

The Right to Die or the Right to Community Support?

by Maggie Shreve & June Isaacson Kailes

The Bouvia Case as Example

In September 1983, a 26-year-old California woman named Elizabeth Bouvia admitted herself to the psychiatric unit of Riverside General Hospital, a government-supported institution. Once admitted, she asked for assistance in starving herself to death. She wanted hospital staff members to provide her with pain killing drugs and hygienic care while she waited to die. However, hospital officials refused her request, so she obtained legal assistance from the American Civil Liberties Union (ACLU) of Southern California. Bouvia's legal maneuvers attracted nationwide attention, and if we are to understand why she wanted to die, we need to explore the background to this disturbing event.

Elizabeth Bouvia came from a troubled family. Her parents separated when she was 5, then divorced. Her mother was granted custody, but shortly after remarrying she placed Elizabeth (then 10 years old) in an institutional setting. Although her father sent money, she was really on her own. Bouvia remained in the same institution until she was 18. She and her mother apparently kept in touch but there had been little or no contact by the time she checked into the psychiatric unit.

Elizabeth received a high school diploma, earned her bachelor's degree in social work, and was working on a master's program in social work until a

Maggie Shreve is a Chicago-based consultant to independent living centers and public agencies. Ms. Shreve served as administrative director for the National Council on Independent Living. For six years she was executive director of The Whole Person, in Kansas City. June Isaacson Kailes is a public policy analyst on disability issues. Ms. Kailes, who has cerebral palsy, has been executive director of the Westside Center for Independent Living in Los Angeles for more than eight years.

For the disability community, Elizabeth Bouvia symbolizes all that is wrong with the way society views disabled people. She represents the myth that disability is worse than death.

faculty member told her she would never be able to find a job in the field.

She began corresponding with a prison inmate; they fell in love and were married after his parole. Bouvia became pregnant but miscarried. She and her husband traveled to Iowa, apparently looking for work, but she did not stay. She moved instead to Oregon and lived with her father; after a short stay he took her to the hospital. The psychiatrist said that she was "medically really stable" and showed no signs of clinical depression. Within a year of Bouvia's admission, her mother died of cancer and her brother drowned.

But most significant is that Ms. Bouvia has severe cerebral palsy affecting all four limbs. She can use her right arm and hand, to guide her own motorized wheelchair, smoke cigarettes, and tear out feeding tubes. She also has rheumatoid arthritis which causes great pain.

Given all the circumstances described, would you have guessed that this woman was not clinically depressed? If you were a physician or court official, would you have assisted in her wish to die the way she wished to die? Should physicians be involved in assisted suicide when a person has decided that suffering and debility make life unbearable?

We should also ask why the ACLU agreed to file a petition on her behalf seeking to compel the hospital to fulfill

her death wish. Was the ACLU so dedicated to protecting her "right to die" that it would ask society to commit the actual killing?

Over a year later, after moving to another facility where she continued to seek assistance with her starvation plan, Bouvia and her attorneys secured an injunction to prevent hospital staff from force feeding her. The attorneys seemed to believe that Bouvia had a right to refuse not only medical treatment but also food and water — even though this would inevitably kill her. As far as we know, Elizabeth Bouvia is still alive, possibly living at the University of Southern California Hospital in Los Angeles. We do not know if she still wishes to starve to death.

For the disability rights community in the United States, Elizabeth Bouvia has come to symbolize all that is wrong with the way society, including the medical establishment, views disability. She represents the myth that disability is

In Germany during the 1930s, people with physical disabilities, "incurable idiocy" or "severe deformity" were granted a merciful death. Physicians became experts on death-making as well as on healing.

worse than death. Ms. Bouvia wanted to die, but her planned starvation did not emerge from the physical limitations of cerebral palsy alone. Instead, Elizabeth discovered that American society is largely uninterested in people with disabilities and unreceptive to the idea of building a barrier-free environment.

continued on page 12

Bouvia is not the first, and probably won't be the last, disabled person to seek legal approval for suicide. A similar case occurred in Georgia in late 1989 when Larry McAfee, a young man with quadriplegia from a spinal cord injury, sought a

Advocates of suicide rights often argue that disabled people are unable to lead meaningful lives.

court's permission to turn off his respirator. The judge granted McAfee the right to die with assistance from another person. Interestingly, McAfee announced several months ago that he no longer wished to die because he had found new hope through a supported employment program which may help him secure employment (income) and related benefits.

Neither of these two individuals was terminally ill, they were merely disabled. But they fit society's stereotype of what disability must be like, and both heard a clear cultural message: death is preferable to life with chronic or severe disability.

History Demonstrates Extreme Prejudice

People with disabilities have been scorned, isolated, ridiculed, physically and mentally abused, even murdered, throughout history. Nomads left people with disabilities to die when the tribe moved on. Early Christianity promoted the belief that disability was a sign of impurity or evil. The Renaissance attempted medical care and treatment for disabling conditions, but only if the person could get better. Even our own American colonies enacted laws restricting immigration by individuals with disabilities, based on the assumption that they would need public support. By 1900, every state had institutions in which people who were deaf, blind, and mentally or physically disabled were placed; many of these individuals lived their entire lives and died there.

Wolf Wolfensberger wrote, "Societies, both past and present, find some method of putting to death those devalued members who are most despised or rejected or possibly constitute a threat to the well-being or even survival of society itself." Hitler's Nazis actually exterminated hundreds of thousands of people with various impairments prior to the

genocide which killed millions of Jews, Gypsies, homosexuals, and others perceived as undesirable.

Wolfensberger unflinchingly describes how such "euthanasia" programs were designed and rationalized. The medical and legal foundations for "mercy killing" were established in a pivotal book published in 1920, *The Permission to Destroy Life Unworthy of Life*. Written by Karl Binding, a distinguished jurist and law professor, and Alfred Hoche, an eminent psychiatrist, this book provided the most important intellectual justification for cleansing society of "worthless" or "unproductive" people, and it achieved sweeping influence. The "experts" who later became leaders of the Nazi euthanasia program learned from Binding and Hoche about the need to put to death people with "incurable idiocy" or those who were "severely deformed." Such death was to be made painless and administered by an expert. Binding and Hoche argued that only persons who are able to save life under other circumstances should have the right to "grant death." This right to administer death was firmly vested in the medical profession, thus the authors anticipated the current tendency for physicians to become the experts on death-making as well as on healing.

Besides Binding and Hoche, there were other influential advocates of systematic "mercy killing" and eugenics, so by the time Hitler officially authorized the euthanasia program in October 1939,

Central to the independent living movement is the belief that management of disability is primarily a personal matter and only secondarily a medical matter.

there was already a powerful commitment to these social objectives:

Reich Leader Bouhler and Dr. Med. Brandt are responsibly commissioned to extend the authority of physicians, to be designated by name, so that a mercy death may be granted to patients who according to human judgment are incurably ill according to the most critical evaluation of the state of their disease.

Against this philosophy, an American

medical witness at the Nuremberg trials concluded that a purely scientific or technical approach to medicine could not survive without becoming corrupt and abusive. For medicine to be a genuine profession, it must be true to its tradition as a moral craft.

Advocates for Assisted Suicide

As medical research and technology continue evolving, many more people will be saved from death — but often with significant disabilities. Larry McAfee, for example, is someone with a high-level spinal cord injury. Ten or fifteen years ago

As long as the medical community dominates the lives of disabled people and society assumes that people with disabilities are not fully human, "mercy killing" cannot be far behind.

he may not have survived his motorcycle accident. Medical technology and enhanced skill saved his life, but now the court (and many medical professionals) believes it is desirable to let him die because of the severity of his disability. What kind of double message is society sending? Paul K. Longmore, Ph.D., is one of the few voices of reason in this debate. In early 1990, he appeared as an advocate for social change on an edition of "Nightline" which featured Larry McAfee. Longmore is a public policy analyst who has a severe disability.

After the publicity surrounding Elizabeth Bouvia ended, Longmore wrote an article for *Issues in Law and Medicine* about assisted suicide and social prejudice. His analysis of the positions taken by advocates of assisted suicide points out clearly the intent of certain groups to eliminate people seen as undesirable in our society, namely those with disabilities.

Both suicide rights and anti-suicide advocates express prejudice in their persistent use of intensely stigmatizing language: disabled people are defective, damaged, debilitated, deformed, distressed, afflicted, anomalous, helpless and/or infirm. In contrast, non-handicapped persons are "normal." But the bias goes deeper than the terminology. Professor

[Margaret Pabst] Battin's response to the anti-suicide position is deeply disturbing. Apparently, to live with disability is to "suffer" and to suffer because of disability. There is no recognition that the greatest suffering of people with disabilities is the socially stigmatized identity inflicted upon them.

Longmore points out that some opponents of suicide and proponents of the right to life see people with disabilities as objects of charity. This may be why right-to-life advocates strongly support life-sustaining medical treatment as a civil right but are absent from the disability rights movement.

Both the advocates of assisted suicide and many proponents of the right to life seem to recognize only three options for disabled persons: live "as objects for our pity and moral elevation," serve as subjects of experimentation, or commit suicide. The false and biased assumption here is that people with disabilities have nothing useful to contribute to society by their own efforts. More importantly, apart from whatever good disabled individuals might contribute to others, it seems not to have occurred to either side that they might find their lives of value to themselves.

Advocates for assisted suicide frequently depict people with disabilities as "victims," helpless and dependent. They argue that disability precludes a meaningful life, that disabled people are emotionally, physically, and financially burdensome to themselves, their families, and society. Longmore argues there is no "real acknowledgement of the intense social stigma and discrimination that segregate people with disabilities more than any other contemporary minority, deny them opportunities for education, employment, marriage, and family, rob them of social dignity and self-esteem, and inflict on many of them what can only be called 'social death'."

Longmore states that the suicide rights advocates completely ignore the disability rights and independent living movements which have been with us since the late 1960s. He believes that the attitude of suicide rights advocates is almost as horrifying as that of the Nazi exterminators in the 1930s. He asserts that suicide rights activists are simply rationalizing the ultimate act of oppression. "Their efforts are an assault on the rights and lives of people who are sick, old or disabled."

What we really need is a thorough understanding of specific community supports necessary for empowering peo-

ple with disabilities to live independently and with dignity. The disability rights and independent living movements articulate this view clearly.

A world where people with disabilities live in an integrated setting with their non-disabled peers is possible, if society eliminates its prejudice toward people with disabilities.

From Euthanasia to Disability Rights

In the United States, advocacy for disability rights was sparked by the civil rights movement. Until the 1960s, people with disabilities rarely questioned society's values regarding disability. As a community, people with disabilities did not think of themselves or their medical conditions as political, but the cultural pride and determination of African-Americans to secure personal, political, social, and economic rights offered insight to leaders of the disability rights movement. Watching African-Americans struggle for basic freedoms was a revelation to people with disabilities who were institutionalized, abused or denied basic services in the community.

A few visionary individuals with disabilities responded to the civil rights movement by seeking their own access to education, housing, medical care, and community support services. They demanded humane treatment by health care professionals and an end to institutionalization. They rejected constant medical intervention and supervision in their lives. They insisted on opportunities for self-help and autonomy. They claimed an equal role in the political process. They demanded access to public buildings, meetings, and events. They highlighted the importance of cooperation from the very system which had been holding them prisoner.

Gerben DeJong, a researcher currently with the National Rehabilitation Hospital in Washington, D.C., wrote a brilliant analysis of this social action, *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research*. This 1979 monograph presented an accurate analysis of the growing disability rights movement

and its operational branch, centers for independent living.

The first independent living center opened in Berkeley in the late 1960s. Directed and staffed by people with disabilities, this organization provided fiscal conduit services so that individuals with severe disabilities could hire, train, fire, and manage their own personal assistants. A personal assistant is someone who, under the direction of the person with a disability, performs all the routine tasks needed to live independently. This may include assistance getting in and out of bed or a wheelchair, help with dressing and undressing, grooming, meal preparation and eating, paying bills, etc.

Most of the early participants in the Berkeley center were students attending the University of California. Many had applied for federal and state assistance through agencies such as the Department of Rehabilitation and the Department of Social Services, but most had been turned down for services as "too severely handicapped." In other words, their disabilities were considered by professionals so severe that they could not benefit from services. Yet these individuals wanted college educations, homes they could call their own, and autonomy in their daily lives.

DeJong concluded that the independent living movement was made possible by the evolution of five complementary movements: civil rights, consumerism, self-help, demedicalization (self-care), and deinstitutionalization (normalization and mainstreaming). Even though they arise from different sources in response to different social problems, these movements share some common values. Each has made major contributions to the philosophy of independent living.

The Medical Model

The major difference between independent living and the other five movements is the problem of the "medical model." Central to the goals of the independent living movement is the belief that the management of medically stabilized disabilities should be demedicalized. People with disabilities insist that the management of their disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of people with disabilities demands behaviors on the part of medical practitioners and "patients" which induce dependency and are thus in conflict with independent living.

continued on page 14

As delineated by DeJong, the medical model consists of the following assumptions and role expectations:

- (1) The physician is the technically competent expert.
- (2) Medical care should be administered through a chain of authority wherein the physician is the principal decision maker.
- (3) The "patient" is expected to assume the "sick" role which requires him or her to cooperate with medical practitioners.
- (4) The main purpose of medicine is to provide acute or restorative care.
- (5) Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy, and the "laying on of hands."
- (6) Illness can be diagnosed, certified, and treated only by trained practitioners.

The disability community has particularly criticized the behavior expectations of the medical model as defined in the sick role (originally articulated by Talcott Parsons in 1951). Understanding the requirements of the sick role is essential to understanding the independent living movement's opposition to it.

The sick role consists of two inter-related sets of exemptions and obligations:

- A sick person is exempted from "normal" social activities and responsibilities depending on the nature and severity of the illness.
- A sick person is exempted from any responsibility for his or her illness. He is not morally accountable for his condition and is not expected to become better by sheer will.

These exemptions are granted conditionally. In exchange:

- A sick person is obligated to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate his or her recovery.
- A sick person is obligated to seek technically competent help and to cooperate with the physician in becoming well.

Because disability is an irrevocable part of a person's existence, a disabled person begins to accept not only the condition, but also the belief, that his or her very own personhood is aberrant and undesirable. Moreover, he or she begins to accept the dependency prescribed under the sick role as normative for the duration of the disability.

The impaired role is ascribed to an individual whose condition is not likely to improve. Occupants of the impaired role have abandoned the idea of recovery and accepted their condition and

dependency as permanent. One might suggest that the impaired role indicates a loss of "human status." As time passes and the person is unable to become well, he or she is allowed to slip into the impaired role. It shouldn't be surprising that the dependency creating features of the medical model and the impaired role are most pronounced in institutional settings.

This analysis supports Wolfensberger's research into society's assumptions that people with disabilities are not fully human. For example, placing people with disabilities in institutions for the duration of their lives may be easy to do because they are not fully human. As long as the medical community dominates the lives of people with disabilities and as long as society believes that disability is "sick," institutionalization and euthanasia or "mercy killing" cannot be far behind.

From Medical Model to Independent Living: A Paradigm

DeJong's work culminated in a set of paradigms which illustrates the differences between the medical model of rehabilitation (including vocational rehabilitation and other social programs built on the medical model) and independent living. These paradigms establish a clear framework for how society must change its attitudes toward people who have disabilities and how the service delivery system must accommodate the natural goal of living independently.

federal and state funding into such a model of service delivery. A world where people with disabilities live and are educated in an integrated manner with their non-disabled peers is possible — if society eliminates its prejudicial attitudes toward people with disabilities. A world where media no longer play out stereotypical portrayals of people with disabilities is possible — if society declares such portrayals offensive and rejects the demeaning language used to refer to people with disabilities.

Elizabeth Bouvia said she saw death as a better alternative to life in a convalescent home or a continuing struggle on the outside. "It's too much of a struggle to live within the system or depend on someone in the system." (*Los Angeles Times*, October 12, 1983).

She is right, it is too much of a struggle. But it is the system's fault, not hers. She should not have to consider suicide as one of the few alternatives available simply because she has a disability.

The outcome for Larry McAfee may be the more typical response of the future. After the Georgia court granted him the right to disconnect his respirator, he chose not to do so because numerous agencies offered services which would support his desire to live independently in the community. When he appeared on "Nightline" he still held the opinion that committing suicide was his only true option, but less than a month after (and a great deal of press coverage), he changed his mind.

	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	physical or mental impairment; lack of vocational skill	dependence upon professionals and others
Locus of problem	in the individual	in the environment; in the medical & rehabilitation process
Solution to problem	professional intervention; treatment	barrier removal; advocacy; self-help; consumer control over services
Social role	individual is a "patient" or "client"	individual is a "consumer" of services
Who controls?	professional	consumer
Desired outcomes	maximum self-care; gainful employment	independence through control over acceptable options for everyday living

A world with totally accessible architecture and communication is possible — if society places a higher priority on such a goal. A world where supportive in-home and community services, directed by the consumer with a disability, is possible — if society moves current

McAfee's situation and the resulting exposure brought him what he needed, but look what it took. The judge in McAfee's case agreed with his attorneys that he was so disabled that he would naturally choose death over such a life. Larry McAfee was so devalued that no

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

Gerben DeJong. *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research*. (Waltham, Mass.: The Heller Graduate School, Brandeis University, March 1979).

Paul K. Longmore. "Elizabeth Bouvia, Assisted Suicide and Social Prejudice." *Issues in Law & Medicine* 3 (Fall 1987), pp. 141-168.

Wolf Wolfensberger. "The Extermination of Handicapped People in World War II Germany." *Mental Retardation* 19 (1981), pp. 1-7.

[Specific citations available on request from Midwest Bioethics Center.]

Euthanasia, "Final Medical Assistance," and the Right to Kill

by Daryl P. Evans

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

By Hugh Gregory Gallagher (New York: Henry Holt and Co., 1990)

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, tubercular, 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 were 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