

Inside and Out: Former Residents Reflect on Their Lives

Below are the stories of two individuals who were once residents of state institutions. Today, they live in their own homes and are actively working to improve the lives of all persons with disabilities through their involvement with Self Advocates Becoming Empowered, the national self-advocacy group.



■ Russ' Story

My name is Russell Daniels. I was 12 years old when I was sent to a state school. When I left there I was 28 years old. I'm 50 years old now. I went in April of '58. It was a rainy day. I went to the institution because I had problems with going to school and stuff like that. You know, when you don't like school

that's what happens. And that's one reason why I had to go to the institution, because I was a problem child. Everybody, you know, sometimes gets in trouble and they don't like to go to school, and stuff like that.

I wasn't allowed to see my family the first day. They give you a week without seeing them. After awhile they start letting you have visitors. In those days they let you go out for the day but when you came back you would be searched. You couldn't have money, watches, rings, or anything. They'd take everything away because that was the rules and regulations.

I'm really proud to be out and I never want to go back to any institution at all. It was terrible. They treat you like dirt. You don't get treated like a human being. They treat you mean, like, you know, you do something, they slap you. "Do this, and do that. Sit down and don't say a word." So, when I got about 17, something like that, I took off. Packed up my lunch and took off and went into the woods and went on the highway and started walking. Then I got picked up by the police. So they brought me back and put me in seclusion. They put you in a room by yourself for awhile and let you stay there, and later on they let you out. Then you couldn't go anywhere for that amount of time.

I wanted to leave because I didn't like it after that first time. I didn't like it at all. I was scared, and didn't know anybody, and all that. But after awhile I got used to it. I got friendly with everybody. Yeah, it was all right then. Yet, I wasn't given any choices. I wasn't abused, but other people

were. Other people got abused, got pushed around, banged around and stuff like that. I mean it was terrible, you know.

During the day they put you in a room with a bunch of other people and they'd stay there. After I got used to being there I went to school and I had a job. I used to help clean the place up and do dishes and set tables. They didn't pay you. That was a job, and that's what you had to do. For fun they would have movies and dances and stuff like that.

You'd have to get up at six in the morning, get dressed, make sure everybody else is up, make your bed, and then everybody went downstairs in the day hall. They are ready to go down for breakfast at seven o'clock. We all had to be in line. The second shift comes in, they go outdoors and play, you know, play baseball or something like that, lunch-time was about noon, and then they come in about five o'clock. Everybody comes in, washes their face and hands, line up and get a tray and get their food in line and sit down. At night they watched TV until nine, which was bedtime. Everything shut off, the lights off and that's it.

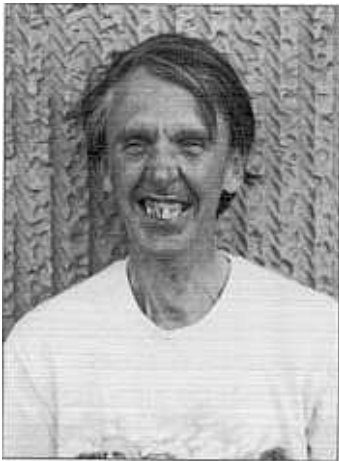
Now, I live like a king. I'm happy I do what I want, go where I want, I can come back when I want. Nobody tells me, "You can't go here, you can't go there." 'Cause that's annoying. I live by myself. I pay my own rent. I pay my bills. I work at the Senior Center. I have been working there for about three years. I'm a janitor. I clean up the place and lock up and help the elderly people out. You know, help them down stairs and stuff. I love it. And they all love me.

I am working on the Self Advocates Becoming Empowered subcommittee, Operation Close the Doors. We passed a petition around for people to sign to show their support. I brought that to some people and they said they wouldn't sign it because they didn't think it was a good idea all places should be closed. So I just looked at them and I said, "Why do you say that?" Because they're not getting the care, treatment like they used to get when they were in an institution. That's what they were saying. When they used to be there, they used to get a dentist, a doctor—everything right there on the campus. Today, doctors may refuse to take a patient with a disability. Like last time I went they took me, but there was another person that used to live in an institution, I know him well, they refused to take him. The next person came in. They took that person and had the other person wait. And I went up there and I said, "This person has been waiting for an hour. It's not right to take the next person when he just walked in the door and this other guy has been sitting there for an hour, and the other guy without a disability that came in, they took him right away. That really bugged me, so I got up there and I told the person. I said, "This is not right for you to do. Have this disability person wait that long and wait on the other person that didn't have

a disability." You know, they said, "Well, you got a point there." So what they did, they listened to me and they took that person and had the other person sit down and wait. Because I got up there and I told them how I felt about it. I told them I used to live in institutions myself and I know how they are when they do something like that.

I have friends that I visit in the institution. They tell me they want to leave because they saw me leaving. They said, "Well, gee, how come this guy is leaving?" So I said, "All you have to do is be patient. You'll be next." There was one person that didn't want to leave the place because he was afraid to go out into the community because he didn't figure he would get the care. I said, "Don't worry about that. You will get the care like everybody else." So, they didn't think he would make it, but he did. He got out, and he made it. I saw him the day I left to come here. He said, "Well, wherever you go, you make sure that you bring up that I made it."

Russ Daniels is a board member of the self-advocacy organization Open Door Club and is active in Operation Close the Doors. He lives in Belchertown, Massachusetts, and may be reached at 413 / 323-6036.



■ Mark's Story

My name is Mark Samis. I was 15 when I went into the institution and I lived there for 12 years. When I entered the state hospital and school back then I was scared 'cause I thought I would never see my family, 'cause there were people up there whose family just put them up there and forgot about their love.

I had no rights. I could not speak up for my rights. If I did, the supervisor or attendants would work me over, flatten me out or things like that. I had no privacy. I could not go to a room to cool down when felt sad about something or didn't want to be bugged, things like that. And I could not sit outside and visit friends of mine who lived on other wards. I could not sit on the merry-go-round, swing set, what have you, to visit with my friends. I had no girlfriend up there. I couldn't talk to my male friends. If I did, an attendant would chase me back. Again, I couldn't say nothing or I'd get slapped up or what have you. A few times they would slap me up for not saying something. They'd use a stick. Like, I could not have friends, they were telling me.

There was this one substitute attendant who would not let me sit at a table, paint-by-numbers, play card games, things like that. He'd force me to watch TV when I didn't want to watch TV 'cause I'm not a soap opera fan. That's all they'd watch. So, if I'm working on this paint-by-numbers

set, he would put his hand on it to smear it up and say, "Nice job." He didn't actually smear it up, though he would have felt like doing it. He just he kept getting on my nerves so I would say something. He was just waiting for me to say something, but I wouldn't play his game. So when he was on, I knew I would just go put away the paint-by-numbers as soon as he walked in the door, and go and watch TV. Sometimes when he was officially on duty he would come over and say, "You're lucky you made this decision. You're over here watching TV." Again, I wouldn't say nothing. He just couldn't get me to play his game, hoping I would say the wrong thing. Then in the evening during prime time when there is programs I wanted to watch, he would not let me watch them.

And they forced me to do things against my will. They intimidated me, put it that way. Now, I would say I was physically and mentally abused. Like speaking up for my rights, my God-given rights, they would slap me up and things like that. They called me every name underneath the sun you can think of. That's how I was mentally abused.

When January 8, 1974 came – the day I was to leave – I wanted to get away from that place. It was the worst experience I ever faced. I don't want nobody to go through that. I felt like I was in a warehouse or something.

Now, I travel telling my story to college students who are being teachers or working in special education and things like that. I just go around and give them a message: Treat people with disabilities as you want to be treated 'cause one day you students might become the parent of a child with disabilities and you would want that child to be treated as anybody else would be treated. I tell them, "Look at a person with disabilities as a person first, not their disabilities. You want respect, so do we people with disabilities want respect."

I also went back to the institution and told my story. The superintendent and I went riding around in these golf carts touring because I wanted to see that building I described where I had no rights. I explained to him what it was like, what this building was like. It's like when survivors of World War II go back to these death camps how they remember this was the gas chamber, this was the barracks and things like that, this is where we ate, things like that – I could remember that building just like it was still there.

Now, in the past few years my life has all turned around. Nothing but great things have happened to me since leaving the institution. Maybe it took awhile. Like they say, patience is always rewarded. So I'm very proud of what I do now. I'm hoping to see these institutions all over the United States close and I don't care what they do with them once they get them closed. As far as I'm concerned they can drop a bomb on them once they get the people out.

Mark Samis is Vice President of People First of South Dakota, Vice Chair of the South Dakota DD Planning Council, a board member of Self Advocates Becoming Empowered, and is active in Operation Close the Doors. He lives in Pierre, and may be reached at 605 / 224-6486.