

Memories of Hale Zukas By Susan Chernilo

I was a live-in attendant to Hale Zukas for about a year in the mid 1970's. Hale had Cerebral Palsy from birth. He had no use of any of his limbs and his speech was almost impossible to understand. He got around using a wheel chair with a helmet on his head that had a pointer attached. He used that pointer to move his chair as well as point to a letter board for people not familiar with his speech. That head-powered pointer was the only working appendage he had, and he made good use of it.

It should be said, before I go further about my experience with him, that Hale was a brilliant and competent person. He was one of the founders of the Center for Independent Living in Berkeley one of the first of it's kind in the country. He got a BA in mathematics from UC Berkeley. And he was a kind of civil engineer, designing curb ramps for people in chairs like himself throughout the city. And an early

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advocate for transportation for the disabled, eventually becoming a nationally recognized expert in the field.

I also did some regular shifts, cooking, feeding and interpreting his speech when he talked on the phone, which I became quite adept at. The main responsibility of the live-in, though, was to be there through the night in case Hale needed anything. I don't remember it happening a whole lot but it kept me on edge when I slept. There were other challenges as well, like being woken up by his morning attendants. It was a complicated relationship. We were boss and employee, able-bodied person and disabled, man and woman. But, basically we were roommates. And in spite of the difficulties and challenges I liked living with Hale. He was good-natured, laid back and down to earth.

I was responsible for the upkeep of the house, but both Hale and I were pretty lax about it. Hale had piles of things that he didn't want moved because he knew where everything was and he couldn't move them back himself. And Hale was very inspiring. His politics were impeccable which made me respect the heck out of him. But just as importantly, he put them into action. As an ex-hippie I was used to idealists, dreamers and armchair politicians, not to mention the idiots who thought that dropping acid would bring about the age of Aquarius. Hale was incredibly practical. To him political change was literally pointing with his head pointer at a curb that needed a ramp. And he was tireless and unrelenting and for me, being around his focused whirlwind of energy was amazing.

Hale helped change my life, essentially transition out of a toxic relationship. The guy worked for Hale first, so he was my link to Hale. For a while we both worked

for Hale. The guy was as mean to Hale as he was to me. Hale helped me validate his cruelty; we bonded over not liking him, and rejoiced together when he finally left town.

Hale was a Berkeley icon. A lot of people recognized him when he rode around the streets and most were in awe of him. Still, it seemed that he was quite lonely at that time. He did have friends. Like tall curly-haired blind Dick Santos who was his ramp building partner. They were quite a pair. Hale provided the sight and Dick the limb dexterity. Dick towered above Hale on his chair. Together it seemed they could do anything and they just about did. He had other friends and fellow activists (usually the same.) But I got to listen to a lot of his phone conversations, since I often acted as interpreter, I noticed that most were all about work. Very few people visited the apartment the year I was there. The only one I remember who wasn't a relative was Malvina Reynolds. Yes, the Malvina Reynolds. She was a friend of the family and came for dinner one night, which I, of course, prepared. They kindly invited me to sit and eat with them.

And there was also his mother. Helen would storm in once every 4 months or so to set the household straight, which for me meant telling me all the things I was doing wrong. Like not keeping the house neat enough or throwing out food. "You should never throw out food!" she'd holler. She was a force to be reckoned with, but, really I think she was a big reason why Hale survived and thrived as much as he did. She was devoted to keeping his life livable. He also had a sister and brother who both lived in the Bay Area and came around from time to time, mostly when their mother was there too.

About six years after I stopped working for Hale, he called and asked me to come with him to Washington DC. He was to testify before a Senate sub-committee about the transportation needs of disabled people, and he wanted me to come as his interpreter. I was flattered and eager for an adventure. So off we went and it was an amazing experience. I remember being in a room with the big-shot important people sitting above us at some high bench, and me and Hale below. I have a lot of performance anxiety so it was scary for me. But he was the one really on the spot. He did his usual mind-blowing thing of listening carefully, thinking and then putting a complicated answer into as few words as possible, still communicating the important gist. (That was his MO, because he had to preserve his speech. And it always amazed novelist me how he managed to do this so brilliantly.) And I repeated what he said to the important people. This remains for me to this day as my main claim to fame, although I really have no claim at all. It was all Hale and I was merely an instrument. Still, it was exciting.

Just a day before we were to leave Washington, there was a huge blizzard, dumping several feet of snow. Not only did the airports shut down, but the metro and the buses did as well. So, there I was stuck in a strange city with Hale, and we could not afford an extended hotel bill. This was before the ubiquitousness of the internet too, but we managed to find out that Amtrak was still running. So, Hale blazed through the snowy streets in his chair, while I slogged along (or actually behind,) and we made it to the station. Hale had an uncle in NJ who met him. And I continued on to NYC where my mother lived.

I only saw Hale a few times after I moved back East in the nineties. One time, Hale had a girlfriend, an attendant who'd morphed into a romantic relationship, and they

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were both grinning from ear-to-ear. The next time, they'd broken up and Hale was sad. The last time I saw him, in the 20teens, he'd aged considerably and seemed to be having a hard time.

When I picture him now, I'm imagining him running and jumping and hollering out with the joy of freedom. Maybe that's ableist. But I really think that with a mind, heart and soul as big as Hale's, being stuck in such a broken body was very difficult. And I imagine if I get to see him again, I'll give him a big hug and he'll be able to hug me right back. Rest in Truth and Dignity dear Hale, as you did in life.