

## Guardianship

Sometimes an ethical dilemma is about more than determining if an action is legal. In the case of guardianship, the ethical problem centers on who is allowed to decide what action should be taken or what decision should be made. The basic question is: *Should a person with developmental disabilities be supported to make decisions that affect his or her life? Or, should someone else be given the right to make decisions on the person's behalf?*

Many people assume that everyone with developmental disabilities is not able to make decisions about their lives. As you can imagine, guardianship is a major issue in the lives of people with developmental disabilities.

When a guardian is appointed, a person with a developmental disability may lose their right to:

- Choose where they live and who they live with.
- Decide whether or not they receive proper, sometimes life-saving medical treatment.
- Decide whether or not they can have a driver's license.
- Purchase or own property or enter into a lease.
- Own a weapon.
- Enter into contracts or lawsuits.
- Get married.
- Have or raise children.
- Vote.

### What is "Guardianship?"

In broad terms, "guardianship" is substitute decision making, an individual's right to make decisions is given to someone else. This power might be given to a parent, a relative, a friend, or someone the individual does not know, such as a person appointed by the government or the social services system. Sometimes another person just takes control of the life of a person with developmental disabilities without any legal right or determination that the person is not capable of making his or her own decisions.

In the 1950s, there were few guardianship options. As a result, guardians had much greater power. Today, there are many types of guardianships. For example, a guardian may be given control only over specific decisions, such as health care, how the person's money can be used or where the person lives. There are many new ways to help people with developmental disabilities make decisions about their lives that support their decisions and independence.

A **guardian** is a person who is given the legal power to make decisions for another person because he or she is considered not competent to decide for himself/herself.

## **The Guardianship Rights of Parents**

Parents automatically become the guardians of their children when they are born or adopted. This means that parents have the right to make decisions for their children because children are not considered competent to make decisions for themselves. The U.S. Supreme Court first defined the rights of parents to control a child's upbringing in 1923 in *Meyer v. Nebraska*.

A parent's legal guardianship ends when the child reaches the age of majority determined by the state. In some states, a parent's guardianship also can end in specific circumstances, such as if the child graduates from high school, gets married, joins the military, etc.

For people with developmental disabilities, the same rules don't always apply. When a person with developmental disabilities reaches the age of majority, his or her personal decision-making power isn't always assumed.

In law, in policy and in common practice, parents and the state often continue to make decisions for adults with developmental disabilities because they are viewed as incompetent.

## **Challenges to Parental Rights**

Sometimes, parents and the state have fought over who has the right to make decisions for a child. In those cases, guardians may be appointed by the court to represent the interests of the individual.

In 1944, the U.S. Supreme Court held in *Prince v. Massachusetts* that the government has broad authority to regulate the actions and treatment of children. A parent's authority is not absolute and can be restricted if doing so is in the child's interests.

Over the years, the idea that a parent's rights could be challenged was supported by other court decisions. States regularly intervened on behalf of neglected or abused children. They also limited a parent's authority to transfer a child's property, withhold necessary medical treatment and deny exposure to ideas and experiences the child may later need as an independent adult. (*Parham v. J.R.*, 442 U.S. 584, 1979)

Today, the law recognizes that sometimes a parent doesn't always make decisions that are in the best interests of the child. Instead, they may make decisions that benefit themselves or put the child at risk. In some cases, the state may step in to protect the child's welfare and interests.

There are many examples where the state has stepped in to protect the interests of children in general. There are not nearly as many examples of the state stepping in to protect the rights and lives of children with developmental disabilities. In many cases, the state supported decisions that protected the interests of everyone *but* the child with

developmental disabilities. This was particularly true in situations where an individual lived in a residential facility (institution). Residents of state-run institutions regularly had property taken away by the state, did not receive necessary medical treatment, and weren't exposed to ideas and experiences they might need to become independent adults.

Many guardianship laws in the United States have been in place for centuries. As new states joined the Union, guardianship laws were among the first ones passed. From that time until well into the 20<sup>th</sup> century, few changes were made. "As a consequence of this neglect, the guardianship laws are probably the most archaic laws related to children on the statute books of the [United] States." (Weisman, 1949, p. 17)

Since the 1950s, several key issues have challenged effective guardianship. They are:

1. Outdated guardianship rules.
2. Lack of planning by parents for the future of their adult children with developmental disabilities.
3. The broad range of decisions that guardians are allowed to make.

### **Problems with the Rules**

In 1949, one of the first comprehensive reviews of guardianship rules identified major problems, including:

1. An individual's need for guardianship usually was not being met.
2. The rules were unclear, making it difficult to request help from social service agencies trying to respond to the needs of children.
3. Federal benefits were being paid to adults who cared for children who often had not been screened or formally appointed.
4. Current legislation was inadequate. (Weisman, 1949, p. 17)

By 1962, rules surrounding guardianship had not improved. Further problems related to guardianship were becoming evident, both for children and adults with developmental disabilities. The President's Committee on Mental Retardation was deeply concerned about the issue and said:

*Most states' provisions for guardianship of the retarded are relics of a time when the mentally retarded individual was considered an incompetent who had to be kept away from normal social and work contacts. They largely consider or assume the retarded person to be without rights, deny him due process or the equal protection of the laws, and often encumber his family's estate for years as the price of the state's assuming his care. The damage done to retarded individuals who are capable of self-support and self-reliance, to those who have become caught up in the judicial process, and to families who can be in effect*

*held responsible for a retarded individual into a second generation is incalculable.*

By 1969, a growing list of problems with the guardianship laws, rules and procedures had been documented by Richard Allen:

- If someone is found “incompetent” in one area of life, they are considered “incompetent” in all areas of life. They lose control over decisions about both their property and their person.
- Guardianship proceedings are cumbersome and expensive.
- The guardianship process creates unnecessary stigma for the person in need of help and unnecessary pain for parents seeking to insure that the person needing assistance will get it.
- When a person is institutionalized, they are treated as if they are incompetent even if they have never been found to be so. In some cases, just because someone is institutionalized, they are deemed incompetent according to the law.
- Most courts do not have the resources to clinically evaluate competence. They do not have enough staff to make sure that guardians and institutions meet their responsibilities as guardians.
- Often individuals are declared incompetent without being truly represented by a lawyer. This happens even when the guardian process requires the court to appoint a lawyer.
- The rules are unclear about when a guardian should be appointed, and what the guardian’s duties should be.
- There is no established procedure to review the competency of institutionalized children when they become adults.
- Guardians are rarely appointed for people in residential care institutions.
- In many cases, an individual may need only limited help with decisions. But guardianship is an “all or nothing” situation. There is no such thing as partial or limited guardianship.
- Few states have set up a system where a state agency can assume some or all of the functions of a guardian when there is no one else to fill this role.
- In some states it is necessary to go through a commitment proceeding to receive needed protective services.

## **Problems with Estate Planning**

Another challenge related to parents' lack of planning for the time when they could no longer look after their children with developmental disabilities.

Often parents did not name a specific guardian or manage their estates in the interests of their children with disabilities. Many estate and guardianship planning rules were inadequate. When rules were in place, many parents did not know about them. If the parents did know about estate planning and guardianship rules, they found them confusing. Parents also had to manage other pressing day-to-day priorities. Some parents resisted naming a guardian because they saw guardianship as a way of taking power and control out of the hands of their sons and daughters.

It took decades to develop guardianship alternatives so that parents could feel secure that the best interests of their sons and daughters would be looked out for, without jeopardizing their independence.

### Problems with Decisions

For centuries, the intent of guardianship has been to protect vulnerable people and to make sure that decisions are made in the individual's best interest. In 1697, in the *Infants' Lawyer*:

*It is most certain that our Law hath a very great and tender consideration for Persons naturally Disabled... They are under the Special Aid and Protection of his Equity, who is no less than Keeper of the King's conscience.*

In the 1950s, many decisions made by some guardians fell far short of "special aid and protection." A few common abuses included:

<b>Forced sterilization</b>	Guardians authorized the sterilization of children and adults with disabilities living in the community and in institutions without their consent. This was sometimes done to prevent pregnancy, hygiene problems, and parental worries. It also was intended to "purify the race" in the name of Eugenics. (You can learn more about Eugenics in <a href="#">Parallels in Time, and Parallels in Times, 2</a> .)
<b>Institutionalization</b>	Parents routinely institutionalized their children.
<b>Permanent placement</b>	Institutions generally refused to return children to their parents after the children had been placed in an institution. This was due in part because the children were not able to live in the community because few or no attempts had been made to teach life skills, employment skills, etc.
<b>Limited parent input and authority</b>	Parents, guardians and individuals were coerced to make decisions about the care and treatment of an individual with developmental disabilities even when they disagreed. Often, parents would agree because they were afraid of what might

	happen if they did not cooperate.
<b>Lack of legal counsel</b>	Commitment proceedings, even though they required the appointment of legal counsel, often managed to deny the requests of individuals and families seeking legal representation.
<b>Dehumanizing practices</b>	Institutions denied children and adults with developmental disabilities access to programs or treatment that would enable them to develop skills and/or return to the community. In fact, the institutions created and supported dehumanizing situations that horrified the nation when they came to light.
<b>Denial of basic rights</b>	In one state, institutionalization alone was enough to prohibit residents from receiving a driver's license, making a will, marrying, subscribing to a magazine, executing a contract, or managing their own property. These restrictions were made without requiring a legal finding of incompetence.
<b>Servitude</b>	Institutions routinely used residents to do the work of the institution, often for minimal or no pay.
<b>No control over how guardians used government payments</b>	Some parents and guardians who received government payments and inheritances to support an individual with developmental disabilities used the funds for their own purposes. Institutions regularly named themselves "substitute payee" for benefit payments and mingled the individual's funds with those of all residents.
<b>Refusal to provide medical care to newborns</b>	Newborns with easily corrected health challenges were allowed to die of starvation or suffocation if they also had some degree of intellectual disability.
<b>Lack of treatment</b>	Guardians allowed medical treatment to be withdrawn from adults who were considered to be "beyond hope." This was not always done because it was in the best interests of the individual but in an effort to avoid emotional and/or financial burdens.
<b>Difficulties obtaining medical treatment</b>	Guardians sometimes had to fight hospitals, ethics committees and the courts to get appropriate medical treatment for people with developmental disabilities.

(Kindred, 1976; Allen, 1969; Murdoch, 1972)

## Conflicts of Interest

Many bad decisions were made because of conflicts of interest. The best interests of institutions and professionals were often at play. Sometimes, the interests of the parents conflicted with those of the child.

The following observation was made in a brief to the court as part of *Wyatt v. Stickney*:

*The parent may be motivated to ask for such institutionalization for a variety of reasons other than the best interests of the child himself, i.e., the interests of*

*other children in the family, mental and physical frustration, economic stress, hostility toward the child stemming from the added pressures of caring for him, and perceived stigma of mental retardation. The retarded child's best interests may well lie in living with his family and in the community, but theirs may not lie in keeping him. (Cited in Murdoch, 1972)*

It also was the case that parents and guardians may be less than able to look after the individual's best interests because of the nature of the system itself.

*The other facet of parental inability to represent adequately the best interests of the retarded child lies in the inability of many well-intentioned parents to deal effectively with the public and private institutional providers of service. For example, the parent of a child in a special education class within the public school system is likely to hesitate to question the quality of the program since the threat of exclusion weighs heavily in the parents' minds. The parent is realistically aware that the cost of a private program is prohibitive and that the public program is better than that which the parent could provide at home. Similarly, a parent of a child who has been voluntarily admitted to a state institution would hesitate to challenge the quality of the care provided because the child is constantly subject to the threat of subtle -- and not so subtle -- retaliation. Additionally, the parent may feel that if he disturbs the status quo, the child may be thrust back upon him. Moreover, the parent is likely to be unaware of the professional standards which the institution must meet and the political and quasi-political pressures which can be brought to bear on the institutions. (Murdoch, 1972, p. 15)*

## **Efforts to Improve the Rules**

Compared to the 1950s, many more formal support options are available today.

One of the biggest changes in the way guardianship is viewed is the idea of "*least restrictive alternative*." In earlier decades, guardianship was seen as more acceptable than institutionalization, which was considered more restrictive. Today, institutionalization is considered unacceptable, and guardianship is increasingly thought of as a "last resort." To paraphrase a statement by the California Supreme Court, a person who has a guardian (or a conservator) appointed may give up more control over his or her life than someone convicted of a crime. (Cited in Geller and Hyman, undated)

Current guardianship laws allow an increasing number of less restrictive approaches than full guardianship. These laws recognize that alternatives to guardianship should be considered.

The following options were identified in a recent overview of alternatives to guardianship available in Michigan. This is only a partial list of alternatives. Options that are available will vary from jurisdiction to jurisdiction. (Hyman, undated)

<b>Supports and Services</b>	<ul style="list-style-type: none"> <li>• Advisors, Advocates</li> <li>• Authorizations for Advocacy</li> <li>• Person-Centered Planning</li> </ul>
<b>Medical</b>	<ul style="list-style-type: none"> <li>• Patient Advocate Designation (Medical &amp; Mental Health Power of Attorney)</li> <li>• Living Will</li> <li>• Social Welfare Act</li> </ul>
<b>Financial</b>	<ul style="list-style-type: none"> <li>• Durable Power of Attorney</li> <li>• Representative Payee</li> <li>• Personal Money Manager</li> <li>• Electronic Bill Paying</li> <li>• Contracts</li> <li>• Protective Orders</li> <li>• Trusts</li> </ul>

Knowing the alternatives that exist in a geographic area is an important challenge. Even more challenging is to know these options are respected by and known to individuals with developmental disabilities and their families and friends. As Kathy Harris notes, many families are encouraged to name guardians by people who do not know other alternatives exist.

*Providers are often not familiar with alternatives, and thus do not promote the use of support circles, family consent policies, powers of attorneys, trusts, and other alternative surrogate decision-making devices. Support circles which function through a person-centered process are an important key to avoiding guardianship. We all have friends, family and others who we call upon when we need help or advice when making life decisions. When we need to make decisions about health care, finances, or where to live, we ask knowledgeable people who make up our “support circle” to help us make these decisions. These people we call upon for help do not file to become our guardians, even though we may be incapable of making good decisions without their help. (Harris, 2005)*

The courts now recognize the power of a personal support system. For example, in Re: Patricia Anne Peery, PA Middle, March 25, 1999)

*In Pennsylvania, not only does the Guardianship Reform Act require the court to prefer limited guardianship, but it also requires the court to “make specific findings of fact” as to the “need for guardianship services, if any, in light of such factors as the availability of family, friends and other supports to assist the individual in making decisions...” (20 PA. Cons. Stat. Ann. §5510, et seq. 2006). This means that even if the petitioner proves that the potential ward is incapacitated for purposes of guardianship, if the potential ward is able to show that she has sufficient supports to render guardianship unnecessary, then those supports, being less restrictive than guardianship, shall be preferred.*

*This meaning played out in Re: Peery where a sixty year-old woman with cognitive impairments, who required supports to maintain her “health, welfare, safety, and medical needs,” was deemed to have sufficient supports in the form of family and friends to render guardianship unnecessary. (Pope, 2007)*

## **Finding Supports**

In an increasing number of situations, finding ways to *support* an individual’s decision-making is preferred to turning control over to another. In 1992 the Coalition on Alternatives to Guardianship in Canada released the following “Statement of Principles”<sup>1</sup>

### **Statement of Principles**

Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express those choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of her/his rights to be accommodated and supported in choosing and making decisions and which appoints a substitute decision-maker based on tests of competence, makes that person vulnerable and deprives him/her not only of his/her rights to self-determination but also of other rights which should be inalienable.

#### **PRINCIPLES**

1. Each individual can choose and make decisions about his/her life.
2. Each individual has the right to make decisions (self-determination).
3. Individuals may want help from other persons of their choosing with whom they have trusting relationships, including family members or friends, to make decisions or have them interpreted, and to communicate them to others. This is called supported decision-making.
4. Individuals who have an intellectual disability may communicate choices, wishes, likes and dislikes in non-traditional ways, which can include actions rather than language. Friends, family members, or others who are trusted by the individual, can help to interpret those decisions.
5. This natural interdependence of people must be recognized and supported. Decisions that are made within such trusted, supportive relationships must be given status and validation.
6. All adults have the right to make decisions with support or to name a substitute (for example, by power of attorney) to make decisions for them.
7. Laws and/or policies that do not recognize supported decision-making or that protect other interests at the expense of the individual’s right to self-determination discriminate against persons who have an intellectual disability and make them more vulnerable.

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<sup>1</sup> This statement was developed in 1992 and is an adaptation of the original statement. The Coalition is made up of People First of Ontario, People First of Canada, Ontario Association for Community Living, Canadian Association for Community Living and Youth Involvement Ontario.

8. Individuals should never be assessed to determine competency; decisions should be reviewable if there is concern that the will of the individual is not being respected or that the individual is being exploited.
9. Any legal system or proceeding which sets up a test of competency to be used to appoint a substitute decision-maker puts the individual at risk of also losing other rights.
10. A decision that could not have been made by the individual without support (for example, consent for non-therapeutic sterilization, experimentation or other non-therapeutic procedures which could offend human dignity) should not be made within supported decision-making relationships.

## Involuntary Servitude and Peonage

The Thirteenth Amendment to the Constitution of the United States prohibits slavery and involuntary servitude within the United States or any place subject to their jurisdiction. The only exception is involuntary servitude as punishment for a crime.

Even though the Amendment was passed in 1865, it did not protect people with developmental disabilities from “involuntary servitude,” or “peonage” as it is sometimes called. “Involuntary servitude” or peonage means that a person is being made to work against his or her will, with little control over his or her working conditions. The work might be paid or unpaid. The basic idea is that a person is being forced to work to pay off a debt, avoid punishment or because he or she has no choice.

In the 1960s, the public learned that thousands of people with developmental disabilities were being forced to work against their will for little or no pay in state institutions. For more than a century, residents of institutions worked as housekeeping, laundry, maintenance and farm laborers to keep the institutions running efficiently. Ironically, this provided some residents with the training they needed to leave the institutions and work in the community, but few were allowed to do so.

The fact was that state-operated facilities could not survive without institutional peonage.

### **Institutional Peonage**

In the 1960s, residential facilities were desperately underfinanced. Many staff salaries were at poverty level. One study estimated that 30% of staff positions in institutions were vacant. The cost of replacing unpaid or minimally paid resident labor with paid workers would be overwhelming.

*The use of residents to perform work necessary to keep the institution running constitutes another problem which arises from under-financing and which is sometimes referred to as "institutional peonage." Although it is highly desirable that residents be productively employed, continued and inappropriate retention of residents in work situations has often been the only way the daily work could get done. Some important services in the ward, infirmary, maintenance, laundry, and kitchen areas would collapse if it were not for continued reliance on resident help. (Krugel, 1969)*

A Minnesota study conducted in 1964 showed that there were 6,350 residents in the state's institutions at the time. Half of these individuals were assigned jobs in the institutions. At the time, Minnesota law said that a person with a developmental disability could not earn more than \$1 a month. The report estimated that replacing institutionalized resident workers with civil service employees would require more than 900 additional positions at a cost of \$2.4 million. This example of “involuntary servitude”

eventually changed, in part because of the Arc Minnesota, Dr. David Vail, and Governor Karl Rolvaag all of whom decried the “institutional peonage” revealed in the study. (Minnesota Governor’s Council on Developmental Disabilities, *With an Eye to the Past*; Granquist, 2008)

A similar study by Pennsylvania's Department of Public Health found that in 1969 approximately 11,900 residents of the state’s institutions were working. If the state could no longer rely on its working residents to keep the institutions running, more than 3,300 new employees would have to be hired. Doing so would increase paid staff by 28% and cost more than \$11 million. (Mental Health Law Project, 1973)

The situation eventually came to the attention of the public, legislators and the courts in July 1964 when F. Lewis Bartlett, a psychiatrist, wrote an article in the July 1964 issue of *The Atlantic Monthly*. The article, called "Institutional Peonage: Our Exploitation of Mental Patients," described how some patients were denied training and therapy so that they could perform the work needed to keep the institution running.

*In other words, state hospitals need "good patients" who are useful, valuable, and expediently indispensable. But these relatively less ill patients, instead of being helped to overcome their illness, as is normally expected on behalf of the patients in any other medical care facility, are doomed by the institutional needs of the state mental hospital to the pathological dependency characteristic of "good patients."*

As a result, individuals who might have been released or “paroled” to the community were held back.

In 1973, the Mental Health Law Project described some of the types of force used to exploit patient labor:

*A resident's refusal to work often results in staff antagonism, restrictions on mobility and other privileges. It is not uncommon for the resident to be labeled uncooperative with negative effects on his efforts to be released when he fails to participate in the "voluntary" work program. (Mental Health Law Project, 1973)*

### **Changes in Law**

In 1966, Congress amended the Fair Labor Standards Act (FLSA) to extend minimum wage and overtime provisions to include all nonprofessional employees of public and private non-Federal hospitals and public residential institutions. The amendments also required the U.S. Department of Labor to enforce these laws to protect these employees.

The Department of Labor, however, did not “undertake reasonable enforcement activities” for resident workers. At first, the Department decided that Congress did not intend the law to apply to resident-workers since there were no specific references to them in the legislative history. Later, the department decided the Amendments did

apply, but it would not enforce them because of a number of “unresolved problems.” (Treatment Advocacy Center, 2009)

## Court Challenges

In 1971, institutional peonage became one of the issues raised in lawsuits challenging the institutional system in the United States.

The challenges focused on the rights of resident-workers in institutional facilities and the lack of protections given workers under the FLSA in violation of the 13<sup>th</sup> Amendment. Because institutions needed the unpaid work of residents to survive, eliminating the practice would seriously threaten the system’s survival.

*Wyatt v. Stickney* was a landmark case that had far reaching implications for institutions across the nation. The suit focused on institutions in Alabama and was filed in October 1970. It took 33 years to work its way through the courts before litigation ended in 2003. *Wyatt v. Stickney* set minimum standards of care, established resident rights, fostered the downsizing of state institutions and eventually led to the development of new community services. In 2003, Federal Judge Myron Thompson wrote that:

*The enormity of what this case has accomplished cannot be overstated. The principles of humane treatment of people with mental illness and mental retardation embodied in this litigation have become part of the fabric of law in this country and, indeed, international law.* (Legacy of Wyatt, undated, p. 3, 13)

An April 12, 1972 order issued by Judge Frank Johnson, identified 35 standards for adequate treatment. He also outlawed unpaid work on the principle that work was "dehumanizing" unless it was voluntary, therapeutic and compensated at FLSA wage rates. Judge Johnson did permit residents to make their own beds. He also required all three of Alabama's mental institutions to pay residents who volunteered to work to maintain the institution. (Mental Health Law Project, 1973; Legacy of Wyatt, undated)

A number of other suits focused specifically on the 1966 Amendments to the FLSA. Those cases required that state officials pay resident workers minimum wage and pay back wages owed dating from the time the FLSA Amendments were enacted. It also required that the Department of Labor enforce the Amendments for all residents working in state institutions. The National Association for Mental Health and the American Association on Mental Deficiency (now AAIDD) were actively involved in these cases.

In 1972, Paul Friedman, a founder of the Mental Health Law Project (now the Bazelon Center), and two other attorneys filed a lawsuit regarding the application of FLSA amendments to resident workers. In *Souder v. Brennan*, the U.S. District Court for the District of Columbia held that the Amendments **did** apply and determined that work done resulted in an economic benefit for the institution. “Consequential economic benefit generally means that the work would have to be done by employees of the

employer who do not have disabilities, if the resident worker with a disability did not do it.”

The court was clear in stating that the institution’s position that the work programs had therapeutic value was irrelevant. This objection “would be to make therapy the sole justification for thousands of positions as dishwashers, kitchen helpers, messengers and the like.” The court described resident workers based on what they do – “dishwashers” and “messengers” -- rather than by their relationship to the institution. Like ordinary employees, they productively wash dishes and carry messages. (Zatz, 2008, p. 898)

The *Souder v. Brennan* victory was short-lived. In 1976, the U.S. Supreme Court held in *National League of Cities v. Usery* that extending minimum wage protections to employees of states was unconstitutional. The Department of Labor, therefore, returned to its original position of not enforcing the FLSA amendments about resident labor in state institutions. (Friedman, 1977) Despite the U.S. Supreme Court ruling, many states eliminated unpaid or low-paid work programs. For instance, Pennsylvania passed the "Institutional Peonage Abolishment Act" in 1973.

*Souder* was not the only suit filed during this period. Other cases argued that institutional peonage violated the Thirteenth Amendment. Unable to pay the wage rates demanded, state officials found it easier to eliminate resident labor than to take on the legal risks of continuing or resuming the practice. (Treatment Advocacy Center, 2009)

The impact of these legal actions has been profound. Eliminating resident labor seriously undercut the ability of states to run their institutions economically. Some institutions developed sheltered workshop programs to replace non-paying patient jobs (Schwartz, 1976). Many simply eliminated work programs all together. As a result, residents in these institutions were offered no work opportunities, therapeutic or otherwise.

## Sterilization

In 1791, Congress adopted the Eighth Amendment to the U.S. Constitution. As part of the Bill of Rights, the federal government was prohibited from imposing excessive bail or excessive fines, and from inflicting cruel and unusual punishment.

On July 9, 1868, Congress adopted the Fourteenth Amendment to the U. S. Constitution. It recognized the citizenship of all persons born or naturalized in the United States. It further stated that:

*No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.*

In spite of these protections, more than 60,000 men, women and children in the United States were sterilized without their consent. More women than men were the victims of involuntary sterilization; and twice as many of those sterilized were black women as white women. (Lombardo, 2003).

### **Sterilization Laws**

Laws requiring sterilizations have been passed throughout the 20<sup>th</sup> century. The first sterilization laws were passed in Indiana in 1907; the last was passed in Georgia in 1970. While no new laws were *passed* after 1970, some states continued to *modify* their sterilization laws well into the decade. But by the end of the 1970s, most states had repealed their sterilization laws. In the early years of the 21<sup>st</sup> Century, Virginia, South Carolina, Georgia, and Oregon apologized for passing these laws in the first place.

While most forced sterilizations took place in institutions, some did not. Individuals with developmental disabilities who lived in the community with their families also were sterilized without their consent. All that was needed was agreement from the individual's parents and doctors.

A landmark case in New Jersey in the 1970s supported the rights of parents and other guardians to approve the sterilizations of people who were considered incapable of making their own decisions. The court positioned its ruling in the context of the Fourteenth Amendment, which protects every citizen's right to equal protection under the law. The ruling stated that since institutionalized adults were being sterilized with the approval of substitute decision makers, therefore it was unequal protection to deny the same "right" to people living in the community.

### **The Eugenics Movement**

The initial motivation for sterilization laws came from the Eugenics Movement that was popular during the early decades of the 1900s.

The first state law requiring sterilization was passed in Indiana in 1907. It allowed the “prevention of the procreation of ‘confirmed criminals, idiots, imbeciles, and rapists.’” On May 11, 1921, the Supreme Court of Indiana declared this statute unconstitutional. However, a second law passed on March 27, 1927 was ruled constitutional. (Wehmeyer, 2003, p. 57)

California passed mandatory sterilization laws in 1909 and 1913. The California legislation provided for sterilization of “the insane and feeble-minded inmates of state hospitals and of convicts and idiots in state institutions.” A later amendment authorized the Board of Trustees of the Pacific Colony for the Feeble-Minded and Epileptic to “sterilize committed feeble-minded, chronic manic and demented people, with or without their consent, before discharging them.”

In 1914, Harry Hamilton Laughlin of the Eugenics Records Office<sup>2</sup> published a “Model Eugenical Sterilization Law” (<http://www.people.fas.harvard.edu/~wellerst/laughlin/>). This proposed law authorized sterilization of the “socially inadequate.” Laughlin’s goal was to ensure the law’s constitutionality and consistency with eugenics principles. Laughlin’s Model Law was adopted by a number of states. By 1924, 22 states had passed similar legislation. In 1927, the U. S. Supreme Court ruled in *Buck v. Bell* that the Virginia version of Laughlin’s Model Law was constitutional.

Ezra Gosney and Paul Popenoe were leaders of the Human Betterment Foundation. The group was established solely to promote the use of eugenic sterilization for purposes of race and human betterment. They reported on the “success” of the California program. The report bolstered the German Eugenics Movement and Laughlin’s Model Law formed the basis of Germany’s 1933 sterilization law. In 1936, Laughlin received an honorary degree by the University of Heidelberg for his work behalf of the "science of racial cleansing."

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<sup>2</sup> The Eugenics Record Office (ERO) at Cold Spring Harbor Laboratory in Cold Spring Harbor, New York was a center for eugenics and human heredity research in the first half of the 20<sup>th</sup> century. Founded in 1910, the ERO was financed primarily by Mary Harriman (widow of railroad baron E. H. Harriman) and then the Carnegie Institution until 1939. It closed in 1944. Its records were transferred to the Charles Fremont Dight Institute for the Promotion of Human Genetics at the University of Minnesota.

**EFFECTS OF EUGENIC STERILIZATION  
AS PRACTICED IN CALIFORNIA**

1. One effect only—it prevents parenthood.
2. It in no way or degree unsexes the patient.
3. It in no way impairs the health of the patient.
4. It is a protection, not a punishment; therefore carries no stigma or humiliation.
5. Patients and their families are among the best friends of sterilization. They know by experience what its protection means to them.
6. It is approved by the medical staffs, social workers, probation and parole officers, who have come in contact with the patients before and after the operation.
7. It permits many patients to return to their homes who would otherwise be confined in institutions for years. It thus prevents the break-up of families.
8. It prevents the birth of children who would probably have a bad heredity, who could not be cared for properly, by their parents, and who would be likely to become state charges.
9. It releases sterilized patients from confinement in state institutions, and leaves room for other waiting patients; thus increasing the efficient care for more defectives without increasing the cost to the tax-payer.
10. It has not increased sex offenses; on the contrary, sterilized patients in California, for various reasons, chiefly educational discipline, show a great improvement over their former record of sex delinquency.
11. It enables many handicapped persons to marry and to have a life normal in most respects, whose marriage without sterilization would be unwise if not disastrous.
12. Conservatively and sympathetically administered, it is a practical, humane, and necessary step to prevent race deterioration.

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NOTE: California has had in effect since 1909, a sterilization law applying only to inmates of state institutions. Up to January 1, 1937, the state had sterilized under this law, 11,484 patients (5933 men, and 5551 women). The Human Betterment Foundation has, for the past eleven years, been making an intensive study of the results to the patient, the family, and the community. For further details write—

THE HUMAN BETTERMENT FOUNDATION  
321 PACIFIC SOUTHWEST BUILDING  
PASADENA, CALIFORNIA

*“Effects of Eugenic Sterilization as Practiced in California” leaflet disseminated by the Human Betterment Foundation, Pasadena, Calif, from the late 1920s to the early 1940s.*

### ***Buck v. Bell* – “Three Generations is Enough”**

The superintendent of the State Colony for Epileptics and Feeble-Minded in Virginia had been sterilizing people in the early 1900s. Because the legislation establishing the Colony did not clearly allow sterilization, a 1918 court ruling warned the superintendent that he was personally liable. He discontinued the operations but then pushed for legislation that would allow sterilization of residents.

In 1924, Virginia passed legislation that allowed residents who otherwise might require permanent institutionalization, to be released on condition that they were first sterilized. The law outlined the procedures to be followed, including approval from the institution's board, appointment of a guardian, a hearing, and appeals to the courts.

Carrie Beck, a young woman who had been raped and became pregnant, came to live in the Colony where her mother also had been institutionalized. After Carrie's baby was born, the superintendent recommended her sterilization and went to court to make sure it did not make him personally liable.

The case eventually reached the U.S. Supreme Court. Justice Oliver Wendell Holmes wrote the opinion for the court in *Buck v. Bell*. He rejected the argument for equal protection under the law. Accepting the arguments presented by supporters of eugenics, Justice Holmes wrote that procedural guarantees had been “scrupulously” followed. Holmes contended that if the nation could call upon its “best citizens” for their lives during war it could demand a “lesser” sacrifice of those who “sap the strength” of society. Preventing people with disabilities (he called them “degenerates”) from having children would benefit society. He said, “three generations of imbeciles are enough” in reference to Carrie, her mother, and her daughter.

*Buck v. Bell* became the standard and opened the floodgates for forced sterilization across the nation. *Buck v. Bell* has never been overturned.

### ***Skinner v. Oklahoma***

In 1942, Oklahoma's Habitual Criminal Sterilization Act of 1935 was challenged on the grounds that it constituted “cruel and unusual punishment” and did not provide “equal protection.” The Act was overturned on “equal protection” grounds since some crimes such as embezzlement, which were felonies in Oklahoma, were excluded from the jurisdiction of the Habitual Criminal Sterilization Act. Neither the Act nor the 1942 ruling had any impact on the forced sterilization of people with disabilities.

In his opinion for *Skinner v. Oklahoma*, Justice William O. Douglas noted that the fundamental right of procreation required close scrutiny by the courts.

*We are faced with legislation which involves one of the basic rights of man. Marriage and procreation are fundamental to the very existence of the race. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. In evil or reckless hands it can cause races of types which are inimical to*

*the dominant group to wither and disappear. There is no redemption for the individual whom the law touches. Any experiment the state conducts is to his irreparable injury. He is forever deprived of a basic liberty.*

## **The End of the Inheritability Argument**

Although *Skinner v. Oklahoma* did not apply to people with disabilities, it raised the anxiety level surrounding the issue of forced sterilization. Even more importantly, the horrors committed by Nazi Germany in the name of eugenics undercut the philosophical basis for much of the legislation.

Most laws requiring sterilization were linked to procreation, especially in situations where institutionalized citizens were to be released to the community, and some demonstration that the individual had an inheritable trait linked to mental disability.

Thinking about sterilization began to change in the 1960s. The argument that developmental disabilities were inherited was replaced by another eugenics argument – “social cost analysis.” Supporters argued that “defective people” made bad parents and would create children who would be a burden on society. In effect, this argument loosened the criteria used to decide who should be sterilized. In the 1950s, sterilizations began to decrease in response to a required “demonstration of inheritability”.

*The final substantial year for California’s sterilization program was 1951, with 255 operations performed. The following year, the number dropped considerably to 51, undoubtedly because of a revision to the statute inserting administrative requirements for physicians and safeguards for patients. This amendment, and another 1953 bill, deleted any references to syphilis (long since understood as microbial, not genetic, in etiology) and sexual perversion; instituted more demanding processes of notice, hearing, and appeal; and removed the terms “idiots” and “fools” from the law. By turning what had been a mere formality into a more taxing ordeal, these modifications deterred many physicians from requesting sterilization orders. Nevertheless, surgeries continued sporadically at every state institution into the 1970s. (Stern, 2005, p. 1132)*

The social cost argument fueled acceptance of sterilization in the South where it became a tool for repressing African American and poor women. California employed a similar strategy to repress Mexican-American women. (Stern, 2005, p. 1132).

*After World War II, however, while the numbers of sterilizations performed elsewhere in the country were slowly decreasing, the numbers rose substantially in Virginia, Georgia, North Carolina and, to a lesser extent, South Carolina. During the late 1950s, sterilizations in Virginia, Georgia, and North Carolina together comprised about three-fourths of the operations performed under eugenic statutes in the United States. (Castles, 2002, p. 8)*

In the 1960s, there was increasing pressure to change the laws in Nebraska by replacing the social-cost analysis argument with the inheritability assumption.

The old law in Nebraska identified five prerequisites to sterilization:

- That the person was feebleminded.
- That the person was able to beget offspring.
- That the offspring would inherit a tendency to feeble-mindedness.
- That procreation would be harmful to society.
- That the person could not be paroled or discharged unless sterilized.

In 1966, the Nebraska law was broadened to include:

- That the person is mentally deficient.
- That the person is apparently able to beget offspring.
- In the opinion of the Board of Examiners, the person should be sterilized as a condition prerequisite to parole.

The Nebraska Supreme Court upheld the law. Part of the ruling argued that the sterilization was not forced. The justices stated that “the order does not require her sterilization. It does provide, in accordance with the statute, that she shall not be released until she is sterilized.” The justices emphasized, “*The choice is hers.*” This reasoning caused such an uproar that Nebraska repealed the law. (Bruinius, 2006)

In 1980, a case in Virginia had a similar outcome. Even though the Virginia law had been repealed in 1974, the ACLU filed a case, known as *Poe v. Lynchburg Training School and Hospital*. The ACLU argued that the state had violated the constitutional rights of anyone who had been sterilized without their consent. The court disagreed and ruled that the sterilizations did not violate the individual’s constitutional rights, remaining consistent with *Buck v. Bell*.

Despite these court rulings, the tide had begun to turn. Sterilization laws across the United States began to be repealed.

In 2001, the state of Virginia formally apologized for its role in eugenics. A highway marker outside Charlottesville was dedicated to *Buck v. Bell*. South Carolina, Georgia, and Oregon also apologized for passing mandatory sterilization laws. The state of Georgia’s apology also recognized that forced sterilization and bans on interracial marriage often went together in an effort to ensure “racial integrity.”

### **Voluntary Sterilization**

The end of forced sterilizations as a convenience for institutions and as a condition of release is only part of the story.

“Voluntary” sterilizations also were routinely performed in the community. For years, parents and doctors agreed to sterilize people with developmental disabilities, usually to make it easier for parents to care for their daughters’ personal needs and to avoid unwanted pregnancies and parenthood. Sterilization and bans on marriage were seen as justifiable.

In 1979, a New Jersey court (*In the Matter of Grady*) ruled that it was constitutional for parents to have their daughter sterilized. Lee Ann Grady’s family thought sterilization would enhance and protect her independence in the community. The court ruled that because people living in institutions were allowed to choose whether or not to be sterilized, this same right should be extended to people in the community. For people who were judged unable to decide for themselves, the New Jersey court agreed that the parents should be able to make the decision on behalf of their children.

The court outlined the “Grady Rules” to determine when a sterilization decision could be made with “clear and convincing” proof of nine elements:

1. The possibility of pregnancy.
2. The possibility of physical or psychological trauma
3. The possibility of sexual activity.
4. The inability of the incompetent person to understand the likely permanence of the procedure
5. The advisability of less drastic measures.
6. The advisability of postponement.
7. The ability of the incompetent person to care for a child.
8. The possibility that future scientific developments will offer preferable alternatives.
9. A demonstration of good faith on the part of sterilization proponents.

Other states decided that the courts had to make the decision. Oregon’s law on informed consent for sterilization, for instance, specifically states that a natural parent or the legal guardian or conservator of a minor child or protected person may *not* give substitute consent for sterilization. A court must decide.

### **Recognizing the “Best Interests” of the Individual**

Oregon, and other states, made it perfectly clear that a final decision about sterilization must be in the “best interest of the individual,” not simply in the interests of the individual’s parents or guardians.

*“Best interest” means that:*

*(a) The individual is physically capable of procreating;*

*(b) The individual is likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy;*

*(c) All less drastic alternative contraceptive methods, including supervision, education and training, have proved unworkable or inapplicable, or are medically contraindicated;*

*(d) The proposed method of sterilization conforms with standard medical practice, is the least intrusive method available and appropriate, and can be carried out without unreasonable risk to the life and health of the individual; and*

*(e) The nature and extent of the individual's disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders the individual permanently incapable of caring for and raising a child, even with reasonable assistance. (Oregon Statutes - Chapter 436 - Sterilization - Section 436.225 - Obtaining informed consent. 2007)*

In 1986, the Supreme Court of Canada ruled in the case of *Eve* that neither parents nor the court had the right to authorize non-therapeutic treatments such as sterilization for a person with developmental disabilities. Only the individual can decide and if the individual is not capable of deciding, sterilization is not an option (*Re Eve* (1986), 31 D.L.R. (4th) 1). Some continue to argue that the Supreme Court of Canada went too far in denying the option of sterilization to people with developmental disabilities who were considered unable to consent.

*Laws forbidding sterilization of the mentally incompetent may be nearly as dehumanizing as the forced sterilization laws they replaced. Weighing the complex medical and ethical issues involved, judging whether guardians' fears are reasonable, and determining patients' best interests require careful, individual case reviews with strict procedural safeguards. Families are often the best substitute voice for incompetent adults. Not allowing a caring family to express preferences regarding such life-altering experiences as pregnancy and childbirth may paradoxically silence the patient's voice. (Pham and Lerner, (2001)*

Gerald Robertson supports the opposing view, saying that this was a case of "affirmative discrimination."

*We must accept that these [forced sterilization] abuses were so significant, so horrific, and so recent, that they are inextricably linked to the very word "sterilization." The abuses may have been in the past, but their legacy lives on. Sterilization has become a symbol of a particular attitude towards mentally disabled people: that they are less deserving, less productive — less human — than the rest of society. In my view, the decision in *Eve* is a courageous attempt to reverse that attitude.*

*Hence the term "affirmative discrimination." Even if the decision in *Eve* does discriminate against some mentally disabled individuals by denying them access to sterilization where this would be in their best interests, this result is justifiable in order to ameliorate the condition of mentally disabled people as a whole. In the*

*interests of the group as a whole, it is preferable that the law be seen to put an end to non-therapeutic sterilization of the mentally disabled.* (Robertson, 1994, p 455-456)

In the United States, however, laws vary from state to state. Most states require the courts, not a guardian, to make the decision. Some courts have noted that allowing the parents or guardians to substitute their decision and consent is not adequate because parental consent to sterilization has a history of abuse.

As a result, it cannot be presumed that the parents have the same interests as their child. This is significantly different from “permitted delegated consent” related to abortion where parents and guardians are frequently given the responsibility to decide on behalf of the child. Courts may be less inclined to allow for the possibility of self-interested third parties when the result of consent permanently affects the individual’s future choices. (Pollack, 2005)

Medicaid’s position is clear. Medicaid funds cannot be used to pay for the sterilization of any individual who is less than 21 years old or who has been declared mentally incompetent by a federal, state, or local court, unless the individual has been declared able to consent to sterilization. If a judicial court orders sterilization for a recipient who is a ward of the county, and is determined to be mentally incompetent, Medicaid is not responsible for reimbursing the costs of the sterilization.

## Baby Does and the Right to Lifesaving Treatment

While the 1970s saw a decline in efforts to prevent people with disabilities from having children, the 1980s saw an increase in efforts to deny them the right to live.

In the 1970s, there were a number of cases where children born with disabilities were denied lifesaving surgeries. In some cases, doctors left the decision totally up to the parents who refused the surgery because they were worried about the financial and emotional burden of raising the child. Many of these cases involved children with Down Syndrome (or Trisomy 21) with esophageal and/or gastrointestinal blockages. If left untreated, this blockage would cause the child to starve to death. In other cases, doctors and families jointly decided not to treat the infant. (Mercurio, 2009)

### The Courts Weigh In

Several court decisions set the stage for the landmark cases related to the right to lifesaving treatment that took place in the 1980s.

In *Schloendorff v. Society of New York Hospital*, the New York Court of Appeal ruled in 1914 that the right to self-determination was important. In the opinion of the court, Justice Benjamin Cardozo wrote:

*Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.*

Unfortunately, this ruling applied specifically to adults, not to children with disabilities facing life-threatening situations. In this situation, parents and guardians are often believed to have the right to give consent for a child's medical treatment.

*Maine Medical Center v. Houle* was the first legal challenge to parental decisions related to medical treatment for newborns with anomalies. In 1974, the Supreme Court of the state of Maine ruled that parents did not have the right to withhold lifesaving treatment and that doing so constituted neglect. The ruling included two other important points. First, a guardian cannot withhold consent for lifesaving medical measures. Second, the ruling affirmed that children with physical or mental impairments have the same right to life as other children. (Kindred, 1976, p. 78)

However, this ruling was limited to those situations in which someone was willing to advocate for the child's right to live.

During the 1980s, a number of advocates emerged. One particularly visible and vocal advocate was C. Everett Koop, the Surgeon General of the United States from 1982 to

1989. Koop and others intervened in two critical cases that are often called the “Baby Doe” cases. These advocates urged Congress to develop and adopt the Baby Doe Amendment to the Child Abuse Law. The Amendment was passed in 1984.

### **Indiana Baby Doe**

In 1982, a baby boy was born in Indiana with Down Syndrome and a tracheoesophageal fistula. The upper part of the newborn’s esophagus was not connected to the lower part. Surgery was both possible and likely to succeed. Without it, the baby would die.

The mother’s obstetrician had a particularly narrow view of Down Syndrome. He told the parents that their baby would not have any quality of life, even if the surgery were successful. Based on this advice, the baby’s parents “agreed not to authorize surgery, food, or water for the child.” Nurses at the hospital initiated legal proceedings to override the parents’ decision. However, the Indiana Supreme Court ruled that the parents had the right to follow the obstetrician’s recommendation. “Baby Doe” died when he was six days old, before the United States Supreme Court could hear an appeal.

The Reagan Administration argued that this was a case of discrimination based on disability. If the courts agreed, hospitals that refused to treat newborns with disabilities in the future could be denied federal funds under Section 504 of the Rehabilitation Act. A refusal to perform surgery to reconnect the esophagus of an infant with Down Syndrome constitutes disability-based discrimination because an infant without Down Syndrome undoubtedly would be treated and corrective surgery performed. However, the courts did not agree with the administration’s position. (Bagenstos, 2006, p. 430)

### **New York Baby Jane Doe**

The second “Baby Doe” case began in 1983 when a girl with spina bifida was born at University Hospital in Stony Brook, New York. Her parents chose not to allow corrective surgical procedures that “were likely to prolong the infant’s life, but would not improve many of her disabling conditions, including her anticipated developmental disabilities.”

A private citizen initiated a lawsuit to challenge the parents’ decision to deny treatment. The appeals court agreed that the court had the right to review the decisions of parents about medical care. However, it also decided that state power should not be used to reverse the decision in this case. The court found that the decision not to do surgery was acceptable because the treatment was not designed to bring about the child’s death. The court determined that the decision was “in the best interest of the child.” Baby Jane Doe’s spinal abnormality closed on its own and her parents eventually permitted treatment to reduce her hydrocephalus. She was still alive in 1986. (Minow, 1990, p. 329)

The U.S. Department of Health and Human Services also took legal action in the Baby Jane Doe situation and based its arguments on discrimination due to disability. Again, it used discrimination based on disability as grounds. The Second Circuit Court of Appeals ruled that the baby's treatment was not discriminatory because the condition to be treated was directly related to the condition that made her disabled.

The Reagan Administration notified hospitals that Section 504 of the Rehabilitation Act governed the treatment of people with disabilities. The Department of Health and Human Services then issued regulations that required the hospitals to post public notice that said withholding medical treatment for newborns with disabilities violated Section 504 and suspected violations should be reported to a telephone hotline maintained by the Department. If a reported violation proved true, the health facility would no longer receive federal funds.

Many health care providers thought these rules were too intrusive and initiated a lawsuit that eventually reached the U.S. Supreme Court. In 1986 the Court ruled that Section 504 did not authorize governmental intervention when the decision to withhold treatment was made by a parent, rather than the health care provider receiving federal funds.

In *Bowen/Heckler v. American Hospital Association*, 476 U.S. 610 (1986), an amicus brief was filed that summarized the disability issues:

*First, they contended that the decision to withhold treatment from an infant with a disability is often based on an erroneous, if not prejudiced, understanding of the "quality of life" experienced by individuals with disabilities... Second, the disability rights groups urged that it was the physicians' biases, and not an unconstrained exercise of parental choice, that led to the withholding of treatment from newborns with disabilities. The briefs argued extensively that parents' decisions to withhold treatment from their disabled infants cannot be understood as free choices. (Kindred, 1976, p. 431-432)*

Nat Hentoff gave the issue national prominence in a 1986 article in *The Atlantic Monthly*. He described how he came to link abortion with the Baby Doe cases.

*For me, this transformation started with the reporting I did on the Babies Doe. While covering the story, I came across a number of physicians, medical writers, staff people in Congress and some members of the House and Senate who were convinced that making it possible for a spina bifida or a Down syndrome infant to die was the equivalent of what they called a "late abortion." And surely, they felt, there's nothing wrong with that.... The simple "fact" that the infant had been born, proponents suggest, should not get in the way of mercifully saving him or her from a life hardly worth living. At the same time, the parents are saved from the financial and emotional burden of caring for an imperfect child.*

While these cases moved through the courts, the Reagan Administration pushed for changes in federal child abuse legislation. President Ronald Reagan signed the Child Abuse Amendments of 1984 (P.L. 98-457) into law in October 1984. These

amendments required state child protection agencies to develop mechanisms to intervene on behalf of infants born with life-threatening conditions but who may not be receiving medical treatment and other care. Hot lines were set up so that suspected instances where medical care was being withheld could be reported anonymously. The Act also established priority adoptions for these infants with life threatening conditions.

The Child Abuse Amendments also established the National Information Clearinghouse (NIC) for infants with disabilities and life-threatening conditions. The NIC was reauthorized in 1988. In 1990, the clearinghouse reported on the extent to which state child protection agencies had developed the required mechanisms. The report noted:

- Some states have actively instituted policies, procedures and training to identify and respond to reports of medical neglect of infants with disabilities... Unfortunately, this appears to be the exception, not the rule. Many states have done nothing. Even though federal funds were available, some states did not apply [for them] and others used the supplemental funds to address more global CPS [Child Protection Services] concerns. The belief continues that the problem of medical neglect of infants with disabilities really does not exist, especially in the context of more overwhelming CPS concerns.
- Although the actual numbers of reported cases and the number of cases identified by the Clearinghouse were small, withholding appropriate medical treatment from infants born with disabilities solely on the basis of disability still occurs.
- A major factor in the decision to treat or not to treat appears to be the financial resources of the parents. In many cases, treatment is refused or stopped and families are told to take their child home because of financial concerns.
- An additional issue involves the enforcement, or lack of enforcement, of the Baby Doe Regulations outlined in PL 98-457 and reauthorized in PL 100-294. There is an apparent lack of knowledge of the issues and limited willingness on the part of CPS to investigate cases of potential neglect regarding infants with disabilities. There is little or no training in these issues for professionals who might be in a position to investigate cases (e.g., CPS, police officers and attorneys). It also appears that if the decision is made not to investigate, then the case is not reported. This may help explain the very low number of reported cases of withholding medical treatment from infants with disabilities. (NIC, 1990, p. 42-46)

## **The Rationale for Withholding Treatment**

In September 1989, the U.S. Commission on Civil Rights issued a report, *Medical Discrimination against Children with Disabilities*. The report identified the standards used to make decisions that complied with the Child Abuse Amendments. It also identified the standards being used in actual practice.

The Commission summarized the standard of care as follows:

*First, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication.*

*Second, all such disabled infants must be given medically indicated treatment.*

*Third, there are three exceptions to the requirement that all disabled infants must circumstances in which treatment is not considered "medically indicated." The exceptions are when in the treating physician's or physicians' reasonable medical judgment:*

- (A) The infant is chronically and irreversibly comatose;*
- (B) The provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or (iii) otherwise be futile in terms of the survival of the infant; or*
- (C) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. (U.S. Commission on Civil Rights, 1989, p. 7)*

Based on its inquiry, the Commission said that it had no doubt "that newborn children have been denied food, water, and medical treatment solely because they are, or are perceived to be, disabled." It suggested that economic considerations and quality of life assessments were major factors in decisions to withhold treatment.

The U.S. Commission on Civil Rights dismissed withholding treatment for economic reasons stating:

*Today, the real economic costs associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, persons considered most severely disabled. The assumption has been that the severity of the disability is the major determinant of lifetime cost and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency. This assumption is a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and nonwork environment that significantly limits that person's capability and entails far more expense than necessary... The Commission emphatically rejects the view that lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society. (U.S. Commission on Civil Rights, 1989, p. 4)*

On the issue of quality of life assessments, the Commission concluded:

*The arguments typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability are often grounded in*

*misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities... To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission rejects the view that an acceptable answer to discrimination and prejudice is to assure the "right to die" to those against whom the discrimination and prejudice exists.*

*The Commission received extensive testimony documenting the possibilities that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Research indicates that a negative parental attitude tends to change over time, with increased interaction with the child....*

*A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proven wrong. (U.S. Commission on Civil Rights, 1989, p. 3)*

Oklahoma Children's Memorial Hospital created a formula to determine the potential quality of life for a child born with spina bifida. This formula was used to determine the level of treatment the infant should receive. The Hospital applied its Quality of Life Assessment protocol between 1977 and 1982.

*Infants born with spina bifida were evaluated by a "myelomeningocele team" shortly after birth. In this evaluation, the team members wrote, they were "influenced" by a quality of life formula:  $QL = NE \times (H+S)$ . In this formula: QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.*

*Based on the assessment, the team recommended to the parents that the infant be given either vigorous or supportive care. Vigorous care involved, at a minimum, closing the spinal lesion. Supportive care, by contrast, consisted of a "regular follow-up...until death or until a decision to treat the child more aggressively is made." The team members acknowledged that "treatment for babies with identical [degrees of mental and physical disability] could be quite different, depending on the contribution from home and society."  
(U.S. Commission on Civil Rights, 1989, p. 20)*

The team recommended "vigorous treatment" for thirty-six infants. One of these infants later died of unrelated causes; the rest survived. The team recommended "supportive care" for an additional thirty-three infants. The parents of five infants in the latter group rejected the recommendations, and three of these infants survived. Several other infants survived without treatment for several months and were subsequently treated. The remaining twenty-four infants who received supportive care died. (*Johnson v. Thompson*, Tenth District Court of Appeals, 1992)

The hospital, now known as Children's Hospital of Oklahoma, changed its practice in 1984. Since then, all infants born with spina bifida have received vigorous treatment, with the exception of one infant. In that case, it was clear that treatment would have been "futile." This determination was consistent with exceptions identified in the Child Abuse Amendment.

In 1985, the American Civil Liberties Union and the National Legal Center for the Medically Dependent and Disabled filed a suit on behalf of Carlton Johnson, one of the children affected by the Hospital's denial of treatment. *Johnson v. Thompson* alleged that the hospital had violated the infants' rights under the U.S. Constitution and Section 504 of the Rehabilitation Act.

In 1992, the Tenth District Court of Appeals supported an earlier district court ruling that the rights were not denied. The Tenth District Court agreed with the decision in *Bowen* (476 U.S. at 640, 106 S.Ct. at 2118) that "nothing in the legislative history... even remotely suggests that Congress contemplated the possibility that 'Section 504 could or would be applied to treatment decisions involving defective newborn infants.' "

(see <http://www.mnddc.org/parallels2/one/sidebar/054a.htm> for Tom Nerney's reflections on this point in history)

### **Much has changed, much has stayed the same**

Much has changed in the quarter century since the Baby Doe cases of the 1980s came to the public's attention. Unfortunately, much also remains the same. Treatment continues to be withheld from newborns. Approximately 60% of deaths in pediatric intensive care units follow limitation or withdrawal of life-sustaining treatment. (Garros, et. al., 2003)

In the past 25 years, major developments in the field of prenatal diagnosis have improved medical care and outcomes for infants born with disabilities. In 1985, few parents knew if their children would be born with severe disabilities. Today, most severe disabilities are identified before the child is born, thanks to advances in prenatal screenings and diagnostic tests. This knowledge allows the parents to arrange to give birth in a major medical center with access to better treatment. In some cases, the parents may opt to terminate the pregnancy based on the results of the prenatal screening. Developments in assisted reproductive technologies have resulted in an increased number of multiple births and a corresponding increase in the number of children born prematurely or with a low birth weight. Low birth weight remains a major issue, and the age at which a newborn has a chance of survival is getting younger and younger. (Mercurio, 2009)

Another important change is the prevalence of Ethics Committees in medical facilities. Such committees were rare in 1985 but are common in hospitals today. Nevertheless, the medical and ethical communities are divided on how to respond to a parent's

preferences to resuscitate or not resuscitate babies in distress. The debate revolves around four issues:

- The extent to which medical professionals should act on their professional knowledge.
- The extent to which parent preferences should hold sway.
- The extent to which the financial and emotional “burden” placed on a family should be taken into account
- The most effective way to determine a response that is in the best interests of the child.

A number of studies have attempted to develop statistical models that predict the survival of low birth weight neonates. Currently, data on low birth weight children born in National Institute of Child Health and Human Development Neonatal Research Network centers is being pooled in hopes of predicting survival and disability so that medical personnel can provide families with a more specific prognosis. However, the pitfalls associated with the Oklahoma Quality of Life formula of the early 1980s are a reminder of the dangers that accompany oversimplification. The following cautions are part of the current considerations:

*Prediction of death is limited even with sophisticated statistical methods such as logistic regression and nonlinear modeling techniques such as neural networks. The difficulty of predicting death should be acknowledged in discussions with families and caregivers about decisions regarding initiation or continuation of care. (Ambalavanan, 2005)*

*Physicians underestimate survival and freedom from handicap in preterm infants. Underestimation of outcome is associated with restriction in the use of appropriate interventions. (Morse, et. al., 2000)*

As life-sustaining technology becomes increasingly available, parents of children with severe disabilities have begun to demand medical treatments that doctors believe will have no beneficial effect. The concept of “medical futility” encompasses treatments that may do no harm, but also are thought to do no good. While the American Medical Association does not recognize the concept of “medical futility,” it does insist that patient or parent demand does not mean that a physician has a duty to treat. No physician is obligated to administer treatment that he or she believes does not benefit the patient. (Jordan and LeBlanc, 2001)

The American Academy of Pediatrics, however, supports the “futility” concept.

*The American Academy of Pediatrics (AAP) has stated that it supports allowing the withholding and withdrawing of a medical intervention when the projected burdens of the intervention outweigh the benefits to the child. The AAP has also stated that treatment decisions regarding an infant should be based on the judgment that the infant will derive net benefit, concluding that medical treatment that is judged to be harmful, of no benefit, or “futile” is inappropriate and should*

*not be offered or provided. Although decisions about withholding or withdrawing treatments when death is at hand are difficult, a broad consensus has emerged that decisions to withhold or withdraw medical interventions are ethically and legally acceptable in many circumstances, and these decisions fall within the authority of parents or guardians in consultation with the child's physician.* (Diekema and Botkin, 2009)

The 1999 Texas Advance Directives Act, or Futile Care Law, allows a health care facility to discontinue life-sustaining treatment against the wishes of the patient or guardian. Treatment can be discontinued ten days after the patient or guardian gives written notice that continuation of life-sustaining treatment is considered medically inappropriate by the treating medical team. The decision must be reviewed and approved by an Ethics Committee before any action is taken. Since the Act was put into effect in 1999, treatment has been withheld from both infants and adults.

In 2002, President Bush signed the Born Alive Infants Protection Act (H.R. 2175). The Act says that every infant who is born alive – including an infant who survives an abortion procedure – is considered a person under federal law. According to Bush, the Act “establishes a principle in American law and American conscience: there is no right to destroy a child who has been born alive. A child who is born has intrinsic worth and must have the full protection of our laws.”

More than a decade into a new millennium, the controversy continues.

## Euthanasia

Two fundamental principles lie at the heart of the Baby Doe debate. They are the “right to life” and the concept of “quality of life.”

When it comes to adults, the “right to life” principle is based on the belief that all persons are fundamentally equal, regardless of their condition, and therefore have a right to the basic entitlements offered by our society. As former U.S. Surgeon General C. Everett Koop said in the context of the Baby Doe cases, “If we do not intrude into the life of a child such as this, whose civil rights may be abrogated? The next person may be you.” The “quality of life” principle allows medical personnel to prolong life if the person will be able to experience a quality of life worth living. This position may support a variety of actions that bring death, including treatment that only alleviates pain, the withdrawal of life-sustaining treatment, or active assistance in dying. (Minow, 1990, p. 314-315)

In the late 1980s and 1990s, these principles were often used in debates surrounding the right of adults to choose when to end their lives, and the right of others to determine when to end another’s life. Two events brought the issues of “right to die” and “right to life” into focus – the case of Nancy Cruzan and the Oregon Death with Dignity Act (1994), and related court decisions.

### **Nancy Cruzan – The Need for Clear and Convincing Evidence**

In 1983, Nancy Cruzan lost control of her car. When she was found, Cruzan was in cardiac and respiratory arrest. Although paramedics revived her, she had been without oxygen for a dozen or so minutes and was believed to have suffered permanent brain damage. She was able to breathe on her own but was being nourished with a gastronomy feeding tube with the consent of her then-husband. Medical experts testified that she was in a “permanent vegetative state” (PVS) and could live another 30 years.

After Cruzan had been declared a ward of the state of Missouri, her parents sought permission to withhold artificial nutrition and hydration so that their daughter would die. A Missouri trial court granted permission to do so, however, the state and Cruzan’s court-appointed guardian *ad litem* appealed that decision to the Missouri Supreme Court. Even though the guardian *ad litem* believed it was in Cruzan’s best interests to have the artificial feeding tube removed, he also felt it was his duty as her attorney to take the case to the state’s Supreme Court because it could be precedent setting.

The Missouri Supreme Court denied Cruzan’s parents the right to withhold nutrition and hydration. Cruzan’s father then appealed to the U.S. Supreme Court asking them to decide if the U.S. Constitution prohibited the state of Missouri from requiring clear and convincing evidence that an incompetent person desires life-sustaining treatment to be withdrawn. In a 5-4 decision, the U.S. Supreme Court held that “a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state.” It then said that “clear and convincing evidence” had not been

provided that Ms Cruzan would want her life ended. Previous observations that she had made a year before the accident "... did not deal in terms with withdrawal of medical treatment or of hydration and nutrition."

The story did not end with the U.S. Supreme Court decision, however. Cruzan's father brought evidence from three more of her friends to a Missouri Circuit Court. That court held that the new evidence constituted "clear and convincing" evidence that Cruzan would not want to continue existing in a persistent vegetative state and allowed artificial feeding to be discontinued. Within two hours of the ruling, Cruzan's doctor removed the tube. Cruzan's family maintained a 24-hour vigil with her until she died on December 26, 1990.

## **New standards**

Court decisions related to Nancy Cruzan's life and death set the precedent for many decisions related to ending the life of someone who is unable to state their wishes. In 1914, Judge Cardozo ruled that "adults of sound mind have a right to make decisions about their own bodies." Those decisions include the right to refuse medical treatment or insist that it be withdrawn. The U.S. Supreme Court stated clearly in Nancy Cruzan's case that the state has a constitutional responsibility to protect human life.

*[The state has an] interest in the protection and preservation of human life, and there can be no gainsaying this interest. As a general matter, the States -- indeed, all civilized nations -- demonstrate their commitment to life by treating homicide as a serious crime. Moreover, the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide. We do not think a State is required to remain neutral in the face of an informed and voluntary decision by a physically able adult to starve to death.*

At the same time, the U.S. Supreme Court argued that many of its decisions, beginning with Cardozo, established the right of individuals to make decisions about medical treatment. The issue hinges on balancing an individual's liberty against relevant state interests. Basically, the Court determined that the individual's liberty to make decisions about treatments must be clearly and convincingly stated to ensure that those interests take precedent over the state's interest to protect and preserve human life.

Nancy Cruzan's case focused on what happens when an adult is determined not to be "of sound mind." The U.S. Supreme Court ruling held that it was up to the states to determine what the rules should be. As a result, state statutes began to be developed across the nation.

The first level of rules addresses the rights of adults of "sound mind" to make their wishes known in a "clear and convincing" manner. Living wills, advance directives, powers of attorney for health care and health care proxies allow adults to make their wishes "clear and convincing."

The second level of rules identifies who can make decisions when the evidence is not “clear and convincing” or when the person whose life is considered incapable of making his or her wishes known.

As of October 2009, all but two states – New York and Missouri – had adopted laws or procedures governing health care and end-of-life decisions for individuals who are considered unable to make these decisions due to illness or injury. Forty states and the District of Columbia have laws specifying who has the authority to make decisions for a patient who does not have an advance directive. In many states, a spouse’s wishes are given highest priority, followed by the wishes of adult children, parents and siblings. Some states have different procedures. For instance:

- In Tennessee, the supervising healthcare provider selects the decision-maker after *giving consideration* to the patient's spouse, adult child, etc.
- In Indiana, *any* of those listed (spouse, parent, adult child, sibling, etc.) can decide for the incapacitated patient.
- West Virginia gives the patient's attending physician or an advanced nurse practitioner the right to select the decision-maker from the priority listing, based on who the physician or nurse believes would be the best decision-maker.
- In Connecticut, decision-making is left to the physician in consultation with the next of kin.
- In California, a patient can orally designate someone to make decisions when treatment begins. That designation is in effect only during the course of treatment or illness, or during the stay in the healthcare institution where the designation is made, or for 60 days, whichever period is shorter.
- Under Florida law, a court-appointed guardian has first priority. A spouse is second to a guardian on Florida's priority list. (Marker, 2006)

The New York State Senate passed the Family Health Care Decision Act (FHCDA), but the New York Assembly has yet to do so. This legislation has been in process for 17 years.

In many states, physicians or others can seek judicial approval for decisions on behalf of patients who have no family or others who can decide for them. Only two states, Oregon and North Carolina, allow decisions for these patients to be made without judicial review. In both states, physicians can decide when to provide and when to stop treatment, including life sustaining measures.

Under New York’s pending Family Health Care Decisions Act (FHCDA), when a patient is determined to be incapable of making health care decisions, the hospital must determine if:

- The patient has completed an advance directive or health care proxy.
- A court has appointed an Article 81 guardian.
- The patient has orally appointed a surrogate prior to losing capacity.

If none of these actions have occurred, the patient's close relatives, domestic partner or friends, can select a surrogate who has knowledge of the patient's values and beliefs and will make decisions from a "patient-centered perspective," based on the patient's wishes. If the patient's wishes are not known or cannot reasonably be discovered, the surrogate must act in accordance with the patient's best interests.

The FHODA also requires the hospital's Ethics Committee to become involved if there is a disagreement between a treating physician and a surrogate. Even after a surrogate has been appointed, any wishes that have been clearly expressed by the patient prior to losing decision-making capacity always take priority.

## **Death with Dignity Acts**

"Euthanasia" occurs another person takes an action that results in a person's death. "Assisted suicide" means another person provides the means by which a person can kill him or herself. Two states have laws permitting physicians to provide individuals with lethal doses of medications that the patient can use to end his or her life.

In 1997, Oregon enacted a "death with dignity" law, the first of its kind in the United States. The law became effective five months after the U.S. Supreme Court held that the U.S. Constitution did *not* guarantee the right to assisted suicide. That decision implied, however, that states have the right to decide for themselves whether to permit or prohibit physician-assisted suicide. The state of Washington passed similar legislation in 2008.

The Oregon Death with Dignity Act expands the right of patients to refuse treatment. It is not surprising that when the right to refuse treatment by competent persons was established, a number of legal challenges were filed. A ruling followed that stated if a competent person has the right to refuse treatment, then an "incompetent" person should have access to the same right. Thus, rules were established to allow decisions to be made on behalf of "incompetent" persons if the decisions were determined to be "in their best interests." Because the U.S. Supreme Court has held that states can recognize the right to assisted suicide, that right also can be extended to people who are considered "incompetent." The Washington and Oregon laws require a competence assessment.

The Oregon law states a patient must be:

- 1) 18 years of age or older.
- 2) A resident of Oregon.
- 3) Capable of making and communicating health care decisions for him/herself.
- 4) Diagnosed with a terminal illness that will lead to death within six months.

The attending physician is responsible for determining whether or not these criteria have been met. Unlike a similar law in the Netherlands, the Oregon law *does not* require the patient to be suffering intolerably.

The Oregon Death with Dignity Act (ODDA) is structured around three concepts:

- **Patient self-determination.** The ODDA confers a right to choose the manner and timing of one's death as a logical extension of a terminally ill patient's expansive rights to refuse treatment. The patient with the terminal illness settles the question of the means of death, not the state, medical professionals or religious institutions.
- **Professional immunity and integrity.** The ODDA provides physicians and other health care providers with immunity from prosecution. Advocates supported the freedom of physicians to practice medicine according to their own standards of best practice in caring for the terminally ill. It also involves a shifting view of professional integrity. Supporters of the ODDA argued that the integrity of the medical profession was not *entirely* subsumed by a commitment to healing but should, at the very least, be complemented by physician respect for patient choices.
- **Public accountability.** Advocates of the ODDA sought to provide a regulatory framework and measure of public transparency for the types of hastened-death procedures many were convinced already occurred in secret. (Campbell, 2008)

The ODDA has been the subject of extensive moral, religious, professional and political criticism and debate. The Bush Administration attempted to block ODDA by filing the *Gonzales v. Oregon* lawsuit. Then-Attorney General Alberto Gonzales argued that it was not medically legitimate for physicians to prescribe substances regulated under the federal Controlled Substances Act for the purpose of hastening the death of terminally ill patients. The Supreme Court disagreed.

Since passage of the Oregon Death with Dignity Act, “the question is no longer *whether* physician-assisted suicide should be permitted within medicine, but *how* to regulate and monitor the approved processes effectively. Instead of grappling with the fundamental moral questions, commentary about the act now often sticks to the far more mundane questions of oversight and administration.”

One question raised in ODDA legal challenges is the extent to which individuals will feel pressure to end their lives because of a family's unwillingness to bear the emotional and financial cost of care. This is the same issue that played out in decisions about withholding treatment from babies in distress. One analysis of the Oregon Public Health Department data concluded:

*...Becoming a “burden” to family and other caregivers emerged as an end-of-life concern for 39 percent of the 341 patients who have used the act in its first decade—a not insignificant number, but still much lower than the percentage of patients who expressed direct self-regarding concerns about loss of autonomy, diminished quality of life, loss of dignity, and loss of control of bodily functions.*

*Less than 3 percent expressed concerns about the financial implications of treatment.* (Campbell, 2008, p. 38)

These numbers were based on patient concerns reported by physicians.

## **The Terri Schiavo case**

In 1990, Terri Schiavo, a healthy, married woman collapsed in her Florida apartment. She stopped breathing and her heart stopped, resulting in extensive brain damage. Schiavo was diagnosed as being in a persistent vegetative state and spent the majority of the next fifteen years in hospitals, nursing homes, rehabilitation centers and hospice care. In 2005, a local Florida court ordered that her life support systems could be disconnected. Schiavo died of the effects of dehydration on March 31, 2005.

Schiavo's husband, Michael, was granted guardianship. In 1998, he applied to the court to have his wife's feeding tubes withdrawn. Her parents objected and the situation made its way to the courts. In summary, the Schiavo case resulted in:

- 14 appeals and numerous motions, petitions, and hearings in the Florida courts;
- Five lawsuits in federal district court;
- Florida legislation that was struck down by the Supreme Court of Florida;
- A subpoena by a Congressional committee to qualify Schiavo for witness protection;
- Federal legislation (the Palm Sunday Compromise);
- Four denials of *certiorari* from the Supreme Court of the United States.

Twenty-six national disability rights organizations presented positions supporting Terri Schiavo's right to continue to receive food and water. According to "Not Dead Yet," "the evidence that Ms. Schiavo would refuse tube feeding is so unclear and conflicted that it does not satisfy legal standards." A number of courts, on the other hand, ruled that Michael Schiavo, as her guardian, had the right to decide that question.

Harriet McBryde Johnson, co-founder of the Disability Rights Committee of the National Lawyers Guild, argued a number of points related to the right of others to decide about Ms. Schiavo's fate, and connections to Death with Dignity legislation, including:

- Ms. Schiavo is not terminally ill.
- Ms. Schiavo is not dependent on life support.
- This is not a case about a patient's right to refuse treatment... The question is who should make the decision for her, and whether substitute decision-maker should be authorized that would result in her death due to starvation and dehydration.
- There is a genuine dispute as to Ms. Schiavo's awareness and consciousness. But if we assume that those who would authorize her death are correct, Ms. Schiavo is completely unaware of her situation and therefore incapable of

suffering physically or emotionally. Her death thus can't be justified for relieving her suffering.

- There is a genuine dispute as to what Ms. Schiavo believed and expressed about life with severe disability before she herself became incapacitated; certainly, she never stated her preferences in an advance directive like a living will.
- Ms. Schiavo, like all people, incapacitated or not, has a federal constitutional right not to be deprived of her life without due process of law.
- In addition to the rights all people enjoy, Ms. Schiavo has a statutory right under the Americans with Disabilities Act not to be treated differently because of her disability. Obviously, Florida law would not allow a husband to kill a nondisabled wife by starvation and dehydration; killing is not ordinarily considered a private family concern or a matter of choice.
- When the issue is the scope of a guardian's authority, it is necessary to allow other people, in this case other family members, to file a legal challenge.
- The whole society has a stake in making sure state courts are not tainted by prejudices, myths, and unfounded fears. While we should not assume that disability prejudice tainted the Florida courts, we cannot reasonably assume that it did not.
- Despite the unseemly Palm Sunday pontificating in Congress, the legislation enabling Ms. Schiavo's parents to sue did not take sides in the so-called culture wars. It did not dictate that Ms. Schiavo be fed. It simply created a procedure whereby the federal courts could decide whether Ms. Schiavo's federally protected rights have been violated.

Although Terri Schiavo died in 2005, the debate surrounding her right to live or die has not gone away. Diane Coleman and Tom Nerney identified some of the continuing trends toward death for people with disabilities in *Guardianship and the Disability Rights Movement*.

*While it is clear that most people, in and out of the disability movement, want to have the right to refuse unwanted medical treatment, the alliance of developmental and physical disability groups and their consensus around the Wendland and Schiavo cases demonstrates a growing concern about nonvoluntary and outright involuntary medical killing through withholding of treatment, even food and water. People with disabilities and allies are feeling the pressures toward death from several directions.*

*First, increasingly throughout the last decade or more (since the fiscal incentives of managed care overtook the health care system), people with disabilities and medical treatment consumers in general experience the need to be knowledgeable advocates to ensure proper health care is provided.*

*Second, while the Patient Self-Determination Act of 1991 purported to help people effectuate their right to make their own health care decisions, whenever people with disabilities are admitted to a facility, the boilerplate forms they are given are not balanced and objective, but exclusively oriented toward refusal of*

*treatment. The community is full of anecdotes of people with disabilities pressured by social workers to sign do-not-resuscitate orders.*

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