

THE EXPENDABILITY CRITERION

By Burton Blatt

This is the time of the year when too many people are made to feel expendable. "Graduates, go forth, commence your new lives away from these hallowed halls."

"Of course, you can take your vacation the first two weeks of July. Take your vacation anytime which suits you. We'll get along fine without you."

"Retire! Why remain here until the bitter end? Do the things you want to do while you can, while you're healthy and of sound mind and body."

And on it goes, the litany of the throwaway culture and their and their disclaimers that anyone is indispensable, their righteous arguments against someone staying late at the office or coming in on the weekend. People think it's kind to let others know that they are not needed, that they are as free to flee responsibility as geese are to flee the north. Society thinks its kind to let everyone off the hook, to have everyone think they are not needed, that they won't be missed, that not only will the world go on without them but everything and everyone will go on as if they hadn't existed.

Of course, all of us are susceptible. The certainty of mortality forever ensures that fact. But it's also true that no one is expendable, that each person leaves an undelible mark on life, that each person makes a difference because of all human beings are collectively unexpendable even as each is mortal. People are people. If someone is valuable as a human being, then anyone is valuable. And if even one person

One question we can ask to sharpen an understanding of who is and who isn't expendable has to do with the ultimate act: Who can you kill and not be accused of murder? You can kill a horse, even a Kentucky Derby winner worth millions of dollars, and while everyone will be very upset with you for misdeed, you don't have to worry about execution for killing a horse, even a horse more valuable in dollars than another human being. In the neonatal clinic, one doctor doesn't treat the newborn weighing less than 600 grams, and across the hospital another doctor stops treating an old man when there was nothing more that could be done for him. Neither doctor is accused of malpractice, much less murder, for deciding not to treat those human beings. But that would not be the case if the newborn weighed two pounds or the old man wasn't quite so old or quite so sick.

One parent goes to jail for neglecting her son, while another parent strives to have a decision not to medically treat her son upheld by the State Supreme Court even though everyone concerned knows that the child will die if he isn't treated. One parent neglected a normal child and went to jail, and the other parent neglected a Mongoloid child and was vindicated by the State's highest court.

Suddenly many families are evacuated from their homes because there are dangerous chemicals which have been permitted to seep into their wells and soil, and just as suddenly, months later, the State hires a group of handicapped workers

a society where thirteen and fourteen year old children are portrayed in our magazines and newspapers as sex symbols, society where the director of the Office of Managements and Budget could say, "I don't think people are entitled to any services."

One can't easily understand a society that inflates an already bloated defense budget by attempting to take free lunches away from children and programs away from the handicapped. What do you make of a government that retains tobacco subsidies but cuts research support for early detection of cancer? Ours would seem to be a society that is bent on despoiling the land, polluting the atmosphere, fouling our nests, and turning away from those who need us.

We have forgotten the purpose of our Revolution in 1776, by definition the purpose of any revolution, which is to guarantee equal rights, equal opportunities, and freedom for the disenfranchised, the weak, the old and fragile. Today's Armageddon? It's the battle waged by the rich and privileged to rescue the worthy poor from the snares of the "lunatics" in our midsts who have deemed all people worthy.

There is the apocryphal story of the military commander during the Crusades whose army marched from town to town, burning everything in sight, killing the men, raping the women, torturing little children. Eventually, his officers confronted him with, "General, you must tell us who can be spared and who must die, which villages can be saved and which must be obliterated, who we should tor-

a little more, live a little more, or permit other people to live a little better?

Why did Lincoln Free the slaves? Did he have evidence that the community was now prepared to accept the slaves as free men and women? Did he have evidence that slaves developed more as free people? Did he seek expert advice to determine if, by freeing the slaves, those "creatures" would become smarter, or be happier, or stimulate the economy, or reduce the tax burden? Before the Emancipation Proclamation, did Lincoln try to figure out where the good and the bad plantations were, how the already freed ex-slaves were faring, whether emancipation was a good idea on economic or educational grounds? No! Lincoln had mixed feelings about blacks in America. Today, people with those same feelings might be called racist. But for whatever other reasons he had, Lincoln freed the slaves because he became convinced that even blacks in this country are entitled to their freedom.

Deinstitutionalization is not impeded by technical problems, or any problems other than those connected to our will to recreate a society in such a fashion that the handicapped and the other disenfranchised can be free.

This movement is being diffused by failure of the spirit and not by an absence of evidence. There is no evidence for or against mainstreaming and deinstitutionalization. This is a moral question we are struggling with, and not one which is amenable to scientific resolu-

the idea of democracy, then why can't parents send their normal children to orphanages, and why can't other parents deny schooling to their normal children, or blood transfusions, or food? Are the handicapped immune from social policy? That question is exactly to the point. Conversely, that there are good and bad universities, there's no reason to disbelieve that there can be a Yale University.

Learn from History

But forget the rhetoric, forget the studies. But remember your history. And, then, if you believe that institutions can be good, you're not willing to accept the lesson from history that its impossible to decently segregate large numbers of devalued people who are cared for by devalued attendants, all of these people seaparated from a society that doesn't know what happens to them and will learn not to care about them. If you can't remember that chronic segregation, wherever it is found, inevitable leads to degredation, dehumanization, pain and torment, then the only thing that you will have learned from the history of this atrocious period in our civilization is that you simply can't learn anything from history.

What can we learn from history? I once had a professor who tried to teach us that it's hopeless, that we don't learn anything from the past. But suppose we could? Better, suppose we had learned something about what we have inflicted on others, what might we have learned? We might have seen that it isn't entirely an accident that the proponents of institutionalization are

valuable. And if even one person doesn't matter, then no one matters.

Most of us have figured out the paradox of expendability, at least sufficiently well so that reasonable people deal with others as if life is invaluable and as if murder is the most heinous crime. Consequently, in spite of what we say at graduation ceremonies and to colleagues departing for vacations, ordinary people think of themselves as needed and wanted.

But what about the not so ordinary? What about the unwanted, the unneeded? What about those who never have a commendement? What about those who never take vacations because they spend all of their days vacationing from life? One needs to work to know when he's recreating. One has to endure the human struggle to appreciate the holiday. One has to have a sense of accomplishment to know the meaning of reward.

The current administration in Washington is instructing the American people in the ways to differentiate between the truly deserving and the many millions of bogus handicapped, phony needy, and affluent poor. There's also something which might be said about differentiation between the ordinary expendable (mortal) human being and the exceptional person who is surplus, excess baggage, permanently and irrevocably unnecessary and unwanted, the individual I want to concentrate on here. Nevertheless, by doing that I also want to remind you that each of us is made to feel expendable. In some final reckoning each of us is expendable. People are people.

Who Is Expendable?

group of handicapped workers to serve as caretakers of those homes until they are safe for people to once again inhabit them.

It isn't that the Grim Reaper is selective, but rather that this grim world is extraordinarily selective. Some people's lives are precious while others are cheaper than dirt, less valuable than the dirt which awaits us all.

Vexing Times

The nation is in a certain mood. These are vexing times.

A President is gunned down and for what reason? Zealots demanding independence for their country? Misguided patriots espousing this or that cause? A lunatic seeking to save the world? No! We're told the deed was done by a love-sick college drop-out who wanted to impress a Yale Freshman who didn't want to know him.

A Pope is gunned down by a Turk, and at least one analyst decided that it was all Israel's fault.

There's a story behind every incident, and one can't understand the story by merely trying to understand the facts. There are stories about women with big breasts and others about women with small breasts. There are stories about people whose parents were immigrants, or alcoholics, or poor, or rich. One man's story is his poison, but to another man that same story is the antidote.

The stories of the assassination attempts on Ronald Reagan and Pope John Paul are incomprehensible if all you have are the facts to go on. Such stories are more comprehensible, if no less horrifying, if you try to understand them in the context of a society that is loosing its values,

conscience, who we should torture and who we should set free." "Kill them all," said the general, "and let God determine which are the Catholics."

There's little that's reasonable about the political and social climate today.

The Case for Deinstitutionalization

We've been asked to take sides. On what? For what? There is a demand for the mainstreaming and the deinstitutionalization of retarded and other handicapped people. And despite recognition virtually everywhere that those are the goals for the future society, there are many who claim that institutions are appropriate places today for profoundly handicapped people, that the deinstitutionalization movement has proceeded too quickly to prevent mere dumping, that we don't have technical resources to make mainstreaming and deinstitutionalization are not technical, that they are in the heart and not in the mind, in the will and not in the ability, in the pocket book and not in the Good Book. There are those who have claimed that the prepotent issue before us isn't treatment but freedom!

What is the evidence to refute the argument that certain people are expendable? Where is the evidence to refute a decision to deny a human being his freedom, his right to live in an ordinary community, his right to travel where he wants and to be with whom he wants? When is it all right to dose a person who doesn't want to be treated but you want to cure his illness? When is it all right to deny him his freedom because you think incarceration will help him learn

amenable to scientific resolution. If in some magic way, Einstein, Leonardo, and Fermi joined in collaboration with Don Campbell and Ed Zigler to design the crucial experiment to satisfy the question: "Whither institutions?", the experiment would fail. There is no scientific resolution to a moral dilemma.

But if facts could resolve the question, the deinstitutionalization and mainstreaming argument has as much fuel in its tanks (or a mite more), than those who would leave well enough alone, leave the expendable remain so. For those who claim that deinstitutionalization is little more than a slogan, how do they explain the thousands of people who are unnecessarily institutionalized, not unnecessarily institutionalized because the zealot liberals say so but because federal judges, state commissioners, even people who are debating in support of continuing institutionalization say so. If people are so profoundly retarded that they can't benefit from any educational programming, what is the lesson to be learned from the story of Victor, the Wild Boy of Aveyron? It can't be that only wild boys are educable, but that all human beings are educable. What are the lessons to be learned from the enthralling story of Helen Keller and Anne Sullivan?

If a community is not prepared to accept the profoundly handicapped in its midst and probably never will be, then are we to perpetuate the injustice? If that's the idea of democracy, then the thirteen million people who died in the ovens of Auschwitz and Buchenwald deserved to die there? If that's

of institutionalization are also the proponents of euthanasia and mercy-killings.

I ask again: "Who can kill and not be accused of murder?" We might have learned what the ancient Athenians tried to teach: that banishment is a worse punishment than death. We might have learned that children, old people, the severely disabled, have rights, and those rights can't be abrogated by parents or whims of a misguided society.

We might have remembered that some parents in Nazi Germany were given opportunities to either take their children home from the institutions for mental defectives or come quickly to bid them good-bye before their trip to eternity. Where does history teach us that parents invariably make decisions in the best interests of their children, when we know for sure that many German parents rushed to those institutions, not to rescue their children but to say good-bye to them?

When will we admit that this field of ours has suffered with its own Viet Nam? As some people believe, it may be too late to turn back after all of the wrong investments and wrong ideology, but knowing about our own expendability — our own mortality — dare we not?

Change the World

We must change the world! When I was a boy, that was a noble ideal which was part of the school curriculum. When I was a boy, leaving the world a better place than how one finds it was expected to be learned as a lesson and also as a practice for a lifetime. How does one start?

(Continued on page 9)

THE EXPENDABILITY CRITERION

(continued from page 8)

With himself. We must work toward deinstitutionalizing, work toward converting the community to a more hospitable environment for all people. You must work toward that end. I must. And our objective should not be to make a determination whether people can live in a normal environment or not, but to so recreate our society that all people will live free — even the handicapped, even the very old, even the “unworthy” poor, anyone who is not adjudicated a criminal.

What's the formula for reducing chronic expendability? We must permit people to live normal lives if we don't gum up the works. The future for expendable people is our future, and their lives are inseparable from ours. So we must ask what kind of a society we want for ourselves, not what kind of society we want for the handicapped. We must start by changing ourselves, not by enjoining others to change. We'll know when we're making progress when we seem to be holding fewer meetings and writing fewer polemics on this question. We'll know we have made great progress when it no longer becomes necessary to debate the issue.

Remember the Past

Of course, not all mischief can be undone. Those whose feet were bound must live crippled in spite of the People's Revolution. Those who gave their lives, will remain dead long after we've admitted that Viet Nam was a mistake. We can cry over spilled blood, but life goes on. But it can go on with dignity if we remember the past.

I want you to remember the past. I want you to remember

you. What follows is a faithful reproduction of a portion of Marion Roe White's autoautobiography. So many of us speak on behalf of expendable people. Too many of us speak as if we are truly representing those people.

We need more statements from the Marion Rose Whites of the world and fewer from their interpreters. In a way, people like her have written virtually all of my works, while I have served merely as translator. And how mixed up translators can get things. So read this. It's the real stuff.

Marion Rose White's Story

I was born March 1, 1920, in San Francisco. I lived with my father and mother until the age of nine years. My father, who refereed in the prize fights in San Francisco was known to the world. His brother was the manager of Young Corbett. When I was nine years old my mother placed me in Sonoma State Hospital for the mentally retarded, for the doctor had told her I was retarded.

The first day I arrived at the hospital, it was on a Monday in November. I walked into a large brick building with a big glass door. I walked up a flight of stairs, walked down a dark, long hallway, to an office called the Main Office. The technician told my mother and I to go up the stairs and rows of beds with white spreads and white shams on them. The dormitory was large. There were more beds than room in the dormitory. I could see it today.

The children were in the room next to the dormitory. And in the room lines and lines of chairs of Mongoloid children. They

to Sonoma where I started my life as a resident at Sonoma State Hospital. In those days you did the work. We were taught to make beds, undress little children, bathe them and put them to bed. I helped with the children though I could not bathe them yet, for I was yet too young. We had to get up very early. We got up at five o'clock in the morning, got dressed, made our beds, polished the floor, and went into the day hall to wait for technicians to come on at seven. When the technicians arrived we all lined up and marched downstairs to eat our breakfast. The girls sat on one side of the dining room and the men on the other. In the dining room you were not allowed to open your mouth or speak a word, or you would get scolded. Every morning we would have prunes and mush. Prunes and mush was the menu. It is the menu till this day.

We would get done with breakfast and go upstairs. Us older girls would comb the younger girls' hair and get them ready for school or to go out to play. We would line up two by two and go on a big porch. We would march around that porch with our arms folded while technicians stood behind us with a stick. Anyone dare make a move, you would get hit in the leg. Things were rough. I should say they were.

They would give us cold baths, and put pillowcases over our heads, and duck us into a cold bath of water. For little things, they would punish us that way; that was their way of teaching us good behavior. To some people, they gave dope medicine for bad behavior. They put me on phenobarb one time, but they had

paper.”

One of the technicians, named Nell Brice — I'm not afraid to name her; she's dead, and will not hurt anybody — she used to beat us girls for no reason at all. One day she gave me such a beating that I ran away from the ward and hid behind the church. I could not get anyone to help me against that woman and that was my only escape, so I ran behind the schoolhouse near the church. When they caught me they brought me back, shaved my hair, put a rope on me and marched me around the auditorium and around the grounds, like a horse. My mother was pretty angry about my hair and told them never to do that again. But you know, they don't listen to your mother. In those days if your mother told on you, you were severely punished.

The Good Things

Anyhow, there were a lot of good things, too, that went on. We had a big auditorium called Dorson Auditorium where we gave many plays. There were many gong shows and other kind of shows — movies, dances, and everything. Dorson Auditorium burned down. On July 2, 1980 it burned to the ground. We miss it very much and I wish some people would put some money in to help the children get a new auditorium. They need their auditorium where they could dance and laugh and have a good time, for that was their escape from the ward, their escape from the noise and excitement of the yelling and screaming of the ward.

The Bad

Lux was one of the worst wards on the grounds. People would dirty themselves. People would

rabbit. I was afraid of men, I was afraid of everything around me, though I out-grew it as I lived there. I lived there 19 years with Nellie.

Nellie McCord is one of the nicest and most wonderful caretakers God put on this earth. We all loved Nellie and that is where I am going for Christmas. I have spent Thanksgiving with Lotte, and her family who I met at People First. I admire what Lotte has done. If my mother had loved me like Lotte loved hers, I believe I would never have gone through the hell and the torture of the hospital.

They Do Not Understand

People loved me at the hospital and I loved the head doctor, Butler. I liked him; he was a nice man. But he closed his eyes on too many things in this world, they do not understand what life is all about. The mean technicians in the years when I was a girl, they did not understand how to work with the people. They thought beating us and being rough to us was the thing to do. They would tie some of the children to a bench — though we had to tie some, for they had epilepsy so bad they could not even walk around the yard without getting hurt.

In those days, though, we had children and people who could speak for them themselves and stand up for themselves. Now they have more severely handicapped children who cannot speak, nor hear, and some of them could never speak for themselves. They have to have people like me and other people to stick up for them. I hope that by the grace of God that I have done right by these people for I would never harm a hair on any of them.

past. I want you to remember that, while there are some who say that there is no evidence to indicate that humane environments lead to great development, they surely lead to human environments. And I want you to remember that once upon a time we didn't have humane environments, and now we do, and we should be thankful. But we must remember those past hells, just as we must remember the Holocaust. We must collect stories from the people who lived in those inhumane environments of long ago. That might be the surest way to remember the bitter past. That may be the surest way to prevent a bitter future.

A few weeks ago, I received an audio tape in the mail from a woman who had been institutionalized more than fifty years ago. Marion Rose White, now a foster grandparent at Sonoma State School, California, entered that institution as a child. She sent the tape to me because, having read *Christmas in Purgatory*, she thought I would be interested in her story. She told me that she was angry with my book, "I cried bitterly at first. I was angry with you for writing such a book, for telling the world what had happened to us. But then I realized that you were trying to help us. And so I decided to prepare my own story, and then I put it on this tape for you and others to hear."

This is a transcript portion of that tape. In a telephone conversation with Marion Rose White a few weeks ago, she told me not to delete her name, the names of other people, or where she had resided all those long years. She wants this story out and I promised that I would get it to

of Mongoloid children. They were sitting there all together. I turned to my mother and asked, "Why did a mother put all her babies here?" To me it looked like a family of unwanted little girls. In those days the children did not have a toy to play with. We had to sit in rockers lined around the wall and fold our arms. Anyhow, we went in.

The nurse said to my mother, "What is your little girl's name?"

My mother did not answer for a minute and I looked up and I said, "My name is Marion Rose."

"I am talking to your mother." I says, "I know my name."

They asked my mother how old I was. I told them I was nine years old. They got mad at me and told me to sit in a chair, and them and my mother went into the office.

I was scared to death and did not know what would happen. I walked out the door, down the dormitory, back down the main building stairs, to the main parking lot, where our car stood. I got into the back of the rumble seat and hid way down. My mother came out and went home. I guess the nurses thought I was in the bathroom, for when we got to Oakland, I jumped out of the car and laughed and ran into the house. My mother took me by the hand and took me in to supper with her. She was very angry with me and told me I was a very bad little girl. But she said, if I would be good and not cry, she would take me to Capwells to look at the toys. I looked up at my mother and said, "We cannot have those toys at that school, the girls are not playing with toys."

Life at Sonoma

The next Monday I came back

phenobarb one time, but they had to get me off in a hurry for I was seeing things that were not in my room or around the ward. They took me off. I got along fine after that and learned to work more with the children and learned to love the work I did.

Behind Closed Doors

One time, as a girl, I worked on Affinity Cottage with cerebral palsied children, for our classroom was closed. One Sunday afternoon I came over extra early and was playing records. We went into the day hall because it started to rain. A mother brought her little girl back to us and put her into my lap. One of the new technicians came in to me and took the little girl and said, "I'll stop her crying."

I said, "Leave her with me please, for she will not cry no more."

But she said, "I do not take orders from the residents." (In those days she said patients.) She took her into the bathroom and put her in the bathtub full of cold water. That evening the little girl passed away.

Things like that went on behind closed doors for many years. I was a victim of a cold bath myself. We were playing hospital in the yard one time and I did something I shouldn't. The technician took me upstairs and put a pillowcase over my head and gave me a cold bath. We were in the bathroom — the funniest thing — my mother walked into the bathroom and said, "I could have you fired if it wasn't for Marion Rose."

"Don't do it," I said, "She only did it because she thought she was doing what was right and what was required of her on

dirty themselves. People would not keep their clothes on. We had people who did not care to be talked to. They would sit in a corner by themselves, next to the wall, and you could not get through to them. We had people who would not walk or talk, who were treated very badly. I know some of the children were left to die in cribs. But in my day there was nothing else they could do.

So Many Need Help

Today they have all the modern science and modern things to work with. Yet, we do not have decent teachers.

There are so many children now, so many different little children, that need help. There are very smart cerebral palsied little boys. I believe they could benefit in an outside school if they had an outside home to live in. I look at those three little brothers and wonder why in the world they are not in school in San Rafael, but there are not enough care homes to go around for these children.

I have known many of the men and women residents of the hospital for many years. There is a girl on Wright Cottage who has one leg, who should never in her life have been put into that hospital. She was there from the age of eighteen until 84. Her girlfriend, who has epilepsy is another one who should have never been put into that hospital. Oh, I could name them down the line. But, they stay. They will not be happy in a care home. You cannot take a person in their late 60's, 70's, or 80's and place them in home care. It is very scary.

The Feeling Outside

At my age, when I first went out of the hospital, it was scary. I walked into a home scared like a

would never... of them.

A Flood of Memories

In your book, *Christmas in Purgatory*, I looked at those pictures and thought to myself, "Were there really such torture chambers?"

When I saw the people locked in their cells, I knew what it meant. In Lux they had a big black girl — oh, that I will always remember! When they punished us they would put us in the ward with her the first day we were punished and let her beat the hell out of us. She had great big feet — I could see her feet till the day I die — and she would step on us or hit us. When they put me into the cell with her, she knew I played records.

She said to me, "You play the records for me tomorrow when you get out of my room?"

"Yes, I will," I said to her.

She hit me but not hard. I made a scream so they thought she gave me a good one. The next day I took the records down into the corridor and played for her.

The technicians never did know what we pulled. But we pulled a hot one that day or I would have been crippled or dead, for many a girl met her death by her. Heaven only knows what happened to her. Whatever did, I hope it's for the best. I feel sorry for her for she was made the beater for the institution. If they would let her beat us up, the technicians could not be blamed for what happened. That was one of the big cover-ups at Lux Cottage.

Another one was that they would take the girls out into the big corridor on the cement blocks and hose them down when they

(Continued on page 10)

EXPENDABILITY CRITERION

(Continued from page 9)

were full of shit. They would get it so caked onto them there was nothing else to do and they had to hose them down. It probably hurt. I know it hurt when it hit me when I was trying to get one of the kids up off the floor. The technicians down there, some of them were real witches.

Oh, I pray to God that someday no matter what happened, there will be better homes for some of these children in other places. Some of them were locked in back wards into cells, as I told you about that black girl. Some had shock treatment as a lot of people know. It was a very bad thing in those days; it blew many a brain. Some were tied to poles and given a whipping many times a day with a switch or a counter brush.

I remember one time when we were very young children. I was so full I didn't want to eat my apple in the dining room so I brought it upstairs. Well, we were taken over a small chair and given "one, two, three, applesauce" with a counter brush. My butt hurt for two days. I guess that's the way life is anyway, you get in trouble for everything.

They used to sit us on the toilet and give us a great big round mush bowl full of epsom salts, and we'd have to eat the epsom salts for punishment. Well, it was the worst thing to eat in your life, if you ever ate it. Don't try it, ain't that good. Well, one time

Study Examines Characteristics of People in Residential Facilities

Detailed information about the needs of people who are developmentally disabled is necessary for the effective planning, development and evaluation of residential services.

One of a series of studies conducted by the University of Minnesota's DD Project on Residential Services and Community Adjustment (funded by the Administration on Developmental Disabilities) included assessment of 2271 people with mental retardation in a national sample of 236 residential facilities. Demographic, behavioral, physical and health characteristics of these people was ob-

whatever it showed me, I can't answer you because, it's a funny thing, I don't know.

Life Today

And so many things happen in my life too. I've met a lot of nice people. I'm back at the hospital now, working as a foster grandparent in the hospital and as a teacher in the classroom with the children. I cannot be a teacher yet until I can find a way to get a diploma so that I can pass the examination and become a teacher at the hospital. I hope to do it some day before I die. I would like to be able to work until I am 73 years old, then retire and say I retired from the job I loved the most.

I am on the People First Committee program, because one of

tained between September 1978 and April 1979.

During the past 13 years, the number of people with developmental disabilities in state institutions has declined by about 30% since it peaked at 194,650 residents in 1967. Earlier studies conducted by the University's DD Project have shown that the numbers of community residential programs have increased exponentially during the 1970s. More than 65,000 people who are mentally retarded were being served in community facilities and foster homes by the end of the 1970s.

Past studies have shown that many of those who reside in state-operated institutions have physical disabilities and severely limited mental abilities. Health related problems and behavior disorders have also been associated more closely with institutions than with community facilities. Mortality rates reported in several studies of institutions are far above those of the general population.

Both first admissions and readmissions to institutions have suggested that community residential facilities may be unable to cope with certain behavioral problems and physical and mental limitations.

The purpose of this study was to present data about the health, physical and behavioral characteristics, and maladaptive

behaviors of people with developmental disabilities who are currently dressed, fed and otherwise directly physically assisted in all daily activities, while 41% of PRF residents required a similar level of care. (What is not known, however, is the relationship of need to the level of staff intervention. It is sometimes easier for staff to dress and otherwise care for people with severe disabilities than to instruct in self-help. We suspect that the path of least resistance is followed more frequently in PRFs than in CRFs.)

PRF readmissions, most of whom had presumably failed to succeed in various community placements, demonstrated basic ability levels that closely matched those of residents who remained in CRFs. The prevalence of maladaptive behavior was found to be much higher among PRF readmissions than among CRF residents, however.

The study suggests that CRFs can manage the same maladaptive behaviors that PRFs can, although at present problem behaviors are exhibited by a smaller proportion of CRF residents.

A great variety of maladaptive behaviors were reported, "Including many that the general public would consider quite unusual," says the report. Only one behavior was reported among PRF residents that was not also reported among CRF residents — attempting to set

staff reported that 30% of their residents exhibited at least one of the four major categories of maladaptive behavior studied, half of these behaviors never required more than a verbal response from staff and never occurred more than once daily. If such behaviors were excluded, only 18.8% of CRF residents would be considered to have behavior management problems within the four major categories (self-injurious behavior, injurious to others, damaging property, and unusual or disruptive behavior). Under the same criteria, 36% of all PRF residents, 42% of PRF new admissions, and 44.5% of PRF readmissions would be considered to exhibit behavior management problems.

Facility staff felt that for less than half of the CRF residents who were reported to have behavior problems did such behavior affect the individual's ability or opportunity for more community interaction.

Hill and Bruininks note that there is a wide range in the degree to which CRFs seem to be prepared to cope with behavior problems. In many of the CRFs studied, residents with a multitude of severe behavior problems were accommodated and extensive effort was made to modify such behavior. In other facilities, residents whose only maladaptive behavior was being "generally uncooperative" or

ain't that good. Well, one time they put five of us on the toilet and gave us epsom salts because I said I didn't want to bathe this one girl because she was too hard to get in and out of the tub. She was twice my size, and I was a pretty big woman at that time. We said, "Let's dump it in. Let's dump it in!" The toilet would flush every few minutes, so we timed just about the time that toilet would flush and we dumped all the epsom salts in. When the technician came, she thought we ate them. Well, she wondered why some of us didn't have a b.m. right away. Oh, I tell you, some of the things we went through you would never believe! You'd never believe it. And I'm telling you, I don't believe it yet.

Another time we had a Halloween party. The technician told me to go in the room and bring out the popcorn table. I couldn't carry the popcorn table by myself and her son was in there, so I said to him, "Would you help me carry the table out, please?" And, you know, she deliberately slapped that boy's face, and slapped my face so hard that my nose bled? She was the meanest woman alive. They said she died of cancer so maybe that was what was eating her and made her so ornery. I don't know. I hope it was. I hope it could be.

Oh, so many crazy things! I used to have a picture of Bing Crosby that stood on a little radio up on top of a mantle piece. I was straightening a row of chairs in the room. We were getting all ready for a party and I was decorating, putting up pumpkins and everything. In she walks, she slapped me across the face and broke my glasses, took Bing Crosby's picture off the mantle piece, hit me over the head with it, and broke it in a million pieces. It's a wonder I wasn't dead.

But, you know, maybe that's the way life is. Maybe it was tr

mittee program, because one of the cerebral palsied boys has asked me to be. It breaks my heart when I sit out meetings to know it is the same group of men and women that were my children in the classroom. It is a wonderful thing when they get up at a meeting, though some of them can hardly speak, and speak up for what their rights are; to see the smile of their face and the joy in their heart when they say, "We have our rights." It is so beautiful to me, and I am very happy to know it.

I know I sound like a funny person to you, but my feelings are very deep. Deeper than a lot of others' because I walked in their shoes.

Blatt Concludes

What does it all mean? As human beings, all people are equally valuable. I've worked hard to teach myself that lesson. It's easy to say, easy to memorize, but a difficult lesson to learn so well that we actually learn it.

People are people. All are equally valuable as people. How do you save the world? First, save yourself. How do you change the world? First, change yourself. How do you make your peace with the world? Be yourself.

Be yourself, and let others be themselves. Then, no one will be expandable. Not even you. Ever. Under any circumstances. That's the definition of a good and decent society.

* * * * *

Burton Blatt, Dean of the School of Education at Syracuse University, needs little introduction. He is a renown writer, speaker, worker in the field of mental retardation.

This article was written from a speech presented to a NAPRFMR/Division on Private Residential Facilities cosponsored session at the AAMD Annual Conference in

behavior of people with developmental disabilities who live in public institutions and community residential facilities. No previous study has provided such a comprehensive description of resident characteristics on a national scale.

Population Studied

The sample studied included 965 current residents of community facilities, 953 current residents of public institutions, 211 people newly admitted to public institutions, and 192 individuals readmitted to public facilities after a previous release to the community. Residents of 236 facilities were examined.

Study Results

The study shows that residents of public residential facilities (PRFs) are generally more limited in ability than those in community residential facilities (CRFs), and are more likely to have additional handicaps and behavior problems.

Chronic health problems of PRF residents, however, were reported to be no more prevalent than health problems among CRF residents.

In comparing CRFs with those studied by O'Connor in 1974, it is evident that there are now many more severely retarded individuals living in the community, and that their relative proportion is increasing. Since O'Connor's study, the proportions of CRF residents with epilepsy, cerebral palsy, visual or hearing handicaps has also increased dramatically, the proportion doubling over that period. Correspondingly, the proportion of mildly handicapped individuals in state operated facilities has decreased in recent years.

The DD Project found that CRFs as well as PRFs are serving residents at all levels of independence, although in different proportions. Fifteen percent of CRF residents were

residents — attempting to set fires. Even for this population the incidence was so low that researchers hesitate to draw conclusions from the sample studied. Only three PRF readmissions were identified as having exhibited this behavior.

Specific behaviors were studied, and the frequency at which various acts were performed was recorded. The report indicates that generally, CRF residents who exhibited a certain behavior performed it just as frequently as did PRF residents.

It was hypothesized that staff response could be a measure of the seriousness of the problem caused by a particular behavior. Five levels of staff response were identified and recorded. It was found that on the average, CRF staff responded to maladaptive behavior among residents at the same level that PRF staff responded to similar behaviors among their residents.

Consideration was also given to the fact that different staff might have different expectations or might tolerate certain behaviors differently. It was possible, for example, that PRF staff might "put up with more" than might CRF staff. Analyses indicate that for specific types of behavior there were no statistically significant differences between the average level of response of CRF and PRF staff.

Hill and Bruininks conclude that, "It seems evident that by maintaining adequate staff to resident ratios and by using adequate behavior management practices, at least some CRFs manage the same maladaptive behaviors that are evidenced by PRF residents."

In elaborating on their study of maladaptive behavior, Hill and Bruininks point out that in the non-handicapped population, many maladaptive behaviors are accepted, ignored or tolerated. Although CRF

screeching "once a week or so" were reported to be in danger of demission. An individual's prospects for remaining in the community are thus dependent upon the characteristics of the facility in which he or she lives.

Health problems are frequently cited as reasons for institutionalization. The DD Project found little or no difference between the residents of PRFs and CRFs as to chronic health problems or health maintenance that required medical care.

The relative frequency of illnesses among all resident groups suggested the desirability of future research on the prevention of temporary illnesses in residential facilities.

Accidents and injuries which required a doctor's attention occurred three times more frequently in PRFs than in CRFs used in the study. A question was raised as to the pain and permanent harm caused to residents, as well as costs associated with medical care and hospitalization of those injured.

Implications of the Findings

Information about people who need residential services must be put to use and incentives developed to encourage the provision of additional community residential services.

As Hill and Bruininks point out in the Project report, "The availability of appropriate community residential facilities, which are especially in undersupply for severely and profoundly retarded people, often dictates placement in a PRF as the only alternative." They go on to say, "It is, perhaps, surprising that deinstitutionalization has progressed as far as it has, given the fact that the development of community residential facilities has relied more upon the spontaneity, good intentions, and entrepreneurial motivations of