

May 1978

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Arthur J. Dyck

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Recommended Citation

Dyck, Arthur J. (1978) "Mental Retardation as a Label: A Problem in Justice," *The Linacre Quarterly*: Vol. 45: No. 2, Article 6.
Available at: <http://epublications.marquette.edu/lnq/vol45/iss2/6>

Mental Retardation as a Label: A Problem in Justice

Arthur J. Dyck

The author is co-director of the Kennedy Interfaculty Program in Medical Ethics at Harvard University and wishes gratefully to acknowledge support from the Joseph P. Kennedy, Jr. Foundation for the completion of this essay.

Scientific medicine rightly and understandably depends upon making precise diagnoses. For each diagnosis, there is a name or label. Labeling a person in the sense of identifying and categorizing a symptom or disease does not usually strike us as improper or unjust. But medical labels, despite their necessity and usefulness, may be unjustly as well as justly used. In this essay I want to examine certain injustices connected with the concept or label "mental retardation."

In Ralph Potter's excellent essay, "Labeling the Mentally Retarded: The Just Allocation of Therapy," certain criteria were developed by which to judge the justice of the way in which labels are applied.¹ Potter argued that the just use of labels in medicine for therapeutic purposes should satisfy the following three criteria. First, no label should be indelible. Any label that is applied to persons should be erasable. Second, labels should establish eligibility for special assistance provided for persons with specific needs. This means that labels should expand opportunities for the persons to whom they are applied. Labels which contract opportunities constitute an ethically unjustified use of power over others. Potter's third criterion is that labels should confirm the treatment of persons as persons. In other words, when one identifies a weakness in a person, this should not prejudice one's expectations concerning the presence of a wide range of valuable human qualities in that person. Applying Potter's criteria is very revealing for seeing the differences and the actual practices surrounding a diagnosis like appendicitis as compared to a diagnosis of mental retardation.

Indelibility

With respect to indelibility, appendicitis is not morally problematic. It is certainly a temporary label. Furthermore, there is no stigma attached to it, at least none that is permanent. Persons who are labeled mentally retarded, on the other hand, tend to carry this label through-

out their lives, and almost always for a very long time. One indication of the expected irreversibility of mental retardation has been the strong tendency to wish to sterilize young, mentally retarded women. Although this tendency has abated, persons considered mentally retarded still risk being sterilized with or without their consent.

Persons who have at some point in their lives been designated as mentally retarded have great difficulty in shaking off this label. Even the most loving and well-intentioned persons will often marvel at what a retarded person can accomplish rather than think about the fact that certain accomplishments on the part of a person once thought of as mentally retarded should lead to the withdrawal of the label of mental retardation. This persistence in using the label of mental retardation for persons who are doing many of the things taken for granted of "normals" is extremely unfair.

Special Assistance

When a person is diagnosed by a duly licensed physician as having appendicitis, one can usually expect that such a person will receive subsequent care and the removal of the symptoms associated with the label. All of us are aware, of course, that there are potential and actual injustices that may be associated with someone who is said to have appendicitis. Unnecessary operations and discrimination in the delivery of health care are examples of problems of justice that the larger society must constantly struggle to rectify. Nonetheless, our point here is that the label of appendicitis as such is not a source of abuse.

By itself, then, being told that one has appendicitis does not involve a contraction of any basic human rights. On balance, it is a great gain to be diagnosed as having appendicitis when one indeed is suffering from it, because it means that one's right to live and pursue happiness will have been enhanced by speedy, therapeutic intervention.

Special assistance in the case of mental retardation is, at best, uneven. Indeed, it is not often possible to do something genuinely therapeutic. For example, an underlying condition of Down's syndrome, which includes mental retardation, is not something that is at the present time reversible. What is all too often overlooked, or at any rate inadequately dealt with, is the fact that the person who has Down's may, in many instances, still be helped to overcome some of the incapacities associated with mental retardation. Our record relative to providing special assistance for the mentally retarded is not at all on a par with our record relative to appendicitis.

The worst aspect of the label of mental retardation is, however, the devastating extent to which persons bearing that label may lose their most fundamental rights. We have already alluded to sterilization, and the reader of this issue of the *Linacre Quarterly* can see in Richard Sherlock's essay a number of ways in which the mentally retarded have not been afforded their full rights as human beings by court

decisions. Harold Vanderpool's essay in this same issue calls attention to a whole system of thought and orientation which is being applied toward retarded individuals in various institutions for the retarded on the basis of B. F. Skinner's ethical reasoning. Calling persons retarded permits Skinner to speak of them as a detriment to the struggle for the survival of the human species. He thinks that retarded persons are virtually of no worth to the human species unless they are used in experiments that will teach us how better to survive. Those who have read the articles by Shaw² and by Duff and Campbell³ will know also that newly-born infants who are considered to be mentally retarded may, with the cooperation of parents, lose the usual right to receive life-saving medical interventions. In short, to be labeled mentally retarded may, in some instances, mean the loss of so fundamental a right as the right to life. Clearly, mental retardation carries with it associations that appendicitis never does.

Treating Persons as Persons

Again, appendicitis is not a problem with respect to losing one's identity and dignity as a person. In fact, it is an excellent label in this regard because it functions precisely to relieve people temporarily of their usual responsibilities and to hold them guiltless with respect to any loss of productivity or inconveniences entailed by their medical condition. The effect of being ill with appendicitis, as with many other cases of illness, is to be given special deference as a person.

Mental retardation poses a real threat to persons. Actually it poses the ultimate threat. Persons so designated may not be regarded as persons at all. Joseph Fletcher has written that a Down's is not a person.⁴ In subsequent publications he has spelled out specific criteria of personhood which include the achievement of a certain IQ level.⁵ If mental retardation is to connote a complete lack of personhood, it not only loses whatever therapeutic value it still retains, but it also becomes a sentence of death, or at the very least, a sentence to second-class citizenship.

There may be some question in the minds of readers about the comparability of appendicitis and mental retardation as medical labels. After all, appendicitis is clearly an acute condition and mental retardation is often associated with conditions such as Down's syndrome which are irreversible or chronic. This is true. However, justice in the use of mental retardation as a medical diagnosis and label requires us to be guided by two important additional facts: first, that a great number of mentally handicapped individuals can be helped to improve their level of performance and functioning, and second, that some individuals who have been described as mentally retarded will achieve a state of independence that makes it inappropriate and unnecessary to continue calling them retarded. Indeed, what we are contending is that it is not just to label persons mentally retarded if the use of the

label does not serve to provide them with help, and if the label is not erased even though the condition that justified its use has been improved to the point where help is no longer needed.

Having contrasted appendicitis and mental retardation as diagnostic labels, some of the readers may understandably ask about other diagnostic labels that may involve injustices. Physicians, for example, have long been uneasy about the extent to which and the way in which diagnoses of cancer or of heart disease are to be communicated to persons with the relevant medical symptoms. Our purpose here in introducing criteria for judging the just use of diagnostic labels is to provide a reminder to those who use medical labels of their potential for abuse and a way of identifying what constitutes abuse in labeling. There is no attempt here to argue that people who have symptoms associated with what is called mental retardation will be greatly helped if other words are substituted for their particular condition or handicap. No, this essay is not about what words or diagnostic labels to use, but rather has to do with identifying and illustrating criteria by which abuses in applying diagnostic labels can be identified and hopefully curbed. It is a plea for more justice for those who are considered mentally retarded.

Perhaps a further word is in order about the basis we have for thinking about even the most severely retarded human beings as persons. There are at least three ways in which people decide questions of personhood: 1) utilitarian, 2) rationalistic, and 3) Good Samaritan.

The utilitarian ideal of personhood would decide that human beings qualify as persons depending upon how useful or productive they are. Sometimes this will include the usefulness that is associated with even limited forms of expressing affection, but sometimes it does not. In *The Gulag Archipelago*, Solzhenitsyn devastatingly documents the complete loss of human rights and personhood that were associated with the seemingly simple and innocent formula of the earliest chief prosecutor of this new Soviet-socialist government. For Krylenko, justice was decided on the basis of what was expedient for the state. Krylenko also used the argument that is part of the basic utilitarian formula, namely, the greatest good for the greatest number. The decisions of the court were always made in the name of the masses, of the great majority. But no basic human rights are secure under this formula. If the rights to life and liberty are not strictly equal, justice has been undermined. And fairness, whether in the courts or in medicine, will not be the norm.

People may have a rationalistic ideal of personhood. Socrates is reputed to have said that the unexamined life is not worth living. John Stuart Mill thought it better to be a Socrates dissatisfied than an animal satisfied. In both these instances, the basic right to life seems to be questioned in instances where a certain measure of intellectual attainment is impossible or not forthcoming. In any event, a certain

intolerance for imperfection of the intellect is a long-standing part of Western tradition and a basis on which some human beings are judged as to their worthiness to be designated as persons and treated accordingly.

If every member of society and everyone born into the human species is to enjoy an equal right to life and liberty, nothing less than the Good Samaritan ideal of personhood will be necessary. What this ideal requires is that the community be pledged to a constraint against killing, the exceptions to which cannot be justified on the basis of criteria of personhood based on utility, reason, or other considerations of merit. To be conceived and to be born of human parents is sufficient reason to be afforded the usual care and solicitousness which we constantly bestow upon persons. There may be many difficult decisions and conflicts that arise from the satisfaction of our basic human rights, but our resolution of these will be unjust if it is based on considerations of usefulness or rational ability.

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