



Center on Human Policy

An Insider's View¹

When I was born the doctors didn't give me six months to live. My mother told them that she could keep me alive, but they didn't believe it. It took a hell of a lot of work, but she showed with love and determination that she could be the mother to a handicapped child. I don't know for a fact what I had, but they thought it was severe retardation and cerebral palsy². They thought I would never walk. I still have seizures. Maybe that has something to do with it too.

My first memory is about my grandmother. She was a fine lady. I went to visit her right before she died. I knew she was sick, but I didn't realize that I would never see her again. I was special in my grandmother's eyes. My mother told me that she had a wish--it was that I would walk. I did walk, but it wasn't until the age of four. She prayed that she would see that day. My mother told me the story again and again of how, before she died, I was at her place. She was on the opposite side of the room and called, "Walk to grandma, walk to grandma," and I did. I don't know if I did as good as I could, but I did it. Looking back now it makes me feel good. It was frustrating for my parents that I could not walk. It was a great deal in everybody's life.

The doctors told my mother that I would be a burden to her. When I was growing up she never let me out of her sight. She was always there with attention. If I yelled she ran right to me. So many children who are handicapped must be in that position--they become so dependent on their mother. Looking back I don't think she ever stopped protecting me even when I was capable of being self-sufficient. I remember how hard it was to break away from that. She never really believed that after I had lived the first six months that I could be like everybody else.

I remember elementary school; my mind used to drift a lot. When I was at school, concentrating was almost impossible. I was so much into my own thoughts--my daydreams--I wasn't really in class. I would think of the cowboy movies--the rest of the kids would be in class and I would be on the battlefield someplace. The nuns would yell at me to snap out of it, but they were nice. That was my major problem all through school that I daydreamed. I think all people do that. It wasn't related to retardation. I think a lot of kids do that and are diagnosed as retarded, but it has nothing to do with retardation at all. It really has to do with how people deal with the people around them and their situation. I don't think I was bored. I think all the kids were competing to be the honor students, but I was never interested in that. I was in my own world--I was happy. I wouldn't recommend it to someone, but daydreaming can be a good thing.

I kind of stood in the background--I kind of knew that I was different--I knew that I had a problem, but when you're young you don't think of it as a problem. A lot of people are like I was. The problem is getting labeled as being something. After that you're not really as a person. It's like a sty in your eye--it's noticeable. Like that teacher and the way she looked at me. In the fifth grade--in the fifth grade my classmates thought I was different, and my teacher knew I was different. One day she looked at me and she was on the phone to the office. Her conversation was like this, "When are you going to transfer him?" This was the phone in the room. I was there. She looked at me and knew I was knowledgeable about what she was saying. Her negative picture of me stood out like a sore thumb.

My mother protected me. It wasn't wrong that she protected me, but there comes a time when someone has to come in and break them away. Sometimes I think the pain of being handicapped is that people give you so much love that it becomes a weight on you and a weight on them. There is no way that you can break from it without hurting them--without bad feelings--guilt. It is like a trap because of the fact that you are restricted to your inner thoughts. After a while you resign yourself to it.

In January of 1963, without any warning, my father died. A couple months later, Ma died too. It was hard on us--my sister and me. We stayed with friends of the family for a while, but then they moved. They told us we had to go. So they sent us to an orphanage for a few months, but eventually we wound up at the State School³. I was 15 then.

Right before they sent me and my sister to the State School, they had six psychologists examine us to determine how intelligent we were. I think that was a waste of time. They asked me things like, "What comes to mind when I say 'Dawn'?"--so you say, "Light." Things like that. What was tough was putting the puzzles together and the mechanical stuff. They start out very simple and then they build it up and it gets harder and harder.

If you're going to do something with a person's life you don't have to pay all that money to be testing them. I had no place else to go. I mean here I am pretty intelligent and here are six psychologists testing me and sending me to the State School. How would you feel if you were examined by all those people and then wound up where I did? A psychologist is suppose to help you. The way they talked to me they must have thought I was fairly intelligent. One of them said, "You look like a smart young man," and then I turned up there. I don't think the tests made any difference. They had their minds made up anyway.

Another guy I talked to was a psychiatrist. That was rough. For one thing I was mentally off guard. You're not really prepared for any of it. You don't figure what they're saying and how

you're answering it and what it all means--not until the end. When the end came, I was a ward of the State.

I remember the psychiatrist well. He was short and middle-aged and had a foreign accent. The first few minutes he asked me how I felt and I replied, "Pretty good." Then fell right into his trap. He asked if I thought people hated me and I said "Yes." "Do you think people talk about you behind your back?" And I said "Yes." I started getting hypernervous. By then he had the hook in the fish, and there was no two ways about it. He realized I was nervous and ended the interview. He was friendly and fed me the bait. The thing was that it ended so fast. After I got out I realized that I had screwed up. I cried. I was upset. He came on like he wanted honest answers but being honest in that situation doesn't get you any place but the State School.

When the psychiatrist interviewed me he had my records in front of him--so he already knew I was mentally retarded. It's the same with everyone. If you are considered mentally retarded there is no way you can win. There is no way they give you a favorable report. They put horses out of misery quicker than they do people. It's a real blow to you being sent to the State School.

I remember the day they took me and my sister. We knew where we were going, but we didn't know anything specific about it. It was scary.

To me there was never a State School. The words State School sound like a place with vocational training or you get some sort of education. That's just not the way Empire State School is. They have taken millions of dollars of spent them and never rehabilitated who they were supposed to. If you looked at individuals and see what they said they were supposed to do for that person and then what they actually did, you would find that many of them were actually hurt--not helped. I don't like the word vegetable, but in my own case I could see that if I had been placed on the low grade ward⁴ I might have slipped to that. I began feeling myself slip. They could have made me a vegetable. If I would have let that place get me and depress me I would still have been there today. Actually, it was one man that saved me. They had me scheduled to go to P-8--a back ward⁵--when just one man looked at me. I was a wreck. I had a beard and baggy State clothes⁶ on. I had just arrived at the place. I was trying to understand what was happening. I was confused. What I looked like was P-8 material⁷. There was this supervisor, a woman. She came on to the ward and looked right at me and said "I have him scheduled for P-8." An older attendant was there. He looked over at me and said, "He's too bright for that ward. I think we'll keep him." To look at me when I didn't look good. She made a remark under her breath that I looked pretty retarded to her. She saw me looking at her--I

looked her square in the eye. She had on a white dress and a cap with three stripes--I can still see them now. She saw me and said, "Just don't stand there, get to work."

I remember the day that Bobby Kennedy⁸ came. That was something. All day long we knew he was coming and he walked around. I got a look at him. He told everybody what a snake pit the place was so it was better for a few days. At least he got some people interested for a while. I really admired that man. You take a lot of crusaders though, like local politicians, they go over to the State School and do a lot of yelling. They only do it when someone forces them to, like when someone forces them to, like when someone being beaten or is overdosed bad.

It's funny. You hear so many people talking about IQ⁹. The first time I ever heard the expression was when I was at Empire State School. I didn't know what it was or anything, but some people were talking and they brought the subject up. It was on the ward, and I went and asked one of the staff what mine was. They told me 49. Forty-nine isn't fifty, but I was pretty happy about it. I mean I figured that I wasn't a low grade. I really didn't know what it meant, but it sounded pretty high. Hell, I was born in 1948 and forty-nine didn't seem too bad. Forty-nine didn't sound hopeless. I didn't know anything about the highs or the lows, but I knew I was better than most of them.

Last week was the first time I went into a state school since I was discharged as a ward of the state--which makes it about three years. I just went up to visit. I purposely avoided going there. I have been nervous about it. There are good memories and bad memories. The whole idea of having been in a state school makes you nervous about why you were ever put there in the first place. I'm out now, but I was on that side of the fence once. Deep down you want to avoid the identification. If I could convince myself that in the end they are going to be cleaned up I might feel better about it. You have got to face the enemy and that's what it is like.

I have come from being a resident of a state school to being on the other side saying they're no good. It has been brought up to me--"Where the hell would you be if it wasn't for the State School." That holds water, but now the dam is drying up as I am on this side. Sure I had a need, but they kind of pitched you a low pitch. There wasn't anything better. I needed a place to go, but unfortunately there was no choice of where to go. When it's all said and done there were those at the school that helped me so I'm grateful, but still some other place would have been better.

I don't have it that bad right now. I have my own room and I get my meals at the house. The landlord is going to up the rent though--\$45 a week for room and board. I'll be able to pay it,

but I don't know what Frank and Lou across the hall will do. They wash dishes at the steak house and don't take home that much.

It's really funny. Sunday I got up and went for a walk. All of a sudden Joan's name came to my mind. She's sort of my girlfriend. I don't know why, but I just thought of her moving in next door to the place where I live. That would be something.

Is there still any magnetism between that woman and me? I haven't seen her in three months, but there is still something, I can tell. We had a good thing going. I opened her up a lot mentally. I saw a very different person there than others see. I saw a woman that could do something with her life. If she could wake up one morning and say to herself, "I am going to do something with my life," she could. I don't think that retardation is holding her back so much as emotional problems. If she had confidence that would make the difference. I know she could build herself up.

The family had respect for me, at least to a point, but they don't think she should marry. We got pretty close psychologically and physically--not that I did anything. They don't have programs at the Association for Retarded Children¹⁰ that say to adults you are an adult and you can make it. She has been at the ARC for a long time now. She was a bus-aide, so in one way they showed her that she could work but on the other hand they didn't build her confidence enough to feel that she could go out to work.

In my opinion she doesn't belong at the ARC. But one thing is her parents don't want to take chances. Like a lot of parents, they send their 30-year-old kids with Snoopy lunch pails. They are afraid financially and I can't blame them. If she went out on her own they are afraid that her social security would stop and then if she could continue they wouldn't have anything. She could lose her benefits.

I never thought of myself as a retarded individual but who would want to. You're not knowledgeable about what they are saying behind your back. You get the feeling that they love you but that they are looking down at you. You always have that sense of a barrier between you and the ones that love you. By their own admission of protecting you you have an umbrella over you that tells you that you and they have an understanding that there is something wrong--that there is a barrier.

As I got older I slowly began to find myself becoming mentally awake. I found myself concentrating. Like on the television. A lot of people wonder why I have good grammar. It was because of the television. I was like a tape recorder--what I heard I memorized. Even when I was 10 or 12 I would listen to Huntley and Brinkley¹¹. They were my favorites. As the years went by I understood what they were talking about. People were amazed at what I knew. People

would begin to ask me what I thought about this and that. Like my aunt would always ask me about the news--what my opinions were. I began to know that I was a little brighter than they thought I was. It became a hobby. I didn't know what it meant--that I had a grasp on a lot of important things--the race riots, Martin Luther King in jail--what was really happening was that I was beginning to find something else instead of just being bored. It was entertaining. I didn't know that that meant anything then. I mean I didn't know that I would be sitting here telling you all of this. When you're growing up you don't think of yourself as a person but as a boy. As you get older it works itself out--who you are deep down--who you ought to be. You have an image of yourself deep down. You try to sort it all out. You know what you are deep inside but those around you give you a negative picture of yourself. It's that umbrella over you.

What is retardation? It's hard to say. I guess it's having problems thinking. Some people think that you can tell if a person is retarded by looking at them. If you think that way you don't give people the benefit of the doubt. You judge a person by how they look or how they talk of what the tests show, but you can never really tell what is inside the person.

I don't know. Maybe I used to be retarded. That's what they said anyway. I wish they could see me now. I wonder what they'd say if they could see me holding down a regular job and doing all kinds of things. I bet they wouldn't believe it.

¹This is an excerpt from Bogdan, R., & Taylor, S. (1976, January). The judged, not the judges: An insider's view of mental retardation. American Psychologist, 31(1), 47-52.

²Cerebral Palsy - a set of motor differences (or impairments--medical term) resulting from some trauma to the brain early in development. There are various manifestations of cerebral palsy depending on the different types of physical movement.

³State School - An institution for those with labels of "mental retardation" or other disabilities. Residents were often sent to the state school without giving their input or having any prior knowledge of it. Institutions were originally intended to be places of rehabilitation, training, and education, but they quickly became overcrowded and abusive prisons for those not valued in society for too many years.

⁴Low-grade ward - "Low grade" refers to the medical or institutional slang of the time for a resident who was deemed incompetent/incapable and beyond help. The low-grade ward, then, is a building or part of a building in the back of the institution far away from the other residents where those deemed the worse off and subhuman were left in awful conditions. They were neglected and abused in too many ways. Geraldo Rivera's 1971 expose at Willowbrook (NY) shows a low-grade ward in all its degradation.

⁵Back ward - similar to a low-grade ward.

⁶Baggy State clothes - Residents were often stripped of all possessions, including their clothes, to prevent theft. They wore clothes provided by the institution that had been donated or once belonged to another resident that were baggy, did not match, and often displayed logos that were childish or ironic considering what they were.

⁷P-8 material - institutional or medical label for a resident of the back ward.

⁸Bobby Kennedy - One of Robert F. Kennedy's (Bobby) many causes was exposing the inhumane conditions at institutions for those with labels of mental retardation. In 1965, as a U.S.

Senator, he visited Willowbrook, a state school for people with mental retardation in Staten Island, NY, unannounced. He publicly criticized the abusive conditions at Willowbrook and challenged them to change. Geraldo Rivera returned to Willowbrook in 1971 unannounced and with a video camera to capture the inhumanity. Kennedy's older sister Rosemary was born with an intellectual disability and then lobotomized per her family's wishes. She was sent to live in a state institution.

⁹IQ - Intelligence Quotient, as measured by the Stanford-Binet Intelligence Scale. Those with an IQ two standard deviations from the norm, that is under 70, are given labels of mental retardation. Many have long argued that intelligence is too complex a process or idea to limit by a single number, especially one with such consequences. Alfred Binet originally intended his test to simply highlight academic areas of need; he did not intend it to be used to divide people into the normal and the retarded.

¹⁰The Association for Retarded Children - Now named The Arc, this grassroots organization of 140,000 members in over 1,000 state and local chapters in the United States works to ensure that those with labels of mental retardation and related developmental disabilities receive the supports and services as well as the opportunities to live the lives they wish to lead. National headquarters are in Washington, DC; Silver Spring, MD; and Bedford, TX. Arc began in 1950 under the former name by powerful groups of concerned parents recognizing that those with labels of mental retardation did not have the same opportunities as successful and happy lives that others without the labels did. Arc challenged institutions and fought for school and community integration and now inclusion.

¹¹Huntley and Brinkley - *The Huntley-Brinkley Report* ushered in a new era of evening news reporting when it aired for the first time in October, 1956 on NBC. Cutting between Chet Huntley in New York and David Brinkley in Washington, DC, the show featured a cutting edge style and quick pace that appealed to viewers much more than newscasters who simply read reports of the day's events.