We are afraid that the debate about euthanasia for people with disabilities will continue. But it will not be called euthanasia; it will be called the “right to die.”

one questioned why he could not find adequate community-based services to support him in leading an independent life. This must change.

Unfortunately, many states do not have adequate support services for people with even fewer disabilities than Larry McAfee. McAfee may now be securing what he needs to live in the community, but what about the millions of disabled people in the United States who are not finding what they need? Because the human service delivery system is based on the medical model, it offers little hope to the very people it was established to serve.

Until the independent living paradigm parallels the strength and funding of the medical model, we are fearful that the debate about euthanasia for people with disabilities will continue. It will not be called euthanasia. It will be called the “right to die.” Many people, including those with disabilities, would not deny any individual the right to die; but we are extremely suspicious — in fact, we anticipate — that society will treat people with disabilities differently in the right-to-die debate. It will be a struggle for society to acknowledge that disability is a normal part of human experience. The independent living paradigm and the people working to implement its model for change offer us hope.

References


[Specific citations available on request from Midwest Bioethics Center.

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Euthanasia, “Final Medical Assistance,” and the Right to Kill

A Review of By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich

by Daryl P. Evans

In a most worthy follow-up to his excellent work, FDR’s Splendid Deception, Hugh Gallagher provides a detailed account of an aspect of the Holocaust that, for the most part, has been overlooked by historians and other scholars. Rather than review the abundant material that exists on the extermination of the Jews in Hitler’s Germany, Gallagher focuses By Trust Betrayed on the killing plan the Nazis euphemistically called the “euthanasia program” — Aktion T-4.

This program (so-named because its offices were located at Tiergartenstrasse 4, just down the road from the Chancellery in Berlin) was designed to conscript the German medical profession into an informal corps of murderers, whose task it was to provide “final medical treatment” to the Reich’s chronically ill and disabled population.

Depending upon whose statistics one accepts, at least 200,000, and as many as 300,000, German citizens were killed by their physicians. There were all manner of conditions that qualified persons for “final medical assistance,” including people who were institutionalized and labeled as insane, severely disabled, tuber- cular, mentally retarded, dwarfs, paralyzed, epileptic, senile, and suffering from encephalitis or Huntington's chorea. The killing program also liquidated many persons who were guilty of “antisocial” behavior, delinquency, perversion, and alcoholism. (page 13) Indeed, the program ultimately became so arbitrary that a person could be killed simply for having been in an institution for at least five years. And before the program was stopped, the Nazi doctors even killed some of the disabled veterans from their own wars. The magnitude of the program is perhaps best seen in the fact that 85 percent of Germany’s mental patients were killed by the end of the war. (page 4)

One of the most disturbing elements of the program was that many of its victims where children. Again, the killing was often arbitrary. For example, conditions for which children could be killed included “such things as bed-wetting, pimples, a swarthy complexion, or even annoying the nurses.” (page 135)

The methods of killing were varied. Most of the adults were gassed and cremated, or they were shot. Many of the infants and children were killed by starvation, slow poisoning, or by exposure. To ensure early detection of expendable children, midwives were paid a premium if they reported a potentially “killable” child and fined and imprisoned if they did not.

Gallagher reminds the reader early in the book that persons who were killed were citizens in good standing with the state. “They were not, in most cases, terminally ill; neither were they often in pain or unusual distress.”

The official centralized euthanasia program lasted from the fall of 1939 through the summer of 1941, although doctors continued the program informally long after that, taking upon themselves what the assessor committees and review professors had done when the program was more formal.

According to Gallagher, the children’s campaign, in which retarded and_ continued on page 16
deformed infants were put to death, continued some time after the end of the war. Children were still being starved to death three months after Germany’s surrender. (page 250) As a matter of fact, Gallagher adroitly observes, “the allies did not seem to realize that the hospitals, asylums, sanatoriums, and orphanages also needed liberation,” because the killing persisted in all these venues even after the bombing and shooting had stopped.

One of the eeriest and most terrifying portions of this book comes when Gallagher takes the reader to Hadamar Psychiatric Institute—a one of the six major killing institutions, where at least 10,000 mentally ill Germans were killed by their psychiatrists. In measured detail that builds a tense despair, one finds him/herself observing the carbon monoxide gas showers, and later, hypodermic injections of morphine and scopolamine. And the chill of Hadamar freezes in the reader’s mind that April day in 1943 when the Institute became a children’s killing center—when it began to dispatch retarded and disabled children, orphans, youngsters from juvenile homes, and those of mixed race. One watches the “good patients” — those who even though they might have suspected or known their fates at the hands of their physicians — following “doctor’s orders” unto their revolting deaths.

In one of his best chapters, Gallagher explores the origins of the killing program. For a reader not versed in Social Darwinism and its bastard child, eugenics, this one chapter of By Trust Betrayed goes a long way toward clarifying Social Darwinism and its twin foundation stones — natural selection and monism. First, we see how natural selection accepts “survival of the fittest” as a biological fact, then follows it as a moral and philosophical prescription. Although Gallagher does not address it, Social Darwinism was, as articulated by Herbert Spencer, an evolutionary philosophy that abhorred any state intervention in the “natural” unfolding of humankind’s evolutionary fate. Only with a completely laissez faire policy toward human evolution could the species hope to approach perfectibility.

Second, we witness the effects of monism on the extension of the Social Darwinist ethos to its reductio ad absurdum. Monism is a philosophical principle that asserts the uniformity of the universe; man and nature are cut from the same cloth and subject to the same rules. Thus, humans are bound by the same laws as nature, the same unavoidable impulse that compels the strong to prey upon the weak, the same principles that permit only the “fittest” (although we scarcely ever ask “fit for what?”) to survive. Moreover, because monism does not accept the division of mind and body, there is a sense in which a person with a deformed body is seen to have a deformed mind. To the monist, the moral order determines the material order; people are weak (and often poor) because they are bad.

Third, there is eugenics, the paradoxical outgrowth of Social Darwinism. Formulated by Charles Darwin’s cousin, Francis Galton, eugenics abandons the laissez faire philosophy of Spencer and seeks instead, during its early phases, to perfect the human race through selective breeding. Finally, in complete contradiction to its Social Darwinist progenitor, eugenics turns its attention to the elimination of those genetic and moral contaminants of society — the targets of Aktion T-4.

As a result of the “eugenic scare,” between July 14, 1933, and the beginning of World War II on September 1, 1939, the Nazis reported the sterilization of 375,000 persons. The frenzy became so pronounced that even some accident victims were sterilized, apparently in homage to a Lamarckian intrusion into what had, by then, become a complete corruption of Darwin’s initial ideas. (page 53)

Basing his views on the unholy trinity of Social Darwinism, monism, and eugenics, it is easy to understand Hitler’s admiration for the Spartans’ infanticide of their weak children. Said Hitler, his Reich “must take care that only the healthy beget children; that there shall be but one thing shameful: to be sick and ailing, and nevertheless to bring children into the world.” (cited on page 52) Given this same ideology, one can better understand the twisted logic of Brandt, Hitler’s personal physician and one of T-4’s primary proponents, when he said in his defense, “Death can mean deliverance. Death is life — just as much as birth. It was never meant to be murder.” (page 258)

Gallagher notes that, in Hitler’s Germany, the Nazis so devalued persons with disabilities that the Nazi textbooks were rife with the eugenic ethos. For example, Gallagher gives an account of a math book that has children calculate the expenditures of the asylums so that the youngsters can see the enormous costs to society of keeping mentally ill persons alive.

One of Gallagher’s most riveting insights is his view of the way murder was bureaucratized in the Third Reich. And this bureaucratization of murder was a multidimensional concept. First, of course, there was the actual process of killing people — a form of assembly line murder in which several different functions would take care of different phases of the extermination; for instance, the driver to transport the victims to the place of execution, the individual in charge of preparing them for their showers, the person in charge of the gas, etc. Not only did this division of labor make the process more efficient, but it diluted the onus for blame. Second, there is the more global issue of how the clean, regimented, obsessive Nazi society got rid of reminders of the untidy, inefficient aspects of the life process — the disabled victims who did not cohere with the ideal of the Aryan “superman.” Finally, there is the rationalization of the exterminators’ thoughts about murder — an enormously

In a German math text, children calculated the expenditures of asylums so they could see the enormous costs to society of keeping mentally ill people alive.

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traceable letter protesting T-4 from a German psychiatrist. (page 179)

Some doctors did tamper with records to keep patients from being singled out for extermination, and a few did say “no” to the T-4 program in unequivocal terms. But this group was a minuscule minority. When one considers this, one is compelled to ask how a profession with such an august tradition as the medical profession enjoyed in Germany could possibly become involved in a horror such as T-4. Gallagher provides some plausible and sobering insights here. Aside from pro-eugenistic leanings of the doctors, one reason they may have been so ready to kill or reluctant to stop it was that German universities had been overproducing physicians for years before the war and consequently, physician incomes had been falling. After Hitler took over, such as those with disabilities or chronic conditions, that cannot be cured. It may be harsh, but, if there is a scientific, political, and economic basis for exterminating a devalued group, a physician may very well eliminate his or her frustrations at not being able to cure someone by killing him.

In all this, the worst of the perpetrators were the German psychiatrists. Not only were they mute in objecting to the implementation of T-4, but also when they did express concern it was about how killing mental patients might put psychiatry out of business!

The judges and leaders at the Justice Ministry seemed not to be fully aware of T-4 until letters of complaint came pouring in from parents who began to discover the deceptions regarding their children’s deaths, and from certain churchmen. And, when knowledge of the killing program became available to the jurists and lawyers, Gallagher argues that they seemed more interested in having the rules for killing codified than having the killing stopped. In effect, the doctors of Germany were given a right to kill with no need for accountability to any law or court. In that environment codification of the law would have been meaningless, except as a means to expiate the jurists’ guilt. Quite simply, all of their professional prerogatives had been preempted by the medical profession. And the result:

Charges against the doctors, brought by relatives of the deceased and by prosecuting attorneys, were quashed. Inquiries and protests were ignored…. The records of vanished wards of the court were simply filed away. At this wholesale prostitution of justice only one judge is known to have protested. (page 216)

And again Gallagher shows us the irony in this prostitution of justice. In a seethingly powerful passage he describes how the German judiciary was enacting some of the most powerful laws protecting the lives and treatment of animals, while it was acquiescing in the murder of its own children. (page 255)

Gallagher paints a multihued picture of the churches’ ethical behavior during the killing program. Although they initially fed into the moral climate that led to T-4 with Reformation philosophies that shored up Hitler’s absolute power, it was the churches that were finally most influential in stopping T-4.

Gallagher does an excellent job of demonstrating how Lutheranism and Calvinism — the two major branches of

How could the German medical profession, which enjoyed such a virtuous tradition, become involved in the Nazi war against disabled people?

Germany became a medical state, with many doctors appointed to important posts; as a result, society operated in accordance with ‘doctors’ orders. Further, procedures such as sterilization raised physicians’ incomes. Many became rich. Thus, status in the Nazi state and economics may have contributed to the perversion of the medical profession in Germany.

Some physicians were afraid that they would be sanctioned or worse if they did not assent to T-4. Some feared ostracism from the profession because of their unwillingness to participate or assent. Gallagher raises the issue of Blutkitt — blood cement — a sense of solidarity created in the common experience of killing; in this case, the “defectives” of the society.

Moreover, Gallagher argues, the doctors who engaged in the killing could conduct this medically-driven genocide in the name of science — Germany’s eugenic science, but science nonetheless. Finally, Gallagher claims that, for some doctors, T-4 was one way of acting out their great frustration in dealing with disabled patients. To wit: physicians are taught to cure and are relatively ineffective in dealing with cohorts of people.
the German Protestant church — set a tone for acquiescing in Hitler’s grip on the German consciousness. For example, he shows how Martin Luther and John Calvin preached that “resistance to the authority of the state was sinful” (page 220). One passage regarding Luther is particularly illuminating:

Luther, who was able to implement his reforms of the German church only through the cooperation of the ruling German princes, was insistent upon the duty of citizens to accord absolute obedience to their prince. He wrote, “The princes of this world are gods, the common people are Satan...I would rather suffer a prince doing wrong than a people doing right” (page 221).

Luther also said, “It is in no wise proper for anyone who would be a Christian to set himself up against his government, whether it act justly or unjustly.” And in another passage he wrote, “There are no better works than to obey and serve all those who are over us as superiors. For this reason also disobedience is a greater sin than murder, unchastity, theft, and dishonesty, and all that these may include.” (page 221). In short, the Protestant churches of Germany were perceived as apologists for, as well as accomplices of, the power of the state.

Not surprisingly, the Protetants also supported the kind of church-sponsored eugenics. Basically, it was a triage system in which large expenditures were made on those patients who had a chance at rehabilitation, while the long-term chronically ill received no more than humanitarian board and custodial care — warehousing.

According to Gallagher’s research, the Catholic Church did not fare much better than the Protestants in its early dealings with Hitler. In agreeing to the tenets of a document called the Concordat, the pope essentially gave Hitler moral carte blanche, provided he did not interfere with the workings of the Church, especially in seizing any of its considerable assets.

Despite their clinging to Hitler on matters of the absolute power of the Fuhrer and obedience to authority, Gallagher points out that both the Roman Catholic Church and Protestant denominations opposed euthanasia, although the euthanasia program had been operating for over a year before religious leaders first voiced public protests. When they did dissent, however, the churches attacked euthanasia as they attacked no other Nazi policy. With more of the German populace protesting the killing of children; with his stalled and unpopular offensive in Russia; and as a result of the unremitting and dramatic protests of brave people such as Bishop von Galen, Hitler officially stopped the T-4 killing program (although it continued informally on a much smaller scale until after the end of the war).

In discussing the efficacy of the churches in terminating Action T-4, Gallagher raises another one of the ironies of the period: What if the churches had objected to the other killing, such as that of Jews, Gypsies, gays, Seventh-Day Adventists? But they did not, partly to protect their own interests and partly because of their respect for secular authority.

The rhetoric of By Trust Betrayed is appropriately subdued, Gallagher letting the magnitude of the crimes provide the reader with his or her own sense of outrage. However, like most Holocaust stories, after a time the horror benumbs the reader and somewhat dilutes the effect of the work. This is exacerbated to some extent by the highly descriptive and anecdotal nature of the book. Obviously, this is characteristic of the careful craft of the historian tuned to minute detail — detail that occasionally further benumbs the “casual” reader.

The “overdetaillization” of the book notwithstanding, it is written in a very clear style. There was not a single passage in the book in which the reader wondered what Gallagher was trying to say. The work reads quickly, and with the exception of some details that should have been added to the already ample appendices, the book reads as engagingly as a book on this theme can.

Although the book is an absolute success in what it sets out to do and will become one of the most-cited works on the subject, Gallagher’s attention to description has left the book somewhat wanting in analysis. With the possible exception of Robert Jay Lifton’s classic, The Nazi Doctors, no one has told the story of the “underside of the Holocaust” nearly as effectively as Hugh Gallagher. But much of the analysis is reprise, and some of it is rather facile, given the complexities at work. For example, take Gallagher’s views on how Action T-4 was a necessary, if not sufficient, condition for the Holocaust:

In fact, the patient-killing program was a major contributor to the Zeitgeist, serving as it did as a precursor of the Holocaust. It was, in fact, a grave collapse of medical ethics. It was a betrayal of the trust that exists between a patient and his physician.

It was the ultimate abnegation of the Hippocratic Oath. (page 6)

Would Gallagher have us believe that if the physicians of Germany had refused to participate in the euthanasia program, the entire Holocaust might not have happened? His own analysis of the church’s willingness to accept the extermination of the Jews while protesting T-4 belies this point. Of course there would have been a Holocaust, with or without T-4 as a prelude.

Among the most universal dilemmas of human history is our readiness to scapegoat people to rid ourselves of fear and social problems.

Another area in which Gallagher is off the mark is in his almost petulant assessment of modern-day physicians and their views regarding persons with disabilities. In discussing these physicians’ contempt for people with disabilities, Gallagher says: “Any handicapped person who has ever spent time in a hospital will have experienced the result: the physicians treat him with a gentle disdain, bordering on antipathy. Often, the disabled patient is not listened to; he is ignored, occasionally actually abused.” One cannot overlook the well-documented short-comings of physicians’ “bedside manner” with able-bodied as well as disabled patients. But to this reader, who spends a great deal of time in medical settings and who has a disability, it seems that Gallagher has missed a growing trend toward a much more caring, communicative, and humanistic attitude toward patients with disabilities. Naturally, there are still the blundering airheads who wear their devalued sense of disabled persons on their labcoats; but they are becoming a minority and no useful purpose is served in criticizing the profession for the transgressions of a few.

Where Gallagher is brilliant, aside from the many ways already noted, is in...
some of his observations about stigma. For example, he identifies the dilemma of an age — and perhaps all of human history — when he discusses how we scapegoat people to rid ourselves of fears and social problems, but after we have victimized the scapegoat and the social situation has not improved, official frustration mounts and persecution and terrorism increase. In that passage alone Gallagher may tell us more about the insidious robustness of racism, sexism, ageism, and all other forms of discrimination than has ever been told before.

In the last analysis, By Trust Betrayed is more than an important piece of scholarship; it provides the crucial antithetaphor for the age we are entering, in which scarcity, demography, and technology clash — when health care is rationed and nearly every death will necessitate a decision based on some form of social calculus. And from the standpoint of persons with disabilities in this calculus of interaction, Hugh Gallagher should have the last word.

If the story of this book means anything, it is that arching over all such assessments must be the principle that society may not — at its peril abandon a person because he has become flawed in mind or body; because surely every man over the course of his life will reach such a state.

Ivy Green, where Helen Keller discovered language, is a national shrine in Tusculumba, Alabama, only fifty or so miles from where I live. Anyone can go there and see the water pump in the front yard where Anne Sullivan’s work set in motion the events to one of the world’s great achievements of communication. When at long last I visited the place, my idealism surfaced with enough strength to form a resolve that all my students should read about Helen Keller and visit Ivy Green. I thought it would teach them something about language that I couldn’t.

Most likely I was right, but except for sharing my good intentions with a few classes, I never followed through. A few of my students knew about The Miracle Worker and thought Patty Duke and Anne Bancroft were good. But they did not seem to understand my attempt to speak about the mysterious connection between water and the word for it. Maybe we were studying Archibald MacLeish’s conundrum that “A poem should not mean/But be.”

English teachers wish everyone occasionally experienced the startling illumination that flashes when objects and words interact. Many of us believe that the insight gleaned in such moments is a key to human identity and a resource for meaningful dialogue about philosophy, art, science, technology, and just living from day to day with ourselves and others.

How do people learn this linguistic equation? We know, at least superficially, how Helen Keller learned, and we devote many hours writing about it in professional journals for teachers of literature, philosophy, language, and psychology. But for all our earnestness in the academy, much of this highly beneficial learning is serendipity — an objectless word, by the way, coined by Horace Walpole in the 18th century.

Stephen Hawking, the Cambridge University physicist and author of the best-selling book A Brief History of Time, was recently the subject of a television program on the Public Broadcasting Service. Hawking, one of the 20th century’s most creative scientists, suffers from amyotrophic lateral sclerosis (Lou Gehrig’s disease), a progressively degenerative disease. At first his words sounded slurred and the rhythms of his sentences seemed rhetorically off-beat, but if you listened closely (as you would to a non-native speaking broken English) you could follow him. At times his speech resembled the eerie sounds made by dolphins, which we believe may be a form of spoken communication. After working with him for only a short time, Hawking’s colleagues and students had no trouble understanding him and even came to forget that his speech was out of the ordinary.

When I was growing up in York, South Carolina, we had more than one counterpart for Hawking, and although none of them was a genius, each provided us with knowledge about the profundity of the gift of speech. The most memorable of these people was Tom Wiley.

Like Helen Keller, Tom was struck early in life by a catastrophic illness, or perhaps he was born that way. Whatever the cause (we were not even curious about it, so accustomed were we to him), Tom’s body, though complete, was twisted and bent the wrong way so thoroughly that his small oak wheelchair had to be made especially for him. His right arm was a tight “Z” close to his body, with the hand pointing down; his left was twisted like a vine and stuck out, immobile, behind his body. His legs, like his arms, did not match in their deformity, but since they were always covered with trousers, we could see only that one sharply pointed knee was much higher than the other.

His misshapen torso was quite small, his flattened head permanently turned to the far left so that he looked at you out of the right corners of his eyes unless you stood beside him. All of this chaotic bone and protoplasm moved only in jerks and pulls, which we came to understand as Tom’s body language.

Tom’s speech was difficult to understand. When he talked, his mouth gaped crookedly, showing strings of saliva and unoccluded teeth. His words were like barks and interjections, some drawn out, others clipped off by an uncontrollable signal from his brain or spine. I remember these things now as I try to describe them, but in 1946 when I was thirteen, I hardly noticed. Tom was my friend, not an invalid but a person whose identity appealed to me.

There was a shady vacant lot across

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