Three Controversial Treatments: Euthanasia, Abortion, and Sterilization

By Wolf Wolfensberger (1934-2011)

Circa 1967 or 1970

EDITORS' NOTE: The original manuscript was untitled, so this title is taken from the first heading. The original context for the text is unclear and the date is approximate. Nonetheless, this paper is particularly instructive in that it demonstrates that Dr. Wolfensberger was alert to the wound of deathmaking very early in his career, and that he was committed to pointing out the moral implications of widespread human service-mediated deathmaking. He also warned of its tendency to spread to multiple societally devalued groups, an increase that has shown itself today in alarming ways, and that is far from over.

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Being a medically oriented text, it would be inappropriate to review those treatment approaches in mental retardation which are primarily socio-behavioral in nature. We recommend that the reader turn to other sources for such coverage. However, there are certain types of treatment which are non-specific (i.e., not specific to a circumscribed syndrome, as a low phenylalanine diet is specific to phenylketonuria) but which have strong medical components. Three such treatments merit special discussion, particularly because of their controversial nature.

Three Controversial Treatments: Euthanasia, Abortion, and Sterilization

There are three types of treatment involving medical aspects that have been advocated and applied to the retarded, but which have profound moral, ethical and other non-medical implications. These are euthanasia, abortion, and sterilization.

Euthanasia or '"mercy killing" is sometimes advocated for the profoundly retarded, for the multiply handicapped retarded, or for newborn infants with severe congenital impairments. In popular language, many such children are felt to "be better off dead". The killing, directly or indirectly, for mercy or otherwise, of the handicapped has a long tradition. It was and is found among primitive cultures, especially those that lead a marginal existence, as well as among more advanced societies such as ancient Greece and Rome, and until recently in Nazi Germany and in certain parts of China. Visitors to institutions for the retarded in Germany will see a relatively small number of older retardates because many institution residents were killed in the early 1940's.

Abortion, sometimes referred to as therapeutic or eugenic, is widely advocated in cases where there is an above-average degree of likelihood that the child is or will be impaired. It may even be advocated if there is a likelihood that the mother's morbid anticipation of bearing a damaged child may affect her mental health.

Sterilization (primarily of retardates) as a means of preventing the rise of further retarded generations had been advocated primarily during the "alarmist period" in retardation, e.g., between about 1900-1940. During this "genetic scare" period, sterilization was perceived as desirable for genetic reasons since retardation was seen as being primarily hereditary. Today, one may hear sterilization advocated once more on socio-behavioral grounds, because it is believed that a major portion of the retarded become retarded because of the non-genetic but none-the-less very real socio-behavioral limitations of their parents.

In considering euthanasia, abortion and sterilization, a clear distinction must be drawn between empirical questions of efficacy, ethical and moral considerations, and administrative and social issues. We will examine the empirical issues first.

Euthanasia of severely damaged infants or clearly identified older retardates is unquestionably the most effective alternative in reducing the number of retardates, and in saving money that might otherwise be spent on care and treatment.

Abortion is much less effective. One can rarely state with certainty that a fetus will definitely be impaired or, if it is impaired, that it will be retarded. In some conditions, such as maternal rubella, there is now enough evidence for making close probability estimates. For many other conditions, probability estimates are poor. From a purely empirical viewpoint, it boils down to the fact that in most cases abortion involves a certain risk that the fetus is healthy.

There is already a fairly high risk of about 5% that any newborn may be congenitally impaired. If an abortion were performed in a condition which has twice the risk level of ordinary pregnancy, chances would still be 9:1 that the aborted fetus would be healthy. There is some reason to believe that physicians performing an abortion may tell the parents that the fetus was impaired even if it was not, for the sake of parental conscience and emotional wellbeing, and on the reasonable assumption that conflict and guilt would be more likely if the fetus had been found healthy.

It is now believed that large-scale sterilization of retarded persons is not likely to diminish appreciably the rate of genetically transmitted cases of retardation. However, there is good reason to believe that mass sterilization of certain ethnic, social and economic groups (all poor Negroes, for example) would drastically reduce the rate of socially transmitted retardation. However, such decisions, including the ones regarding euthanasia and abortion, as many other decisions, cannot be made on a purely empirical basis. They must be made on a social policy and value level, and involve profound ethical and moral judgments. It is indeed unfortunate that scientists sometimes do not recognize this distinction, and are occasionally seduced into confusing their role as scientific experts with their role as citizens who all share equally in determining social policy.

In approaching the value-determined problems of the three treatment types it is useful to make a distinction between questions of religious morality on the one hand, and question of secular ethics on the other. As far as many people are concerned, the moral question is quickly settled. For instance to

most devout Catholics, all three treatments are morally objectionable, and empirical considerations are irrelevant. To other individuals, one or more of the three treatment types may be morally unacceptable, or may be unacceptable in many relatively well-defined situations. Yet others hold no moral-religious precepts that would rule out any of the treatments. However, among those who have no moral objections some may have grave doubts about the permissibility of one or more of the three treatments on ethical grounds of a non-moral and non-religious nature or on social policy grounds. Several such considerations will be examined below.

The issues can be most clearly drawn in the case of euthanasia. In institutions, one may see hydrocephalic children with heads so huge and heavy that the weight of the head has resulted in vast sores which may extend down to the skull bone. The child may be blind and in pain, requiring constant attention, and may have to be stomach-fed. In such specific instances, it is easy to think favorably of euthanasia without giving much consideration to the broader issues involved. However, aside from one's views on individual cases, it is crucially important to give the most careful consideration to broader principles and issues at stake. Indeed, a person involved with severe retardation on the actual contact level should make an effort to come to grips, to his own satisfaction at least, with ultimate questions regarding the meaning, nature and purpose of human life.

Some relevant questions one should ask oneself might include the following:

a) When does human life start? At conception–as believed by Catholics? Upon quickening–as believed by Jews? Upon birth–as recognized by law?

b) When does a human organism first acquire rights? Before conception as implied by those who say that a child has a right not to be born to certain people? At conception, as those maintain who speak of the "rights of the unborn"? At birth? Or from the moment from which a fetus can live outside the womb, as maintained by some?

c) What determines the value of a person? Is it one thing, two things, three, or how many? Is it potential for walking; for talking; for being like the neighbor children; for reading and writing; for becoming a doctor, lawyer or merchant-chief? Does the degree of intelligence or education have any bearing upon the value of a person?

d) What makes any life worth preserving, and what, if anything, makes one life worth more than another? How is an abhorrence of capital punishment to be reconciled with liberalized abortion laws? Is the vicious killer worth preserving when we are willing to risk killing perhaps five healthy fetuses to destroy one unhealthy one?

Even after value-charged questions such as these are answered, administrative and legal problems still loom large. A major one is as to who should and will be charged with the responsibility to decide on questions of euthanasia, abortion and sterilization. For example, the abortion decision is often presented as if it was a purely medical one when, in fact, it is much more complex and has extensive psychological, sociological and even political

implications. Is each medical decision really so clear-cut, and is each physician really so well-trained and competent as to arrive at the best answer to the non-medical questions involved? Should a physician be both scientific expert witness, judge, and "executioner"? Such questions deserve profound thought.

The possible erosion of principles, once qualitative barriers are broken, was exemplified by the events in Nazi Germany. Once any segment of the population is perceived and defined as having less of a right to live than others, it becomes easy to progressively deny this right to an increasing number of groups and individuals. Once the Jews were denied basic human rights, it was easy also to deny these rights to "half" and "quarter Jews", as well as to another group perceived as unproductive and parasitic, i.e., the gypsies. The next step was to kill the retarded, and then it was only logical to kill the chronically mentally ill on the back wards of mental hospitals. If it seems permissible to kill the severely retarded and chronically disturbed, why stop at the aged infirm–and there was no stopping. Soon "Eastern European riff-raff" was included and mass extermination of the Slavic population west of the Urals was planned in case Germany won the war. By the end of the war, Germany celebrated its *Gotterdämmerung* in an orgy of killings where no one was safe. Even soldiers were shot or hanged wantonly on the merest suspicion of disloyalty.

It is to be recalled that such things happened in this generation, and in a country with the highest intellectual and academic standards. Furthermore, we too have our minority groups perceived as undesirable "riff-raff" by major segments of our population, and we have the evidence that constitute signs of

danger. For example, studies have shown that if a Negro and a caucasian retardate both committed a sex offence, the Negro would be more likely to be sent to an institution. Females are twice as likely to be sterilized under court orders than males. Indigents accused of murder have been much more likely to be convicted and executed than affluent persons. If euthanasia became legal, is it not conceivable that already existing patterns of prejudices and social injustice might be aggravated? What would be the implications to minority groups such as the Negroes in Mississippi, the Indians in Colorado, the Mexicans in California, the Puerto Ricans in New York, especially if poverty-stricken and disease-plagued?