

THE NINE PILLARS OF MENTAL RETARDATION

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During the years, my work has been connected with examining the hypothesis that human development is influenced by need, motivation, training, and practice; i.e., capability is educable (Blatt, 1973a). However, although I have often encountered verbal support for this so-called educability hypothesis, rarely have I observed concomitant fiscal and program commitment. Nowhere in our field is there greater discrepancy between polemic and practice, between what we say and what we do. Nowhere does there appear to be greater ambivalence; yet no pillar of the field is more central to its understanding and evolvement than is the one connected with this hypothesis. In virtually every policy decision and practice of any consequence relating to so-called mentally retarded people and their families, the educability hypothesis is embedded. It is so central to the field that when it isn't part of a particular argument it usually means the participants are engaged in either a trivial or unrelated activity. Consequently, I begin here, and you may also find that the educability issue is never far from the surface of other, seemingly distinct, issues.

1. Educability--Incurability

There is little "scientific" evidence, and nothing conclusive, permitting firm answers to the so-called nature-nurture question. On one side, Jensen, Shockley, and Herrnstein have their reasons, their "evidence." On the other, Sarason, Kagan, and Heber have theirs, as Harold Skeels had

his, as Helen Keller once served as the living exemplification of the concept that a human being can change. Similarly, the work of Itard, Mae Seagoe's biography of Paul Scott, Kirk's research, my own modest studies, lend support to the educability hypothesis. However, as others before have discussed more eloquently, it's an open question whether capability is plastic, whether the occurrence of mental retardation among the so-called cultural-familial is preventable or curable. Yet, evidence aside, what is our mission? To make decisions who can learn and who can't, or to help people grow?

I am led to conclude that, research evidence or the lack of it notwithstanding, we must behave as if human capability is modifiable. As with the research itself, there are two kinds of errors we can make: We can erroneously reject the null hypothesis, i.e., by indirection accept the hypothesis that people can change; or, we can erroneously accept the null hypothesis, i.e., reject the contention that capability is educable. For purposes of research, type I errors--the erroneous rejection of null hypotheses--are the most serious, the unforgivable errors. However, for purposes of program planning and development, I am convinced that type II errors--the erroneous acceptance of the incurability concept--is inexcusable and, unfortunately, the error we are most likely to commit.

2. Science--Syllogism--Metaphor

All too often, mental retardation is discussed as a scientific concept; yet, we did not need Tom Szasz to inform us about the ways in which it is more a metaphor and an administrative tool rather than a

scientific term. The too-numerous efficacy studies, our periodic nomenclature studies, and the litigation in the field all contribute to a clarity about this term, mental retardation, a clarity about a term which is more myth than real, more subjective than objective. We understand it by reason and argument, not through precision and science.

All who meet the American Association on Mental Deficiency (A.A.M.D.) definitional criteria are mentally retarded.

Charlie meets A.A.M.D. definitional criteria for mental retardation.

Charlie is mentally retarded.

But, wait, the criteria have been changed.

Charlie no longer meets A.A.M.D. criteria.

Then, Charlie is no longer mentally retarded.

But, mental retardation is incurable.

Then, Charlie never was mentally retarded.

Wait again, that criterion was changed too.

Then it is possible that Charlie was cured.

Mental retardation is a metaphor. It is what we agree it is, and it means what we think it means. We have changed criteria for inclusion, prospects for cure, incidence and prevalence parameters, not by doing something with the mentally retarded but, merely, by reformulating our definition and the language about the definition (Blatt, 1961). Understanding what mental retardation is requires one to better know the language of mental retardation; and, I believe, those who control the language moreso than the "substance" control so-called retarded persons. This is by way of saying that it is impossible to understand what mental retardation is, to estimate the incidence and prevalence of the condition,

to formulate programs on behalf of those so labeled without operational agreement on the definition of the condition. And, the definition is not a "given"; it is not something that is commonly understood and acknowledged; in a sense it can't even be "discovered." The definition must always be invented and negotiated, and agreement about it must be achieved; it is never something to seek but, always, it must be created for the purposes of specific administrative, political, or policy action. In this very important regard, the definition of mental retardation is entirely unrelated to definitions of such conditions as pregnancy, leprosy, or acne. More or less, and with pregnancy it's everything, the definitions of the latter conditions may be found within individuals. With mental retardation, the definition is always found no more within those labeled than within those doing the labeling, no more within the so-called retarded than within you or me. One can learn about mental retardation by an examination of his culture, or himself, as fruitfully as in the examination of a person noted for his defectiveness. This is the important distinction between retardation and rubella, or roseola, or retrolental fibroplasia.

3. Defective Person--Defective Society

Individuals differ, programs for them differ (this is what we often refer to as individualized instruction), and goals differ (something that even the most individualized programs resist; but that is neither here nor there insofar as this discussion is concerned). It is the aim of educational research to document how people differ and explain why they differ. We have said elsewhere that, for some researchers, description is an end in itself (Blatt and Garfunkel, 1973). Yet, description

inevitably leads from and to something. There is no "unbiased description." For example, when groups are given I.Q. tests, invariably they will have different averages. Are these objectively derived differences? No. Then, what does contribute to variability? Is it heredity or environment? Is it school or home? Discipline or therapy? What is the main, most significant, most pervasive dependent variable? What is the best, the very best, way of undoing problems? 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? There is great confusion and disagreement concerning what people should do, how they should do it, and when it should be done. Who is to judge? Are the judge's values my values, or yours? How can it all be put together: poverty, delinquency, retardation, values, disabilities, learning? Or can't it? Is it psychological, sociological, anthropological, epistemological? Some individuals in some groups do not fit. Therefore, 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 important differences in being an individual who does not fit (or is not well-matched) as contrasted with a group that does not fit (or is not matched). For example, the relatively new field of learning disabilities has epitomized the Individual-No-Match: Find out what is wrong, then treat it. The client will get better. Mental retardation has always been in the individual-no-match category. Unfortunately, this was a strategic error, interfering with progress in our field. In contrast, 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 it developed Black Power and Pride, i.e., until it assumed a group-no-fit strategy, until it demanded that society--not Blacks--change.

Mental retardation has a long history of deficit orientation, of associations concerned with retardation not with development, of defectiveness rather than disability. We have been keen to blame the victim, hardly even the victimizer. We have been sensitive to the needs of society, and insensitive to the person labeled as different. Our programs are focused more in changing the so-called defective person who doesn't fit into our conception of what society should be than in helping society to become more flexible, more receptive, more concerned with the acceptance of human variance.

4. Human Value--Human Sacrifice

One believes that, as human beings, all people are either equally valuable or that some are more valuable than others. Although the ethical and religious teachings of prophets, poets, philosophers, and historians since the dawn of civilization provide us with uncountable expressions of faith in the human ethos and the primary value of each human life, it is not easy for most of us to make our decisions and live our lives as if each human being is precious. And, that which makes it difficult for private citizens to be faithful to such belief, makes it even more difficult for governments to guarantee the rights of each individual. Externally surrounded by starvation in Africa and Asia, holocausts and cruelty beyond human endurance everywhere, and with internally mired insoluble problems arising in natural disasters, wars, and

depressions, we seem to have become a people insensitive to human suffering. We are not any longer our brothers' keepers and, for some of us, the concepts of brother, or friend, of human being, are no longer remembered.

In Paris, about two years ago, I attended a meeting on mental retardation at the Pasteur Institute. One of the speakers was Lejeune. He, with a group of colleagues, first described the abnormal chromosomal pattern associated with Down's Syndrome. We were prepared for an erudite scientific presentation by this great scholar. However, he surprised but did not disappoint us. Lejeune did not speak about scientific concerns but about concerns of the heart and the soul. He reminded us that medical science can do little about mental retardation, that the problems we have are not those that science will eliminate; rather, those which human callousness has created can be dealt with only by human compassion.

As human beings, all people are equally valuable or, if not, there is something of lesser value in being human than we had supposed.

5. Mainstream--Polluted Waters--Drowning

Each person should be "prepared for life" in a typical world, not a segregated world. Furthermore, the very best preparation occurs in "ordinary" society. Yet, although most people support the concept of integration, human beings have a penchant to segregate others, to separate them, to stigmatize them, even to make pariahs out of those who are unable, unappealing, weak, or aged. In recent years, I have written and talked so much about segregation and mainstreaming, "normalization" and what I choose to call the "pariah industry," that--because of space

limitations here and parlor games intruding into my consciousness as I work on this essay (How simply and briefly can I communicate in this paper what once required books and interminably long papers?)--I want to say plainly here that I believe more than ever that it is good for people, all people, to live in maximally heterogeneous communities, that it is both good and decent for a society to plan for the dismantling of its physical and ideological barriers that separate the free from the enslaved. The evidence is all there for one to review, evidence that should encourage us to plan for integrated public schools, community-based services for the so-called mentally ill and mentally retarded, and a return to those values of our forebearers who found not only the room but a need for the aged to remain as valued contributors to community life (Blatt and Kaplan, 1966; Blatt, 1970; 1973b).

An obvious danger, not of the mainstreaming movement but of the claims for mainstreaming, is the perennial danger: Words will substitute for behavior, slogans for thoughtfulness, doing anything for doing what should be done. One hears today of the abuse of mainstreaming policies in the same manner that once we were instructed about the evils of Head Start and, decades before, of universal education. There are people today who would tell us that Head Start will mongrelize "the race" (What race?) and that universal education has destroyed the once high standards of our public schools. To be sure, thoughtless mainstreaming drowns rather than integrates children, as clear streams become polluted waters, and as integration may be as unequal as separation.

I oppose segregation, in any of its forms and permutations. I believe that, in the best of all possible worlds, it is to the benefit

of society to discourage the unnecessary segregation of segments of the human family and, further, much of the segregation I have observed in the public schools and in our departments of mental health and mental retardation appears both unnecessary and unwise.

6. Principle-Expediency

Polemics are voiced and counterpractices gain expression, which support counterpolemics, which give rise to practices antagonistic to the counterpolemics but sympathetic to the original polemics. It's a crazy business we are in, and the following are but a few of the numerous documented examples (Blatt, in press).

In Syracuse, in New York City, in other cities that I have visited, mainstreaming principles have been enunciated strongly by the leadership in the public schools; integration is in the air everywhere and, explicitly, it is the public policy of the schools. Yet, even while the integration banners fly for all to pledge allegiance, one board of education after another consummates negotiations with teachers' unions, agreeing that teachers in regular classrooms may choose to exclude handicapped children from regular class participation. On the one hand, mainstreaming is the official principle and, on the other hand, there is equally official agreement drawn to exclude the handicapped from regular programs.

The New York State Department of Mental Hygiene in fiscal year 1974 conducted its business in mental retardation with an appropriation of approximately 235 million dollars. It is the official policy of the Department of Mental Hygiene to promote community-based programs and

activities on behalf of its clients. During that fiscal year, approximately 233 million dollars were allocated to institutional facilities and 2 million dollars for community activities.

The 1972 congressional amendments to the Head Start legislation mandated that at least 10 percent of enrollment opportunities in Head Start programs be reserved for "more severely" handicapped children. Legislation elsewhere--in Florida, for example--either notes similar mandates or anchors fiscal supports to the demonstrated integration of stipulated percentages of handicapped children. I have found that, probably in Head Start and possibly elsewhere, those kinds of attempts to include and integrate the handicapped in community programs may have accomplished little more than to cause greater numbers of children to be defined and labeled as handicapped, children heretofore included but not labeled. In fact, during a recent trip to Florida I learned that screening teams, organized for purposes of identification and placement of children in special programs, are called "headhunters." I could continue, regaling you with anecdotes, each of which is difficult to believe, albeit true, a few of which are very funny, albeit depressing. I could tell you of the circumstances behind the decision of the New York State Legislature to change the names of our state schools to developmental centers. Or, you might want to learn about the new Carol Burnett Good Housekeeping Award, inaugurated recently in one of the most infamous of the infamous state schools of this country. Or, I might share with you information about a new and very costly playground built for the also new Syracuse Developmental Center, the one difficulty being that the playground was "unplayable."

However, this essay will soon exceed the space allotted me by your editor. Therefore, I dare not say any more about these pillars of mental retardation except to note that three remain to be discussed at another time: Technical problems--creative needs; protection--freedom; and, what is known--what is attempted. For those who doubt that there will be another time, or cannot wait easily, may I suggest your consideration of two recent papers (Blatt, 1974, in press). For the others, it probably won't matter.

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