
Challenges Across the Life Span For Persons with Disabilities

by Christine Rinck and Carl F. Calkins

Health care issues for persons with developmental disabilities have raised numerous bioethical dilemmas. These controversies bridge the life span from the prenatal period through old age. Some key discussions focus on the impact of genetic testing and amniocentesis on the birth of children with disabilities and the survival of very low birth weight babies. Other issues center on transplants for persons with disabilities, sexuality, and advance directives. With the movement away from institutionalization and toward independence, people with disabilities have more choice in all aspects of their lives. This choice can pose dilemmas for the individual and those who are care providers.

Ethical issues surrounding health care of persons with developmental disabilities occur from the prenatal period through old age. This article offers a framework for understanding and discussing these issues. Legal and ethical rights of persons with disabilities provide the context for the discussion. Brief scenarios with a description of the background and ethical issues related to these challenges provide examples and springboards for discussion.

Legal Rights

The enactment of legal rights and humane practices toward people with disabilities has occurred only after the initiation of lawsuits and subsequent legislation requiring change. Key lawsuits resulted in education for all persons with disabilities (for example, *Mattie T. v. Holliday* 1977; *Armstrong v. Kline* 1980; *Brown v. Board of Education* 1957), closing institutions (for example, *Halderman v. Pennhurst State School and Hospital* 1977, 1981), and labeling practices (for example, *Hobson v. Hansen* 1967; *Larry P. v. Riles* 1972; *Hoffman v. Board of Education of the City of N.Y.* 1976).

Federal legislation has also been responsible for effecting changes in the lives of people with disabilities. The first federal legislative bill focused on sensory deficits (for example, blindness and deafness), creating "asylums" in 1827. Recent leg-

islation has covered a wider array of disabilities. Many legislative actions were precipitated by advocacy of family members and consumers as well as professional organizations. Some key examples include the following:

- The Americans with Disabilities Act (ADA) PL 101-336: broad sweeping implications for all persons with disabilities with regard to employment, residential living, and access to community services including health care
- Individuals with Disabilities Education Act (IDEA) PL 101-476: targets more specialized areas (for example, the right to free appropriate education for all children including those with severe disabilities from birth to age twenty-one)
- The Developmental Disabilities Act (PL 103-230): planning for, protecting and advocating for individuals with a substantial disability

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that occurred before age twenty-one (for example, developmental disability)

The movement away from segregated living, working, and recreating is characterized by competitive or supported employment, independent or supported living, and community-based lifestyles that offer opportunity for self-determination and friendships. The traditional "service" model has been replaced by a "support" model (Bradley, et al. 1994).

Shifting paradigms of support also altered lives of individuals with developmental disabilities, providing more opportunities and choices as individuals are integrated into the community. Natural and programmed supports are individualized and made available for individuals to exist in the community environments.

Many factors influence health care decisions for persons with developmental disabilities in this environment. First, people with disabilities are living longer than was predicted, and the requisite social programs and health care systems are not prepared (Lubin and Kiely 1985). The average life span of a person with Down's syndrome has tripled over the past fifty years (Eyman and Borthwick-Duffy 1994) through medical advances and technology (Richards and Siddiqui 1986).

While an increased life span is desirable, developmentally disabled individuals often present in middle age with serious medical and neurological symptoms that are more characteristic of older age, for example, Alzheimer's syndrome, early deafness and cardiac pathology (Buchanan 1987; Carter and Jancar 1983; Dalton and Wisniewski 1990). Individuals with other disabilities also experience early onset of medical symptoms usually associated with the elderly, such as muscle degeneration in cerebral palsy (Zigman, Seltzer, Adlin, and Silverman 1991; Rudelli 1985). Social programs are also focused on younger ages (Janicki 1986). Retirement often means moving to a more medically-oriented facility away from friends (Colton and Spurison 1986).

Second, the preparation of health care professionals to assist persons with disabilities has been

neglected (Campbell, Bellamy, and Bishop 1988). While a federal grant program from the United States Bureau of Maternal and Child Health prepares specialists for leadership roles with children having special health care needs, there are no training programs targeted for an older population. Even specialized care for children is scarce in small towns and more rural geographic areas. Meeting the needs of this special population with limited resources is a difficult task.

Third, the movement toward managed care offers a challenge and a potential support to persons with disabilities. In the traditional health care delivery system, access is often limited for people with disabilities due to the lack of acceptance of Medicaid patients by physicians. Moreover, many physicians who do take Medicaid patients are often not in the mainstream of medical care. Little preventive medicine has occurred. Managed care, with its emphasis on prevention, may enhance the life of persons with disabilities. If, however, the emphasis focuses on cost restraint, needed specialized care could be curtailed. These factors and situations are important components in a discussion on ethical issues in the health care of persons with developmental disabilities.

The issue of long-term supports to people with disabilities, however, may be even more challenging. The capping of Medicaid will limit the amount of funds available to finance innovative programs. This comes at a time when the array of services designed to foster independence and productivity (for example, individualized supported living) costs more than the traditional services (for example, group residential homes). Managed care in itself requires extensive discussion in regard to health care of persons with developmental disabilities and is beyond the scope of this paper.

Decision Making

The issue of decision making for a person with a developmental disability is complex. For a person with some cognitive limitation, a guardian may make all decisions. For others, functioning may be perceived as impaired and they are not given the opportunity to make decisions even though they are their own guardians. For still

others, they make their own choices, just as any citizen does. In all of these situations, the question arises as to who is the best person to make health care decisions.

Case 1

After an amniocentesis, Steve and Dottie knew their newborn would experience Down's syndrome. They were faced with a difficult decision: should Dottie abort or carry the baby to full term?

Recent technological developments have brought a revolution to prenatal decision making. Genetic testing prior to pregnancy can indicate the odds of having a child with a congenital disease, as in the case of Huntington's chorea and cystic fibrosis (Sumner 1994). If positive results are found, the couple faces a personal and ethical dilemma (Mennuti 1996). Should they bring a child into the world when there is a high probability the infant will have a limited life span or exhibit a serious illness?

Research indicates that approximately eighty-eight percent of women who know they are carrying a fetus with Down's syndrome elect to abort (Glover and Glover 1996). Abortion laws in these situations differ from those for a woman whose fetus has no defect, allowing for second and even third trimester abortion (Henshaw 1995). There are some who believe the Americans with Disabilities Act should protect the rights of a fetus with a disability.

The ethical dilemmas raised by these situations are difficult ones. Some believe abortion in these cases is a form of genocide (Cohen 1986) because everyone has a right to life, including those with severe disabilities. They refer to research that indicates individuals with Down's syndrome do enjoy a quality of life and are able to make personal choices (Niesson and Hamberger 1990). Others argue that abortion could "avoid an anticipated burden." However, some figures indicate that the majority of parents of children with Down's syndrome do not consider the disability to pose a burden. Parent advocacy groups have "come down strongly on the side of the child" in

lieu of the parent (Federal Register 1984, p. 1629).

Case 2

Louise was born at twenty-eight weeks and weighed <1000 grams. She was put on high technology equipment. After four months, it seemed that she would survive but her quality of life was questionable. Her physician predicted that she would never walk or talk. Her peak function would be at a four-month developmental level.

In 1960, a baby born with Louise's statistics would not have been put on a respirator because all babies in such cases died (Cohen 1990). Today that situation has dramatically changed. Neonatal intensive care, sophisticated technology, and an arsenal of pharmacotherapy have decreased infant mortality from 12.6/1000 to 8.5/1000 between 1980 and 1993. The follow-up statistics, however, are sobering. Of those born with birthweights under 750 grams, thirty-seven percent had behavioral problems and forty-five percent were in special education programs (Hack et al. 1994). Another study reported fifty-six percent survival at twenty-four weeks, but that only twenty-six percent avoided brain bleeds and fifty percent experienced retinopathy (Allen, Donohue and Dusman 1993). The mean cost for a pre-term infant with a birthweight of < 749 grams was \$119,339.

For years, health care professionals practiced benign neglect and these infants born with disabilities died. This was halted by the Baby Doe regulations (Young and Stevenson 1990). Incensed by a case in Indiana in which parents refused consent for treatment for a child born with severe disabilities and withheld nourishment, the Reagan administration required hospitals receiving federal funds to prohibit this practice (Angell 1986). Congress followed with an addition to the Child Abuse legislation classifying the withholding of treatment as child abuse. Since the implementation of this supplement, the pendulum has swung toward the middle with life and death decisions being made on a case-by-case basis. The majority of neonatologists respect parents' decisions concerning the issue of providing intensive care (Sanders, Donohue, Oberdorf, et al. 1993). Another

survey found that aggressive treatment was provided for infants weighing at least 623 grams if no intracranial hemorrhage was present (Wolder, Driscoll, and Fleischman 1993). European countries do not pursue such an aggressive course, recommending against neonatal intensive care for infants below 600 grams or twenty-five weeks gestation in Denmark (Danish Medical Research Council and Danish Hospital Institute 1992); and Australia (Buchanan 1987). In underdeveloped countries, such care, even if available, would be given only to infants above 1000 grams or more (Wainer and Khuzwago 1993; Renzong 1987).

Many ethical questions arise from these situations. In situations in which the outcome is questionable, should one try to continue life? How open should health care professionals be with parents about the bleak future and quality of life for their child? Some parents argue for a reasonable quality of life for their child, but the term itself is difficult to define. Other parents believe all life should be cherished. Who should judge the extremity to which one implements life-preserving measures? If health care rationing occurs due to fiscal restraints, will regulations about medical decisions regarding low birth weight babies alter current practices?

Flech, Lorenz, and Tyson (cited in Tyson 1995) have proposed a matrix for neonatal intensive care decision making ranging from cases in which there are no easy decisions to be made (for example, full-term child with only respiratory problems) to cases in which there is potential for a reasonable quality of life (for example, a 600-gram infant). Here the parents would decide aggressiveness of treatment, but in unreasonable scenarios, aggressive treatment would be seen as "futile" and only comfort measures would be provided. The concept of "futility," however, leads to other questions: How would futility be defined quantitatively and qualitatively (Schneiderman, Jecker, and Jonsen 1990; Lantos, et al. 1989)? Would a percent be affixed to each possible array of infant characteristics? The decision as to aggressiveness of intervention, according to the Judicial Council of the American Medical Association combines

- medically beneficial standard: would benefit derive from the treatment
- quality of life considerations: would the infant enjoy a reasonable quality of life (never defined)
- parental decision making in which parents have the final decision of the type and quantity of the intervention (Weir 1983)

Adding to the burden of decision making is the attitude of the health care provider when infants are born with defects or "imperfect." While some providers take time to discuss all options, others sometimes avoid the parents or are paternalistic in interacting with the family (Singer and Power 1993). Parents, however, want to be informed about potential treatments and their ramifications in order to have control over their child's destiny (Summers, Behr, and Turnbull 1989).

Case 3

Calvin was born deaf. At three years of age, his parents sought assistance from a medical specialist for a cochlear implant. Since the surgery, Calvin can understand his favorite character on television, Big Bird.

Children born with hearing impairments pose other ethical decisions. One of the first choices is whether an oral method of language or sign language should be taught (Calvert 1976). The oral method allows a child to speak more competently and to be better integrated with the hearing population in school and in work settings (Gatty 1986).

Many children who would have lived in a silent world now have the opportunity to hear with cochlear implants. Some in the deaf community, however, claim implants rob children of the richness of their deaf heritage (Hilliard 1993). Who, then, should make decisions for a child as to which world they will live in: the world of hearing or that of the deaf? What definition of quality of life is the appropriate one?

Case 4

Carol, age twenty-one, is a person with moderate mental retardation. She is an attractive young woman who was raped and subsequently became

pregnant. The rape occurred at the sheltered workshop where she works and was committed by one of the staff.

People with disabilities are more often victims of rape than the general population (*Mental Health Disability Law Reporter* 1986; Sobsey 1994). The first ethical and legal concern is the obligation of society and the care provider for individuals with disabilities who are sexually assaulted while under the state's care. These obligations include a holistic treatment program, for example, counseling, education, intensive therapy, and advocacy training (Arelllo 1986). This is especially true for those who reside in institutions where sexual education is usually non-existent (Hall and Morris 1976) and where abuse has been reported (McDonald 1987). Unique counseling techniques (for example, therapeutic imagery, reframing) should be tried for individuals with disabilities, especially those with cognitive impairments (McDowell, Bills, and Eaton 1989). One major deficit is the lack of training of health and sexuality educators about effective teaching strategies for this population (Bartel and Meddock 1989; Baugh 1984; Matson 1987).

Seven critical problems have been identified for this population: (1) confused self-concept; (2) sense of isolation; (3) lack of knowledge about sexuality; (4) "secretness" of sexual behavior; (5) lack of positive sexual experiences; (6) inconsistent social milieu; and (7) lack of personal power (Hingsburger 1987). Effective therapeutic interventions addresses these problems. A Kansas City, Missouri agency, the Metropolitan Organization to Counter Sexual Assault (MOCSA), has begun working with Carol and her family, but many issues remain unattended (for example, unresolved hostility, fear of reoccurrence).

A third issue relates to the pregnancy. Carol wants to keep her baby; her parents feel she should have an abortion. Who decides? Since Carol does not have a genetic disorder, the child will probably be normal. Legally, Carol could keep this child since she is her own guardian. Her parents, however, are strongly opposed to this and

are considering going to court to obtain guardianship.

The issue of child rearing by parents with mental retardation raises the question of competence in decision making and maintenance of requisite support systems. Tymchuk, Andron, and Rahbar (1988) indicate that with adequate training, significant improvement can be demonstrated for high risk situations. Likewise, Feldman, Towns, Betel, Case, Rincover, and Rubino (1986) suggest that mothers with cognitive limitation can be taught to provide effective and stimulating interactions to their children. However, Heighway, and Kidd (1988) indicate that parents with low intellectual functioning experience considerable difficulty in negotiating the maze of human service agencies. Without adequate training and support networks, the issue of child rearing for parents with mental retardation is, at best, difficult.

The issue of sterilization is a related concern to practitioners. Parents frequently request sterilization of female family members with disabilities, especially in light of increased risk for victimization. Historically, people with disabilities were involuntarily sterilized as soon as they were institutionalized (Applebaum and La Puma 1994). A Supreme Court case (*Buck v. Bell* 1927) supported this practice. The *parens patriae* argument has been utilized for legally incompetent persons where proper procedures are followed (Burgdorf 1983). Over 60,000 individuals with mental retardation experienced sterilization between 1900 and 1921. Should physicians agree with families and perform sterilizations, or should the person with the disability be given a choice?

Case 5

Ida has lived in a restricted supervised residential care facility for years. She found an apartment and the state has provided her the supports she needs to live independently for the first time.

Prior to 1960, people with developmental disabilities resided at home or in institutional settings. Paternalism and benign neglect pervaded the care provided (Ward 1990). In the 1970s, some individuals moved into the community, resulting

in smaller institutional settings but still with highly supervised environments. Recent trends toward supported living, which provide the supports to individuals in their own apartments, have given people with developmental disabilities new autonomy. A Missouri study (Rinck 1996) found that individuals residing in supported-living environments (ISLs) had significantly more choice over everyday activities. Those in ISLs also had a lifestyle more like people without disabilities (for example, having house keys, coming and going at will). In addition, ISL residents were better self-advocates. The freedom in ISLs, however, brings responsibilities. The more autonomous individual is at higher risk of being a victim of crime or accident. Also, the cost of ISLs is significantly higher than group settings. The higher cost setting results in a higher quality of life, but can this take precedence in a period of federal cutbacks and block grants? This question will be addressed by state policy makers and taxpayers as well as by advocates of persons with developmental disabilities.

Case 6

Jane, sixty years old, has been told she has breast cancer. What should she be told about her diagnosis and proposed treatment? What role should she have in treatment decisions?

Persons with disabilities experience the same maladies as everyone else. However there are complications, especially for the person with cognitive limitations, in making choices. Receptive and/or expressive language may be limited. The ability to make informed decisions could be questionable. How does one assure informed decision making and enhance choices for an individual with a cognitive limitation? Even if a person is adjudicated as incompetent, ethical questions arise: What should they be told about their condition? Should they have any part in the decision-making process about their course of treatment? How can one access informed consent?

It is generally agreed that informed consent occurs when a *competent* person reaches a *voluntary* decision, based on *sufficient information or knowledge* (King 1986). However, the precise

meaning and requirements of each element continue to be defined by case law. For all who are their own guardians, competency must be assumed or legal determination sought, yet no standard tests exist for competency (Roth, Meisal, and Lidz 1977).

For the individual with a disability, competency and a standard with which to measure it is problematic (Applebaum and Roth 1981). Communicated choice and the presence of delusional beliefs need to be considered in assessing competency. "Ability to Understand" refers to the person's ability to understand risks, benefits, and alternatives and is probably most consistent with the contemporary doctrine of informed consent. There is, however, no consensus in the depth of understanding required. In addition, mental processes can only be observed from the patient's concrete behavior. Under the test of "Actual Understanding," a different competency model, the physician is obliged to provide relevant information to the patient and then ascertain whether he or she has actually understood. Here, competency to make a treatment decision would be, by definition, the person giving evidence of having made a knowledgeable decision.

Social pressures which inhibit voluntary decisions are magnified for people with disabilities who have been allowed few choices (Edlund, Craig, and Richardson 1985). Pressure from providers or health care professionals may cause individuals to feel that, if they disagree to certain therapies, privileges will be reduced. Even when individuals with a disability do not feel coerced, there is a tendency to acquiesce (Sigelman, Schoenrock, Budd, et al. 1983; Sigelman, Winer, and Schoenrock 1982). It is difficult to ascertain when a decision is truly the individual's choice and not influenced by outside forces.

The final element in informed consent is sufficient information. This includes an understanding of

- the nature of the procedure or treatment
- any risks that would be material to a reasonable person making a decision

- the anticipated benefits of the procedure or treatment and the probability of success
- alternative treatments (including no treatment) with the benefits and risks (Rappaport and Parry 1986). Clearly this is often a complex and difficult process when working with persons with developmental disabilities.

Case 7

Jim has difficulty controlling his impulsive behavior. Psychotropic drugs help minimally as does behavioral support. Without better control, his continued presence in the community is tenuous.

New pharmacological and technological advances have improved quality of life for people with disabilities, while at the same time creating dilemmas. Inclusion is important for persons with disabilities. To achieve it, a level of social competence must be achieved (Calkins and Walker 1990). Aggressive behavior works against this goal.

There are several accepted "treatments" for such behavior, one organic and the other behavioral. Each has inherent problems. Pharmacological therapies often have side effects that interfere with quality of life (Gualtieri and Burnhill 1988). The use of psychotropic drugs is dependent on several conditions, including informed consent (Guidry, Rinck and Rinck 1988). Other behavioral methods should be tried prior to the use of neuroleptics and when they are used, it should be the lowest effective dosage (Keppel and Gualtieri 1989). Finally, the effectiveness of medications must be measured and proven (Rinck, Guidry, and Calkins 1989).

Behavioral management, especially aversive therapies, can impinge on human rights issues (Turnbull, Guess 1986). Aversive therapy generally refers to procedures instituted to challenging behavior that inflicts physical or emotional pain or discomfort. Legal cases have examined the use of aversive therapy in diverse populations (for example, mentally retarded, Wyatt v. Stickney 1972; psychiatric, Knecht v. Gillman 1973; and prisoners, Mackey v. Procunier 1973). In the first case, the use of aversives was upheld if it was admin-

istered by a qualified mental health professional, approved by the person or their surrogate decision maker and approved by a human rights commission. Some aversive therapies, however, were ruled as a violation of rights and as cruel and unusual punishment.

For years, the major behavioral approach was aversive therapies. The effectiveness of these therapies was questioned, especially long-term consequences. In 1990, a determination of effectiveness and humanness of behavioral interventions in the broader social context began a shift away from aversive treatment (Schroeder, et al. 1990). Although some authors still argue for the need for aversives (Mulick 1994; Carr and Newsom 1985; Iwata 1987), the shift toward the application of more positive supports continues (Carr et al. 1994; Horner, Sprague, and Flannery 1995; Schroeder, Oldenquist, and Rojahn 1990). Criteria have been established for looking at the context of behavior, including utility, desirability, social consequence, and adaptability (Sailor, Goetz, Anderson, Hunt, and Gee 1988). This facilitates the use of positive behavior supports.

Questions remain in this area. What quality assurance measures should be implemented to enforce accountability? Moreover, what role should the individual with a disability have in deciding his/her own behavioral/pharmacological treatment? Self-determination is now recognized for persons with disabilities, and many believe they should make their own decisions, even if those decisions results in a poor outcome.

Case Eight

Richard is a seventy-year-old man with mild Cerebral Palsy and mild mental retardation. He has recently been diagnosed with end stage kidney disease and is experiencing considerable pain. What life-sustaining measures should be implemented?

The selection criteria for dialysis and renal transplants usually centers on the finding of a team — a surgeon, a psychiatrist, a psychologist, a social worker, and other physicians. The associated condition of renal failure produces at least

three areas of lifestyle stress: physical discomfort, psychological distress with increased dependency on the dialysis and the renal team, and social limitations with substantial financial investment (Rabinowitz and Van Der Spuy 1978). According to the team, Richard is not a good candidate, even though he indicates he can handle the social and emotional limitations as well as the diet. An underlying concern is that he is not competent to handle the treatment regime, much less the financial burden. Is there a way to reverse the team decision? An appeal is being filed under the ADA to reverse the decision. In the meantime, Richard is painfully dying.

The question surfaces as to who should decide what is one's quality of life. In this period of fiscal restraint in medical care, some rationing may necessarily occur. What should be the criteria for deciding who lives and who dies? Should education or IQ be the criteria? Who determines the "value" of a person? Should only those with advanced degrees be given these life-saving operations? Who will make these types of decisions?

Conclusion

Death inevitably happens to all people. Recent initiatives have fostered the practice of empowering individuals to have a role in making their own decisions about how they will die. Advance directives allow for choice in what measures should be employed in continuing one's life in the face of a terminal illness. More ethical considerations arise when considering these directives for people with disabilities than for the typical person. Assurances must be made that the individual understands the ramifications of his or her actions. If someone cannot verbalize a choice, who should make this decision and how should it be made?

Throughout the life span of a person with a disability, bioethical decisions abound. In light of a changing health care paradigm, these issues become even more complex. Careful discussions and analyses of all these issues, a thoughtful probing of the pros and cons of each one, will help ensure that the voice of people with disabilities is heard

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