

9. The Executive

Burton Blatt

The contents of this chapter derive from activities during my years as administrator in government and academe. Essentially, the plan is to present a personal analysis of this crazy business we call "mental retardation." It may strike some readers that this chapter's organization is the reflection more of idiosyncratic conceptualizations than of logical processes. I must admit that I believe that, in this crazy business, one fights general craziness with any resources at one's command, even those which are paradoxical or illogical. In this regard, my long suit has always been independence. Some people may define such resistance as hostility, a transference mechanism, or whatever; I choose to interpret their definitions as other examples of this crazy business. In a world of continuous war on peace, where people incarcerate, and even kill each other, because of labels ascribed to or withdrawn from human beings, should anyone be surprised to read here that I call this business crazy, that there may be some who will think me crazy for it, and that I would find such reactions to be but additional illustrations of the craziness in our field?

Dreams and Means

One should start at the beginning, and the beginning for me must include the language of theory, laws, beliefs, and prejudice—statements of principles-goals and their pragmatic translations. So, first the principles and goals and, secondly, with a degree of diffidence, how I have interpreted them.

Ideas

It seems entirely reasonable to suggest that goals represent important ideas to be achieved during some future period. Stated another way, I envision the term "goal" as including to some degree, and embodying but not encapsulating, such other terms as "objectives," "hypotheses," "dreams," and—most of all—"ideas." At least while I write this chapter, I have persuaded myself that there are compelling ideas that seek expression, that there are people in this field who agree and disagree with these ideas, that one way of gaining

a perspective on the "mental retardation" business is to evaluate those ideas.

The ideas are everywhere—in the literature, at the conventions, in the academy, in the aide. Typically, we express them as researchable hypotheses or as pragmatic goals. Typically, we find them substantively discussed: (1) as the educability hypothesis, or the nature-nurture controversy, or the human potential movement; (2) in agreement that human beings are entitled to fundamental services and opportunities, or that there should be options available to all people; (3) in the belief that the state has certain responsibilities to the people, and the people have certain rights; (4) or as more specific goals, such as the recently publicized White House hope to reduce the incidence of mental retardation by one-half by the year 2000; (5) or as very general goals, such as to guarantee each person the right to be born healthy, the right to habilitation, the right to the least restrictive placement, the right to an appropriate education, or the right to equal protection and due process under the law.

There are goals, objectives, dreams, and hypotheses; but, at the beginning, there must be ideas. Unfortunately, one reason why many ideas are timeless and persistent, yet feeble, is that they haven't fully existed in reality; we don't feel compelled to implement them. And, one reason why we aren't so compelled is that ideas, like people, are themselves mixtures of weakness and strength—which itself may be an important idea. Possibly, such mixtures are inevitable, the products of dissonance between intent and practice, noble hope and dismal realization, and shared bitterness. The lesson is plain. Be humble or one has very little to rely upon.

The following are some ideas that I feel are now in the air, not always because they are loud or striking but, rather, because they are fundamental and each possesses the sound of truth:

The idea that each human being has unique value. Not only is each person educable, not only is capability a function of practice and training,

motivation, and expectations, not only must all developmental programs be individualized, but so must one's life objectives. This is by way of saying that, although we believe that people can change, an individual's value as a human being isn't bound to his educability but to the intrinsic and inalienable right to be respected—because he is a human being, if for no other reason.

The idea that children represent our great hope to improve society. An individual is born and he dies, and during the interim, he struggles to realize his gifts, while the group—the government, the bureaucracy, what we call society—seeks to trap him, tame him, certainly standardize him. But, sometimes for good and sometimes for bad, there have always been people who would not be molded. They cause us problems; yet, they are our major investment for the future. The dilemma has always been to know who should be molded and controlled and who should be as free as the wind, who is dangerous and who is our prophet. And, so, we encourage freedom and individuality, while we weed out those who appear to be dangerous and maladaptive, while we pray that serious blunders have not been perpetrated in the name of society. And children must always exemplify humanity's universal continuing enthusiasm for a better future; therefore, if we fail with them we fail with everything.

The idea of the creative person. Each human being has a will to live, but also a dream to express himself, to realize his individuality in unique ways. Someone once said that living well is the best revenge. And, I truly believe, if we can agree that "living well" means living on one's unique manner, that living well is the only way. It's not enough to live, to exist, to be; all people seek to unfold, work to create something, and struggle for a principle or some different future.

The idea of freedom. A jaundiced assessment of our culture is that we revere life but disdain freedom. In our zeal to protect the weak, the aged, the so-called handicapped, and the ugly, we segregate and separate and stigmatize and make pariahs out of legions of people. We build industries to incarcerate—out of sight and out of mind—the blind and the retarded and so not only do we accomplish little to help them "see" and understand us but we preclude any possibility that we—the sighted, the brilliant, even the humanitarian—will "see" and understand them. Where is the liberty that our fathers wrote of in our declarations and constitutions? Where is the

liberty that children every school morning across America claim their country guarantees for all of its citizens? Where can we find total implementation of the principle that a human being is entitled to freedom under the law?

All Ideas Have Histories

Each of these ideas has a history, long and bloodied. Wars were fought and lives were lost because of them; the idea that all people are entitled to freedom under a just law is one that has turned red the soil of most lands. So, today, these ideas struggle against other powerful ideologies, moving ahead, then falling back, in favor during one generation and out of favor in another. Today, at this very moment, it is no different, except for the difference in time and perspective. However, ideas dealing with freedom, individuality, human values and human resources continue to intrude into public consciousness, crying for legitimacy and support.

I have learned that one way to at least partly understand what our values are is to read the papers and listen to the public communicators. As the saving goes, look it up in the newspaper; everything begins with the birth announcement and ends with the obituary. Unfortunately, people may draw wrong conclusions from discrete facts; hence, this attempt to relate "word" facts with "deed" facts. It's necessary; for as all ideas have histories, so do all people. But some leaders tend to think they don't, that each day is a clean slate in a new world.

The following items have appeared in our New York State newspapers in recent months:

"A bill passed last month by the state legislature and sent to the governor for signature changes the names of all department facilities for the mentally retarded from. 'State School' to 'Developmental Center' . . ."

No longer will we have to contend with the Syracuse State School, the Willowbrook State School, the Letchworth State School, the Wassaic State School, or the Newark State School. Rather, there is a new model; new progressives and humanitarians appear to be in control. We now have the Willowbrook Developmental Center and the Letchworth Developmental Center. We change the names and, as if by magic alone, things are expected to get better.

"The playground of the Syracuse Developmental Center is going to be

remodeled stressing safety and more creature comforts. Protruding bricks removed from all play areas and smooth epoxy applied to the sides of the slide to prevent abrasions are just two of the improvements to be made according to Al Clinton, assistant business officer of the Center. Improvements are being made to provide more safety to the retarded children that the Center serves”²

Some who read this announcement in our local paper remember that the Syracuse Developmental Center (formerly Syracuse State School) was once the oldest unremodeled and unchanged state school for the mentally retarded in North America and, just a year or two ago, it was torn down and rebuilt at an expenditure of approximately \$25 million. The aforementioned playground, constructed at a cost of several hundred thousand dollars, received more than one national award for its innovativeness. Unfortunately, children couldn't play in this playground without submitting themselves to unusual physical dangers. Essentially, this award-winning playground built by the New York State Department of Mental Hygiene was, and probably still is, “unplayable.”

“A State Comptroller's investigation of Matteawan State Hospital in Beacon, N.Y. has uncovered a pattern of fraudulent transactions and irregularities, including the bilking of inmates through doctored commissary records.

“A still-confidential audit report obtained by the *New York Times* showed that, in one recent six-month period, inmates were overcharged \$12,235 in commissary purchases.

In some of these cases, the report said, inmates ‘appear to have been charged for non-existent items’”³

Mental health and mental retardation are big business. In each state, not only is the state itself the “biggest” purchaser of new construction, but the state is in the position to offer millions of dollars in food, linen, garbage, you name it, contracts. Further, state employees handle transactions involving millions upon millions of dollars, oftentimes “on behalf” of incompetent, or presumably incompetent, inmates. So, the *New York Times* reports that “A Matteawan audit shows inmates were defrauded.” What else is new?

“It was a scientific experiment. For 30 years Federal health offices allowed 400 poor Black men known to have syphilis to go untreated despite the discovery that penicillin could cure their devastating disease . . .

“Eight years ago, as part of a study of immunity to cancer, a leading New York cancer specialist injected live tumor cells into elderly clinically ill patients without ever telling them in plain English what they were being given and why . . .

“Nearly 400 poor women—most of them Mexican-Americans who had already borne many children and had come to a San Antonio Family Planning Clinic for contraception—were enrolled in a study a few years ago to determine whether oral contraceptives did in fact cause psychological changes. All of the women were given identical-looking drugs, most of them active contraceptive agents. But 76 women received a ‘dummy’ or placebo drug. Seven pregnancies occurred before this study was ended, six of them in the placebo group.

“In 1967, coercion was charged in conjunction with a study in which live hepatitis virus was injected into mentally retarded children at Willowbrook State Hospital on Staten Island . . .”⁴

Probably also reflecting its revulsion from the above kinds of human treatment, all of it despicable, probably some of it criminal, the *New York Times* headlined the above article by Jane Brody, “All in the Name of Science.” Yet, let's now read a portion of a recent editorial in that same newspaper, reputed to be, and deservedly, the paper of record. Let's read the view of a newspaper that is not too immodest to claim that it published “All the News That's Fit to Print.”

“A wasteful dispute has long been seething between civil libertarians and elements of the psychiatric profession. The issue, in effect, is whether the mentally ill should ever be hospitalized against their will or must at all times be left to their own resources as a recognition of their rights as free citizens . . .

“What are needed are open halfway communities, preferably located in rural areas, where the less afflicted can work at farming or crafts . . .”⁵

Why did the *New York Times* print this lead editorial, titled “Civil Liberties for What?”

With the world at war, Watergates, impeachments, runaway inflations, pollution, crime, Henry Aaron and the new baseball season, with a whole world of problems and happy and sad events to choose from, why did the *New York Times* feel compelled to report to the world that mental patients really need communities away from typical society, preferably located in the country? Apparently, even the *New York Times* can be misled, possibly by a few influential colleagues or, just as possibly, by a great many Mr. and Mrs. Citizens who plunk down their twenty cents on weekdays and one dollar bills on Sundays for the privilege of not only reading the paper of record but giving it advice.

Apparently, the people in New York City have "had it." So too, apparently, has the New York State Department of Mental Hygiene. For, in an April 28, 1974, front page article, also in the *New York Times*, it was reported that the ". . . Department of Mental Hygiene, in a private memorandum and directive, has made a major change in its policy by telling its hospitals that 'we should not take the initiative in discharging the patient to the community.'" "Why, after the scandals of Willowbrook and Letchworth, the reports of joint commissions, with a new morality and in a supposed era of concern, does the *New York Times* ask us to slow down, if not apply the brakes? Why does it appear that the State Department of Mental Hygiene is doing one of its familiar herky-jerky about-face dances, tiptoeing in a 180 degree turn, skimming over the issues and principles that honest people would not ignore? Well, the Department of Mental Hygiene not only has "had it," but was "had"—by the "anarchists," the too-liberal psychiatrists, the reformists.

When they were persuaded to evacuate some of their more embarrassing units, they were not told that many people would be unimpressed with the idea that mental patients should live in ordinary neighborhoods, especially unimpressed if the designated neighborhoods were theirs. The Department of Mental Hygiene apparently never did develop a contingency plan that would permit them to deal with community resistance. Further, the Department of Mental Hygiene doesn't quite understand that, when mental patients or state school patients are released, it would be best to diversify their placements, not consolidate them in one or a few locations. And when the residents of Long Beach, New York complained to the State Department of Mental Hygiene that, in fact, the Department was creating new quasi-institutions in

the community with the purchase of converted motels or hotels for subsequent assignments of large numbers of mental patients to these facilities, the State Department of Mental Hygiene responded with lectures to the citizens on their moral responsibilities and the need for increased community acceptance and good will.

The irony of it all is that the community lay people had a much more insightful analysis of the situation, the problems, and possible solutions, than the State Department professionals. The community group said, "O.K., send your mental patients into our neighborhoods. However, if you want them to live in a normalized fashion, in ordinary neighborhoods, don't congregate them together. Permit us to continue to have normal communities—not places where there are large numbers of peculiar or different people, herded together in abandoned, dilapidated, or second-rate hotels."

The State Department of Mental Hygiene did not heed the community's advice, then pleas, then threats. They merely lectured at the community, to be good citizens, to accept differences, to have forbearance, to understand, to possess all of those virtues that the professionals in the State Department seemed to lack themselves. So we had to backlash, and a new and strange coalition of conservative average citizens—people such as our own mothers and fathers, our friends—and the *New York Times*. Wonders—and those who answer the question negatively are probably correct—will they ever cease? And so, we have a new state policy to slow mental patients' releases. Don't suggest discharge to them lest they request release. Cool it, boys; the natives back in the boonies are getting restless. Even the New York City sophisticates have "had it."

"The State Department of Mental Hygiene, defying city officials, plans to transfer 240 mostly helpless mentally retarded patients from Willowbrook to a four-story nursing home on Staten Island that has never been used because the city twice refused it a permit to operate . . .

"The (community) residents stress that they were not opposed to the plan because it would bring retarded people into the community, but because the nursing home in question would be a 'prison' and a 'zoo.'"⁶

"The city's top health officials and the heads of psychiatry at leading hospitals here have

clashed with the State Department of Mental Hygiene over state plans to reduce drastically the number of beds planned for the new Bellevue psychiatric center . . .

“‘Everybody who is a top professional in the city is absolutely agreed that the number of beds must not be cut’ said one of those at the meeting . . .”⁷

Rebuff after rebuff; yet the dauntless State Department continues to seek solutions to the problems of this crazy business. Like Don Quixote jousting with windmills, our mental health leaders, ever sensitive to both the community and current professional metaphors and slogans, would evacuate institutions by creating new ones in the community, would evacuate them altogether. So they claim, but they don’t have an analysis of what must follow. They are dedicated to “integration” and “humanization,” as they integrate inmates by segregating them in nursing homes, and humanize the large institution by dehumanizing the community. Unfair? Probably! Is there another way of analyzing this news? Certainly! Yet, does the Department deserve the censure? No, if nobody deserves censure for what we have perpetrated; yes, if anybody deserves censure.

“The Elmira School Board was told Wednesday afternoon that the district may receive nearly \$1 million more in state operating aid next year than was received this year . . .

“Weeks (the district business manager) said that he had nothing in writing and cautioned that \$700,000 of the aid increase might have to be used in programs for the handicapped and students with special needs.

“However, School Superintendent Dr. Paul R. Zaccarine said that his impression is the district already offers the programs for which the \$700,000 would be earmarked”⁸

Find a way, boys. Bring in the resources but, unless there is no other choice, don’t use your precious scarce funds for the handicapped. You have more important priorities, even if those funds were earmarked for the handicapped.

“Manly Fleischmann, the Buffalo lawyer who was chairman of the Commission (on the Quality Cost and Financing of Elementary and Secondary Education in New York State), was asked last week what had happened to his recommendations (made two years earlier). His first reaction was to laugh . . .

“Cost of the Commission: \$2 million.”⁹

So, again, what else is new? Problems occur, statements are made, tempers rise, newspapers report, commissions are appointed, funds are allocated, and the more things change the more they remain the same; except, things remain the same differently from the ways they remained the same before. And, so it seems, that’s all the people want. Things can remain the same so long as the color and rhythm of the sameness change hues and tempos from time to time. The major task is not to change but to satisfy everyone: first, the conservatives, but, also, the radicals; the conservatives, because they are in control and pay the bills and the radicals, because—if they are not under control—they will try to upset the delicate balance between no-change that appears as change and no-change that’s discovered for what it is. Satisfy everyone, those who pay the bills because they pay the bills, and those who are potentially, or really, irritating to the true power groups.

The ultimate aim is to not only “freeze” the present but establish some type of “warrant,” a hold on the future. It appears that one of the goals of a large segment of our society is to guarantee to their progeny what was guaranteed, and later delivered, to them—places of relative prominence and affluence in their society. And who could question that ideal? Who doesn’t want to prepare for his coming generations? Who doesn’t want a world for his loved ones that is at least as safe, and cozy, and comfortable as it was for him? The answer is obvious: those who never had anything, those who want something different for their children, if not for themselves. So, there is a conflict between variance and invariance, between the haves and the have-nots, between those who are more and those who are less selfish, between those who have more to protect and those who have more to gain, between the power block and the powerless, between the *New York Times* for the underdog and the *New York Times* for the overlord.

All ideas have histories, and the proper study of the histories may illuminate for us not only what occurs in the “name” of certain ideas but what the ideas actually mean. That’s the first lesson; a goal or an idea is nothing without its history, and then it’s only something in a special context and perspective. Therefore, let’s continue examination of a few of the more provocative ideas that we seem to be romancing at this time. And, if these love affairs weren’t made in heaven, there may be

a more appropriate place to bear witness to such unions—and if not to the marriages themselves, to what they have become.

Mainstreaming, The Community, and The Teachers' Union

As enunciated again and again, during informal discussions and in official or scholarly documents, our nation's educational leaders have now decided that handicapped children are best served in integrated settings. "Mainstreaming" will be, if it isn't now, the law, if not the practice, in this land. The Regents of the University of the State of New York urge a greater commitment by society to the education of handicapped children, with the primary responsibility for programs placed with local school districts and as integral facets of public education (1973). The litigation in our field exemplifies the centrality of the "integration-mainstreaming" issue.^{10, 11}

An analysis of the official reports of the various public committees and commissions responsible for formulating national policy on behalf of the handicapped indicates the marked escalation of concern about the integration issue. From the first annual report of the National Advisory Committee on Handicapped Children to then United State Commissioner of Education Harold Howe II in 1968¹² to its subsequent reports to later Commissioners James E. Allen, Jr.¹³ and Sidney P. Marland, Jr.,¹⁴ mainstreaming does not appear to be an important issue, at least an issue that deserves identification in annual reports. Contrast its virtual total absence during the late sixties and early seventies with the most recent report of the Committee.¹⁵ Now, priority recommendations reaffirm the Constitutional right of all handicapped children to a tax-supported appropriate education, regardless of their physical or mental capabilities. Further, the Committee now urges that regular education environments should be made available and, when there are differences between, for example, parents and school authorities, due process procedures should be operational to insure an equal educational opportunity for each child.

A comparable analysis of *MR '67*,¹⁶ the first major policy statement of the President's Committee on Mental Retardation, and all of the subsequent reports, including its most recent one in 1974, *Silent Minority*,¹⁷ illustrates a major shift in policy discussions from an earlier deficit-oriented and categorical segregation model, based on the assumption that handicapped people need special and separate services to be delivered by

professionals, to an avowal of principles of: advocacy, normalization, least restrictive alternatives, due process, and rights rather than privileges. Witness that, in 1967, the President's Committee appeared to be very proud of the fact that there were nearly 700,000 children in special classes for the educable and trainable mentally retarded. Note that, in 1967, there was little distinction made between special class and special education; special education was special class. Note, again, how "needs" were discussed in 1967, in terms of more services, not "open" or integrated services. And, although in 1974, the realities for people with special needs may not be very much different, the rhetoric surely is—with the language today expressing concern for an individual's rights, his freedom, his entitlements, his need to be a part of a world that includes rather than excludes him.

I don't know of a professional organization, or a municipal, state, or federal system or agency, that is plainly antagonistic to the mainstreaming principle. Certainly, there are individuals within those organizations and programs who take a dim view of the mainstreaming movement. However, mainstreamers seem to have the segregators on the run, at least for now. Or do they really?

Item 1: A debate is currently smoldering in Syracuse, and it will probably rage again as it did a year or two ago. It's a complicated matter, as all of these things are; suffice to say, I think there is one group who want a special school for the trainable retarded and another group who believe that a special school is neither desirable educationally nor responsible fiscally.

Although they have difficulty in believing they've won, the special schoolers have won; the Syracuse City Council, the Board of Education, and the school administration have all agreed that a special segregated school for trainable children is necessary, desirable, and defensible. Those of us who have raised questions concerning the need for a separate school, during a period of significant pupil enrollment decreases (e.g., a 600 drop for 1974-75 alone) and in a supposedly new egalitarian era, have been accused of insults against children. It seems ironic, at least to me, that in an age when unusual efforts are being exerted by local communities to integrate, for example, Black children, more unusual efforts are being exerted to segregate retarded children. While the courts in Boston and Detroit insist that minority youngsters be integrated—irrespective of long bus rides and

significant program modifications and costly expenditures—the Syracuse City Fathers continue their plans to segregate handicapped children, whatever the costs.

Item 2: Syracuse is in Onondaga County and, reflecting the same “disease” of that city, the County Board of Cooperative Education (BOCES) has been seeking citizen approval for an additional new segregated school for the handicapped and for those youngsters enrolled in what was once called vocational education but now is referred to as career education. Probably, more out of anger in again having their “pockets picked” than for any reasons concerning principles or morality, the voters recently turned BOCES down—for the first time in New York State history, denying a BOCES program the opportunity to expand its segregated mission.

Why does BOCES want a new school? Again, the polemics run rampant during these kinds of discussions and, trying to be fair but probably not succeeding very well, I should point out to anyone who hasn't noticed that I am singularly unimpressed with any efforts to expand or strengthen segregated settings for people. Having said that, I can now claim that the special education officials in the county want a new school because, since the beginning of organized society, bureaucrats want larger budgets, more staff, bigger and newer facilities, and control. Certainly, the current segregated school for the trainable mentally retarded in Onondaga County is inadequate. It is old, crowded, inaccessible to many families, and inappropriate. On the other hand, the only virtues I can see in constructing a new school is its newness and, possibly, its greater square footage per child. Yet, irrespective of its newness, size, or even beauty, a segregated school is still a segregated school; it will be centrally located and, therefore, inaccessible to many families; it will not permit the integration of the handicapped with the nonhandicapped and, as importantly, vice versa. However, exactly as with the Syracuse group, time is on the side of the county segregationists. Someday they will have their new school, if not after the new referendum, then the referendum after that, or the next one, or the next one.

Item 3: Ideological banners fly from the public relations staffs of the New York State Department of Mental Hygiene, proclaiming: deinstitutionalization, community programming, advocacy, priority reassessments, normalization.

Yet, in the city of Syracuse alone, during the past three years, more than \$50 million (plus millions more in interest) has been expended by the State Department of Mental Hygiene for the creation of new segregated institutions.

The Syracuse State School, created in 1854, the oldest state school for the mentally retarded in North America in continuous operation on its original site, has now been torn down and rebuilt, almost brick by brick, on that site. Where, formerly, it had a resident population of 250, the new state school is built to serve 750 residents. Permit me to remind you that not only is the facility larger but it is no longer a state school; we now have in our community a brand new concept as well as facility, the Syracuse Developmental Center, that has replaced the old state school. Similarly, what was once the small, essentially outpatient, Syracuse Psychiatric Hospital is now the brand new \$25 million Hutchings Psychiatric Center, capable of “bedding down” 750 inmates.

Item 4: “Everybody” in Syracuse had agreed that we should return state school residents to the community as quickly as possible. Therefore, the school's director acquired a small residential facility to develop as a group home. Neighbors-to-be learned of this plan and, very quickly, drew up a petition which they presented to Mayor Lee Alexander; said petition denying any hostility to the concept of community integration but, on the other hand, providing a number of compelling reasons why this community residence would be inappropriately placed in that particular neighborhood. Mayor Alexander agreed with the petitioners. End of group home plan. And, when I was interviewed on television soon after the Mayor's decision, I received a number of rather hostile calls and letters, the following among them:

Dear Dr. Blatt:

You should live next door to mentally retarded like I do. On the weekend they go all over surrounding streets, scavenging big pieces of metal trash and wooden trash (they have superior physical strength to make up for lack of mentality) and so on Sunday the peace of the Sabbath is broken by their hammering on it (trash is picked up Monday a.m. in our neighborhood).

One looks about 30 and plays like a little kid. The other looks about 7 or 8. He thinks he is a method of transportation all the time. And goes down the street making like a

motorcycle, an airplane, a racing car, etc. Sometimes he just stands and yells as loud as he can yell. They both do this.

They have not one but two dogs that bark 24 hours a day.

I say these people have no business living in a normal community—whoever sold them the house should get a medal!

I say these people should be provided with a community of their own; live with their own kind.

I understand there is one at Liberty, New York. I sure would like to be able to send these people there.

(Signed)

Has had it.

Item 5: Now, the most puzzling for last, the quintessential hypocrisy for the finale. My friends in the Syracuse City Schools, many of whom have been students in my classes, others of whom have served with me on committees, a few of whom are—truly—my friends, collectively agree that handicapped children deserve to be integrated in regular programs. Yet, circumstances and promises made by their predecessors force them to support the construction of the aforementioned new segregated school for the trainable in Syracuse. Yes, precedence, teacher prejudices, and practicality require them to continue their elaborate segregated special education program. However, if they had their way in the best of all possible worlds, they would integrate more children with special needs, especially the mildly handicapped. Similarly, members of the Board of Education agree fully with the concepts of mainstreaming and normalization.

And, as if to add insult to injury, in spite of public pronouncements in support of the principle of integration, the Syracuse Board of Education, with the concurrence of school officials, has entered into a negotiated agreement with my friends in the Teachers' Union which discourages school authorities from requiring regular class teachers to accept handicapped or disruptive youngsters in their programs.

It is the ultimate nonsequitur to claim to foster integration in a system where those same claimants support segregation. Not only is this crazy business, but it is also funny business.

The Year of the Child and Other Indecencies

Surely, there are reasons, related chains, that make indecencies almost inevitable. The reader has a right to ask why these indecencies occurred. I have some notions to "explain" them and you probably will develop yours. But I don't have truths, and you might not find those either. Someday, maybe, but for now, I only claim to collect and publicize indecencies, not adequately to understand them.

Item 1: Sometime during the spring of 1970, an administrator in the Massachusetts Department of Mental Health was in San Francisco. Upon his return, he remarked to colleagues that the California Chinese seem to always have a Year of something or another, and he suggested that this would be a good time for Massachusetts to have the "Year of the Child."¹⁸ The idea caught fire. The Commissioner of Mental Health announced that 1971-72 would be the "Year of the Child" in the Commonwealth. Finally, attention would be given to the needs of children, priorities would be reordered, and an increased proportion of the Department's resources and programs would be allocated for children.

Unfortunately, this commitment to children was made after the Department of Mental Health had submitted its budget requests to the legislature. No resource shifts would be possible. Additional state assistance was equally impossible. Additional federal funds to meet the commitment didn't materialize. The "Year of the Child" was never more than a gigantic hoax, a public relations ploy created out of innocence, "implemented" by the cynical, and finally exposed publicly amid embarrassment and frustrated disclaimers from the insiders and righteous anger from the muckrakers. The grand objective, the beautiful logo on thousands of wall posters, the fervent promises made, were all garbage, like confetti after the parade, like a kewpie doll the morning after in the noon day sun. All this from the chance notice of a wall poster in a Chinese restaurant. How easy it is to do something, and how difficult to accomplish anything.

Item 2: I can hardly wait to complete this next section on advocacy. In my study, I am surrounded with piles of books, monographs, chapters and papers—all dealing with the definition, theory, implementation and practice of various forms of human help we now term "advocacy." Who really knows, but that, when I finish this section, I will find a paper I wanted to

use earlier but is now hopelessly irretrievable in a morass of advocacy paper. But, to paraphrase what a colleague once said in an entirely other context, do we have a knowledge explosion on advocacy or merely a paper explosion? One wonders, and here's why.

Wolfensberger described the various advocacy roles for children, including those that are primarily instrumental, some instrumental and expressive, and even one that is primarily expressive, the advocate-friend.¹⁹ As he and others noted, there are advocates who assume roles as guardians, friends, adoptive or foster parents, legal advisors, and "helpers." However, the one characteristic advocates must have in common is a partisanship, a primary interest to serve the client. Literally, the advocate is one who pleads the cause of another person, not conflicted by self-interests or loyalty to an organization or to one's profession. This partisanship, as a matter of fact, is one of the significant factors in the case Wolfensberger makes for the utilization of citizen-nonprofessional advocates on behalf of people who are mentally retarded.

The idea of advocacy has so captured the thinking in our field that, as happens to all good ideas, there are now groups attempting to appropriate—capture for themselves—the idea. Why must the advocate be professionally disinterested and nonpartisan, preferably a lay person? Why indeed? Wouldn't it be best for an advocate to be a spokesman for the deliverers of services so the program as well as the advocate can be held accountable for the work of the system? Would it? Some people think so.

As a matter of fact, the Regents of the University of the State of New York not only believe this but have developed a sure-fire method to implement an advocacy system that, in my opinion, will only lead to the destruction of the concept of advocacy in the public schools of New York State. The Regents have designed an ingenious method to co-opt an idea intended to serve clients but which now would serve the providers.²⁰ They recommend the creation of a new advocacy system for children with handicapping conditions. They claim that a good advocacy system requires strengthened cooperation among agencies in the public and nonpublic sectors. Therefore, to be effective, any system of advocacy and service delivery must provide for cooperative arrangements agreeable to the Commissioner of Education and to those people responsible for the supervision of

institutional programs at the state level. Consequently, the Commissioner of Education should be given the responsibility for the overall supervision of programs for handicapped children. Further, the state-wide system of advocacy should be vested by statute with the Commissioner of Education, and ". . . local school districts, BOCES, and other state agencies (should) have a proper role to play and that, wherever possible, parents represent the starting point."

Imagine a state-wide advocacy system, where the advocate is employed by the state yet uses his expertise or services only to serve his clients, with the chief advocate being the Commissioner of Education, and with other state and local agencies and individuals having proper roles in that system—including lastly, but including wherever possible, parents. Just imagine!

Item 3: During the past several months, the R. J. Reynolds Tobacco Company, manufacturers of Camels, have been conducting a vigorous advertising campaign to attract the "honest and independent" smoker. Each of the advertisements in this series began with the question, "Can you spot the Camel Filters smoker?" The scene is in an airplane, at a party, or on the beach. Various people are pictured, saying something or doing something or appearing in some distinctive manner. The reader is to deduce who smokes Camels and, presumably, why. Surely, you have seen these ads. I have but, as with most advertisements, my observations were mindless; for so much of today's reading, advertisements or otherwise, mindlessness is a fairly safe and respectable condition to be in. If not for Liz Smith, an attorney who is a member of our Center on Human Policy staff, I never would have noticed that a particular Camel ad was vicious, bigoted, and unfair—but as typical of our culture as apple pie and baseball games. Among five other people on the beach, ranging in "beautiffulness" from zero to everything, is Tyrone Shulace, "beach pest." We are told in the ad that the "58" on his shirt stands for his I.Q. Further, Tyrone thinks that "off shore drilling is something Marines do." He smokes "Huff'n Puff" super filtered cigarettes. Obviously, that makes him retarded, unappealing, and deserving of whatever ridicule is heaped upon him.

Liz Smith wrote to the president of the R. J. Reynolds Tobacco Company, Mr. Collin Stoker of Winston-Salem, North Carolina. Within a week, she received a reply from C. A. Tucker, Vice

President and Director of marketing for the company. He was apologetic. He said that:

"We do our best to create advertising that will appeal to large numbers of people. We have found one of the best methods to be humor. The 'Can you Spot' ads are intended to be much like a cartoonist's caricatures with the larger-than-life portrayal of the subjects not meant for literal interpretation . . .

"We have a great deal of empathy for the kind of public spirited work you are doing (our company supports local organizations involved with mental health)." ²¹

And, I think Mr. C. A. Tucker is right. This ad will appeal to large numbers of people. It will be thought very humorous. And, besides, R. J. Reynolds does have a lot of empathy for the kind of public spirited work we are doing. And, I am sure, the company supports local organizations involved with mental health. They're as clean as a hound's tooth.

Item 4: Behavior modification, operant conditioning, behavior shaping, there are those and many names for a relatively new technique that has fast replaced psychotherapy as America's mental aspirin. The following bizarre story ²² is not intended to repudiate the importance or effectiveness of behavior modification techniques. There is no intention, at least on my part, to dissuade the reader concerning the great promise this method holds if used judiciously and appropriately. Rather, the Miami Sunland Training Center scandal is another indication of good ideas gone awry, good intentions misanthropically realized, potentially good people turned sour.

Sunland Training Center, in Dade County is a state institution in Florida, domiciling 900 people, each labeled mentally retarded. Like most state institutions, some of the residents are very retarded, some mildly retarded, some "retarded" only because they had once been labeled retarded. Like most large institutions, the age range represents a very wide spectrum indeed, young children to adults; and the range of behaviors represented at this institution is uncommonly broad and multidimensional. In essence, Sunland has a very heterogeneous group of residents, some of whom are at least adequately identified by the label "mentally retarded." Enter into this scene a new superintendent, one with a good reputation for "getting things done," for doing the right things, for being truly concerned about the mentally

retarded. Enter also a psychologist who is given a free hand, who believes he has answers to the developmental problems these residents present, who is strongly devoted to behavior modification techniques as the foundation, the beginning direction, for behavioral improvements.

The consequences: homosexuals compelled to wear women's underwear; "thieves" who steal Cracker Jacks required to eat bars of soap and wear special signs noting each as a "thief"; those found masturbating, forced to masturbate in public; one inmate, who defecated in his pants while in seclusion, required to hold his soiled underwear under his nose before washing the pants out in the toilet; another "thief," caught stealing Sugar Pops, placed in restraints except to go to the "potty"; another boy who didn't want to go to bed locked up in a seclusion room; and on, and on, and on—children cleaning up their own vomit, rinsing their mouths with soap, denied meals, denied "privileges," tortured. Surely, this is not what Skinner planned for a new Walden. Surely, this is not what Barrett, Lindsley or Sidman envisioned. But, in this business, good ideas are often spoiled and altruistic motivations are corrupted.

Item 5: A letter to the writer of this chapter.

"In reviewing your book, *Souls in Extremis*, I am informed that the pictures in "Central" State School are in reality . . . State School. I would suggest that the material is quite out of date . . . the conditions you mention have definitely changed.

"One of my main criticisms would be the picture of the Community Store. I cannot identify the page as it does not have a page number, but the entire paragraph there is incorrect. The interest for residents is strictly regulated by law. There is a small amount left over because of bookkeeping difficulties. This amount is never used for the Community Store, never used for a retirement banquet, employees' gift fund, etc. The purposes for which this money is used must be itemized and presented to the Department of Mental Hygiene for approval. I take strong objection to this . . ." ²³

But here is an entirely different letter, from the above superintendent's immediate supervisor:

"By chance, I must confess, I was going through the Department library and found your book, *Souls in Extremis*. I have not been

able to start reading it yet but was caught by the pictures in the chapter, 'A Photographic Essay, 1971,' by Mark Blazey. What struck me was your straightforward description of Community Stores and the use of money for the benefit of employees. This came to my attention last Christmas when I found that these funds were used to pay for employee Christmas parties. I am enclosing a memorandum which was sent out concerning this problem and I think procedures are such that this misuse of money should be a thing of the past."

STATE OF
DEPARTMENT OF MENTAL HYGIENE

February 15, 1974

DIVISION OF MENTAL RETARDATION
AND CHILDREN'S SERVICES

Memorandum No. 74-5

TO: State School Director, Deputy Directors for
Administration

Central Office Distribution Schedule 2

SUBJECT: Review of Community Stores, Donations and
Patient Accounts by an Institution Ad-Hoc
Committee

No proposed budget for community stores, donations, or patient interest accounts for fiscal 1974-75 will be accepted unless reviewed by a Committee whose size shall not be more than seven (7) members and whose membership shall consist of one-third parents, one-third resident, one-third employes, and one member of the Board of Visitors.

The Division policy will be that all funds from these sources shall be used primarily for residents' benefit. Recommendations will be made to the Director who will make final decisions.

Each institution will notify Dr. . . . 's office in writing upon the selection their review committee.

This memorandum will be in effect until superseded by future directives.

The supervisor adds:

"I am also enclosing our memorandum on burials and maintenance of cemeteries (also discussed in book, with our treatment similarly criticized by aforementioned superintendent) which hopefully will start solving this problem."

August 12, 1974

DIVISION OF MENTAL RETARDATION
AND CHILDREN'S SERVICES

Memorandum No. 74-30

TO: Directors, Deputy Directors, Clinical and Deputy
Directors for Administration of all Division of

Mental Retardation and Children's Services
Facilities

Regional Directors

Central Office Distribution #2

SUBJECT: Burials and Maintenance of Cemeteries

It has come to the Division of Mental Retardation and Children's Services' attention that many graves in our institutional cemeteries are unmarked or marked only by a number. To correct this situation, the Division of Mental Retardation and Children's Services enunciates the following policy:

1. All graves in Mental Retardation and Children's Services' facility cemeteries will be distinguished by a marker with the person's name, date of birth and death, and appropriate religious symbol. No numbers will be used.
2. All burials will have a religious ceremony, unless such a ceremony is waived in writing by parents or guardians.
3. All state cemeteries will be maintained, and whenever possible, no new plots will be opened and community cemeteries should be used.
4. All graves, whether in state or community cemeteries, will be distinguished by a named marker.

The correspondent continues:

"The other things that are photographically highlighted are obviously more difficult given the inertia of the system. However, we have a number of projects which I hope will make some dent in the problems."²⁴

The institutional superintendent claims that I am unfair, that the problems we portrayed have either been corrected previously or were never present. Her supervisor informs me that he has observed the same institutional abuses we described. He also tells me that, given the inertia of the system, other aspects of this photographic essay will not be corrected very easily. Yet, I am threatened in a subsequent letter by the superintendent who warns me that, because she is an advocate for the residents, she intends to "pursue this (our) transgression further." We have been waiting and, although I have heard several rumors that I will be sued, our last communication from this superintendent was January 23, 1974. Who is deceitful? Who are the advocates? And, if as claimed, the superintendent is an advocate, what does advocacy mean?

Innovation is the Name of the Game

Innovation is the name of the game, but it's not the stuff in the game. We may convince ourselves that we are truly in an innovative era in mental retardation. There is a plethora of monographs, books, and full journals devoted to innovative approaches to evaluating, placing, treating, dealing

with, serving, and counting the mentally retarded; there are even claims that innovative approaches to paying for it all are now available. We read about innovation in special education²⁵ and innovation in other mental retardation settings²⁶ and we are tempted to believe. However, notwithstanding instructional materials centers, engineered classrooms, "hot" new dyslexia treatments, the effects of early educational intervention programs, new directions, and exciting frontiers emerging, notwithstanding the wish to believe, the jaundices and disappointments of the past remain, and therefore one tends to doubt. It isn't that we don't want to believe; we do or, I should say more correctly, I do. It's not that the evidence isn't piling up; we now have a Mental Retardation Source Book²⁷ and, believe it or not, I am currently serving on a committee that is optimistic enough to think it can develop a Mental Retardation Fact Book. Who would have thought that?

Nevertheless, I don't think that there is very much innovation in our field: first, because innovation requires new ideas (that's always a rare commodity) and, secondly, because we seem to be deliberately planning to achieve the antithesis of innovation and diversity.

Essentially, ours is a monolithic system, a single block of ideological stone; ours is a massive and solid, uniform, no-option, no-alternative, slot machine type of strategy that would seek the single best method, the single best procedure, the single best something or anything.²⁸ The Monolith is not the special class, or even the segregated institution, or any other special setting or procedure or model. Rather, the Monolith is the one way, the unavailability of alternatives for clients, families, therapists and others concerned with the education and treatment of people with special needs. The Monolith supports "innovative" programs that evolve into either carbon copies of what is currently available or distortions of something that was once good, bad, or indifferent but will, surely, become tomorrow's new fad or the "magic" of the next modern-day alchemist. One thing that I've learned from all of this is the value we must assign to truly creative thinking and planning; it's an infrequent occurrence, often unrecognized, usually feared, and commonly disdained.

Essentially, I am claiming that innovation is more a myth, or a dream, in our field than a regular occurrence. Our schools and teachers' colleges are

akin to national franchised educational supermarkets that encourage almost-infinite varieties of methods and curricula, that foster open schools and contiguous traditional schools, that support both free schools and special schools, and—in spite of the seeming flexibility—demand an oppressive conformity to the products, the methods, the materials, and the curricula available in the supermarkets. Sameness of mind is the mortar that binds and strengthens the Monolith—in the elementary classrooms, in the teachers' colleges, and even in the minds of the consumers. So, too, our mental health planners now struggle to develop not only better but the the best health delivery systems, each in their ways promoting an invariance of opportunity and a technological influence on people that usually leads to the technology as the end, not the means.

The consequences are around, everywhere. We advertise segregated schools, open schools, free schools, and ungraded schools in the educational supermarket, for the same reasons others advertise Chevrolet, Camels, and Popsicles. We advertise group homes, halfway homes, regional centers, and even large institutions because we believe we have the best product or, in any event, we want to convince the consumer that, all things being equal, our products offer the most value. As a result, our field presents an appearance of innovation, when it is more a striving towards conformity and agreement. We offer many methods and tactics, not because we prefer diversity but, rather, because we are uncertain as to what is best among competing claims. We encourage new models, not because we believe that thoughtfulness emerges from struggling with the creation of a new model which is only for the good, but rather because we hope that the new model will offer a better solution and, eventually, a universal solution. We develop new curricula, new delivery systems, new techniques and prescriptions, hardly ever because we believe it would be instructive to our colleagues to inform them about how we attempted to solve various human problems, but because we are unable to believe our colleagues think or know enough to solve their own problems. That is, we seem to believe that the value in developing treatment models lies in how they can help us understand better the process in developing prescriptions. Fundamentally, the majority among us believe that there are best methods and best prescriptions, and we must train technologists to teach, to dose, to supervise, to serve others with those "best"

procedures. There is a minority which believes that, although technicians will always be needed and are important, professionals must be prepared not as technicians but as creators of environments; there are no best methods in the human services; the process of creating a human environment may contribute more to the excellence of that environment than the objective and technical characteristics of the environment itself.

Definitions, Labels, Incidence and Prevalence

Wedged by Executive and Squeezed by Academic Views

Years ago, when I first began seriously to study institutional life, I learned that, in New York State, residents of state schools were labeled "material" and their attendants and supervisors were labeled "items." More recently, while attending a meeting on the so-called geriatric problem in mental retardation, I learned that human beings are called "inventory" by some state department employees who have been designated responsible for their care and humane treatment. During the years, I have learned that labels are important, because they picture the feelings we have for people and things, and because they serve to peel away the concealment of our prejudices.

Labels may not be of consequence in a clinical setting; in fact, their usage with individuals should be restricted, if not discouraged. However, there are people who need service and the administrative assignment of resources to programs and groups requires the utilization of identifiers, labels. We can't even discuss policy priorities, much less programs, without naming people and things. For better or for worse, we have and will continue to have, and suffer with, labels. Hence, we will need to contend with an "epidemiology" of mental retardation—withstanding the knowledge that mental retardation is neither a disease nor a condition with "lawful" characteristics.

The labels we use are critical in understanding that epidemiology, because incidence and prevalence estimates have little meaning when separated from a definitional context. Therefore, notwithstanding the President's Committee on Mental Retardation, which has reported that there are 6 million mentally retarded individuals in the United States (a convenient application of the three percent estimate) and other approximations, I believe it remains essential for us to review what

else may be known about these complex matters. I begin here with where I began the paper itself, discussing metaphors, language, and the relationship between our words and our values. We should begin by noting again that incidence and prevalence data are not grounded only in objectively derived disease entities.

The American Association on Mental Deficiency has recently revised its definition of mental retardation. Before 1959, there was more or less general agreement that the incidence of mental retardation is approximately three percent. That is, mental retardation was assumed to be normally distributed in the population and it was further agreed that the psychometric "cutoff" would be seventy-five I.Q. or one and one-half standard deviations away from the mean. In 1959, the Association's terminology and Classification Committee, chaired by Rick Heber, redefined mental retardation and, included in the revised definition, there was the statement that subaverage intellectual performance refers to a psychometric score which is greater than one standard deviation below the population mean on tests of general intelligence.²⁹ With that change in definition, 16 percent of a typical population would be, psychometrically at least, eligible to be designated as "mentally retarded."

In 1973, a subsequent committee of the Association, now chaired by Herbert Grossman, again revised the definition to include as mentally retarded only those who are "significantly" subaverage in intellectual functioning, where "significantly" means performance which is two or more standard deviations from the mean or average of the tests.³⁰ With the figurative, and possibly literal, stroke of Herbert Grossman's pen, a committee sitting around a conference table reduced enormously the potential incidence of mental retardation, never having to see or dose or deal with a client, only having to say that, hereinafter, mental retardation is such and such rather than this or that. We cannot redefine measles, or cancer, or pregnancy with such external procedures. It's obvious; mental retardation and emotional disturbance, and even such seemingly objective conditions as blindness and deafness, are less objective disease entities than they are administrative terms; they are metaphors more than anything else.

It is important to understand that merely having a low I.Q. neither legally nor functionally jeopardizes how society views a person or deals with him. Sixteen percent of the population have I.Q.'s

below 85; three percent of the population have I.Q.'s below 75; but probably no more than one percent of the population are ever in their lifetimes administratively adjudicated as "mentally retarded." This is by way of saying that the incidence, prevalence, and characteristics of mental retardation depend upon such influences as definition and criteria, program supports, cultural value, social class, and other factors that have more to do with political and administrative rather than biological or psychological matters. This situation exists across all so-called disability areas, and consequently, estimates of various categorical handicaps vary from study to study, from culture to culture, and from time to time. Disability means no more or less than being placed in a special class, a special program, or a special category or setting, as a consequence of that disability. The most relevant definition of a disability must refer to the fact that it is essentially administratively determined.

Incidence and prevalence estimates, predictions of program needs, and cost-benefit analyses are extraordinarily hazardous when dealing with these diverse administratively-defined populations. For example, in one state, attempts are made to integrate so-called educable mentally retarded children in regular grades, in another area (e.g., Prince Edward Island, Canada) such youngsters are in regular grades and are not even thought of as "mentally retarded." In yet another state, every effort is made to place as many children as possible with I.Q.'s less than 75 in special classes for the mentally retarded. Then, we might ask, what is the prevalence of mental retardation in the public schools when, on the one hand, there are school systems that deliberately attempt to identify such children as retarded and others, equally interested in their well being, that deliberately attempt to integrate such children fully into the mainstream of educational life?

Table I summarizes prevalence estimates of handicapping conditions obtained from several recent studies. Some cautions should be emphasized: with the exception of our yet unpublished preschool data, summarized in Column One, the prevalence estimates are for age groups 5 through 19. Therefore, I am presenting prevalence of handicap among preschool children with prevalence estimates for school age children, while entirely neglecting adult prevalence rates. Secondly, none of these estimates account for what is now called minimal brain dysfunction, learning disabilities, or Strauss Syndrome. Intentionally, I have not included prevalence

TABLE I.—Prevalence estimates of various types of handicapped children

Handicap	Prevalence estimates by percent				
	1 ¹	2 ²	3 ³	4 ⁴	5 ⁵
Educable mentally retarded.....	0.5	2.0	2.3	1.30	1.30
Trainable mentally retarded.....				.24	.24
Hearing-impaired.....	1.1	1.5	.575	.10	.575
Visually handicapped.....	.6	.2	.1	.05	.1
Speech impaired.....	3.4	2.0	3.5	3.60	3.5
Physically handicapped... ..	1.0	1.5	.5	.21	.5
Brain injury and learning disabilities.....	1.7	(⁶)	1.0	1.12	1.0
Emotionally handicapped..	1.0	2.0	2.0	2.00	2.0
Multiple handicaps.....	(⁶)	(⁶)	(⁶)	.07	.07
Total.....	9.3	9.2	9.975	8.69	9.285

¹ Estimates based on a Syracuse University-Systems Research Inc. Head Start questionnaire; T.M.R. and E.M.R. combined; no estimate on "Multiple Handicaps."

² Estimates by Romaine P. Mackie and Lloyd M. Dunn, College University programs for the preparation of teachers of exceptional children, USOE bull. No. 13, Washington: GPO, 1954.

³ Estimates prepared for Bureau of Education for the Handicapped, USOE, in "Estimates of Current Manpower Needs in Education for the Handicapped, 1968-69," Washington, December 1968.

⁴ Estimates used by Rossmiller, Richard A.; Hale, James A.; and Lloyd E. Frohreich, "Educational Programs for Exceptional Children: Resource Configurations and Costs." Madison, Wis.: Department of Educational Administration, University of Wisconsin, 1970, p. 129.

⁵ Conservative estimates used by "The Fleischmann Report on the Quality, Cost, and Financing of Elementary and Secondary Education in New York State," Viking Compass, vol. II, p. 260.

⁶ No estimate.

estimates for this condition if, indeed, it is a separate condition; those that have made attempts to estimate the prevalence of learning disabilities indicate data ranging from a 5 or 6 percent estimate to 20, 30, and 40 percent. Next it should also be noted that some of these prevalence estimates did not include multiple handicaps as a separate category; rather, they chose to indicate only the primary handicapping condition. Further, Table I hardly illustrates the enormous range of estimates available. For example, a recent Rand study on services for handicapped youth summarizes prevalence rates reported by 11 different groups.³¹ They range: in total prevalence of handicapping conditions, from 4.08 percent to 24.50 percent; in mental retardation, from 1.54 percent to 7.00 percent; in speech impairment, from 1.30 percent to 5.00 percent; in emotional disturbance, from .05 percent to 5.00 percent; and in learning disability, from .03 percent to 7.00

percent. Lastly, one should mention that, for most people, in our field, prevalence and incidence estimates are either meaningless or valueless, or both. Many such colleagues would claim that institutions, or schools, or clinics have what they have. What possible differences could these data offer?

While you may legitimately inquire, therefore, what value can prevalence studies provide, you might also ask what other comparable data are available to permit us to plan better, however crudely. And, while you ponder that unsatisfactory question, we should return to Table I, and our data, and—eventually—some recommendations. The reader will find a rather striking similarity between data derived from our Head Start questionnaire and other estimates—with the exception of the prevalence of mental retardation. Ours is low (0.5 percent) in contrast with estimates of 2 percent and 2½ percent in the others studies. We believe this discrepancy is accounted for in our earlier discussion on factors influencing prevalence rates. Further, our reported low prevalence of mental retardation is entirely consistent with the numerous so-called educability studies concerned with the preschool deprived.^{32, 33} Specifically, we account for the low prevalence of preschool mentally retarded children in

communities that traditionally include high prevalences of school age mentally retarded children to be a function of the nature of this thing we term “mental retardation”. Mental retardation is essentially unidentified in the preschool years except when it is accompanied with central nervous system pathology or clinical stigmata and, therefore, usually with moderate or severe disability. So-called cultural familial mental retardation, quite common in later years, is essentially nonexistent among infants and preschoolers. What was probably reported to us as “mental retardation” by Head Start Centers were observable stigmata and moderate or severe cognitive disabilities. However, for this condition of “mental retardation” as well as others, it is not possible accurately to assess the influence of such factors as coercion, political motivations, and naivete, in the determination of our, and these other, prevalence estimates.

The ostensible purpose for defining groups, labeling individuals, and developing incidence and prevalence estimates is to serve better those individuals defined and labeled. If labeling does not lead to services, and it often doesn't, it reduces what might have been a helpful procedure to a pejorative and detrimental act.

TABLE II

Estimated Needs for Special Community and Residential Services for
Children and Adults in a Modal Region of 500,000 Population

Category	Percent of Total Population in Categories	Estimated Number in Categories
I. Major Categories		
a. Percent of total population needing special services due to their mental retardation.	1% of total population: .75% EMR; .20% TMR; .05 SMR.	5,000
b. Percent of total population needing special services due to their behavioral disturbances.	1% of total population: .50% Severely ED or SM; .50% moderately or mildly ED or SM.	5,000
c. Percent of total population needing special services due to moderate and severe sensory and/or physical disorders.	1% of total population: including .03% blind, .08% deaf; .14 severely sensory and/or PH; remainder partially disabled.	5,000
II. Sub-Categories		
a. Mental Retardation		
1. Individuals in need of special programs in public school at any one time.	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school years.	50% of entire mentally retarded population	2,500
3. Individuals in need of residential placement, at any one time, with alternative programs available.	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and pre-school programs	5% of known mentally retarded population	250
(b) Day Care Programs	5% of known mentally retarded population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Day Activities	10% of known mentally retarded population	500

TABLE II (Continued)

Category	Percent of Total Population in Categories	Estimated Number in Categories
II. Sub-Categories		
b. Behavioral Disturbances		
1. Individuals in need of special programs in public school at any one time.	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school years.	50% of entire emotionally disturbed population	2,500
3. Individuals in need of residential placement, at any one time, with alternative programs available.	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and preschool programs	5% of known emotionally disturbed population	250
(b) Day Care Programs	5% of known emotionally disturbed population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Activities	10% of known emotionally disturbed population	500
c. Sensory and/or Physical Disorders		
1. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school years.	50% of entire sensory and physically handicapped	2,550
3. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and preschool programs	5% of known sensory and physically handicapped population	250

TABLE II (Continued)

Category	Percent of Total Population in Categories	Estimated Number in Categories
II. Sub-Categories		
c. Sensory and/or Physical Disorders		
4. Individuals requiring other services		
(b) Day Care Programs	5% of known sensory and physically handicapped population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Day Activities	10% of known sensory and physically handicapped population	500

Therefore, I too should at least present some estimates of needs and types of programs that may serve these special populations. I include in these estimates (Table II) not only those whom we label "mentally retarded" but people who have other handicaps. The overlapping nature of these disabilities and the frequent occurrence of multiple handicaps among the moderately and severely disabled dictate a more global assessment of needs than what a single categorical approach could provide. Given all of the aforementioned caveats, and the additional one that I think I know a good deal more about the prevalence and incidence of mental retardation than about other disabilities, I nevertheless believe that these estimates may be helpful to those who have been forced to design programs without even the grossest notions of how many people they should plan for and what those people may need during their developmental and adult years.

In a perverse and ironic manner, we may be fortunate that needs seem always to be bottomless, endless and never met. That is, we haven't suffered from an overabundance of services for so-called handicapped people. On the other hand, especially with limited resources—which we will probably always have to confront—it may be useful strategically to place those resources where they can do the greatest good for the greatest number.

While many experts in the field of mental retardation have argued that, for example, 16

percent or 3 percent or 5 percent or 2 percent (AAMD) of the population are mentally retarded, or "psychometrically mentally retarded," or own study³⁴ indicates that a 1 percent estimate is more valuable for program planning and development. Similarly, estimates as high as 20, 30, or 40 percent in the relatively new category, "Specific Learning Disabilities," are provocative, certainly, but do not appear to be helpful in program planning. Further, prevalence estimates of various types of handicapped children (not including the new general category, "Learning Disabilities") conclude that approximately 10 percent of all school age children are "handicapped." Unfortunately, there are problems with this estimate for the same reasons that epidemiological data on mental retardation have never provided satisfactory guidance for program planning.

The studies that have been completed indicate that there are important differences between what we might call "administrative disability" and "objective disability." As mentioned, a clear example of this dichotomy is the discrepancy between psychometric mental retardation (at least two percent of the total population) and administratively designated (or known) mental retardation (approximately one percent of the total population). Therefore, taking these factors and their resultant problems into consideration, I believe it is reasonable to consider using population estimates that are based on available studies of known cases in the various disability categories.

From our own demographic studies of mental retardation, our evaluation of the epidemiologic literature in the field, and from a careful analysis of the data obtained from both our Head Start questionnaire survey and our observational studies of selected Head Start programs, we estimate that one percent of the total population (incidence) need special services because of their mental retardation, another one percent require it because of behavioral disturbances, and another one percent because of moderate and severe sensory and/or physical disorders (see Table II). We would not include the so-called speech-impaired in such designations; nor would we include the so-called learning disabled.

We believe it is not in the best interests of either the children or the programs to label children with mild disabilities, who could otherwise be adequately dealt with in ordinary classes, as "handicapped," "retarded," "speech-impaired," etc. We believe it is in the interest of both the children who have been so labeled until now and those others who are now denied a normal interaction with them, to reserve the categories of handicap only for those who have such severe and moderate needs where they will not be able to be served adequately in ordinary classes under ordinary conditions.

For that group with such special needs, we estimate that there is no more than a three percent incidence across populations and age categories, and possibly, a four percent and no more than five percent prevalence during the preschool and school years. Therefore, mild speech impairment, as mild retardation or disturbance, could not be considered a handicap requiring special attention in the traditional sense. Those children with mild disabilities should be served within the context of regular school settings. Those with severe or moderate speech impairments will be found to have general language disabilities and, more probably than not, learning, behavioral, sensory, or physical disorders.

Obviously, the above recommendations will not solve all of the difficulties inherent in estimating the incidence and prevalence of conditions that are grounded more in political-metaphorical issues than in scientific ones. However, at least in some modest manner, we may be able to reduce the harmful effects of unnecessary labelling and the resultant stigma to many children and their families. We may also move from a disease-oriented planning model to a developmental model,

one that seriously considers the benefits of integration and decategorization of both children and programs, one that is committed to the concept that people are educable, that development is a function of not only endowment but training and opportunity and encouragement.

Research

Like the emperor's clothes, for many years research concerned with disabled populations proceeded along experimental, quasi-experimental and other traditional lines of investigation. And, in spite of the null hypothesis consistently obtaining, in spite of our inability either to learn very much or to help very much—not necessarily related matters—we continued to apply traditional approaches to the study of very complex field problems, invariably with very unsatisfactory results. The problem of relevancy of research methodology has been particularly troublesome in the broad field of research on children with special needs.³⁵

We need to develop research strategies that are in harmony with discovering and evaluating what actually occurs in natural settings, be they classrooms, clinics, institutions, homes or neighborhoods. Possibly, this orientation to research offers a solution to what Blackman³⁶ described as the serious and ambivalent dichotomy between those who prefer experimentation as the method of proof and those who view education essentially as an art form, one which could lose its color and vitality if the movement to fractionate the teacher-pupil interaction achieves its apparent goal.

In numerous ways, individuals function differently. Research attempts to record these ways and to explain the way. For some researchers, description is an end in itself. However, the history of social science has, at least, one certainty about it; description always leads from and to something. There is no "unbiased description." For example, when several groups are given I.Q. tests, almost invariably they will have different averages. Are those objectively derived differences? We believe not. A good deal went into the development of the I.Q. test, selection of items, and procedures for administering the test. The testing format is, itself, a very special structure for communication. Tests are validated in specific ways using specific criteria. They are developed to do something. The narrower the something is, the easier it is to validate the test; however, the test becomes more biased when used with other groups at other times.

We often talk about variability. What makes the great difference? Is it heredity or environment? Is it school or home? Latin or home economics? Discipline or therapy? If a child has a problem, what (or who) had the most to do with it? What is the main, most significant, most pervasive cause? What is the best, very best, way of undoing the problem? Does the answer to the first question (cause) lead to the answer to the second (Undoing)? Does what is wrong indicate what should be done?

Eventually the question is: What should we do? And, how do we obtain that answer? Does it depend on who does it? or where it is done? or how much time there is? It is wishful thinking to expect that there is a clear relationship between what exists, why it exists, and what to do about it. Useful reductions are impossible, at least in the usual sense. Prescriptive education is a reduction. Therapeutic education is a reduction. Montessori, Frostig, Kephart, Cruickshank, Bereiter, A. S. Neill all offer reductions. To a degree, what we say about reductions is a reduction; hence the tautology of it all and, if we're not careful, the self-inflicted delusionary trap. In this paper, we attempt to discuss the potential dangers of any reduction—be it "theirs" or ours. Reductionists say this is what to do with children who present or behave in this manner. Whatever this is, there is the assumption that this can be identified, described and distinguished from something other.

What contributes to difference? Some children are poor, come from families who have inadequate housing, food, medical services, space—are crowded into cities (or rurally separated)—and they do not do well in school! Or on tests! Or on the 'cello! Often, they are migrant or immigrants. And they do not speak Standard English. They are different. They do not fit well.

A lot of confusion exists about what people should do, how they should do it, and when it should be done. Who is to judge? Are the judges' values my values? Or yours? How can it all be put together: poverty, delinquency, migration, retardation, language, values, anthropological, epistemological? Some individuals in some groups do not fit. The first problem is to decide about fit: individuals who do not fit, groups that do not fit, or individuals who do not fit groups that do not fit.

There are several differences to being an individual who does not fit (or is not well matched) rather than being in a group that does not fit (or is not matched). The new field of learning disabilities

has epitomized the Individual-no-match.³⁷ Find out what is wrong, then treat it. The patient will subsequently get better. Mental retardation has always been in the Individual-no-match category. Unfortunately, this was a strategic error and interferes with progress in our field. For example, the Black population of the United States may be an illustration of an Individual-no-match category that did not begin to move out of a repressive society until they developed Black Power and Pride—i.e., until they assumed a Group-no-fit strategy.

The literature in our field indicates that the preponderance of published research is experimental. Most studies of teaching have used traditional designs, whether they were efficacy studies, follow-up studies of children in special and regular classes, studies of different methodological approaches, or studies of different curriculum approaches.

We believe there are more appropriate ways to study teaching-learning in classroom, clinic, or tutorial situations. However, it is well known that researchers engage not in what they want to do but what they are able to do, not in what is important but what is possible, not in what is risky but what is safe and gives assurance of completion. People do what can be supported and most of us engage ourselves in activities that are comfortable and appreciated by others. Possibly, the most accurate judgement we can make about research with disabled populations is that this is what the people in the field want or, possibly, there is not anything else known that they can or wish to substitute for their current mode of activity.

We conclude here that:

1. There is nothing inherent in disability to produce handicap (i.e., a belief in one's incompetency). Further it is not the primary responsibility of the behavioral sciences to determine the validity of the aforementioned statement, but to make it valid. We have supported far too many studies purporting to demonstrate differences between groups or the disorders of one child in contrast with another. All these years we should have promoted and encouraged research that sought to make it come true that a child would learn after participation in a special program or curriculum.
2. The above leads directly to a second recommendation, viz., the study of particular methods, for the purpose of demonstrating their

efficacy, is rather fruitless and whatever is demonstrated will eventually be contradicted by subsequent research. Such "all or nothing" studies of methodologies prove little. By "all or nothing" we mean studies that compare the efficacy of one method with that of another or compare the superiority of one type of individual with that of another.

Or, as Campbell and Stanley incisively concluded, ". . . we must increase our time perspective, and recognize that continuous, multiple experimentation is more typical of science than once-and-for-all definitive experiments . . . we should not expect that 'crucial experiments' which pit opposing theories will be likely to have clear-cut outcomes."³⁸

On the other hand, we are not ready to suggest that there is nothing but uniqueness in an educational setting. There must be possibilities for building generalizations for, if "knowledge" is an objective, we must be concerned with degrees of nonuniqueness or lawfulness. Unfortunately, as we stated above, the numerous dimensions of child-teacher interactions have been neglected and, consequently, hardly understood.

As methods do not exist outside of psychological-educational setting, and as they are implemented by unique groups of human beings, only a naive researcher could conclude that the demonstrated superiority of his method has direct and specific transferability to other educational settings. Our research preference is to study children and how they change in different educational environments. We believe it is more defensible, and will make a greater difference, to generalize about children interacting with each other and with adults in situations than it is to generalize about procedures. It is from evaluations of varieties of methods, with varieties of children in more or less formal and informal settings, utilizing teachers with heterogeneous backgrounds, that hypotheses will be generated that will lead to viable theories concerning human development and learning. It appears to us that, with this kind of strategy, theory construction shifts from methodological concerns to those involving human interactive concerns. However, even this isn't "everything." True enough, there is value in theory for its own sake, but we should not expect that there always will be additional practical value, that the theory be helpful to the retarded, or the disadvantaged, or whomever. For instance, although nuclear physics may have much to say about tables,

should a nuclear scientist attempt to instruct the carpenter? Is it possible that much of our research in mental retardation is akin to a nuclear scientist trying to learn to make dovetail joints in a cyclotron? Or, to offer another analogy, here is a favorite "likely story" of a colleague in philosophy.

She: "Look, dear, that's our star."

He: "That's not a star. That's a planet."

There are situations in which science and research is neither useful nor appropriate.

We have attempted to discuss a relatively unpopular position among researchers, a position that assumes that human research should not be an activity that is separated from life or from values and prejudices about people. Further, we believe that it is impossible for the researcher to separate completely his beliefs from his research activities, even if he makes deliberate efforts in that direction. Therefore, research with so-called disabled persons should proceed, first, from a statement of values, then to an intervention and evaluation, with careful efforts to explicate the former, rather than to submerge it in an unsatisfactory and contrived research design.

What is our bias? Put as simply as possible, we believe that capacity is a function of practice and training (e.g., intelligence is educable). And, as we have said earlier, it is a task of researchers, as it is the task of all clinicians, to validate the bias. In the ultimate sense, this is our central mission.

Business and Finance

The newly emerging literature on the economics of mental retardation is important and was long awaited by the professional leadership, the political community, and the consumers. I wish to address myself in this section to aspects of "business" that are rarely, if ever, discussed in professional publications or, for that matter, in polite society. And I believe what I am about to discuss is somewhat important for those struggling to understand why we make the decisions we make and why past experiences and data are incidental to such decision-making.

For one year, during a leave of absence from my university, I was the Commonwealth of Massachusetts Commissioner for mental retardation programs for the Department of Mental Health. At least theoretically, if not always pragmatically, I was responsible for the conduct of all of the Commonwealth's state institutions for the mentally retarded, and all of the Department's

community educational and clinical programs for those people designated as mentally retarded who, for one reason or another, “escaped” institutionalization.³⁹

I will begin with the conclusion. Mental retardation is big business. It is very big business. One research group reported recently that there are 2,800,000 mentally retarded youth in the United States and that government agencies expend \$2.8 billion annually to serve them.⁴⁰ Its dollar volume does not approach expenditures for mental health. But how many businesses do? Let’s look at some of the “evidence.”

I have observed in several states that the largest purchaser of buildings in a state is the state itself. Further, within state governments, departments of mental health are oftentimes the most consistently largest purchasers of buildings. Even in the wake of a national clamor to invest our resources in programs, not real estate or buildings, giant steam shovels are ripping large chunks of land across this country, harbingers for institutional monstrosities, that must always disillusion some and totally defeat others.

New York State, in the wake of public scandals and anguished outcries, after promises to do better and differently, continues to build large—although not as large as Willowbrook and Letchworth—ugly institutions at costs of \$40,000 to \$60,000, and more, per bed. Within the past few years, the state has been engaged in a half-billion dollar institutional building program in mental retardation. Why? Answers aren’t easy and those that are readily available may be potentially libelous. However, even a school boy can deduce that six percent of a half-billion dollars—architects’ fees—is a great deal of money. Even the most unsophisticated citizen will appreciate the importance major construction programs have for contractors, suppliers, land developers, the unions and, especially, the banks who together will “earn” a half billion dollars on this mental retardation construction. Even the most naive and apolitical citizen will remember that, when an official in a high federal government position was forced to resign for kickbacks taken while he was once governor, those who provided the “kick” and the “vigorish” were all either contractors, land developers, or architects. How can we terminate institutional building programs when, in many states, they are literally the source for political party, and even private, payoffs and patronage?

Let’s look at operating expenditures. In New York State during the 1974 fiscal year, the mental retardation division in the State Department of Mental Hygiene was allocated a budget of \$235 million. Of that amount, only \$2 million was earmarked for community programs. Why? Well, one answer is that buildings, the staffs, and the inmates are there; so, the resources must go to the institutions. To a degree, this is a reasonable explanation. But why do we continue to use outmoded, sometimes disgraceful, always less than desirable or logical institutional settings?

First, there are unions, who find it convenient to have their members together in one facility; dispersal to many community programs may impair a union’s strength and effectiveness. Secondly, there are administrators and supervisors who, similarly, find it compatible to have their staffs working in centralized facilities; dispersal of inmates leads to the dispersal of staff and the realization that neither all of the administrators nor all of the direct care personnel are necessary. Certainly, it would be difficult for an institutional superintendent to speak any longer about “his institution” if the institutional population were evacuated and resettled in integrated communities. Thirdly, if there were no institutions there would be no million dollar laundry contracts, multimillion dollar food contracts, milk contracts, ice cream contracts, automobile contracts, service contracts, utilities contracts, even funeral contracts. Certainly, as matter is neither created nor destroyed, people must eat and soiled clothes must be washed. However, it’s not the same, especially for larger influential businesses, to contemplate one contract for a million dollars as it is to contemplate competing for a thousand contracts for a thousand dollars each, or thousands of purchases by free citizens.

There are analogies in public education, contrasting segregated schools with integrated programs. There are analogies in comparing specialized clinics with generic clinics. As the Blacks learned, as the Jews learned, as the Indians are now learning, segregation, bigotry, and prejudice can be big business. In our field, considering our modest number of clients and our relative low priority in the scheme of things, mental retardation is big business, and it’s big essentially because it’s segregated and monolithic and, therefore, controllable. Either we must find a way to remove the overly attractive rewards that some people seek and find in this business or we must desegregate our programs and clients;

otherwise little will change. Rhetoric, promises, or even good intentions, will not alone discourage half-billion dollar state building programs or \$50 million operating budgets for places like the Willowbrook Developmental Center. Either we demand a total moratorium on all construction, and quickly and efficiently remove other fiscal incentives, or we deal with this problem from the other end, reorder priorities (but, remember the "Year of the Child") and evacuate institutions and special segregated schools; otherwise mental retardation will continue to be big business—and great despair for those who truly want to serve others, and for those who must be served.

Decision-Making

Subsequent to my year as an "executive" in mental retardation administration, I wrote a book about that experience. Chapter Ten, "Life with the Decision-Makers," dealt with that aspect of government concerned with insiders and outsiders, accountability, the civil service, relationships with the executive and legislative branches, and how people "hide" in government. Having nothing new to say on the matter, I will repeat here what I wrote then under the heading of "Decision-Making and Accountability":

"Few people are forced to make decisions because few people are accountable for specific programs or activities.

"Obviously, those people who are accountable for specific activities must make decisions. How are these decisions made? A better question might be, 'What causes an individual to make one decision rather than another?' For many months my experiences at 15 Ashburton Place puzzled me because I was completely unable to 'read' the System vis-a-vis decision-making. For example, several of what I considered to be very reasonable requests were denied by various business offices without explanation or apparent reason. Other requests were ignored. Still others were quickly and categorically honored to our complete satisfaction. There was no apparent logic to these responses. It seemed as if some mad table of random numbers was at work here, approving one thing, denying another, and ignoring the third. It must be admitted that in each instance when I did require an explanation for a decision, there was some law or regulation or policy that seemed to lend credibility and wisdom to the decision. However, on other occasions, similar requests—in equal violation of the regulation or policy—would be granted. All one can do is speculate about the

basis for decision-making at 15 Ashburton Place—as, obviously, one can't read the decision-maker's mind and there seems no logical pattern to his activities. My speculations have led me to three insecure and tentative conclusions: (1) It is thought much simpler and less perilous to make no decision, or to decide negatively, than to decide positively. (2) The System make it more satisfying to decide negatively than to decide positively. (3) The process of working with laws, regulations, and policies encourages their utilization to prohibit activities and developments rather than to promulgate such activities and developments.

"Because so few people have accountability and, consequently, so few people may make a final decision about a matter, most requests for one thing or another pass through several hands if, eventually, they are to be approved. With the exception of upper echelon business office personnel, there are few so-called 'middle management' professionals who make final positive decisions. In innumerable situations, these individuals may make final negative decisions, i.e., they have the authority to ignore or deny a request but do not have the authority (or do not believe they have the the authority) to approve it. Further, to approve a request for funds, personnel, a specific program, a transfer of personnel, or some other change from the 'usual' is to—in effect—approve the wisdom of that action and certify the legality of that action. To ignore or deny the request permits the decision-maker freedom from accountability for his decision, yet permits him to make a decision. Inasmuch as the laws, the regulations, and the policies are not always without ambiguity and discrepancies and are, in fact, frequently open to multiple interpretations, one can more easily find his safety in that part of the law or policy that permits the decision-maker to ignore or deny than in that part that permits him to approve and, thus, requires him to stand behind his decision.

"Whatever the central cause or causes are, there are many more negative than positive decisions made at 15 Ashburton Place.

"As in the System the decision-maker rarely has the authority to approve, he is caught continuously in the frustration of 'shuffling papers' from his desk to a higher desk, and of getting entangled in the red tape, bureaucracy, and inertia that are companion to such activities. It appears to be so much 'cleaner,' manly and authoritative to deny a request than to involve oneself in the frustrations

implicit in passing on this request to higher authority. It is, therefore, not difficult to surmise that there are negative decisions made whose sole purpose is to 'satisfy' the decision-maker. And further, this narcissistic behavior is understandable, if not completely forgivable, in light of the untenable position most decision-makers are forced into. That is to say, most decision-makers may make no decision or a 'no' decision but very infrequently have the option to make a positive decision. It is this set of circumstances that, I believe, causes more unhappiness and job dissatisfaction, frustration, and mutual ill will at 15 Ashburton Place than any other—including such problems as salaries, working conditions, job pensions, and the enormity and complexity of the departmental mission.

"Lastly, the innumerable frustrations and roadblocks one encounters in the decision-making process must eventually wear down a man's will to move things along in the proper direction and to make the proper decisions. From my limited observations, it appears that the Commonwealth laws and the Departmental regulations and policies are used—not to facilitate or permit positive decisions to be made—but to determine if it is legally possible or departmentally justifiable if a positive decision should be made. Essentially, and I know there is a fine line of distinction here between what may and may not be legal or prudent, the departmental *modus operandi* is first, to find something in the laws or regulations or policies that prohibits one from doing something rather than view these statutes for the purpose of finding justification for doing something. I have observed that departmental officials do not comb the statutes to find new opportunities to offer services and facilities, but they do comb the statutes for any prohibitions or incumbrances to a request that has been presented to them. Laws and regulations and policies being what they are—and Massachusetts being a Commonwealth long in the mental health business—it is often very difficult to 'get something done' in the face of governmental and departmental restrictions, precedents, and inertia. I do not wish to communicate the impression that I am advocating flagrant violation of laws or regulations. Nor do I believe it unwise to proceed carefully and thoughtfully before decisions are made that affect the lives of patients or the careers of personnel. However, if a System is based on convictions and standards and precedents that make it easier, less perilous, and more satisfying to make negative

decisions than to make positive decisions, to the degree that this assumption is true, laws, regulations, and policies will be interpreted in the light of their prohibitory powers rather than in the light of their enabling powers."⁴¹

Concepts of Mental Retardation

Mental retardation is not something that can be simply and scientifically defined, discussed, dissected, applied or studied. Mental retardation is related to our very understanding of humanity, of human potential, of educability, of equality, of rights and privileges, of everything we are and everything that relates to us. Asking someone to comprehend a concept of mental retardation is akin to asking him to comprehend a concept of spirituality or decadence, beauty or ugliness, strength or weakness, good people or bad people. Mental retardation can't be encapsulated and "pictured" by I.S. parameters, or even etiological descriptions, or behavioral assessments. It must always be anchored to other people, a community, values, expectations, and hopes. Therefore, the epidemiology of mental retardation can only be discussed in a psychological-social-political-economic context. Further, the economic factor, or any other factor or problem, can be appreciated only in this same context. Unfortunately, we have neither a manual on terminology and classification nor a curriculum that will permit us to shortcut this conceptual process.

Also, unfortunately, one's concept of mental retardation may impair seriously otherwise good judgment. Prejudices concerning those whom society calls "mentally retarded" may cause even the most distinguished and wise among us to do thoughtless things and issue silly pronouncements.

Reform or Revolution

I've asked the question many times, yet there is no answer for me. Possibly, there is no answer because I'm not pleased with the answers I see. I cannot tolerate the invidious comparison between the promises made and the institutions created. And, what were the promises that our field was to keep? What did the institution, the special education program, the community mental health-mental retardation movement contribute? We have been faithful, some have worked unselfishly, some have raised large sums of money, many have supported humanistic precepts and philosophies on behalf of people with special needs. What good was to come of all of this? The hope then, and remaining today, was that people would gain

strength, would deepen their optimism and faith in the human ethos, would develop more genuine concern for our brethren, would eventually have the wisdom to believe that all human beings are equally valuable, and that our work is not to judge who can or can't change but to fulfill the promise that all people can change, that each person can learn. The promises made were to coalesce around the demonstration, especially to those of us most intimately involved, that society is each person, not multiplied but singular, each person unique and valuable.

Yet, what have we created? We find that, in institutions and in many special schools, both the caretakers and the clients victimize and are victims. In the institution, and in many special school programs, there are not sufficient options for children, for families and, equally important, for staffs. In plain fact, the research available confirms the shambles that too many special programs and facilities are.

Yet, in spite of powerful critical reports on institutional life,⁴² and the scientifically questionable but numerous reports on special class life,⁴³ we continue to build more and more institutions and pass more and more mandatory rather than permissive special education laws—regardless of the well known fact that we have yet to demonstrate either the efficacy or moral rectitude in continuing, much less encouraging, those segregated programs. To turn to an earlier theme, such proliferation on the basis of trivial evidence is but another illustration of the monolithic influence.

We have made as many concessions, we have so bent the data to suit our ignorances and confusions, we are so anxious to please the people, that we lie to spare them the anxiety we feel because of what we have created. I'm expecting that, at any time now, somebody will propose a new concept, a remodeling of the old French triage system for sorting out and treating battlefield casualties. However, the neo-triage model will deal, not with the militarily wounded, but with those whom bad luck, accident, and society inflict their insults upon. I'm expecting to read someday an "erudite" paper advising us to set aside the hopeless, for their very designations demand we should not waste time with them; and, we might best benignly neglect those who will probably do as well without us, those who puzzle us, or those whose problems—although real—do not fully incapacitate them; and, consequently, we should

reserve our resources and energies for those who most need our help. Possibly, in war, triage is a valid concept; where some will live and some will die, and resources are particularly scarce, the whole thing—ghoulish as it may be—makes at least a little sense. However, when the new triage is trotted out, will there be anyone to say, "But, we are not at war"? And, will there be anyone else to say, "no, we are not at war. Yet, we should have been. It was always a war, but most of us thought of it as merely a debate."

References

1. Mental Hygiene News, New York State Department of Mental Hygiene, 24.5.74, p. 1.
2. Syracuse Herald-American, New York, 7.7.74, p.28.
3. New York Times, 7.7.74, p. 1.
4. Ibid, 30.7.72, Section 4, p.2.
5. Ibid, 8.4.74, p. 34.
6. Ibid, 4.5.74, p. 7.
7. Ibid, 11.8.74, Section 1, p. 1.
8. Elmira Star-Gazette, New York, 9.5.74, p. 14.
9. New York Times, May 5, 1974, p. 45.
10. Collings, G.D. and Singletary, E: Case Law and Education of the Handicapped. Florida Educational Research and Development Council, Summer 1973.
11. Syracuse University Law Review: Symposium on the Legal Rights of the Mentally Retarded. Syracuse, New York, 23: pp. 991-1165, 1972.
12. National Advisory Committee on Handicapped Children: Special Education for Handicapped Children. Dept. of Health, Education, and Welfare, Washington, D.C., January 31, 1968.
13. National Advisory Committee on Handicapped Children: Better Education for Handicapped Children. Department of Health, Education, and Welfare, Washington, D.C., June 30, 1969.
14. National Advisory Committee on Handicapped Children: Third Annual Report. Dept of Health, Education, and Welfare, Washington, D.C., June 30, 1970.
15. National Advisory Committee on Handicapped Children: Basic Education Rights for the Handicapped. Dept. of Health, Education, and Welfare, Washington, D.C., June 30, 1973.
16. President's Committee on Mental Retardation: MR '67: A First Report to the President on the Nation's Progress and Remaining Great

- Needs in the Campaign to Combat Mental Retardation. U.S. Government Printing Office, Washington, D.C., June, 1967.
17. President's Committee on Mental Retardation: Silent Minority. U.S. Government Printing Office, Washington, D. C., 1974.
 18. Task Force on Children Out of School: Suffer the Children: The Politics of Mental Health in Massachusetts. Task Force on Children Out of School, Boston, Mass., 1972.
 19. Wolfensberger, Wolf: Citizen Advocacy for the Handicapped, Impaired, and Disadvantaged: An Overview. President's Committee on Mental Retardation, Washington, D.C., 1972.
 20. Regents of the University of the State of New York: The Education of Children with Handicapping Conditions. The State Education Department, Albany, N.Y., November, 1973.
 21. June 7, 1974.
 22. Miami Herald, Florida, 5.4.72.
 23. Personal correspondence, January 3, 1974.
 24. Personal correspondence, August 16, 1974.
 25. Aaronson, W.J.: Innovation in Special Education: Title III ESEA. Dept. of Health, Education, and Welfare, Washington, D.C., 1972.
 26. Stedman, D.J.: Current Issues in Mental Retardation and Human Development. President's Committee on Mental Retardation, Washington, D.C., 1971.
 27. Dept. of Health, Education, and Welfare: Mental Retardation Source Book. Publication No. (OSOS) 73-81, Washington, D.C., 1973.
 28. Blatt, B.: The Monolith and the Promise. Therapeutic Recreation Journal, Vol. III, No. 4, Fourth Quarter, 1973, pp. 4-32.
 29. Heber, R. (ed): A Manual on Terminology and Classification in Mental Retardation. Monograph supplement to the American Journal of Mental Deficiency, 64, 1959.
 30. Grossman, H.J. (ed): Manual on Terminology and Classification in Mental Retardation. American Association on Mental Deficiency, Washington, D.C., 1973.
 31. Kakalik, J.S., et al.: Services for Handicapped Youth: A Program Overview. Rand Corporation, Santa Monica, Cal., 1973, p. 276.
 32. Blatt, B. and Garfunkel, F.: The Educability of Intelligence. Council for Exceptional Children, Washington, D.C., 1969.
 33. Blatt, B. and Garfunkel, F.: Teaching the Mentally Retarded: in Travers, R.M.W. (ed): Second Handbook of Research on Teaching. Rand McNally & Co., Chicago, 1973, pp. 632-656.
 34. Blatt, B.: Souls in Extremis: An Anthology on Victims and Victimizers. Allyn and Bacon, Boston, Mass., 1973.
 35. Blatt, B. and Garfunkel, F., op. cit., 1973.
 36. Blackman, L.S.: A Scientific Orientation for Special Education. Teachers College, Columbia University, New York, 1969.
 37. Blatt, B.: Learning Disabilities. Seminars in Psychiatry, 1, 1969, pp. 237-361.
 38. Campbell, D.T. and Stanley, J.C.: Experimental and Quasi-Experimental Designs for Research. Rand McNally & Co., Chicago, 1963.
 39. Blatt, B.: Exodus from Pandemonium: Human Abuse and a Reformation of Public Policy. Allyn and Bacon, Boston, 1970.
 40. Kakalik, et. al., 1973, op. cit., pp. 2 and 13.
 41. Blatt, 1970, op. cit., pp. 107-109.
 42. Blatt, 1973, op. cit.
 43. Blatt and Garfunkel, 1973, op. cit.

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Biography

BURTON BLATT was born in 1927. He studied at New York University, the Teachers College at Columbia University, and at Pennsylvania State University, where he received his doctorate in special education. During World War II, he served with the United States Navy in the Phillipine Islands.

He has taught special classes for the mentally retarded in New York, and held a teaching position at Southern Connecticut State College from 1956 to 1961. From 1961 to 1969 he was professor and chairman of the special education department at Boston University.

Since 1969 he has been the centennial professor and director of division of special education and rehabilitation and the center on human policy at Syracuse University. Dr. Blatt has published numerous articles and books on a wide range of subjects.