

April 25, 1988

PAT WORTH -

I was labeled retarded by my parents.. I didn't understand why - they thought I was different. I was raised in Antigonish Nova Scotia. I didn't fit in the family. It was like being in a room with a dozen people and still being isolated.

I was forced to go to a segregated school. I was robbed of an education. In that school I learned how to do crossword puzzles, telling difference between circles and squares, colors. Because of my label, everyone assumed I couldn't do it and never gave me a chance.

The teacher was the biggest puzzle. I wondered what I was doing there. At age of 16 I couldn't write my own name. I could print it - but writing was too difficult. The label labels the person. If you are labeled mentally retarded, your intelligence is in jeopardy. You can't play with the other kids because they were told you were at the "retarded school". They learned it from their parents.

I used to sit on the step waiting to be invited to play with the kids in the park. But it never happened. My parents never gave me a chance.

Lesson - don't label.

We are PEOPLE FIRST. If you don't value the person - they will land up in a institution.

I ended up in a thirty-five bed group home because I couldn't get into any school in Ontario. The label travelled with me. Everyone said - "he has special needs".

I haven't associated with my parents in 16 years. That is a tragedy - we all need friends - a support circle. You need to be able to count on people even if you make mistakes. I had no alternatives.

My group home was an institution - not a home. There were curfews, and rules and punishments. If you were late for dinner you didn't get any. If you talked back to the staff, you could get you face slapped or insults - " you can't make it on your own."

I wanted to be independent. I had benefits - but it all went to group homes. I had to go to a "sheltered workshop" because no one else would hire Me. I was deprived of my rights and privileges. I didn't want to list retarded on my application.

In the workshop, I worked a full shift - for \$10 per week ~ jobs like packing, twist tying. They promised me a job after 4 months - but I was there 7 years.

It is demoralizing - it robs your spirit and dignity. You can't earn \$10 per week and feel good. I wanted a real job with real income.

No matter what disability - there is always ability. You can concentrate on the ability - or disability. Get to know the real person - and then they will become your friend

People First - self advocacy across Canada

I needed a place to help people to listen to me. Today we teach people about our rights - about mislabeling. I used to believe the label. No more. If you don't give people a chance to speak about their rights they are condemned to institutions across Canada. There they use cattle prods - there is money for that.

WE need people to shake our hand and hug us - not to use cattle prods. I now work and live on my own.

In order to get family benefits you must sign a form that says you are permanently unemployable. That is condemning a person . That means you will be poor for life.

Cry Freedom - Biko called Woods a white liberal - and challenged Woods to see what is really like. Workshops and institutions are like apartheid. I was isolated in rooms and tables in homes and workshops. Occasionally they hit me.

WE have been demoralized and abused. Our dignity removed. Our rights have been taken away. That is why our organization is called "People First".

An institution comes from the thinking of people - it is "Our" behavior.

I finally left - a took a risk. My life was going down hill. If I hadn't left, I likely wouldn't be alive. There were times I wished I were dead.

When I got the job at Arch I was proud. I got a real pay cheque of the first time in my life. I felt like I was contributing.

I think a lot about the silent cries of people who are still locked away.

I was a witness at an inquest of a man who lived in a Toronto Boarding house. It was a 55 bed residence without privacy. He ran from it constantly to get privacy. He was punished for this constantly. - No dinner, lectures, etc. HE had a speech problem. He weighed 98 lbs. at death. No one took him to see a doctor. No one noticed he was losing weight. He couldn't speak, so he couldn't demand attention. He got drugs instead - to control him. He got nothing for his health. Imagine living with 55 people can you couldn't ever be alone. There were 4 people in his bedroom. He had to stand in line for meals - and everything.

Our lives are made up of standing in lines. Packaging diapers, doing things that others have told us to do. This man had dreams.

What was worse than his death, was the way he lived. No one helped him to make his dreams come true.

You MUST LISTEN. Even if you don't understand, try - people will now you are listening.

When I go to institutions I listen - because I was there. Don't walk by just because you don't understand.

WE have been walked on and all we want - "WE want a chance to be equal". We want to live with our families , earn a living - just like Biko wanted.

The government here doesn't shoot us, but the demoralize us . It is the same thing. They take away our pride and dignity. I get up in the morning and do the best I can. I can do it. No one labels me at work. I have a network of friends.

They have made me a more powerful person - not to hurt people - but to stick up for your rights and help others to do that.

Still, there are people who label me retarded. I can live and work on my own - and still people label me. I Can write. I stayed up late at night learning from the Bible with my uncle who believed in me. That was the beginning of my learning.

I defied the system. I ran away. Some people haven't been so lucky. Some have died. No one wants to be labeled retarded. It is a death sentence. The label means poverty for life.

This year had been a rough year for me. I learned that I was diabetic a few months ago. There is tons of support for my diabetes. But I went through my whole life and couldn't get help as a person.

There is nothing special about wanting to be a person, wanting friends and a place. There are many people who are deciding how to shock people and incarcerate them.

My friend, Peter Park spent 18 years locked up - 9 years in solitary confinement - because he was "retarded". He was told he wouldn't make it. Today he is President of People First Canada - married and working. Don't try to control and punish us. Listen to us and there will come a time you will understand. Don't try to demoralize us - we are people first.

I am just as human as you are. It is simple - reach out - touch my hand. We don't want punishment and workshops shops and institutions. We want to be free. We are crying for freedom.

WE want to be a part of the community you are a part of. WE just want your support.

Marsha - Doctors must sign the documents that put people in institutions are doctors. Judith can't get a parking sticker without a doctors signature.

Question: Discuss: What is the assumption underlying what happened to Pat.

After coffee, we will discuss the Eve case and the Kingston case.

POST COFFEE

QUESTION: WHAT MAKES YOUR LIFE WORTHWHILE? - Make a list

family
friends
meaningful work
travel
freedom
independence
affection
challenges
good life
beauty
sunrise every day
loving and being loved
learning
pride and self esteem
goals and hobbies'

music
walks and hiking
laughter
being a person
being involved - connected

Note: The faulty assumption is that Pat's needs and aspirations are different than ours. They aren't. Relationships are important to ALL of us. Institutions socially handicap people - take people away from friends.

The ASSUMPTION IS THAT HE IS LESS OF A PERSON THAN YOU!

Unexamined assumptions kill people.

It is right to say that institutions are bad - sitting around waiting for food, etc. it is hard to think of the positive things. But it could be done better in the community. There may be good people in the system, but they usually leave because they can't change it. If you get good things in an institution, you can get it better in the community.

I met Justine Clarke - who used to live in a institution.

The nature of an institution is "walls" which limits social interaction. You don't meet people. Scotland has largest number of people in retarded hospitals today in Europe. 150 years ago they were leaders in reform. Now, they are decades behind.

There is movement away from institutions - into community - but often includes the 'Institutional mentality.'

But people are still thinking "this person is less valuable. It becomes a "we-they" rather than "us".

Marshq - Pat was sentenced to mental retardation. We believe that ALL" people want family, friends, etc.

* What about people with different learning capabilities? Should they all learn together - getting the same?

Pat - nothing is tailored to individual needs in special schools. It is a myth. Unfortunately. it is all focused on our disability - not our ability. We don't focus on dreams. No one believes them. We aren't even given a chance. We aren't given support. You can be alone in a class of people. Their needs weren't being met either. Teacher forgot about individual needs. In workshops they 'put you' on jobs. They don't ask. They don't want to take the time to train you for real jobs.

You don't have the vision of what could be because you haven't seen it. I did not say everyone should get the same thing...but rather that they should respect differences.

There are approximately 30,000 people in institutions for the mental retarded in Ontario today. (Not counting private institutions). Does not count prisons, etc. Many of these places are prisons and are run under the guise of therapy.

KINGSTON CASE

2 years ago _ at Queens Medical school - training students used Ongwanada institution for practice. Institutions agreed. Students practiced rectal examinations on people who were labelled mental retarded. 2 of the medical students objected. Prof. was charged and it was stopped. Most of the ~~times~~ speaks up. Practising on "retarded" so you can get ready for real people. It was sanctioned by authorities.

People ask about shock therapy and behavior modification?
There are alternatives - but they are people intensive.

I ran away from the group home because they were going to use a cattle prod on me. McGee shows that your hand can be used as a reward instead of a weapon.

I used to hit myself when I lived in the group home - because I was bored - and there was so much screaming - I had to get out of it. Herb Lovett writes about "Gentle teaching".

People who survive shock therapy have severe emotional scars that they can't shake for life.

Eve Case in P.E.I. a woman got caught holding hands in a workshop. Parents decided to have EVE sterilized - because she couldn't handle being a parent. Eve didn't want to be sterilized. the case went to the Supreme Court. Barb Goode (People First B.C.) had been sterilized and fought so you couldn't be sterilized without consent.

Doctors don't tell people - and don't know the consequences.

Eve didn't want this interference with her body - her dignity - her rights. Eve should at least have the right to have kids.

The case went on 4 years. The first time it went to Supreme Court there was no decision. Then it became public. People First and advocates made it public. CACL lawyer, Orville Endicot, fought it. 1986 - second hearing. Unanimous decision not to sterilize without consent. No one has the right to risk our lives. Many people who have been labeled were told ~~and~~ they that they were going to have their appendix out. This was a great victory.

Judges have said it, but many sterilizations are still unreported. It took people like Barb Good to make it an issue. I remember thinking about being threatened with a cattle prod.

Sterilization is not an alternative. It is a choice.

There are people who have been labelled who have families. It is a matter of support - not punishment. The Major problem is "attitude".

People have differences. Explore and support them. I have a friend who is an artist. He can't get a job because he is labelled - even though he is a great artist. My friend is labelled, married and they have just had twins. They are great parents. They are proving the system wrong. Yet, they still have visits from Children's Aid checking. Loving fathers and mothers need support sometimes. We don't need threats, or demoralizing. We do need support.