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JUL 5 1988

**Minnesota D.D.
Council**

THE THEOLOGY OF TAXONOMY

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May 17, '84

Presented at the National Open
Forum on the Prevention of
Mental Retardation, Boca Raton, Fla.

This intimidatingly prestigious group is here for a few pricey days to rap about preventing retardation. We stand on definitional quicksand with both words. Amorphous is the kindest adjective you can use for either.

The term "retardation" has a depressingly unstable aspect. It changes from culture to culture, society to society, profession to profession. It is determined by different instruments; tested for under inconsistent conditions by people who carry their own bag of transmissible prejudices. It is simply a label. It damns the whole person after testing only a small part of the person. It has all the dependability of divining from entrails. It satisfies the theology of taxonomy's need to have a high group, a low group, prioritizing, a judgment of values. Salvation by categorization.

In one of his provocative writings on the unreliability of labels, Gunnar Dybwad describes the miraculous overnite curing of millions of people with retardation when AAMD's 1973 rewritten Manual lowered the upper cut-off point for mental retardation to not one but two standard deviations. I expect no one here will have the temerity to suggest the heroic measure of truncating another standard deviation or two (what's a standard deviation between friends?). So, given that reluctance, we must look to the definitions of what we are about as the terms stand now.

I tried hard to find a synonym for "prevention", to vary this writing. "Prophylaxis" is the only choice. We usually associate that word with birth control or cleaning teeth, so we're stuck with "prevention", for we think we know what that means.

Do we?

Nothing I say here is unique. It's all been said before by a parade of un-

impeachable paragons: Mercer, Blatt, Taylor, Dybwad, Edgerton, Hobbs, Branginsky, and dozens more.

I'm adding simply the reinforcement of the non-scientific observations of a thirty-year advocate/parent/change-agent. . . .in the vernacular. My epiphany stems from seething years watching specious labeling, and the no-sense of it all. The damage of it. The sin of it. The stupidity of it. This defilement by labeling is initiated and constantly reinforced, ironically, by parents and professionals, we whose see ourselves as the people most interested in the welfare of those we make sure to tag as unworthy.

Prevention usually means not letting it happen. In this meeting's context it means seeing to it that pre-natal mothers are fed right, protected from diseases and directed away from such people as obstetricians who use too much anesthesia. It means that children must be protected from disease and injury before and after birth. It now means that lots of kids must be killed in fetu. God forbid they should add to the statistics or to the special education budget. All these measures belong in the medical world.

I suggest that there are still other areas of prevention possible. The term "retardation" is an arbitrary one with criteria capriciously arrived at. One group of self-designated authorities has slapped a demeaning social status on another group of humans. Since the term does not refer to an entity with scientifically provable elements common to all people labeled with it, it is easy to "prevent" by not labeling. We can describe and deal with an area of deficiency and refuse to devalue the whole person.

The villains are many. None worse than the physicians, however, for 1) they should know better, 2) they refuse to learn, 3) their god-like status gives their advice an Olympian power. Iatrogenic commitments equal malpractice. It is amazing that the same patients who will seek legal recourse for a limp or the loss of a limb when caused by the ineptness of a medical practitioner, will accept a doctor's condemning their child to a hellish life in a warehouse. The incarceration deprives the child of every opportunity to develop, to enjoy the attention and stimulation of its family, to live with a reasonable rhythm of life; in short, to be free.

I have never brought up the subject of intelligent babies who show some stigmata of Down's Syndrome that I don't find a professional or two who know of verifiable examples of children institutionalized at birth who have no retardation. In this state a particularly poignant tale from from the head of one of our more atrocious institutions. He, a physician, had tried to return a child with physical signs of Down's Syndrome to its family when it was clear after a few years that she was superior in intelligence. They refused to take her back and she lived there 'til adulthood, traveling alone daily to regular schools (long before 94-142.) This is not to say that institutionalizing any child with Down's Syndrome is appropriate. The mischief and havoc wrought by "putting away" on the basis of superficial criteria is

best illustrated by their situation, however. I really don't care to hear of the defense that true mosaicism may or may not have been involved. Heck! Doctors are still suggesting institutionalization on the basis of epicanthic folds and creased palms. They likely think mosaics are tiles.

Medical ignorance in this field has always been profound and pervasive. I see not much improvement. The doctors who would attend such a meeting as this are different from the average hands-on primary physician whose often insensitive and unknowing advice is too often followed by parents too traumatized to think straight. So let's not have any knee jerk defense. On the other hand the knowledge gap could be high level. In 1961, when I noticed that one of my children was using World Book as a reference for his senior-year paper on retardation, I read the article (noting it was on "Feeble-mindedness"*) expecting it to be the usual concise accurate precise of the subject I had learned to expect from World Book. I wrote them, saying that... it was totally inaccurate in the light of today's knowledge. It was full of terms and archaic language that every force of NARC and all its member units are working daily to correct. Shuddering horror and disbelief, I thought with irony of the 165 speeches we have made recently locally to every group from the Bar Association to the Women of the Moose, in an attempt to erase those dark-age ideas from the mind of the public. Multiply that by the efforts in all other cities and towns and you can understand our despair that every day World Books are being put into homes to spread further inaccuracies. Who IS this author? And how long ago did he die?" They replied that he was the head psychiatrist at Yale, still breathing. As I remember the article, it described people with retardation as requiring institutionalization for the most part, mainly because of their dangerousness.

With such medical marvels as leaders, is it any wonder then, that we have iatrogenic retardation as well as commitment. Yes, we still have that too_____for those unlucky enough to have sufficient monies to afford private warehouses. We could cure or prevent retardation by the simple education of some of the still insensible doctors who might then guide parents to an acceptance of the child's disability as a discrete and minor part of the whole.

As Ivan Illich says in THE MEDICAL NEMESIS, the physician often acts as an actuary and his diagnosis can defame the patient for life. He goes on to describe the situation I have heard about from parents almost daily for three decades. Medicalized prevention labels: "...it turns the physician into an officially license magician whose prophecies cripple even those who are left unharmed by his brews."

Sometimes I wonder at the ironies of our working hard to assure special education services, and then our realizing that a lot of people with minimal mental deficiency do better if they are never smeared with the tar of being a special student. I had such a blood relative. We applied and applied, but the special education people said- this child would do better in the Catholic School environment which ignored the low 70's I.Q. They drilled on

phonetics and produced a superb reader and writer. They emphasized the virtues which are nonquantifiable but which now enable this person to hold appropriate jobs.

A close friend had a child who escaped special education - through inadvertance and a clogged waiting list. His job with the Post Office has escalated to a level of responsibility which supports his wife and two children very well and allows him to lend money often to his four siblings who have degrees. No one remembers he was once classified as educably retarded. Whether that I.Q. would still test in the high 60's is irrelevant. He was not labeled permanently.

The advantages of expectation of normalcy came home to me when I lived for awhile in the Middle East and had an opportunity to assess the state of the art on children with learning problems in Lebanon and Syria.

There, they hadn't found and labeled all those people. It made our U.S.A. officials nervous that the not-so-smart- population was working, along with the smart, on family farms, in family shops. They were contributors. They were respected for the necessary work they performed. Nobody categorized. Nobody labeled. I realize our daily life is different. Children are not useful people necessary to the family's sustenance. Pity. But maybe, with thotful purpose, we could try to expect more of them.

Some of my children have been very critical of our not demanding more work and responsibility from my son who is labeled retarded. They tell me that my husband and I contributed to his inadequacy by excusing him. It's true. I now see that we helped make him more "retarded". Our treatment of him dictated that of the people in the society around him. He is perceived as less capable than he is.

We parents assure more retardation by denying any life experience which has risks. Risk-taking is the only way anyone learns. Much has been written on the dignity of risk. Ordinary examples have to do with physical risks - e.g. in traveling and recreating. But how about voting and marriage, for instance? They are the real tests to see if we talk out of both sides of our mouths.

We demand, properly, education, transportation, training, employment, housing and living subsidies. We who advocate declare that our advocates can succeed if only given the preparation and a chance. Then, inconsistently, we lend our assistance for marrying and voting to only a select few. We say to all the world; "I have respect for my child as a person with opinions and needs and the right to make choices, but when it comes to marrying and voting, I deny that right, those needs, those choices. After all, I believe that for marrying and voting one must have intelligence". Whoop-de-do. Let us now have a few minutes to consider the marriage record of most of us and of our intelligent friends. then let us contemplate for a painful moment the excellence of the leaders, our own intelligent vote has put into office.

There are thousands who could vote but are not helped toward it or who are blocked when they want to. We create more retardation by these unthinking attitudes. Our actions scream to the world that we consider our offspring flawed and unworthy of involvement in our most precious institutions.

As a political animal, with every genetic imperative an Irish inclination to involvement, I try outrageously to influence my friends and family. That includes my son who is labeled retarded. He doesn't buy it. I tell you it really hurts when I have to pull the levers he dictates when they are not my candidates. And it hurts even more to tell you that observing his candidates in office a few years, proves him right as often as I. So much for "intelligent choice".

For the quintessential comment on this subject, beautifully handled, see the story Bernie Posner wrote on the political decision - making of Richard, Eleanor and Phil Elkin's son. It was in one of Bernie's exquisitely written recent newsletters from the President's Commission on Employment of the Handicapped.

Who is to say that many parents are wrong in curing or preventing retardation by refusing to accept the label? Thus by their acknowledging a psychological or learning disorder which does not fall within a medical rubric, they save their children from being tarred with a mythological condition and social stigma called retardation.

Countless numbers of cases of what we call retardation are cured by re-naming them learning disabled. Sometimes it's a long-overdue and accurate correction. Sometimes it's a funding facilitator. Sometimes it's a sought-after social balm to the unfaceable pain of having a defective child.

To put in a good word for parents, I like to tell my elevator story. When I was on the faculty of the State University here in Boca Raton, I taught non-verbal communication and had a particular interest in the territoriality and tactility dimensions of elevator behavior. They are rigid. I often test them, with dramatic results. One day my son, Greg, did too, and illustrated that parental attitudes are contagious. Society will mirror our opinion of our child.

Greg has learned, by example I guess, that compliments bring good reactions. His speech is not clear. On the elevator he said to the man next to him: "I like your tie". The man, startled and wary, his territory invaded, said: "What?" sharply and with a frown. I interjected, "He said he liked your tie!" in a tone which translated into: "So why don't you answer him, you dope?" "Oh", said he, brightening, "Thank you very much". Had I told Greg not to bother the man, the man would have remained threatened and affronted. As it happened, he responded positively to my expectation of civility and probably felt better for it. I do believe we intensify the labels when we absorb and reflect them.

So, what am I saying?

That no one needs special education? Of course not!

That all physicians give bad advice? Not when they stick to medical subjects, which retardation is not (and besides, even there they may be educable).

That our children will be respected by society if we act differently and are consistent in showing our own respect for them?

In deed, yes.

I believe that if we insist that "retardation" be used as a useful term for only those discrete cognitive and behavioral processes, individually evaluated and defined, where special help is needed, we can prevent retardation as we know it.

I believe that if we adamantly refuse to accept a damning label of "defective" for the whole person, when only a part of the person is below average, we can prevent retardation to a remarkable degree.