

# Each Man Has Value

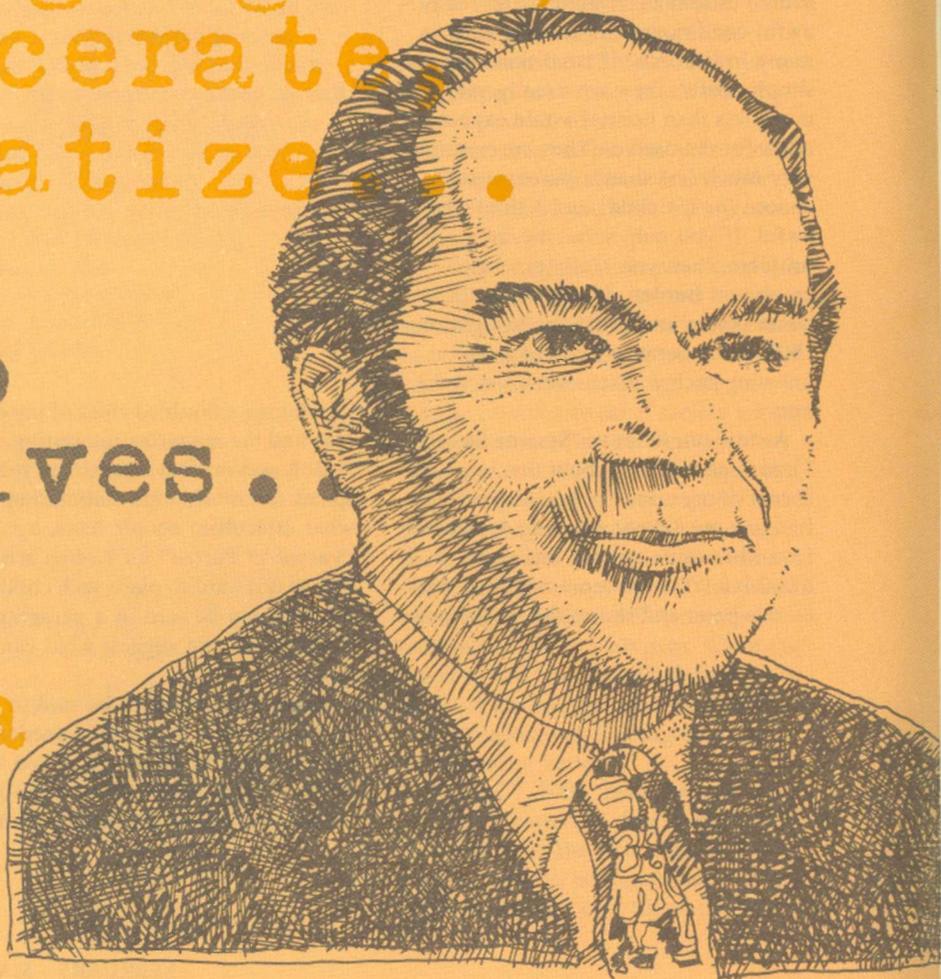
••know more  
do less...

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The Exceptional Parent is pleased to be able to publish as a guest editorial the summary of a lecture by Professor Burton Blatt of Syracuse University. He is a distinguished educator and has dedicated his life to the problem of human abuse. He is the author (with Fred Kaplan) of a searing photo-documentary of public institutions, *Christmas In Purgatory*; published by Allyn and Bacon, a more recent book of essays and reflections from his broad experiences, *Exodus From Pandemonium*, and numerous other articles and books, published by Allyn and Bacon and others, covering a variety of disabilities.

He recently visited Boston to attend a scientific meeting. During that visit, he addressed the students at Boston University where he was formerly chairman of the Special Education Department. The Exceptional Parent was in the audience and even we, who have known him for years, were moved by his presentation. The students were enthralled and are still discussing the evening. Our office staff was excited just listening to the tape.

Dr. Blatt did not want us to publish this address because it was informal and, more or less, "off the cuff." It does not have the precision or elegance of his more carefully crafted papers, but it does reflect the excitement he brings to all his work. Because it is so much from the heart of this devoted servant of disabled children, we wanted to publish it. He finally consented. We are certain you will agree we were right to insist.

I was asked to talk about those things that concern me most, things that have occupied my energies during the past twenty or more years. You will probably conclude from what I say that I am anti-institutions or anti-special education. I am not.

It may be true that I am not a particular devotee of either institutions or special classes, but the problem I have is not with institutions or with special classes; the problem is that there are *no alternatives*. The monolith is not the institution; the monolith is the unavailability of anything *but* the institution. The monolith is not the special class; the monolith is that, in the universities, and most of the textbooks, and most of the speeches, and most of the polemics, *special education is special class*. With the rarest of rare exceptions, for certain people there are *no alternatives* to segregation in our culture.

Mankind has a penchant to segregate, to incarcerate, to stigmatize, to make pariahs out of its people. There are more of us segregated today than ever before. If one were forced to predict the future society in five or ten or twenty years, he should say there will be more people segregated than ever before. What is more, if one had to predict what the world of the institutionalized will be in ten or twenty or fifty years, his prediction must be that institutionalized people will have to live lives similar to those lived by people in today's institutions.

In spite of new laws, and new buildings, and money, things have not changed very much since the 60s. In little more than a very general way, there has not been

change insofar as humanizing and integrating the lives of the so-called handicapped.

Why? Maybe Ivan Illych was right. Maybe the most important thing he has taught us is that the world is so opaque, so secretive, that it is nearly impossible to communicate the nature of Man's real problems, that people do not know or understand what the devil does, that they certainly do not understand how to correct publicly sanctioned human abuse. How can I illustrate some of these concerns?

Not too long ago, we had a visitor to Syracuse, Bengt Nirje, who was once the Secretary General of the Swedish Association for Retarded Children. He met with students and faculty on campus talking about many things, and about America, he said, "You paid a price in this country when you civilized a raw wilderness in just 100 or 150 years. You created a great civilization, you conquered so-called savages, built roads, bored through mountains, railroads came, great factories. You became the most powerful country on earth.

"But," he said, "truly civilized nations can't grow so freely. There's still the frontier rawness in this country that surfaces in such places as your institutions, and how you deal with your more grievous legal offenders, and how you deal with your aged, and how you deal with those children who don't do well in school."

In another context, he began to tell me what he had just done, prior to coming to the States. Bengt Nirje had taken a group of retarded and blind adults on a skiing vacation. These were adults who lived in state sponsored group homes of one kind or another. At some appropriate time during the winter season, they decided they were going to go on vacation.

He explained to us the marvelous week or two that these people had in the Alps. There was something that did not sit right in my head, however. I could not understand how blind people could ski, knowing that it is certainly not as easy as it looks.

However it was quite simple. What they did was send the retarded folks down the hills first. They kind of made a path, smoothed down the snow. Then, they attached little bells to the backs of their sweaters; they would go down the hill first and the blind vacationers would follow them.

Now, just think about that! Think about an American State School, in your state or mine. Think about sitting down with the oftentimes incredibly dedicated, but always harried superintendents of these places, and suggesting a skiing vacation; you would probably get arrested! Going on a skiing vacation, or *any* other kind of vacation is so far from the reality of their world that it is not only incomprehensible for you or me to think in those terms, it may be some kind of mental aberration.

Nirje left a little pamphlet with me which he had just put together. It resulted from a conference that a group of 15 mentally retarded adults had in Malmö, Sweden. The purpose of the conference was to conceptualize

their unmet needs.

They met in small seminars and sessions. They talked out what they *need*. They talked out what they *want*. They talked out what they should *demand*. Then, their efforts were presented to the National Government and the Swedish Parents' Association.

I almost dare any professional or consumer to remember the last time a policy decision was made when the patients, or the residents, or the inmates, or the victims, or the "kids," or whatever they are called in various settings, had *anything* to say about what happened to *them*.

What I am trying to suggest is that the problems of the so-called mentally retarded, insofar as being heard concerning their needs and demands, are very similar to the problems university students faced until a few years ago. University students had very little to say concerning what goes on in their schools. They were almost considered an infringement on academic freedom by the faculty and administration. Then, some group of students got the idea: "Hey! We are part of this! Maybe we don't own the university, but the professors don't own it either."

The retarded people who met in conference for a few days in Malmö, Sweden put together a set of statements which, to me, has more profundity than any I have yet to see a professional group prepare. The work of the Malmö group is but one of a cluster of examples to suggest that the so-called disabled be part of the decision-making process, of program development, of priority-setting, not just because it is the right and moral thing to do, but because, in fact, they have a lot to offer.

For example, among other things, these Swedish citizens found from their experiences that, as far as their leisure time is concerned, they want to be together in *small* groups. They want dance evenings with no more than 14 or 16 people. Under no circumstances do they want to walk in large crowds in town, and they do *not* want to ride around in a bus which says, "Malmö Association for Retarded Children!"

Some more suggestions came out of the conference in Malmö. They all said that one should decide for oneself what to do during a vacation. These are folks, many of whom are supported by the state, making the demand that, in spite of complete or partial state-support, as *human beings* they are entitled to a vacation, and one of their own choosing at that.

Our problem in America is not a question of vacations, or who decides when and where they will be taken. Our problem in America is getting some people out of the thousand acres of the institution, and some others out of the mere buildings and for *some*, the problem is getting them out of their rooms or cells. There are people in our institutions who have not left their *rooms* for five or ten years.

On the one hand, we are dealing with such painful facts as solitary seclusion, human experimentation, no

alternatives to permanent segregation, and an America that cares little for some of its brothers.

On the other hand, in Sweden, we encounter a group saying, "We think visiting abroad is enlightening," and by "abroad" they mean another *country*, "but we don't want to go with other disabled people; we want to go with the non-disabled too." I could go on with a list of more examples, but I will not. I will not hurt you by sharing the injustices I have collected, because the list speaks volumes about discrepancies between that culture and ours. Possibly, the most illuminating summary of the differences between our culture and some others was offered by yet another Scandinavian, who said that the people of the United States know more about the problem of mental retardation than any other nation. Yet, while they know *more*, they do *less* than most others.

In fact, not only do we know more, but many of the great foreign programs for the mentally retarded, which we envy, were developed and tested and reported in *this* country. The whole gamut of special education services, the development of programs for the so-called trainable, *many* of the great international medical, psychological, and educational achievements were *created here*.

The Swedes and Danes and Dutch came to the United States, visited our centers, examined our prototypes, read our reports, and they *believed* us. They returned home and implemented our experimental models, while we wrote our reports and then went on to other things.

Some have come to the conclusion that, insofar as people with special needs are concerned, the more things change, the more they remain the same. They say that, in spite of laws and buildings and institutions and more teachers trained than ever before and more Ph.D.'s, the world is very much the same. There has been some progress but, considering our good intentions, the massive efforts and immense financial and material investments, it has been negligible.

We come back again—*why*? When one thinks about where we have been during the last 25 or 30 years, and where we are now, and where we are heading, he knows that the problem is in our heads and in our hearts. He knows that the problem has literally *nothing* to do with laws or buildings or appropriations of money, or how many people are trained in special education.

The problem has to do with how a society conceptualizes what a human being is, with how a society begins to describe the criteria for being human.

Since the beginning, I have been engaged in but one work, sections of which have been published as research monographs, papers, prose, verse, books, and, now, this talk. The focus of my work is Man, his capability for changing, his perfectibility, *his* reform, *mine*. Possibly, this is my way of saying that, while living may be plotless, all lives are part of a Grand Design. Each man has value. ■