

Moral and Ethical Issues: Guardianship, Sterilization, Involuntary Servitude, Baby Doe, and Euthanasia

Since ancient times, moral and ethical issues have surrounded society's treatment of people with developmental disabilities. While times and circumstances have changed, many of these basic moral and ethical dilemmas have not. The same debates continue to shape their rights and the role that others play in determining how people with developmental disabilities live, work and receive medical treatment.

Since the 1950s, society has begun to recognize and respond to the ethical, moral and legal issues threatening the lives and freedoms of people with developmental disabilities. Heated ethical discussions and legal challenges have focused on their rights to:

- Make their own decisions.
- Bear and raise their own children,
- Work at meaningful jobs that pay competitive wages.
- Live and receive appropriate medical care.

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 20th 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:

Forced sterilization	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 Parallels in Time, and Parallels in Times, 2 .)
Institutionalization	Parents routinely institutionalized their children.
Permanent placement	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.
Limited parent input and authority	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.
Lack of legal counsel	Commitment proceedings, even though they required the appointment of legal counsel, often managed to deny the requests of individuals and families seeking legal representation.
Dehumanizing practices	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.
Denial of basic rights	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.
Servitude	Institutions routinely used residents to do the work of the institution, often for minimal or no pay.
No control over how guardians used government payments	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.
Refusal to provide medical care to newborns	Newborns with easily corrected health challenges were allowed to die of starvation or suffocation if they also had some degree of intellectual disability.
Lack of treatment	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.
Difficulties obtaining medical treatment	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)

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

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”¹

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.

¹ 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.