

The Difference SRV Made in My Life

by Peter Park

Hi. As I was introduced my name is Peter Park. Yes I have been wounded in many different ways but I have been asked to tell you how SRV has affected my life. For many people I have been labelled as having an Intellectual Disability or whatever it's called today.....I am an Epileptic, which I don't see as a great big issue however some people do. Well, when I took my first course in SRV...it was Normalization now Social Role Valorization or commonly called SRV. Then it was called and PASS today it is known as PASSING.

This was back in 1981. I have always felt that I wanted to be challenged to do things in a different way both for me and inadvertently this flows into my everyday life. 24 years later I am still learning and I would like to continue working at taking more SRV courses and hopefully I will be a better person as a result.

Different people who knew that I am interested in SRV and Passing have told me of courses and encouraged me to be present.

I think I have learned a lot about Social Role Valorization and it has assisted me to put what has happened in my life in a place where I am able to deal with it.

I have been encouraged to participate by different people at different times in my life, and I would like to thank the people that suggested that I become involved.

Back when I took my first normalization/SRV course I was in the sheltered workshop The Executive Director of the workshop called me in front of everyone, as it was payday. I used to get a whole \$20.00 for two weeks and this was considered to be top wages for the consumer. She said "Peter whose time did you use, did you get my permission, you had no right to take that course as it is for my staff only and who paid for it, whose time did you use?"

Well, I lost my cool I told her I wanted to know what your so-called staff were going to do to me. Not that it's any of your business but I paid for the course & the information flyer said: it's for parents, consumers, citizen advocates, advocates interested people, family members, staff & others. I think I have more than a vested interest.

Again it's none of your business but those are my holidays I took them in March; I will be here working in July when you decide for everyone that they can have holidays. I stated that as of this moment I am walking out of this workshop and you can go ahead and cut off my social assistance but I AM QUITTING THE WORKSHOP TODAY

I will be back long enough to put my written resignation on your desk at 9:00 tomorrow morning.

I was going to leave anyhow this just gave me the courage to say I have had enough sooner...only my older sister and brother knew that I was going to quit the workshop eventually.

After 18 years of institutionalization I still didn't control my own life. Maybe he was afraid I would uncover the truth about the system. Of course I didn't need to take a course to learn that the so-called helping system hurts.

I also moved out of the Apartment setting to what I call "Pete's Pad" sooner.

About 10 years before the philosophy of Normalization was developed, in 1960, I moved to Oxford Regional Centre. I was 20 years old. I had lived at home with my family until then, going to regular High School, having regular friends of my choosing, getting into regular trouble, learning how to drive and all those typical things. My parents and some friends were advised by the doctors that my epilepsy could be brought under control in the institution, so there I went. I was naive to have believed them when I look back.

The doctors said they could CURE my epilepsy.

What hit me first, and what I remember most, was the regimentation. It was a lot worse

than what I imagined the army would be like. There were about five thousand people existing there. This was in 1960. Little did I know I was about to spend the next 18 years of my life here. I can't say living, we existed. At the time we were called inmates. We spent all our time on wards or in "cottages". The only activity was listening to the radio later watching television that the institution staff controlled. They chose the station and the volume that they thought was good. They thought that we should listen to childish programs. Because we were in that institution didn't mean we didn't like to watch the great Canadian sport of hockey. Games were several hours long. Often times they started at 8:30 P.M. and we had to be in bed at 9:00 P.M. So much for watching the hockey but the institution staff did.

I slept in a room with 18 other people, all of whom were total strangers to me. I wasn't related to these other males. We did everything there. We ate in a large dining hall-regimented again, slept or wandered aimlessly around the ward or cottage. Someone who I didn't know or see had developed, this mysterious schedule that everyone with the exception of the staff were supposed to follow without question. Our input was never asked for we weren't supposed to think, have feelings, or express opinions.

I had eighteen inches of space between the bed on the other side and eighteen inches between my bed and the wall on the other side. That was my space. You wouldn't decorate your patch of wall because you never knew from one day to the next if you were going to be moved. I had two sets of institutional clothes - I never saw the clothes that I wore into the institution. You had to use their Doctors, their Dentist, I didn't even have the right to pick my own barber - the cuts sure showed it too.

I found the empty time unbearable. In those early years there was absolutely nothing to do. You couldn't go outside unless you were escorted by the staff. You weren't encouraged to read. The staff would physically take any books away saying that it was for your good. My Father would bring me books on subjects that I wished-usually mystery novels. Remember the staff would take them away for my good-they tried and they found that they were billed for the books for they came from our Public Library and the card being used was mine. You never had a chance to read the newspaper and find out what was going on in the world out there. You were already isolated enough but that kind of thing makes you feel even more cut-off.

I went to ceramics for the first three years just so I would have something to do. After that I luckily managed to get a job in the "Stores Department". Here we handled all the supplies for the institution.

I knew someone who was quitting and I asked him to tell the boss that I would be interested. No pay of course, but at least I was busy from 9 to 5 each day with the exception of the week-end.

I spent a lot of time on the punishment ward, especially at first because I hadn't learnt their rules yet. Most of the time I was in a locked cell, no clothes, 4 bare walls bare ceiling bare floor and no furniture or even a bed. Just a few times was I just on the ward, here you had clothes but the door was constantly locked. At a guesstimate which upon my recollection was I was in the lock-up ward as it was called for nine of eighteen years there. You were always heavily drugged on "D" ward. One major misdemeanour was looking at members of the opposite sex. I was often sent there for that and other misdeeds like getting angry or refusing to take medication. I wouldn't take some medication that they tried to give me because I didn't know the reason for it and I was afraid of the side effects. We knew we were being used as "Human Guinea Pigs".

By 1972 or 73 we were called residents. They started talking to me about getting out. It was just talk though. They did set up a life skills program and eventually I was moved to a room that I shared with another resident. We could hang pictures on the walls and arrange the furniture to our liking.

Why we could move around our institution chairs, our beds, and the institution dressers. I question why the dressers when we still had only three sets of institutional clothes and all the institution rules. We actually got one more set of institutional clothes than the other people had.

Around 1977, they also started paying me \$3.50\ week for my work in the Stores Department. I didn't see it as a big deal as there was no place to spend this huge amount of money. Looking back I know that was the readiness training model. I didn't really care, because the only thing that kept me going was the thought of getting out. I always kept that ray of hope in my mind.

The "moving out" that I had longed for just happened one day in 1978. At noon someone told me to go back to the cottage after lunch and at 1:30 that day I would be leaving. I wasn't asked nor were my parents informed. In fact, 3 years later I phoned and asked for some financial help was when my parents found out that I was out of the "House-on-the-Hill". I had lost all contact with them. I had often wondered why they hadn't called. When we finally talked Mom said she was sorry I was out because she thought I was better cared for in the institution, and that she did not have to worry about me there. I said I'm the one having to live with this and I'm glad I'm out. That conversation was very hard. My brother and sister had known about the move but they had kept this from my mother. This was hard, but the hardest thing was that my Dad died while I was in the institution and no one had told me that he was sick. I guess the staff at the institution knew. This

and no one had told me that he was sick. I guess the staff at the institution knew. This was one of very few times that I left just to go home and be with those that were grieving.

When I moved out I was moved to a Group Home in a small town called Ingersoll, in the province of Ontario, Canada. There were 10 people in that house (Group Home) and during the day I was bussed back to the institution for work each day. I didn't like living there but it was some better than the institution. I realized that to have the life I had dreamed about I would have to advocate for myself. I got moved to a smaller/different group home in another city. There were six people living there.

I had wanted and dreamed of having my own apartment and made sure that people were aware of this fact. Within a short while (about three-and-a-half months) I was in an apartment with two other fellows (not of my choosing) in the Supported Living Program. I had gone right through the continuum. That process took 22 years of my life.

The most ironic thing about that experience was, that the problem of uncontrolled seizures, the reason for the move to the institution in the first place, was only resolved after I left and found a good doctor who specialized in epilepsy. I was actually allergic to Dilantin and phenobarb, which they gave me in the institution. So much for that helping system.

Today, my wife, and I live in an apartment of our choosing in a cooperative apartment of our choosing.

I use things daily that I have learnt in other Social Role Valorization, P.A.S.S. or more recently PASSING courses.

Reflecting back I have used a lot of things in my own life for example; seeing that it is wrong having to ask for a lawyers permission to get married. People with disabilities according to our wonderful misled society rightfully or wrongly assume that people with labels enjoy 5 pin bowling in a separate league. We do not choose to take part in something that sets us aside or segregates. Well, we don't like 5 pin bowling anyhow. We enjoy 10 pin bowling that everyone takes part in. We like bowling in the same places as the rest of society. We do valued things like going on holidays to places like Cuba where and when we have chosen to go. Believe it or not we enjoy horseback riding when we can.

For those of you who know me I am a DREAMER. I dared to have this Dream that one day I will get out of the Institution ... obviously that dream came true and I dared to dream again-little did the Group Home Staff realize then I dared to dream in the Group home and this time was that I would have a place of my own where I made the rules and I answered to me. Yes...eventually I got what I called Pete's Pad. I dared to dream again and this time I didn't think it would occur for I had identified that I wanted to share my life with another person and enough of these bachelor ways. I wanted to get married and the right person came along and swept me off my feet. We are still married with all our faults but we both work at it. We are happy and we like it when we can celebrate with others and them with us.

To-day we live in an intentional co-operative. Our family is made up of 2 people and 1 cat. She is spoiled rotten and rules the roost

Although most people when they marry they only have to ask the other person... but because I have a disability I had to ask a couple of lawyers and a clergyperson if it was okay this was in 1983 scary huh and in North America where we consider ourselves quite at the forefront in disability issues...SRV has helped me see that this is a violation of my fundamental human rights

I used to think I was at fault for a lot of things. SRV has helped me to see I was not the problem but our wonderful North American Service System is the real culprit. Again; The Helping System Hurts.

This wonderful system tries to dictate what labelled people do. In fact at one time in my life in order to get Social assistance I had to sign a document that said I was permanently unemployable. I worked for 17 years as the coordinator of the organization known as People First of Canada, which is recognized in other parts of the world as well as in North America.

At PFC we are working towards similar goals as SRV: E.G. at People First we are working towards people who have been labelled living in a place of their own. You use the term De-Institutionalization

People First is an autonomous self-advocacy organization that encourages people to speak for themselves rather than a staff person do the talking for you. Also, a lot of people who have an Intellectual disability are not aware of the basic human rights.

Although you out there take for granted things such as a home owner it is also a valued thing and people with labels see it as more important to live where you have control of your life. This is valued.

I have many valuable roles. I am husband, married, taxpayer, bread winner, renter, coordinator of People First of Canada, friend, neighbour, coon member, board member

coordinator of People First of Canada, friend, neighbour, co-op member, board member, Vice president of the board of our co-op, brother, brother-in-law, past-president of People First of Ontario, a founding member, the ♦Godfather♦ of the People First movement, a people first member, a teacher, an uncle, a great-uncle, an employee, an advocate, a self-advocate, an International speaker, a consultant, a researcher, a facilitator and a team player.

I use the words getting people out of institutions to live in homes of their own with whatever supports might be required to make this happen and that there be ongoing supports in the community and here at SRV you may use the word de-institutionalization

On a very personal comment I feel that if SRV is put into words that the janitor off of the street and other everyday citizens can understand many more people may participate.

SRV has helped me see that it's not my fault having been institutionalized but that that is part of my history and it's important to remember our history but we can effect positive changes in our future and that of other people. SRV has helped me realize that regardless of what I do I am still Peter and I need to feel good about me.

Often I am a teacher helping people realize throughout all these experiences, good and bad, I have been Peter Park, a man who just wants to do a decent days work and go home at night to the place where I have chosen to live and to the person I have chosen to live with.

My story is still evolving, but now I choose the direction. I live in a different kind of institution-- marriage. My wife, Rhea and I are building a life together.

Submitted by Peter Park. Peter is Past-President, People First Canada, co-founder of People First of Ontario



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