fair to the other people working there so in January, I asked someone who I knew could do the job. It's low pay, so you won't find many people who will take it who can actually do it, because the reports are complicated.

I lost 40 pounds in three months. I was crapping all the time—sometimes 10 times an hour. It was uncontrollable—just gas and liquid and blood. So I had the experience of periods there. And my friends could not believe just how horrible it was. I couldn't either. Then I got in the hospital they switched drugs from Gancyclovir to Foscarnat. And that did a whole turn. Much earlier they should have done the test they did to show the strain of CMV I had that is resistant to Gancyclovir. Gancyclovir is four times cheaper, so that's what they start everybody on. At that point my doctor prescribed Prednisone for the arthritis and that helped a lot.

**How do you take that medicine?**

It's a four hour a day intravenous process, two hours in the morning, two in the evening.

**At that point you were infusing it, from a shunt in your chest. How was that?**

I was so sick at the time, I thought I was going to die, so it was just something else. I couldn't really go out and do anything anyway. A movie maybe once every three weeks, and that was an ordeal.

**And now you have the drugs in plastic bags and can walk around while you're infusing it. At that point you had to lie in bed?**

Next to an IV pole. Also at that time I was fighting an insurance company. They had given me one drug to control diarrhea in December, prescribed by my doctor and a gastroenterologist, who were hooked up with their health plan, which was Qual-Med at the time, it's Health Net now. In April, they decided they weren't going to pay for it anymore, because it was off-label use. It was approved for diarrhea caused by cancer but not diarrhea caused by AIDS. They were doing this with another drug GCSF for neutropenia which is low white blood cells. Since it was approved for cancer they'd approve it if it was caused by cancer but not if it was caused by AIDS.

We ran a tremendous campaign against this greedy HMO. We took out newspaper ads and raised money, tried to get employer groups to drop it, tried to get consumers, especially healthy consumers, to switch health plans. We ran ads in the *Daily Californian* and *UCSF* paper. The University of California, San Francisco and Berkeley, was their largest employee group. The day the full-page ads came out they wanted to settle.

They settled with me right before the ad came out, hoping to pacify me. They settled with the HIV patients union within a week after the ad ran. They were paying for an off label use for Septra, which is approved as a general antibiotic, for the prevention of PCP pneumonia. So there were some contradictions—if it was off-label and cheap, okay, but if it costs \$2,000 a month, they balk. I managed to net the drug for shipping charges through the drug company, Sandoz. Sandoz has a compassionate use program.

**During this time you're getting your health back, while you're out waging this campaign, going out leafleting with your walker.**

Or hobbling—at that point I could hobble. The best one was when Qual-Med sponsored a Halloween Health Fair at University of California, San Francisco. It was also enrollment period for health plans, so Qual-Med was sponsoring it with a campus group but all the health plans had tables and there was a band. I hit everyone going in and my friend Scott hit people who were already inside. We had flyers with a Halloween motif so security would just walk by us. I think they thought we were part of the Halloween celebration. We got out 500 leaflets. I thought it was very effective. Happy Halloween Health Care From Qual-Med. And I know they had spent over \$5000. to do this.

**Before we were talking about major things that had affected your life, one was going to Wounded Knee, obviously having AIDS is changed everything, what other things have you thought of as major in between there or after that.**

Nothing major, I've sort of always done what I wanted to do or what I felt was right to do at the time.

**That's sometimes an unusual thing for people to do what they want to do.**

For the band, I had a great day job. I could make my own hours to a point.

**At the Senior Center.**

I liked the job, there wasn't a day I dreaded going to it. When I came to the Senior Center, it was \$3,000. in debt, and audit problems, and eight years later I left it with nearly \$30,000 in the black and much more equipment than it had before.

**One of the things you'd do is go on the Reno trips.**

Yeah. It's interesting that after I was sick, I wrote a farewell newsletter. It's a way to reach a thousand people, and all of a sudden they know someone who has AIDS. The first Reno trip about a year after I had left the job, they took up a collection for me on the

bus. Everyone made a point of coming up to me and shaking my hand or hugging me or something. I don't think there was a person on that bus who didn't touch me. It was very heartwarming.

I had a retirement party in March of 1992. January was when I was near death. They took up a collection of \$600. They hit up a few people who worked for the city, because I worked for the City part time too.

**What was that job?**

Administrative aide to the most radical Berkeley City Counsel member, Maudelle Shirek. She's 82 years old. Once we got arrested in civil disobedience to keep an AIDS ward at the County Hospital one of the police women came in and said, 'Is there a mistake here? We have someone who says they were born in 1911?'

Maudelle Shirek moved to Berkeley in the '40s and got a job during the war, because they had plenty of industry here. She was very smart and she had a college degree. She was the first black woman hired by the Berkeley Co-op. The first black woman hired by the Berkeley Credit Union. She would picket stores here in the '50s, Walgreen's and Woolworth's, until they hired blacks. She convinced Ron Dellums to run for Congress. Then she founded a couple senior centers and had been a union activist. Another person, like myself, who is instinctively right all the time—in terms of politics.

**You started ACT-UP East Bay?**

Yeah. I started the Berkeley Needle Exchange also, in 1990, right before I got sick. In Berkeley. ACT-UP was a year earlier.

**At that point Needle Exchange was illegal.**

Yeah. We went six months before someone was arrested. In Berkeley we went through two trials. One was a hung jury, the second one was acquittal. But the DA here is so warped he also charged people in Oakland, a different municipality. Since they are charging with misdemeanors, there is no precedent. We just won an acquittal in Oakland.

**So this has been going on for five years?**

Four years in Berkeley. So this one person, Scott Halem, was in all three trials. In Oakland, five people were being tried. So this person has been tried for needle exchange or facing charges for four and a half years.

**How has the legal process gone on this in terms of money for defense?**

Lawyers did it for free. In Oakland it didn't take them long to acquit. Members of the jury knew people at work or had family members who had AIDS or had HIV. So it's just much more prevalent in society and society is much more aware. They're also aware that needle exchange works and that this was the only area in the country where it was being prosecuted to such an extent.

**Why do you think that was?**

The former DA and the new DA had a hair up their butt about needle exchange. It was just their morals. Also the fact that Governor Pete Wilson of California vetoed needle exchange legislation three times after the senate and the assembly passed it.

**What is your life like now?**

I infuse a drug four hours a day, so even if I'm running around with it, I have to have sterile things with me, gloves, special soap, if I'm going to put it in or take it out somewhere else. I take about 80 or 90 pills a day. My feet are deformed from the arthritis, so it's still not that easy to walk great distances. Although last year I did go to London and walked a lot. That was one of my goals, to get back to London before I croaked. London is my favorite city in the world, because theater and music are cheap. There's a lot of good museums. Cheap and good.

There is something medical to do everyday. I get acupuncture and I'm now trying to see this chiropractor and running to the pharmacy. One day a week I volunteer at the Senior Center, running the Bingo for the Senior Center where I used to work.

**You're constantly on the telephone, organizing, writing articles, ACT-UP, Needle Exchange, Cure Act. You want to talk about the**

# Voices: A Series Of Oral Histories

(continued from pg. 17) )

## Cure Act?

It's a radical proposal, somewhat nationalizing a certain section of AIDS research. It's still a pittance compared to what is done at the NIH (National Institutes of Health.) The pharmaceutical companies have their hands in that. They are part of the problem, the old boys network between the pharmaceutical companies, the NIH and university researchers. In the '50s, it was the military-industrial complex. Now it's the NIH-Pharmaceutical complex. C. Wright Mills' *The Power Elite* is still valid today.

The act (HR7611) will provide \$350 million a year, for five years for independent researchers who didn't want to go the drug company route. To me it makes a lot of sense.

It's not a lot of money. It was sponsored by Jerry Nadler, your Congressman. Opposition for it came from 'people in the AIDS industry.' Sadly, I don't think they can look at this as something that's adding to the struggle. They see it as 'Well, if we did this, the AIDS Cure Act, our budgets might be cut.'

## What do you think about the changes in the struggle of left wing politics?

It's exacerbating to see socialism crumble. It's sad and it's also ridiculous, that

## Alienated Nation

(continued from pg. 10)  
smiling embarrassed.

"Read it well." I did not give it to him, nor do I tell this now, for my own glorification; but rather simply because it was an important need which was going unfulfilled. There are so many more cases out there just waiting to be addressed. I'm not trying to be self-righteous. It's just for some reason this kid moved me enough to act. I just wish that I, and every one, had the fortitude and motivation to respectfully intervene in another's (even a stranger's) life to help them on a consistent basis. And to do so without self-serv-

ing motives. I must admit I was more interested in preserving the memory of these forgotten legends than anything else. They were rejected once by White society. They don't deserve the same from their own grandchildren.

"Thanks," the guy offered. As I turned to leave I heard him saying: "Yo, Joe, look. She bought me this book, man. This is what I was telling you about. The old Negro League teams.

"Oh man, let me see. She just gave it to you?"

"Yeah, check it out."

"Oh man, look at this..."

we don't have national health care and we don't have a tax structure of a country like Sweden, Norway, Denmark, how actually we seem to be going backwards. Looking back, Nixon doesn't look so bad, given Reagan and the Republicans today, dismantling the New Deal and dismantling the social structure that was put in place from the '30s to the '60s.

## How do you think that people on your side have changed?

I'm really disheartened by the left's whole response to AIDS. We've got 250,000 people dead here. The Viet Nam war was 50,000 dead and people, I get calls 'oh, I got your number on the radio, oh, it's AIDS. Well, I'm not really interested in that.' To me that's a little sickening, given that by the year 2000, 40 million people world wide are going to be infected. By the year 2025, Dr. Haselteen, at Harvard, said there will be a billion cases of AIDS, half those people will be dead. That's the world you'll have to worry about, because I'm checking out early.

## Not of your own accord.

Right.

## So how are you dealing with all this stuff emotionally?

For some reason I've always been optimistic, I get that from my parents I think. They're working class and union and you play with the cards that you get dealt. So I've never let it get me down. Plus the fact that everybody dies. The main worry I have here is suffering rather than death itself. I've got other interests, reading, music, that keep me going too.

Some of the people I respect are Cesar Chavez and Delores Huerta, of the Farmworkers. Before I was guided by Karl Marx or Che Guevera. Now Frederick Douglass' quote, 'If there is no struggle, there is no progress,' is my maxim.

## It kind of puts things in perspective. What was John Iversen Day?

That was the day of my retirement party at the Senior Citizen Center. It felt nice to be honored for plugging away for 10 years with Senior Citizens and for starting the Needle Exchange in Berkeley. I also produced and oversaw distribution of a pamphlet about AIDS that was mailed to every resident in the city in 1988. The City of Berkeley proclaimed it John Iversen Day. The mayor and about three or four city council members came noting the work I had done in the Berkeley community.

I may give the proclamation back. The newly conservative Berkeley City Council turned down funding for AIDS housing. Three of us with AIDS from ACT-UP have filed a fair-housing complaint with HUD against the mayor and city of Berkeley.

For more information write to: AIDS CURE Coalition, c/o John Iversen, POB 8074, Oakland, CA 94608.