

Suicide Intervention for People with Disabilities: A Lesson in Inequality

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The American commitment to equality, which affirms the value of all individuals and their entitlement to the pursuit of a good life, is by no means a “hands off” ethic. It is backed by a determination to support and protect vulnerable individuals (and, as we have seen recently, even nations) during hardship. America’s prominence in suicide prevention is certainly consistent with this tradition.

A different belief system—one that weighs the value of human life in terms of its costs, that idealizes mental and physical superiority, and that endorses termination of weak individuals in the name of “mercy”—is one we tend to associate with other cultures in other places. In reality, we know these beliefs, too, are part of America’s history. Some argue that social Darwinism and the eugenics movement are becoming as influential in American thinking currently as when they flourished early in this century.¹

When a culture values human life conditionally, suicide intervention becomes selective. Devalued populations fail to receive rigorous protection, assessment, and treatment.² Already at heightened risk from their oppressed status, devalued people are further endangered by deprivation of psychological support. Current research indicates that unaddressed social stress factors (not any inherent physiological or racial defect) account for high rates of depression and suicide in certain minority groups in the United States.³

People with disabilities compose a minority group for which little suicide data have been collected. A great deal is known, however, about the virulent social oppression endured by this population. In employment, interpersonal acceptance, economic stability, freedom of mobility, and community access—all variables thought to have a significant bearing on suicide potential—people with disabilities are among the most disadvantaged.⁴ Moreover, current

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¹Nat Hentoff, *Are Handicapped Infants Worth Saving?* VILLAGE VOICE, Jan. 8, 1991, at 18; Richard J. Neuhaus, *The Return of Eugenics*, COMMENTARY, Apr. 1988, at 15-26.

²ROBERT KASTENBAUM & RUTH AISENBERG, THE PSYCHOLOGY OF DEATH 426, 463 (1972).

³GEORGE H. COLT, THE ENIGMA OF SUICIDE 251-58 (1991); *Culture Blamed for Women’s Depression*, CHI. TRIB., Dec. 6, 1990, § 1, at 9; HERBERT HENDIN, SUICIDE IN AMERICA 88-93 (1982); KASTENBAUM & AISENBERG, *supra* note 2, at 463.

⁴Harlan Hahn, *Disability Policy and the Problem of Discrimination*, 28 AM. BEHAV.

research indicates people with disabilities experience more environmentally induced depression than average,⁵ suggesting an increased potential for preventable suicide.

Ironically, this population, on whose behalf so little suicide research has been conducted, is subject to a burgeoning number of legal and medical decisions concerning the management of intentions to die. Critical life and death precedents and policies are being established at alarming speed, with little concern for the facts and gaps existing in our understanding of disability and suicide.

Often in psychology, the precursor to sound research documentation is careful clinical observation. In the area of disability and suicide, I have endeavored to make such observations on the basis of specialized training and practice in psychological crisis-intervention (including suicide treatment), thousands of therapy hours working with disabled people in rehabilitation and individual practice, and more than three decades of personal experience living in the world as a disabled person actively involved with other people with disabilities.

Over the years of my “continuing education” and clinical experience with disabled individuals, I have heard their problems, fears, needs, and desires with growing force and clarity. At the same time, I have become increasingly concerned by the dearth of resources available to support their impressive efforts to pursue a good life in a frustrating, unwelcoming environment. Particularly alarming is the current trend to deny basic suicide prevention services to individuals who are severely disabled, those most exposed to high risk factors.

Identification

The discriminatory treatment of disabled people who express a desire to die begins with the initial interpretation and labeling of that desire. When a nondisabled person reveals a desire to die, ordinarily it is categorized as “suicidal,” and the individual is treated accordingly. For persons with severe disabilities, however—particularly persons who use a respirator, feeding assistance, or other life aids—the desire to die has acquired labels such as “refusal of treatment,” a wish to avoid prolonged suffering or dying, a desire to let a terminal disease take its natural course (used in cases of long-term disability lacking any evidence of terminal illness!), and “not committing suicide.”⁶ The implication is that there is something natural, reasonable, or proper about a disabled person’s dying as opposed to a nondisabled person’s dying.

Complicating matters is the fact that disabled persons’ communications of suicidal intent are frequently confounded by their own negative statements regarding disability. The public misunderstands “right to die” cases in which the troubled individual laments the disability itself or the need for “life supports.” Lacking an informed perspective and harboring intense fears of

SCIENTIST 293-318 (1985).

⁵R. Jay Turner & Morton Beiser, *Major Depression and Depressive Symptomatology Among the Physically Disabled*, 178 J. NERVOUS & MENTAL DISEASE 343, 345-46 (1990).

⁶Mary Johnson, *Suicide Lessons*, DISABILITY RAG, Jan./Feb. 1990, at 25, 27 (quoting Judge Edward H. Johnson).

becoming disabled, the public, including judges, ethicists, and media reporters, takes such complaints at face value and looks no further for their significance. Such people readily conclude that the disabled person's wish to die is reasonable because it agrees with their own preconception that the primary problem for such individuals is the unbearable experience of a permanent disability (and/or dependence on life aids). If permanent disability is the problem, death is the solution. In this analysis, the wish to die is transformed into a desire for freedom, not suicide. If it is suicide at all, it is "rational" and, thereby, different from suicides resulting from emotional disturbance or illogical despair.

These assumptions betray a faulty understanding of both living with disability and considering suicide. Addressing the latter, Edwin Shneidman, pioneering researcher and clinician in American suicide prevention, has described suicide as "a multidimensional malaise in a needful individual who defines an issue for which the suicide is seen as the best solution."⁷ He explains that any deliberate act of self-annihilation is suicide, even if effected through the acts of others (e.g., when individuals ask to be killed by others) or coerced (e.g., when captives are forced to kill themselves by the brutality of others). He emphasizes that all suicidal behavior is motivated by need, not reason alone. Although the choice of dying seems logical to the suicidal individual, it is a logic distorted by need, distress, and constricted perception. According to Shneidman and other suicidologists, every suicide, no matter how calm and rational on the surface, involves emotional distress or "perturbation."⁸ By this definition, disabled people's requests to die are, indeed, suicidal. Furthermore, they are emotional. While some suicides seem to make more sense to us than others, none is exclusively based on reason without an element of untidy, irrational, human distress.

It is impossible to appreciate the suicidal aspect of many right to die cases unless one understands not only suicide but the realities of living with a disability. The fact is, with sufficient time and support, people generally adjust to disabilities. People of all kinds buck social prejudice regarding disability and gradually change their perspectives on quality of life.⁹ They learn to use human and technological assistance to enhance life, integrating the use of such things as respirators, attendant services, urinary devices, and assisted feeding—all referred to in this article as life aids—into their daily routines as gracefully as many people have adjusted to their need for computers and fax machines. Social attitudes notwithstanding, people with disabilities generally feel neither heroic nor tragic because they use life aids. They view such assistance as a mundane aspect of their life-style.

When an individual with disabilities expresses intolerance of life aids or living with a disability, then, it is symptomatic. Such distress may arise from a variety of factors. Often it

⁷EDWIN S. SHNEIDMAN, DEFINITION OF SUICIDE 203 (1985).

⁸H. S. Olin, *The Third Wish*, in WHAT WE KNOW ABOUT SUICIDAL BEHAVIOR AND HOW TO TREAT IT 77-84 (S. Lesse ed., 1988); K. Siegel, *Psychosocial Aspects of Rational Suicide*, 40 AM. J. PSYCHOTHERAPY 405-18 (1986); SHNEIDMAN, *supra* note 7, at 208.

⁹R. Stensman, *Severely Mobility-Disabled People Assess the Quality of Their Lives*, 17 SCANDINAVIAN J. REHAB. MED. 87-99 (1985).

represents an unresolved adjustment reaction to either a new disability or a change in an existing disability. With appropriate support, information, and time, the distress usually diminishes.

Other times, the distress signals underlying emotional illness, particularly acute or chronic depression. People who struggle to survive in a thwarting environment occasionally despair or “burn out.” Before assisted suicide for people with disabilities became popular, severely disabled Lynn Thompson carefully engineered her own death after learning she would lose her independent living funding. Her recorded message left no doubts about the cause of her despair. The threatened cut in her support funds was, she said, “the straw that broke the camel’s back.”¹⁰

For people with disabilities, as for anyone else, bouts of depression may lead to suicidal impulses. Depression and psychopathology of long standing may also be expressed indirectly in somatic complaints, including complaints about disability. Research on depression indicates a tendency in troubled individuals toward global negative thinking and internalization.¹¹ For people with disabilities, this suggests that when depressed for any reason, they are more likely to “internalize” society’s rejection and devaluation of disability. More vulnerable, at such points, to the negative regard they sustain on a daily basis, they express the depression as a global disdain for the disabled self. Any features of the individual’s life that represent disability or “abnormality,” e.g., life aids, become intolerable.

For some persons with disabilities, the distress they express regarding life aids is particularly misleading because it is expressed in the service of a secondary goal. This occurs when an individual selects discontinuance of life aids as a *method* of suicide precisely because it is likely, these days, to elicit a cooperative response from the environment. For example, if I am a respirator user and I have decided to commit suicide because of a romantic breakup, it would make strategic sense for me to convince others that I can no longer tolerate the respirator. They might not support my death over a romantic loss, but they might accept it—even assist in it—if I present it as an escape from disability. If I receive approval or assistance to commit suicide, not only is the result guaranteed, but I am also relieved of the usual tension of sole responsibility for making the decision and implementing it. People with severe disabilities characteristically are master survivalists. They learn by necessity how to influence others to assist them. It is an essential, creative skill that, unfortunately, can also be applied consciously or unconsciously for self-destruction.

In the special matter of requests by institutionalized disabled persons for discontinuance of life aids, an element of self-destructive anger may be operating that is dangerously overlooked.¹² The underlying psycho-logic of such requests may be: “If people won’t help me live my life the

¹⁰See *60 Minutes* (CBS television broadcast, Oct. 1, 1977).

¹¹S. Deutscher & P. Cimboric, *Cognitive Processes and Their Relationship to Endogenous and Reactive Components of Depression*, 178 *J. NERVOUS & MENTAL DISEASE* 351, 352, 356 (1990).

¹²PAUL G. QUINNETT, *SUICIDE: THE FOREVER DECISION* 53 (1987); P. Tridon et al., *Abandon ou refus thérapeutique: rite de passage chez l’adolescent handicapé et malade chronique*, 31 *NEUROPSYCHIATRIE DE L’ENFANCE ET DE L’ADOLESCENCE* 407-08 (1983).

way I wish, at least I'll make them help me die." When disability activists and other supportive individuals intervened to prevent quadriplegic Larry McAfee's death, for example, it released his considerable anger towards people and policies responsible for his institutionalization.¹³

The point is, whether a nonterminal disabled person's request to discontinue life aids results from a disability adjustment crisis, an internalized rejection of the disabled self during depression, anger turned inward, or solely an attempt to solicit environmental assistance in performing the suicidal act, such requests are clearly pathological and clearly suicidal. To view them otherwise is to deny the dignity and value of ordinary life with disability and those who live it.

Disability and Suicide in Clinical Practice

The tendency on the part of the public and the legal system to deny the suicidal intent of disabled persons requesting death assistance could possibly be attributed to lack of information. It is more difficult to comprehend this behavior in medical and mental health professionals. Yet in publicized right to die cases involving disabled people, medical experts have been guilty of a striking denial of suicide risk and depressive disorder in the face of significant evidence of psychopathology.

According to the *Diagnostic and Statistical Manual of the American Psychiatric Association* (DSM-III-R), a major depressive episode is characterized by depressed mood, a loss of interest in usual activities, or both. For definitive diagnosis, there must be a significant number of symptoms from a list that includes appetite disturbance, sleep disturbance, psychomotor agitation or retardation, loss of energy, feelings of worthlessness, difficulty thinking or concentrating, and thoughts of dying. Additional features may include withdrawal from friends and family, soft or slowed speech, guilt, suicide attempts, panic attacks, preoccupation with physical problems, irritability, antisocial behavior, and abuse of drugs or alcohol. The average onset is in early adulthood. There is interference in social and occupational functioning; in severe cases the individual may be incapable of self-feeding, dressing, and personal hygiene. Psychosocial stressors, such as the death of a loved one, marital separation, and childbirth, can precipitate a major depressive episode. The manual alerts practitioners to suicide as the most

¹³Larry McAfee touched off a public controversy in 1989 when he filed for judicial permission to have his ventilator disconnected to cause his death. He had been injured by a motorcycle accident and as a result had lost the use of his arms and legs. He required constant care. Eventually the Georgia Supreme Court affirmed his right to refuse ventilation. *See State v. McAfee*, 385 S.E.2d 651 (Ga. 1989); *see also* Peter Applebome, *Judge Rules Quadriplegic Can Be Allowed to End Life*, N.Y. TIMES, Sept. 7, 1989, at 10 (nat'l ed.). During and after the court proceedings, McAfee befriended and then was assisted by numerous individuals to obtain job training and secure independent living outside the nursing home environment. These developments persuaded McAfee to reverse his decision to die and instead continue to live. *See* Peter Applebome, *An Angry Man Fights to Die, Then Tests Life*, N.Y. TIMES, Feb. 7, 1990, at A1 (nat'l ed.).

serious complication in this disorder.¹⁴

A brief review of two famous cases exemplifies how professionals sometimes abandon medical diagnostic guidelines, such as those just described, when confronted with disability. At age twenty- six, Elizabeth Bouvia, a woman with cerebral palsy, expressed the wish to die after a series of severe losses, including a miscarriage and marital separation. Essentially homeless and impoverished, she voluntarily entered the hospital, anorexic and seeking narcotics. Her verbalizations focused narrowly on somatic complaints and death. She had a plan to bring about her death. She made demands for support and care from the hospital staff. She said she was unable to feed herself, a fact that people who knew her disputed. In sum, she presented more than the necessary number of signs to qualify for a diagnosis of depression with suicide risk of moderate lethality. Yet, several professionals pronounced her free of disorder and labeled her plan reasonable.¹⁵

In an interview videotaped before his death from respirator disconnection, David Rivlin, a man with quadriplegia, presented classic symptoms of depression.¹⁶ He was tearful, his speech slow and flat, his affect consistently depressed. He talked about being sad and fearful. He expressed anger at society for its attitudes toward people with disabilities. He said he could no longer tolerate life in an institution and asked the public to “reach out to others before they lose hope.” Records indicate that Mr. Rivlin had been increasingly isolated in his last year and that he had withdrawn from past interests.¹⁷ He indicated reluctance to die but said he saw no alternative. In the face of this evidence, it is difficult to imagine how mental health professionals could have overlooked his depression and suicide potential. Mr. Rivlin died with the assistance of a physician he barely knew following a farewell party in which he saw friends and family who had failed to visit him for years.¹⁸ The assisting physician lauded his death as “a beautiful event”

¹⁴AMERICAN PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 218-24 (3d ed. rev. 1987).

¹⁵Stanley S. Herr et al., *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 ISSUES IN LAW & MED. 3, 9 (1992).

¹⁶*The Life of David Rivlin* (WDIV, Detroit, television broadcast, Aug. 6, 1989).

¹⁷PEOPLE MAG., Aug. 7, 1989, at 58.

¹⁸Before his death, Rivlin had sought judicial approval to have his life support withdrawn. Petition for Removal of Life-Sustaining Apparatus and Incidental Relief, *In re Rivlin* (Mich. Cir. Ct. 1989) (No. 89369904). In an oral ruling, however, Judge Hilda R. Gage of the Michigan Circuit Court of Oakland County held that the court lacked subject matter jurisdiction because Rivlin’s petition was unopposed and the case failed therefore to present a justiciable controversy. The court would not issue a declaratory judgment unless the petitioner amended his petition to plead an actual dispute. Rivlin declined to do so. Apparently, the court was of the opinion that Rivlin’s case was not a right to die action but a right to refuse medical treatment action. Thus, no court order was issued approving or restricting the intended refusal. See Letter from Bruce Brakel, Law Clerk for Judge Hilda R. Gage, to Theresa Kealy, Staff Counsel, National

and “good medicine.”¹⁹

Discriminatory Treatment of Suicidal Persons with Disabilities

Suicide treatment involves several activities or strategies that are thought to be crucial steps in helping individuals at risk.²⁰ They can be summarized as follows:

1. Conceptualizing the problem for which the individual has chosen death as the solution.
2. Identifying and treating the individual’s urgent needs.
3. Offering alternate solutions to break through the individual’s constrictive thinking.
4. Supporting and reinforcing the life preserving side of the suicidal ambivalence.
5. Preventing death.

Examining each step in the treatment process while referring to recent right to die cases will, hopefully, illustrate the problems of discriminatory suicide intervention for people with disabilities.

Conceptualizing the Problem

It is in the identification of the problem, perhaps, where the unequal treatment of people with disabilities is most blatant. In all the public right to die cases involving conscious nonterminal disabled persons, there is scant evidence of anyone looking beyond the obvious, the disability, as the cause of distress. In fact, there has been a tendency to discount readily available clues leading to other suicide precipitants. Dismissed have been predisposing historical factors such as multiple losses, family dysfunction, childhood abuse or neglect, current stresses (e.g., work, finances, housing, romance), alcohol or drug problems, isolation, loss of control over life-style, and low self-regard.

David Rivlin repeatedly expressed despair and anger over his confinement to a nursing facility. He talked about his death as the only avenue to freedom from the imprisonment of

Legal Center for the Medically Dependent & Disabled, Inc. (Sept. 27, 1989) (characterizing oral ruling issued from bench by Judge Gage) (on file with the National Legal Center litigation office).

¹⁹Statements made by John W. Fin, M.D. (WMUZ), Detroit, radio broadcast, Mar. 2, 1990) (direct quote from broadcast), and *The Life of David Rivlin*, *supra* note 16 (direct quote from broadcast).

²⁰Shneidman, *supra* note 7, at 225-35.

institutionalization. Apparently, his signals of distress were in vain. No professional ever identified his institutionalization as the problem to be addressed. No one helped him find a way to live independently with assistance (as many with similar disabilities do) or to live at all. Kenneth Bergstedt stated his problem so clearly that no one could miss it.²¹ Physicians, reporters, and judges all agreed that Bergstedt wanted to die because he was afraid—afraid of losing his ill father, afraid no one would look after his needs.²² No one treated Bergstedt's fear or despair. No professional even suggested helping him accomplish a healthy separation from his father or teaching him the skills of living he needed to survive. Professionals trained to help and heal allowed Kenneth Bergstedt to be suffocated by his father, as if assenting to a primitive right of filicide.

Physicians and mental health practitioners who hastily conclude in such cases that disability itself is the problem violate their most basic responsibility to conduct a thorough examination. They allow personal bias to distort their grasp of the problem, thereby precluding the quality of assessment required for appropriate intervention.

Addressing Needs

Without an accurate view of the problem, it is impossible for helping professionals to guide desperate persons with disabilities in fulfilling critical needs. A person exhausted by the struggle to live in a world of frustrating barriers may need a variety of things, some concrete, others more spiritual: money, equipment, a place to live, an attendant, nurturance, control over life-style, outside stimulation, creative outlets, love, work, or validation of personal worth. However, if permanent disability itself is the only problem acknowledged, the need to escape the disability receives undue emphasis. A therapeutic response that focuses on one impossible need while neglecting all others maybe more detrimental than no response at all. It reinforces the individual's own sense of hopelessness that life can be fulfilling enough to justify living. Rivlin and McAfee needed a way to conduct their lives outside an institution. Kenneth Bergstedt needed to secure quality attendant services as well as support to cope without his father. Elizabeth Bouvia needed many things, but, perhaps above all, she needed time—time to heal and re-emerge as she had during past crises in her life.

Offering Alternative Solutions

²¹The father of Kenneth Bergstedt, a twenty-two year old person with quadriplegia and dependent on a ventilator, petitioned the Nevada courts for authority to remove his son's ventilator. Though Kenneth died before the case was resolved, the Nevada Supreme Court went on to rule that he had a right to refuse life support and that such action would not constitute suicide, nor assisting suicide if carried out by others. *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990).

²²Mary Johnson, *Unanswered Questions*, *DISABILITY RAG*, Sept./Oct. 1990, at 19.

One of the most dangerous aspects of despair is the development of rigid, constrictive thinking, sometimes referred to as tunneling. When death seems like the only solution, death is likely to follow. Here, the task of the therapist is to present as many alternatives as possible, seeking help and information as needed from family members, agencies, and other professionals.

All too often, however, persons with disabilities are offered few viable alternatives to death. The professionals assigned to help them are frequently as afflicted by tunnel vision regarding disability as their clients! Unfortunately, most physicians, nurses, psychologists, and even rehabilitation staff know little beyond the medical facts about living day to day with a disability.²³ Disability and quality living seem antithetical to many. This bias prevents many professionals from realizing they lack information that their clients deserve. The fatal error, literally, is their failure to consult disability advocates for advice and resource information, thus cutting their clients off from a world of possible solutions.

Siding with Life

In the management of suicidal ambivalence, people with disabilities have been treated with striking discrimination. Suicide experts explain that in despairing individuals the desire to die and the desire to find life worth living teeter in balanced opposition until something tilts the equilibrium. A central tenet of suicide treatment is that the helping person must ally with the life-desiring side of the dilemma.²⁴ Quite the opposite occurred for Bouvia, Rivlin, McAfee, and Bergstedt. Ambivalence went unrecognized. Doctors, judges, and family members agreed with the self-destructive impulse, calling it “rational,” “courageous,” and “the solution.” Clearly, people with disabilities find the scale of ambivalence heavily weighted on the side of death.

People with disabilities who have been suicidal often tell us how important it was in their recovery to receive unwavering opposition to their death wishes from key people in the environment. In her account of how she coped with suddenly acquiring quadriplegia, “Tough Love” co-founder Phyllis York describes her battle with initial depression. Her husband and close friends adamantly protested her desire to die. She writes:

People who tell me they understand my wanting to commit suicide are not helpful. They say that they have been in bad places, too, and can understand my desire. But I hear them silently telling me to do it—that I’m such a mess I shouldn’t want to live. People who tell me to shut up make

²³H. G. GALLAGHER, BY TRUST BETRAYED: PATIENTS, PHYSICIANS, AND THE LICENSE TO KILL IN THE THIRD REICH 40-41 (1990); Carol J. Gill, *A New Social Perspective on Disability and Its Implications for Rehabilitation*, in SOCIOCULTURAL IMPLICATIONS IN TREATMENT PLANNING IN OCCUPATIONAL THERAPY 49-55 (1987).

²⁴EDWIN S. SHNEIDMAN ET AL., THE PSYCHOLOGY OF SUICIDE 430 (1976).

me angry, but at least they don't sanction my death.²⁵

Preventing Death

The most basic policy of suicide prevention is to protect the client from dying. Not only are disabled individuals often denied this protection, increasingly they are given assistance in committing the act. In the *Bouvia* case, the ACLU (American Civil Liberties Union) actually intervened to restrain Riverside General Hospital from treating Ms. Bouvia as it would a nondisabled person in similar circumstances.²⁶ In the cases of Rivlin,²⁷ McAfee,²⁸ and Bergstedt,²⁹ courts sanctioned their deaths without even ordering suicide assessment or treatment from professionals qualified to work with disabled clients.

The Signs of Suicide in People with Disabilities

If stereotypes can be surmounted, it is possible to learn the signs—the red flags—of treatable suicidality in people with disabilities. Dynamically, disabled people who are suicidal present a contextual and symptomatic picture much like that of nondisabled people who are suicidal. Contributing historical features, current correlates or hazards, and immediate precipitants are often similar for both groups. The major difference lies in the significance for people with disabilities of social stress factors associated with their minority status, many of which may not be apparent to observers lacking disability sophistication. Any professional working in suicide assessment should learn the predisposing factors and signs of risk for people with disabilities, including the following:

Family History

Neglect or abuse in childhood

Loss of parent through death or divorce

Suicide of a family member

Family dysfunction (including mental illness or substance abuse in a parent)

Childhood separation from family

²⁵PHYLLIS YORK, *GETTING STRONG IN ALL THE HURTING PLACES* 208 (1989).

²⁶See Diane Coleman, *Withdrawing Life-Sustaining Treatment from People with Severe Disabilities Who Request It: Equal Protection Considerations*, 8 *ISSUES IN LAW & MED.* 55, 55 (1992).

²⁷See *supra* note 18.

²⁸State v. McAfee, 385 S.E.2d 651 (Ga. 1989).

²⁹McKay v. Bergstedt, 801 P.2d 617 (Nev. 1990).

Personal Dynamics

History of depression
Previous suicide attempts
History of drug or alcohol use
Low frustration tolerance, poor coping skills, masked dependency
Intense need for control, rigidity
Low self-esteem, unstable sense of identity

Stressors, Contributing Factors

Relationship loss or threatened loss (death, separation)
Abusive relationship
Loss of role or self-esteem, failure
Loss of control over life (due to confinement, restriction, domination)
Social isolation
Health problems, physical losses, pain
Work problems
Housing problems
Financial problems
Legal problems
Major life changes (such as moving, childbirth, job change)

Disability-Specific Risk Factors

New disability, changes in existing disability
Difficulties with “the system” (e.g., financial support programs, government agencies, vocational rehabilitation; includes legal problems—many disabled people resort to the concealment or misrepresentation of reported facts in order to obtain adequate funding for health care and independent living; consequently, they live under threat of exposure)
Difficulty obtaining personal assistance services, assistive technology, equipment, and other life aids
Stresses of chronic poverty
Stress of chronic social devaluation, stigma (may be internalized as hatred of the disabled self)
Loss of primary relationships due to the economic and social stresses of disability (e.g., the spouse exhausted by providing personal care when there is insufficient funding for an attendant; the parent who distances himself or herself from a child with a stigmatizing disability)
Loss or threatened loss of independent living; feared loss of self-determination and control of one’s own home and life-style (deriving not from the disability itself but from loss of resources)

Institutionalization or hospitalization (this involves the stress of confinement/restriction, loss of privacy, loss of sexual expression, social and sensory isolation, loss of control over lifestyle, loss of identity, infantilization, loss of own home)³⁰

Discrimination experiences (in work, housing, education, relationships, health care, transportation, community participation, environmental access, recreation, cultural pursuits)

Experiences of disability-related abuse, defamation, hate, violence (people with disabilities experience a significantly higher incidence of abuse than average)³¹

In short, people with disabilities turn to suicide in response to the usual factors, with the addition of risks specific to living with a disability in our culture. There is nothing about any of the signs and factors on this list that renders them untreatable. As far as we know, people with disabilities benefit from appropriate emotional support and suicide intervention as much as any other group.

Recommendations

To address the problem of discrimination in suicide prevention for people with disabilities, the following recommendations are offered. They are not intended to be complete. They are listed in the hope that they will underscore the urgency of this problem and stimulate concern, discussion, and action from other quarters.

Better Scrutiny of Disabled Persons' Intentions to Die.

When a person with disabilities wants to die, the most appropriate response (and, sadly, these days, the most neglected) is, "Why?" The death request of a person with disabilities should be explored as rigorously and objectively as it would be for anyone else, including the specific reasons behind it and possible solutions. Mental health professionals who work with people in crisis are trained to be meticulous sleuths. They are taught not only to hear their clients' obvious complaints but also to look further in order to uncover latent problems. Unfortunately, this process is commonly abbreviated or bypassed when the client is severely disabled, with dire results.

Millions of people live with disabilities. Disability is no more a sufficient or acceptable reason for wanting to die than romantic failure would be for an adolescent. Both losses may seem, at times, like the end of the world to those who experience them; but if important people in the

³⁰Emile Durkheim's notion of fatalistic suicide may be relevant here. Durkheim characterized the act as "suicide deriving from excessive regulation [by others, and exercised by] persons with futures pitilessly blocked and passions violently choked by oppressive discipline." EMILE DURKHEIM, SUICIDE 276 (J.A. Spaulding & G. Simpson trans., 1951).

³¹L. Camblin, *A Survey of State Efforts in Gathering Information on Child Abuse and Neglect in Handicapped Populations*, 6 CHILD ABUSE & NEGLECT 465-72 (1982).

environment address this sense of hopelessness rather than acquiesce to it, the individual has a fighting chance of mastering despair.

The Evaluation and Treatment of Disabled Persons Who Wish to Die Should Be Conducted by Professionals with Disability Expertise

Standards of practice in mental health enjoin professionals from practicing beyond the limits of their training and experience. Particularly, practitioners are cautioned against treating minority clients before obtaining adequate education regarding their clients' minority cultural experience. This dictum has been egregiously violated in the treatment of people with disabilities. Basic medical training by itself is grossly insufficient for dealing with the daily social/economic/political problems of disability. Professionals with little appreciation of the complexities of the disability life-style mishandle the needs of disabled clients in despair. Disabled people who want to die deserve to be seen by therapists who speak their language and understand their experience.

Persons Reacting to New or Changing Disabilities Should Be Given Sufficient Time and Support for Adjustment

When the suicidal wish derives from a troubled adjustment to disability, it should be treated as aggressively as any other kind of crisis. Suicide prevention should be implemented. Additionally, the support of family, friends, and community organizations should be enlisted for problem-solving to enhance life quality. This may ultimately require education and treatment for the family to correct prejudices that could sabotage the adjustment of the disabled individual.

Persons Experiencing "Disability Burn-out" Should Be Treated for Stress

Disabled individuals who are exhausted by their struggles with economic, social, and structural barriers in the environment need protection and time to recover. They need guidance to comprehend and rechannel their feelings and an astute counselor who neither downplays their struggle nor shares their temporary loss of hope. They also need to connect with disability advocates to help them through the barriers ahead.

Psychological Disorder Contributing to Suicidality in Persons with Disabilities Should Be Treated

This recommendation may seem too obvious to warrant listing. It should be beyond question that a person with disabilities who is suffering from depression, situational crisis, panic, and other disorders is as entitled to the full range of therapeutic interventions as a nondisabled person in distress. However, the personalities and emotional problems of people with disabilities are often overlooked when helpers fixate on their physical status. Equal treatment includes not only suicide prevention and, when needed, psychiatric hospitalization, but also the option of continuing long-term treatment for any remaining disorder or life problems once the crisis phase has passed.

Legal Protections Must Remain in Place

In a society that fears and rejects life with disability, people with disabilities need laws and the courts to safeguard their equal access to suicide prevention. In cases such as Bouvia's and McAfee's, the time delays and argument inherent in the court process itself may have permitted their change of heart. Many right to die proponents argue for the private right of families (with physicians' consultation) to make expedient life and death decisions for incompetent loved ones. This is a misguided position. Any therapist who has worked with disabled people has heard tragic stories of harm inflicted by loving, well-meaning family members making decisions on their behalf. The commonness of such recollections reminds us that loving someone with a disability does not naturally confer insight or even immunity from prejudice. Moreover, society does little to encourage families in their efforts to support the lives of relatives with disabilities. Consequently, families of people with disabilities often function under considerable economic and emotional strain. They are bombarded with dim assessments of potential life quality from others, including the media and the medical professionals who advise them. Unquestionably, the most caring families can make mistakes. Their authority in life and death decisions must remain amenable to the checks and balances of the legal process.

Disability Experts Must Be Involved

The views of many parties—physicians, family members, attorneys, religious advocates, politicians, ethicists, civil libertarians, right to die proponents, and journalists—have been well represented in court and in the media when persons with disabilities have asked to die. Less often heard and rarely heeded has been the voice of the disability community. Briefs filed by disability advocacy groups have been virtually unacknowledged in court proceedings. Views of experts who are disabled are rarely sought or recognized by the legal system, medical establishment, or media. One might wonder if people with disabilities have credibility only when asking to die! An extreme example of the neglect of the disability perspective is the Bergstedt case, in which the court sanctioned the death of a conscious, nonterminal adult without even speaking directly with him. He was represented, in part, by a parent in questionable mental health and by a doctor who acknowledged but saw no need to treat Bergstedt's depression.³² Disability advocates were allowed no opportunity to intervene. The only instance in which disability activists and others familiar with disability issues managed to intervene was in the McAfee case. Here the disability perspective dramatically altered the course of events, and a life was saved.

To guarantee nondiscriminatory treatment of disabled persons who are suicidal, right to die proceedings must be informed by disability awareness. No assistance in dying should ever be considered without evaluation and intervention by qualified professionals and advocates who either have personal disability experience or extensive familiarity with disabled people and their life issues. Competency training for professionals should be developed incorporating key

³²Affidavit of Jack A. Jurasky, M.D., *Bergstedt v. McKay* (Nev. Dist. Ct. 1990) (No. A281607).

contributions and monitoring by disabled professionals, consumers, and advocates. Physicians, allied medical personnel, suicide prevention staff, hotline workers, and psychiatric intake workers should receive such training to sensitize them to the social dynamics of disabled people's despair.

Last Words

For a country that purports to embrace human diversity, citizens with disabilities constitute the acid test. Our integration into American culture would involve radical changes in such concepts as independence, normality, and quality of life. The belief that life with a severe disability, including the use of life aids, is untenable rudely rejects the culture—the customs and ways of living—of people with disabilities. Reminiscent of the days when many people preferred to “be dead than Red,” current opinion reflects an overwhelming public preference for death to disability.³³ Tragically, this sentiment is only too apparent in the lack of suicide prevention services offered to people with disabilities.

As long as society supports suicide prevention services for anyone, it is morally and legally obligated to extend these services to people who are disabled. To accept a suicide is to encourage it. Encouraging the self-destructive urges of persons with disabilities who despair is not merciful or compassionate. It is dangerous for those individuals, for all disabled people as a devalued group, and ultimately for a society founded on equality. Persons with disabilities demonstrate that they value their lives a great deal more than others do.³⁴ Those who give up on life do so only after struggling with the very human pain of unmet needs. Society must not silence those needs by death but by assisting in their fulfillment. That is the authentic compassionate response.

³³Barbara Brotman, *Ruling Prompts Paper Chase to Get Affairs in Order*, CHI. TRIB., July 6, 1990, § 5, at 1.

³⁴N. Weinberg & J. Williams, *How the Physically Disabled Perceive Their Disabilities*, J. REHAB., July 1978, at 31-33.