



Dr. Burton Blatt

*Dr. Burton Blatt is Dean of the School of Education and Centennial Professor at Syracuse University. From 1949 to 1955 he taught mentally retarded students in New York City. Since that time he has taught special education and related courses while serving as departmental chairman at Southern Connecticut State College, Boston University, and at Syracuse. Dr. Blatt is a prominent educator, having published extensively on a wide range of topics. Perhaps his most publicized work is **Christmas in Purgatory: A Photographic Essay on Mental Retardation** (Allyn & Bacon, 1966).*

This interview was conducted on November 16, 1979 by telephone. The interviewer was Dr. Thomas M. Stephens, Executive Editor.

Why Christmas in Purgatory?

It was 1965 and I had been doing traditional work — field experimental studies and so forth. During the course of my research, I had been in institutions for the retarded many, many times and had seen bad things, but in such ways that I didn't have to trouble myself with what I had seen; I could continue working.

But a series of coincidences occurred. About that time, I read in the New York Times that Senator Robert Kennedy held a press conference and denounced the horrible facilities and inhumane treatment programs in the state institutions. I told myself, "Good for you."

A second coincidence happened the next day. I went to a regional AAMD meeting in Portland, Maine, to give an address. While there, I got into a discussion with several old friends of mine. The question of Kennedy's press conference came up. And what astonished me was these people—decent, thoroughly professional colleagues for whom I have enormous respect—took a very negative, in fact vicious, attitude towards Kennedy's position. They



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asked, "Why did he do this? It's not going to do any good; this is the nature of institutions, and the nature of mankind. That's the way the institutions have always been and that's the way they are always going to be. It's obvious that he made these disclosures in order to get some political mileage . . ." and so forth. It was their view that he was raising these questions for political purposes, and that institutions are about as good as they could ever be.

So, the implication was that he wasn't sincere about his criticism?

Yes, I can understand when people say politicians aren't sincere about their

convictions, but I was absolutely dumbfounded with their assessment of what institutions are and what they must necessarily be! On the drive back to Boston I got churned up about this incident. Just a few days after that, at Thanksgiving, a very good friend, a professional photographer, Fred Kaplan and his family came to our house for dinner. I said to him, "Why don't you and I visit these institutions?" He asked, "What would I do?" and I said, "You'll take pictures." He said, "That's easy." I told him how difficult it would be, that he would have to take pictures with a concealed camera. So Fred hooked up this camera to his belt,

and we went into these places, and I looked at those institutions as I have never looked at them before. The more we went into them, the angrier I got about the way we had totally ignored these problems.

You were angry at yourself?

Of course, I was angry at myself for ignoring what I had seen for so many years. Well, anyway, he took pictures; and as Fred developed them I studied them, and I finally told him that I had to write a book about those hellish places. It was written during the week which precedes Christmas, 1965.

That's why the title had Christmas in it?

Yes. I had spent the Christmas season in Purgatory. The title hit me one day as I was walking in New York City, the one day during that period when I was away from looking at these institutions. One of those churches which list its sermons for the weeks ahead announced as its Christmas Eve Sermon, "Do you want to spend your life in Purgatory?" Instantly, I came up with the title of the book, *Christmas in Purgatory*. It was written the next week, in 5 or 6 days. My wife and I matched the pictures with my words, designed the cover, and we published one thousand copies. With Fred Finn's help, we sent it out with a mimeographed note to every governor, to every U.S. Senator, to every State Commissioner of Mental Health and Mental Retardation and to about 100 professors. I received two or three thousand letters back! People looked at it and passed it on to other people. I got letters from people like Eunice Shriver and Muriel Humphrey. One day my secretary said, "The President wants to talk to you," of course, I thought it was the President of Boston University. It was President Johnson, and he wanted copies for people in his office. Then I got a call from Charlie Mangel, a Senior Editor of *Look Magazine*, who had a copy passed on to him. He asked me to do a story for *Look*. Then, an editor from Allyn & Bacon called and said they wanted to publish the book. I agreed, with the condition that all royalties go to the Southeastern Connecticut Association for Retarded Children, the organization that put up \$1600 or \$1800 for the original edition to be published and sent without charge to all of the aforementioned.

Is it still in print?

Allyn & Bacon published about eight printings; they sold thousands & thousands of copies. About four years ago, The Center on Human Policy began publishing it. It can still be bought from the *Human Policy Press*.

Have you taken other looks at those same institutions?

Yes, in 1976—about 10 years later—I thought I ought to go back to those



places, and to do it systematically. I also decided to visit some of the newer residential programs that have been created in order to respond to the many criticisms that came out since *Purgatory*; as you know, after that book there was an avalanche of investigations and suits. I wanted to know how we have responded to those criticisms and the subsequent promises made. Have the new facilities, new programs, and new ideas like normalization, deinstitutionalization, zero reject, and least restrictive environment helped? So I decided to visit those five institutions and a few of the newer ones. One of the hypotheses I wanted to examine was that *small can be better* — that small living environments are better. And if I really believe that, why not try to implement such a project for the smallest budget possible? So we did the entire study for \$3300, sponsored by The Presidents' Committee on Mental Retardation. It is to be published in about three weeks, by Longman. It's called *The Family Papers: Return to Purgatory*, and I was fortunate to have two splendid young co-authors, Andrejs Ozolins and Joe McNally.

Well, what did you find?

Today the institutions are much smaller. Where they used to have 4 or 5 thousand residents, they now have 2500. And they're much more expensive. Before, the per capita expenditure nationally was about \$6 or \$7 a day; \$2500 a year. Today, at least in the Northeast, it exceeds \$30 thousand a year in many institutions. And remember, we are talking about *public* institutions. One institution we visited spends \$60,000 a year per resident. And as a matter of fact, there is one I haven't been to where the expenditure is \$90,000! So you see, the costs have become enormous. Of course, many more residents are severely involved than mildly handicapped. And of course, more people are now wearing clothes, and there is a much higher staff to resident ratio. Where ten years ago we saw 100 naked residents milling about in day rooms with nothing to do, today we see 50 in that same day room, all dressed,

but still milling about and still with nothing to do.

The obvious has been done?

Yes, society did the obvious, and what we conclude in the present study is that, while everything has changed, nothing has changed. There's more schooling, there's more programming, there's more sensitivity to problems, but there remains nothing to do there; institutions are not normal environments. There are still many unfortunate things that occur in these places; there are too many accidents, there are too many medication errors, there is too much restraint. There is still too much of all the sad things we saw before, except not as blatant, not as gross, not quite as pervasive.

What should be done?

Well, we call this book *The Family Papers* because there is a "family" in mental retardation work. We know each other. Not only do we know each other, but we know what's going on and we know what needs to be done. But there's a silence about institutions. "Everyone" knows that they're unworkable. "Everyone" knows we must evacuate them. Why can't we evacuate them? For different reasons, by different people, in different places. In New York State, for example, all of the new institutions have been financed by a mechanism involving issuing bonds. In New York, we have a billion dollars in bonded debts. These bond holders must be paid. And the only way they're being paid is by Title XIX payments on behalf of institutionalized residents. And if those people aren't in the institutions, the State is morally obligated to come up with a billion dollars. Bondholders own our institutions. How do we close them?

And we have unions. In New York State, we have some 55,000 union members in mental health and mental retardation. Even if the government assures these people work in the community, many of them prefer to work where they are. And they are well organized.

Also, there are other constituencies who have vested interests — like architects, builders, and suppliers. There are parents who were told a generation ago that their children belonged in institutions. Now they are adults. Now we are saying to parents, "No, we made a mistake." So you see, we have significant forces against deinstitutionalization. Nevertheless, the institution is an unworkable system!

What is your current view of advocacy. It seems that you have shifted your position?

You noticed that! I have shifted, but I haven't! You know, I have been in this field a long time, and have seen a lot of movements come and go, and I have come to a few conclusions. One is that

there is no large group of evil people running institutions. As a matter of fact, right now there are people in institutions truly trying to help other humans in spite of that unworkable system. When I started in this business, nobody wanted to know whether those places were good, bad or indifferent. We wanted to believe that they were good, so we believed it. And we have this same sort of know-nothingism today. But today, it's shown mainly by those who want to mainstream. Of course, I too want mainstreaming. But it has to be accompanied by thoughtful people. Before jumping on a bandwagon, study the problem, try to give some deliberation to the decisions to be made. But the people are jumping on and off bandwagons, just to be in fashion. This is a destructive way for us to behave. It isn't at all that I am opposed to advocacy; I really think that it's necessary—the advocacy movement, the consumer movement. But I don't want those of us who have tried to develop more decent programs for the handicapped in America to perpetuate errors in the name of advocacy. We ought to remember that, years ago, we believed that the right things to do was to segregate the handicapped. Now we are pushing for deinstitutionalization. You know the old story. "Be my brother, or I'll kill you."

Are you concerned that the advocacy

movement will become institutionalized itself?

Of course. It's like institutionalizing friendships! Some business establishments tell their employees to smile at their customers, to say "Have a good day," and so forth. We don't need somebody to smile at us because he's required to smile. And the thing that makes advocacy such a powerful movement is the inner commitment—the passion of the people for good. But when it's business, then it becomes artificial.

Do you feel that there's been some irresponsibility on the part of some advocates?

Sure. But that is to be expected. When you start up a movement in response to a national disgrace, you are going to have some irresponsible people. And there are second or third generation followers who are on the bandwagon and don't know why. That's always the case.

Thank you.

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From the Editor

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rent(s) within the following two weeks. For conferences which were satisfactorily completed by both parties, a simple "Thank you" note (or letter) may be all that is needed. In situations where home/school interventions have been arranged, regularly scheduled communications will be needed; use either telephone or written notes as routine ways to exchange information and to evaluate the effects of the intervention. When parents seem distressed or when it is apparent that much more needs to be accomplished between school and home, a phone call to the parents a few days after meeting is sometimes helpful.

Through effective conferences, parents', teachers' and students' relationships take on differing perspectives over time, and teachers can extend their usefulness to their students far beyond schools and classrooms.