HOW I IMAGINE DISABILITY IS SEEN THROUGH THE EYES OF SCIENTISTS

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The Science Fantasy

Many of the accounts of research reported in our disability journals appear to concentrate on what can be done to subjects. Notwithstanding, the more important research question is what can be done for those who aren't disabled to live more compatibly with those who are disabled. It isn't that cure and amelioration aren't compelling issues. However, for two reasons those questions are incapable of providing us with important answers which are readily available. That is, primary and secondary prevention--medical, psychological or educational--are most often pertinent for very narrow problem areas, especially in my field, mental retardation. Essentially, we don't have ways for ameliorating the effects of damaged sensory nerve tissue. We don't have ways to systematically reverse intellectual deficits. And our various curricula, methods and classroom innovations have not systematically proven that such educational procedures can prevent mental retardation, on the one hand, or reverse or ameliorate it on the other. The second reason why people such as myself in mental retardation should get off the "science fantasy" is that if cure and amelioration actually become realities--if damaged brain tissue ever is to be regenerated--the methods will be developed in the laboratories of anatomists and physiologists and not by specialists in mental retardation. Consequently, we, who actually work with and for the mentally retarded or other disabled should be more interested in what can be done to help those who aren't disabled live more comfortably with those who are disabled. The fantasy is that we can prevent, cure and ameliorate in the obvious ways. We probably can't. But we can "prevent", "cure" and "ameliorate" by helping those with disabilities to be less handicapped, less segregated, less outsiders of normal society, less different from those ordinary people who have been indifferent.

Scientists and other scholars devoted to the disabled may benefit from examining other ideas and possibilities insofar as how to spend their working lives.

Mental Retardation As A Case Example

The question I'm grappling with may be illuminated in terms of the metaphor of mental retardation as seen through the eyes of the scientist. If the future historians of the field were to assess the period between 1960 and 1980 searching for the compelling issues faced by workers and families concerned with the problem of mental retardation, they might be misled to the extreme if such an assessment were based on the published scholarship as represented in our most prominent archival journal, The American Journal on Mental Deficiency. If future historians analyze those volumes in order to gain an understanding of what the scholars, policy leaders, and administrators were worrying about and studying in mental retardation, they will probably conclude that the greatest problem facing mid-20th century America vis-a-vis the mentally retarded was how a severely retarded subject behaved with a manipulandum, or the effects of drug X on Y performance, or the anatomical differences between a child with X syndrome in contrast with a child with normal central nervous system development. Of course, none of those albeit important questions are even nearly related to the problems facing either families who must contend with mental retardation or professionals who must treat, dose, evaluate or place people with mental retardation. Dendrites, neurons, manipulanda, and drug X have about as much to do with mental retardation as highways (which retarded people travel on) or airplanes (which "even" retarded people sometimes ride in). It's as if a study of lymphoma among American farmers had something to do with agriculture rather than cancer. In the eyes of the physiologist, mental retardation may be a problem of physiology; and in the eyes of the anatomist, mental retardation may be a problem of anatomy; and in the eyes of someone interested in learning theory, mental retardation is understood in terms of pulling a manipulandum. But that's no different than saying that a study of learning rates of United States Marines (because that happens to be the subject population available) has some central connection with the Marine Corps. Of course, in some ultimate fashion, there is a connection between how quickly a Marine learns and our defense capability, but it isn't the connection that's terribly useful insofar as trying to keep a field (or an army) understandable. There is virtue in taking the obvious seriously.

In The Name Of Science

Seeing disability through scientific eyes presents another problem. It may be exemplified by the now classic Milgram experiments on obedience to authority (Milgram, 1973). Providing data to support some of our greatest worries, Milgram set up a series of experiments to find out how far people will go in following orders from authority, even when those orders demand the infliction of pain and, quite possibly, even when the orders put the "subject" in supposed mortal danger. What Milgram found was that, when otherwise prudent and intelligent people come to believe that the work they are doing is for a higher cause, they obey the "scientists" without too many qualms and anxieties. As one observer remarked, "Such are the roots of man's inhumanity to man."

In Milgram's basic experimental model, two people are invited to the psychology laboratory to participate in the study of memory and learning. One is designated "teacher," the other "learner." The experimenter describes the study to "teacher" and "learner," explaining that the intention is to determine the effects of punishment on learning. The "learner" is then brought into a room, seated in something akin to a small electric chair, and told that he will be read lists of simple words, then tested on his ability to remember those words. If he makes an error, he receives an electric shock. The more the error, the greater is the intensity of the shocks. Although not known to him, the actual focus of the experiment is on the "teacher," who is seated before what is described to him as a "shock generator." The "learner" (actually an actor) misses words, and the "teacher" shocks him. More words are missed, and the shocks become (in the eyes of the "teacher") more and more severe, even terrifying. The "teacher" is encouraged, even prodded, and for whatever reasons usually continues with the experiment. Of course, some "teachers" enter into the experiment with glee, even while inflicting great pain; and others worry that they are causing harm to the "learners," but nevertheless doggedly go along with the experiment, knowing their duty on behalf of a higher cause--Science.

Is it any wonder that there were cruel experiments reported out of Nazi Germany, or the state institution for the mentally retarded? Is it any wonder that, in the name of Science, people have been tortured--as in God's name they have died on the cross, or have died because their ancestors may have had something to do with death on a cross? Science is a powerful metaphor, and we in the field of mental retardation must remember it--whether it has relieved more suffering than it perpetrates, whether it brings us closer to the truth than to a diversion from it. Science, and all it conjures up, is both a powerful metaphor and a very powerful explanation--even when the work or the explanation has little if anything to do with Science itself. "In the name of Science . . ." is in our field a stronger rallying cry than "In the name of God . . ." is in Rome or Jerusalem.

The Patient And Subject Have A Right To Know

There is yet another related problem. Specifically, I raise here the issue of the patient's (or subject's) right to know about the treatment he is getting and, furthermore, his right to decide whether he wants that treatment. The case of William Rehnquist, the Supreme Court Justice, raises interesting questions in this regard. If it was "merely" an issue concerning the patient's right to know, the problem would be complex enough, but the situation is exacerbated when the issue of the public's right to know is injected into the drama. The problem has numerous permutations. But first, let's briefly discuss the Rehnquist dilemma. The Justice acquired a dependence on a sedative he was taking for a degenerative lumbar disc disease, which caused severe back pain (Marshall, 1982). By the time his illness became public, he was required to enter a hospital to be detoxified after lengthy usage of large doses of that drug. Hospital officials were in a quandary, trapped on the one hand between their obligation to their patient and his natural desire for privacy and, on the other hand, by the public's demand to know about the medical condition of an important national figure.

There are many instances in research as well as clinical practice--in our and other fields--which pit individual rights against what has been commonly called the public good. In the Rehnquist situation, it is a patient's expectation that his medical condition is a private affair. Notwithstanding, a voracious public wants to know about its presidents, movie stars and Supreme Court Justices. On still another level is the distinguished pediatrician who feels justified to experiment with institutionalized mentally retarded residents of a New York State institution for purposes of solving important problems associated with infectious hepatitis. Whether in that situation parents were coerced to "sign off" on permitting dangerous experiments with their children (else they could not gain institutionalization for their children) has been debated in the courts as well as the journals. But there is no doubt that such experimentation was accomplished and, indeed, a significant number of children institutionalized by the State of New York were medically imperiled as part of an intentional experiment supervised by a doctor (who swore obedience to the Hippocratic oath) in an institution which was created and is sustained to protect the physical and moral well-being of its "incompetent" clients (Blatt, 1981, p. 130). Elsewhere, I have written about the reports concerning Black men known to have syphilis, but deliberately not treated in order to compare the progress of their disease with the curative powers of others given penicillin. We have read documented stories about the use of ill elderly patients for dangerous cancer experiments, the uninformed if not unwilling participation of Mexican-American women enrolled in a study to examine the psychological effects of oral contraceptives, and the utilization of prisoners to participate (although willingly) in dangerous experiments with promises of reduced sentences or special privileges. Of course, there aren't many in this field who have been unaware of the various cases involving passive and active euthanasia, performed not only on a case-by-case basis but also as general policy in prestigious medical centers. Even insofar as the retarded, mentally ill, or homeless person's "after life," there is greater danger that what we assume are one's natural rights will not be protected. Here, we are referring to the assignment of unclaimed cadavers for use by medical school students.

Even the wisest decisions with regard to "protection of the individual" versus "service to society" will not be totally satisfactory. I understand that medical students need cadavers and medical scientists need to perform those last crucial experiments _in vivo_. I am even sympathetic (but not necessarily in agreement) when a family elects not to permit surgery which may prolong a life but not restore a mind or body. I have no salvaging recommendations to make, no wisdom which will ease the suffering of a patient, or prevent his jeopardy while society makes progress on all scientific fronts. But I do want to emphasize the right of each individual to be informed about what is in store for him if he permits this procedure or that dose. And if the individual is truly incompetent, then I think it would only be a cruel and indecent society which would have a decision made not for _his_ benefit but on its' _own_ selfish behalf.

On the other hand, in spite of these admonitions, in spite of my fundamental belief that what is good for the individual is good for the collective body, I remember a conversation years ago with a now famous colleague who said to me that, if he could cure schizophrenia, he would gladly sacrifice not only his subjects but his own wife, his children and himself. He said that those sacrifices, and much more, would be well worth the price of such a glorious victory on behalf of humanity. And consequently, it came as no surprise when he also said that he would be perfectly willing to use obtrusive measures to collect relevant data. He would even use punitive treatment protocols to learn about that which is now a mystery, and potentially corrosive drugs and other treatments to eventually alleviate pain and suffering. In fact, my colleague expressed the conviction that, put to the test, he would do virtually anything to learn how to relieve suffering, even if the price for such knowledge is to deliberately cause people to suffer.

I can't agree with him. Indeed, I think he's dangerous to his subjects and to society in general. Notwithstanding, his feelings--however attenuated they are in most of us--remain in most of us. He is especially dangerous, not because we too haven't thought his thoughts, but because most of us lack his exuberance and conviction for the idea that the ends justify the means, that killing can be justified if it eventually prevents even greater killing. It's exactly because Science has been held up as the eventual solution to mankind's ills that we find such zealots among its ranks. That's exactly the reason why I can both sympathize with the scientist and demand surveillance of his activities. That's the reason why there must be workable methods to control his passionate quest for the truth at whatever price to society, at whatever cost to the individuals ensnared in his net. This all sounds very prejudiced, and of course some of it is hyperbole. But there is also substance to the worry that certain scientists under certain provocations can be tempted to disregard the moral if not legal codes of our society.

How Abuse and Deception Is Justified

The trivialness, the wrong tracks, the wrong fantasies, the abuses in the name of Science, the abuses in the name of professional ethics--how is it all justified? "Scientific battles" is a non sequitur?

Academics and other people who should know better seem to enjoy writing about the ethos of the academic enterprise in terms of community, collaboration, freedom, and the spirit of inquiry. Watson's The Double Helix (1968) was but one of a number of reports in past years which "let the cat out of the bag." But even the more recent disclosures of probable scientific chicanery perpetrated by Cyril Burt and others--such as the report of "doctored" mice at the prestigious Sloan-Kettering Cancer Institute, and the ever-recurring accounts of the "wars" and accusations among academic luminaries--do not still the myth of Pristine Science. Why does the myth persist? Why do the scientists themselves, believe as true believers believe?

Before he died, the Italian poet and essayist, Caesare Pavese wrote that, from the time he could think until the moment of his demise, a person is consumed by a constant occupation--his self-justification (Pavese, 1961). We evaluate all matters and ideas in terms of how our existence, our behavior, our worth, and destiny is justified. Is it any wonder that, even if there is only a semblance of validity to Pavese's observation, the institutions we have created for the mentally retarded--the segregation, the experiments, the sterilization and other indignities heaped upon them, the euthanasia and other forms of death inflicted on them--would be justified by the perpetrators? Of course, "self-justification" doesn't "explain" all the absurd policies, programs, and rhetoric in the broad field as well as in my narrower area. Virtually by definition, "absurdity" is difficult to explain. Even the powerful forces which seek to justify one's life, flounder when it comes to a defense of this field. Notwithstanding, there are pervasive attempts. Else, why is there so much "mischief" pervading the field? Why are there so many "leaders" who work at gumming up the normal ebb and flow of society when it comes to these people we call disabled? Why is it that professionals who otherwise light up lives, some who heroically save lives, look to darken life for the disabled? Why don't more professionals see the horror that's being perpetrated, see the callousness that is found in many places where programs exist, see the neglect where programs don't exist?

Parts of the answers lie in Pavese's idea of Man's preoccupation with his self-justification. Parts of the explanation lie in the observation that it's one thing to live the horror and another to perpetrate it; it's one thing to be cast in the back wards for experiments or dumped into segregated schools, while it's another thing to be superintendent of the institution (never having to actually visit the back wards) or director of special education (never having to spend much time in the segregated school). Then, of course, there is the difference between those who are close up to the terror and those who see it from the perspective of a laundered annual report in the comfort of their central office. For all of these reasons, and possibly more, the abuses and insensitivities continue relatively unabated. For all of these reasons, while there are good rationales for the programs, and while there are people (even in central administration) who comprehend precisely the realities, injustices prevail. Life goes on as usual--for the victims as well as the perpetrators.

Science is not the pristine, clean, altruistic occupation of saints. The <u>metaphor</u> of Science may be inspiring, but the <u>work</u> of scientists is temporal. People are people, and scientists are merely people.

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