



CHAPTER 3: TYPES OF SUBSTITUTE DECISION-MAKING

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A person or an institution can act as a substitute decision-maker for an individual with disabilities in certain situations. This chapter describes the different types of substitute decision-makers, the circumstances under which they can make decisions for the individual, the scope of their authority, and some of the possible advantages and disadvantages of using each type of decision-maker.

I. NATURAL OR INFORMAL SUPPORTS

A. Description

Sometimes known as a "circle of friends," natural or informal supports can include family, friends, or advocates who know the individual with the disability and can help him or her to make decisions in a variety of contexts. Technically, these natural supports are not "substitute" decision-makers in the sense that they do not make decisions for the individual, but, rather, simply help the individual to make his or her own decision.

B. Circumstances When They Can Act

People who provide natural supports are often involved in helping individuals to make decisions about their daily life. For instance, family members, friends, and advocates are allowed (with the individual's consent) to participate in the development of the person's Individual Support Plan (ISP), including choosing the types of services and providers that are desired and appropriate. Family members, friends, and advocates might

also provide assistance (again, with the person's consent) to manage his money, choose and participate in recreational activities, and vote.

C. Limits on Authority

Beyond the right to participate in ISP development, people who act as the natural supports for individuals with disabilities have no formal legal authority to make decisions on behalf of such individuals. Their "authority" would stem from: (1) the choice of the individual with the disability to seek their assistance with decision-making; and (2) whether there are other formal substitute decision-makers who have been given authority to make the decisions.

D. Advantages

There are two key advantages to using natural or informal supports. First, it maximizes the personal autonomy of individuals with disabilities. Since informal supports are not substitute decision-makers, but rather, only facilitate the individual's own decision-making capacity, it is the individual with a disability who retains the ultimate decision-making authority and exercises that authority to the maximum extent feasible. Second, no courts or other agencies are required to confer authority on natural supports to provide such assistance (and, as a result, there are no costs to having natural supports involved).

E. Disadvantages

There may be a disadvantage in relying on natural supports due to the informality of the relationship. Outside of the ISP context, there may be circumstances in which third parties are not willing to accept decisions of individuals with disabilities, even if made with the assistance of family, friends, or advocates. For instance, a bank might be hesitant to allow an individual with a disability to open a bank account on her own or a doctor might not be willing to accept a decision by such an individual. In addition, this type of informal situation with no oversight can pose some risk of exploitation.

II. PARENTS OF MINORS

A. Description

Parents of minors are natural or birth parents, adoptive parents, foster parents, or court-appointed guardians of persons under age 18.

B. Circumstances When They Can Act

Parents have the authority to make almost all decisions for their minor children, regardless of whether the child has a disability, including financial decisions, health care decisions, and education decisions.

C. Limits on Authority

Parents may not act on behalf of minors who have been "emancipated," i.e., legally released from their parents' authority. In addition, the authority of parents of unemancipated minors does not extend to the following situations:

- Refusal of **life-preserving treatment** -- Courts may intervene to override decisions of parents (even for religious reasons) not to authorize the administration of treatment that will preserve the life of their child.
- Abortion -- Parents cannot force a minor child to undergo an abortion.
- Mental health treatment -- There seem to be inconsistent laws in Pennsylvania regarding this issue. The Mental Health Procedures Act of 1976 does not allow parents of children between the ages of 14 and 18 to consent to psychiatric treatment for their children. Act 147 of 2004, while not overruling the prior law, indicates that parents do have authority to admit children between ages 14 and 18 for psychiatric treatment. Even under Act 147, however, a youngster between the ages of 14 and 18 who objects to inpatient psychiatric treatment authorized by his or her parent can file a court petition, and a hearing will be held within 72 hours to determine if treatment is within the child's "best interest."

D. Advantages

Parental authority to act has the benefit of decisiveness. There is usually little question or debate about whether a parent can make particular decisions, and so decisions can be quickly made and implemented. In addition, parents usually are aware of their children's preferences, can take those into account, and are presumed to act in their children's best interests.

E. Disadvantages

Disadvantages of parental authority can sometimes occur as children age and become more independent, and as their interests and wishes may diverge from those of their parents. Yet, their parents remain their decision-makers and can ignore their children's wishes. In addition, there is always some potential for financial exploitation, particularly for children with disabilities who receive government benefits, since there is often little oversight of parents' use of those funds.

III. GUARDIANS OF THE PERSON

A. Description

A "guardian of the person" is someone who has been appointed by a court to make personal decisions on behalf of someone who the court has determined to be "incapacitated." A person will be deemed incapacitated if his or her ability to receive and evaluate information effectively and to

communicate decisions is so impaired that he or she cannot meet the essential requirements for his or her physical health or safety.

B. Circumstances When They Can Act

The authority of a guardian of the person to make decisions on behalf of an incapacitated person depends in large part on the scope of the court's order. The court can appoint a person to act as a "plenary" guardian of the person or as a "limited" guardian of the person. If the court appoints a "limited" guardian of the person, it must designate the guardian's specific duties, such as general care and maintenance of the individual; deciding where the individual will live; assuring that the individual receives necessary services and health care. A person who is the plenary guardian of the person can make all such decisions on behalf of the individual and many other significant personal decisions.

C. Limits on Authority

As noted above, the court may impose limits on the duties of a guardian of the person in its order. The court also may limit the duration of the guardianship. In addition, a guardian of the person is supposed to respect the expressed wishes and preferences of the individual to the greatest extent possible.

The guardian also is supposed to encourage the individual to participate to the maximum extent of the individual's abilities in all decisions that affect him or her.

The guardian of the person must submit annual reports to the court concerning the services the individual is receiving, the number and length of times the guardian visited the person during the year, and any major medical or mental health problems the individual experienced during the year.

Pennsylvania law also imposes other limits on the authority of a guardian of the person, such as the following:

- Admission to an inpatient psychiatric facility or a state intellectual disability center -- A guardian never has the power to admit an individual to a psychiatric facility for inpatient treatment or to a state intellectual disability center.
- Termination of parental rights -- A guardian never has authority to consent to the termination of the individual's rights as a parent.
- Abortion -- A guardian cannot force an individual to terminate a pregnancy against her will.
- Refusal of life-preserving treatment -- A guardian does not have authority to refuse to authorize the provision of medical treatment

necessary to save the life of an individual in his or her care who does not have an end-stage medical condition or is not permanently unconscious.

- Marriage and divorce -- A guardian can only prohibit the marriage or divorce of an individual if he or she secures a specific court order following a hearing at which the court makes specific findings of fact on the subject.
- Sterilization, psychosurgery, electroconvulsive therapy, or removal of a healthy body organ -- A guardian can consent to these procedures only if she or he secures a specific court order following a hearing at which the court makes specific findings of fact on the subject.
- Consent to experimental procedures or participation in experiments -- A guardian can consent to these procedures only if she or he secures a specific court order following a hearing at which the court makes specific findings of fact on the subject.

Sexuality issues such as marriage, divorce, sterilization, and abortion are discussed in more detail in the Capacity, Sexuality & Family Life chapter of this Guide.

D. Advantages

The advantages of guardianship stem primarily from the clear authority that is conferred by the court's order so as to prevent delays in making and implementing decisions. In circumstances where delays can have consequences (such as the medical context), this clear-cut authority can be beneficial.

E. Disadvantages

Guardianship of the person is one of the most, if not the most, intrusive forms of substitute decision-making and imposes the greatest limits on the personal autonomy of the individual with a disability. It also is usually unnecessary since lesser forms of substitute decision-making can be used in most situations without imposing the same restrictions on the individual's choices and right to control his own life and services.

IV. GUARDIANS OF THE ESTATE

A. Description

Guardians of the estate (also known as fiscal guardians) are individuals or entities appointed by a court to manage some or all of the financial affairs of a person who has been determined to be incapacitated. Incapacity, for purposes of appointment of a fiscal guardian, means that the person is so impaired in his or her ability to receive and evaluate information effectively and communicate decisions that he or she is partially or totally unable to manage his or her financial resources.

B. Circumstances When They Can Act

The authority of a fiscal guardian to make decisions on behalf of an incapacitated person depends in large part on the scope of the court's order. The court can appoint a person to act as a "plenary" fiscal guardian or as a "limited" fiscal guardian. If the court appoints a "limited" fiscal guardian, it must designate specifically which of the individual's assets and/or income the guardian will control. A "plenary" fiscal guardian is deemed to have responsibility for all of the individual's assets and income. Fiscal guardians generally control issues relating to insurance, contracts, real and personal property, and investments.

C. Limits on Authority

A fiscal guardian's authority may be limited by the scope of the court's order in terms of both the powers the guardian is assigned and the duration of the guardianship. In addition, fiscal guardians must submit annual reports to the court about the state of the individual's finances during the report period and how the fiscal guardian has provided for his/her needs.

D. Advantages

The advantages of a fiscal guardian, like that of a guardian of the person, stem from the clarity of the guardian's authority. Banks, landlords, and others generally will not question the ability of a court-appointed guardian to

make financial decisions on behalf of an individual. This clarity can speed up financial and related transactions on behalf of people with disabilities.

E. Disadvantages

Again, like a guardian of the person, fiscal guardianship often strips the individual of his authority to make his own decisions and direct his own finances by conferring often absolute authority on another person. Fiscal guardianship is almost always unnecessary if the person's sole income stems from Social Security benefits since a representative payee (discussed below) can be appointed to handle those benefits.

In addition, although fiscal guardians are supposed to submit reports to the court, there is still the potential for financial exploitation in this situation since the courts have limited resources to determine whether such reports are being filed or to check the accuracy of these reports.

V. REPRESENTATIVE PAYEES

A. Description

A representative payee is an individual or agency appointed by the Social Security Administration (SSA) to receive Social Security or Supplemental Security Income (SSI) benefits for someone who cannot manage or direct his or her own money.

All individuals who have been determined by a court to be incapacitated and have had fiscal guardians appointed must have a representative payee. The fiscal guardian will usually serve as the representative payee.

SSA presumes that any adult who has not been determined to be incapacitated can manage his or her own Social Security or SSI benefits. However, if SSA receives evidence to the contrary, it will investigate to determine whether a representative payee should be appointed.

B. Circumstances When They Can Act

When a representative payee is appointed by the SSA, he is responsible for everything related to the benefits that a capable beneficiary would do for himself or herself. Representative payees' duties include:

- Determining the beneficiary's needs and using the benefits to meet those needs, including food, clothing, shelter, utilities, medical and dental care, and personal comfort items.
- Saving any money left after meeting the beneficiary's needs in an interest-bearing account, a savings bond or a trust to be used for the future needs of the beneficiary.
- Helping the beneficiary to get medical treatment when necessary.
- Ensuring the beneficiary's income and resources stay within the

criteria limits to continue eligibility for government benefits.

C. Limits on Authority

Representative payees cannot:

- handle any of the beneficiary's finances (such as income or pensions) other than those related to his or her Social Security or SSI benefits, unless he or she has some other source of authority (such as a fiscal guardianship order or a financial power of attorney);
- sign legal documents on behalf of the beneficiary, other than Social Security documents;
- use a beneficiary's Social Security or SSI benefits for the payee's personal expenses or spend the benefits in a way that leaves the beneficiary without necessary items or services;
- charge the beneficiary for services unless authorized by the SSA to do so.

In addition to these prohibited actions, representative payees must permit the beneficiary to have some discretionary spending money for his or her own use if there is money left after the beneficiary's basic needs have been met. The representative payee cannot deny access to discretionary

spending money because he or she does not approve of how it is used by the beneficiary.

D. Advantages

For many people with disabilities, Social Security or SSI benefits are their primary, perhaps only, source of income. The representative payee program provides a relatively informal means to appoint a substitute decision-maker to manage the money of people whose disabilities prevent them from doing so themselves. It is both less intrusive and less expensive than having a guardian appointed and it is also easier for an individual with a disability to challenge a decision to appoint a representative payee as a substitute decision-maker.

Representative payees assure that funds are available to meet the basic needs of the individual, including food, clothing, and shelter, and thus prevent potential misuse of the benefits by individuals who cannot manage their money. In addition, it helps to prevent financial exploitation by individuals who might trick or coerce the beneficiary.

E. Disadvantages

Again, any time a substitute decision-maker is appointed, the personal autonomy of the individual with disabilities is undermined. If an individual with a disability has a strong natural support system, a representative payee may be unnecessary. Family, friends, or advocates can assist the individual

to manage his or her own benefits in a manner that meets the individual's basic needs.

VI. TRUSTEES

A. Description

A trust is a legal instrument in which a person (known as the "settlor") places money or other property (known as the trust "assets") in a special account for the benefit of one or more persons (known as the "beneficiaries"). The trust designates a third-person (known as the "trustee") to control the trust assets in accordance with the specific directions in the trust. An individual can create a trust for his own benefit (known as a "self-settled trust"), but must appoint another person to act as the trustee.

Trusts can be created by a settlor to take effect during his life, or they can become effective only when he dies (though, obviously, this does not apply to self-settled trusts). Trusts can have an impact on the continued eligibility of a person with a disability for government benefits and must be carefully drafted to avoid such impact. Trusts that are designed to protect a beneficiary's government benefits are often called "special needs trusts." Trusts are discussed in more detail in the Substitute Decision-Making through Trust chapter of this Guide.

B. Circumstances When They Can Act

A trustee's power to act depends on terms of the trust instrument. Some trusts mandate that the trustees make mandatory payments to beneficiaries while others give the trustees discretion as to when to make payments to beneficiaries. Some trusts provide specific information about whether and how to invest the trust assets while others provide the trustee with discretion to make the decisions he or she feels are optimal.

C. Limits on Authority

The trustee only has authority over the assets that are placed in the trust. Thus, a trustee generally has no authority over government benefits received by the individual, income earned by the individual, or pension payments received by the individual. The trustee also has no authority to make any other financial decisions on behalf of the beneficiary (such as entering into contracts or other legal agreements or purchasing property).

D. Advantages

Trusts can be very advantageous to allow assets to be transferred to an individual with a disability without jeopardizing his or her entitlement to government benefits, such as SSI and Medical Assistance (MA). It is imperative, however, that such trusts be carefully drafted to assure that the individual's government benefits are not jeopardized.

Trusts can also be beneficial to protect the government benefits of an individual with a disability who receives a lump-sum payment (for example,

as the result of settling a lawsuit). Again, though, there are very specific rules that govern the type of trusts that can be used in these circumstances to assure that the person's benefits are not jeopardized.

E. Disadvantages

In order to assure that a trust does not endanger a beneficiary's continued eligibility for government services, the trustee must be afforded complete discretion as to whether, when, and how much of the trust assets will be distributed to the beneficiary. This means that there can be no guarantee to assure that the trustee will make decisions (by distributing assets) in a manner that meets the beneficiary's needs.

To assure that a self-settled trust does not jeopardize government benefits, the trust generally cannot be revoked by the individual. Moreover, such self-settled trusts must be set up so that the government receives at least some of the funds remaining in the trust after the settlor/beneficiary dies, up to the amount of MA payments made by the state for the individual.

VII. HEALTH CARE AGENTS/ATTORNEYS-IN-FACT/PROXIES

A. Description

A health care agent is a person designated by another individual (known as the "principal") in an advance health care directive (including a living will or health care power of attorney). Some health care advance directives may refer to health care agents as a health care proxy or a health care attorney-

in-fact. Service providers and their employees cannot serve as health care agents. Health care agents, health care representatives, health care advance directives and other related topics are discussed in more detail in the Health Care Decision-Making chapter of this Guide.

B. Circumstances When They Can Act

The health care agent can only act when the principal's attending physician has determined that the principal is not competent to make health care decisions for himself or herself.

C. Limits on Authority

The health care advance directive can set forth limits on the health care agent's authority. Many advance directives (particularly living wills) identify specific types of treatment that the principal wants or does not want. The health care agent cannot override those decisions.

Even in the absence of specific instructions, the health care agent's decisions should conform to the principal's values and preferences, including his or her religious and moral beliefs. These values and preferences can be set forth in the health care advance directive. For example, the document can say that the principal's goal is to preserve life or to relieve suffering. In such a case, the health care agent must make decisions in furtherance of that goal.

D. Advantages

There are many advantages to designation of a health care agent to act as a substitute decision-maker in the event an individual becomes incompetent to make health care decisions, including the following:

- The health care agent is able to make decisions immediately upon a determination by a physician that a person is not competent. There is no delay or expense associated with going to court to secure guardianship for a person who becomes incompetent.
- The individual can decide while he or she is competent who he or she wants to act as the health care agent, can identify some specific types of decisions that he or she wants made, and can set forth the values and preferences that the agent should follow. This helps to assure that treatment decisions made by a person after he or she becomes incompetent are as close as possible to those that he or she would have made if not incompetent. It is less a "substitute" decision than a decision made by the individual.
- A health care agent has authority to make decisions for a principal who becomes incompetent even if he or she is not at the end of life.
- A person can revoke or modify a health care advance directive (including changing the designated health care agent) at any time before he or she becomes incompetent.
- Even after a person becomes incompetent to make decisions, he or

she still retains authority to countermand any decision made by a health care agent that would withhold or withdraw life-sustaining treatment.

E. Disadvantages

Only individuals who are competent to make health care advance directives can appoint health care agents to act as their decision-makers. As a result, many individuals with cognitive disabilities are unlikely to be able to make health care advance directives and appoint health care agents.

Another disadvantage stems less from the nature of health care agents than from the reality of implementation. Simply put, there are few checks and balances to assure that health care agents in fact implement the wishes of the principals as set forth in the health care advance directives. Yet, although this may happen, a carefully selected health care agent implementing a carefully written health care advance directive is more likely than other forms of substitute decision-makers to make decisions that closely align with the wishes of the principal.

VIII. HEALTH CARE REPRESENTATIVES

A. Description

A health care representative is a person authorized by Pennsylvania law to make certain health care decisions for an individual (known as the

principal) who does not have a guardian, has not executed a health care advance directive, or whose health care agent is not reasonably available or is not willing to act.

An individual can designate a health care representative while he or she is still competent either by a signed writing or by personally informing his or her attending physician or health care provider. If the individual has not designated a health care representative, the following individuals can act as the health care representative in descending order of priority: the person's spouse; adult child; parent; adult brother or sister; adult grandchild; or an adult who has knowledge of the person's preferences and values sufficient to assess how he or she would make health care decisions for himself or herself. Service providers and their employees cannot serve as health care representatives.

B. Circumstances When They Can Act

A health care representative can act only when the individual's attending physician has determined the individual to be incompetent to make his or her own health care decisions and only if: the principal has no guardian; has no health care power of attorney; or has a health care agent who is unavailable or unwilling to act.

C. Limits on Authority

There is some dispute about when a health care representative has authority to make decisions on behalf of a person who is incompetent. The Pennsylvania statute that authorizes health care representatives to make decisions suggests that a health care representative only has authority to make decisions for a principal who has an end-stage medical condition or is permanently unconscious. Many health care providers, however, have interpreted the law to allow health care representatives to make decisions for an incompetent person who is not at the end of life.

D. Advantages

There are several advantages to health care representatives as substitute decision-makers:

- Health care representatives can make decisions for persons who were never competent to create a written health care advance directive. Thus, family or friends can make important health care decisions for individuals who have cognitive disabilities without the difficulty and expense of going to court to secure a guardianship order.
- Health care representatives will usually be individuals who are familiar with the principal's values and preferences and will make decisions for the principal that reflect his or her values and preferences.
- A principal has authority -- even if he or she becomes incompetent --

to countermand a decision by a health care representative to withhold or withdraw life-sustaining treatment.

E. Disadvantages

A person may have priority under Pennsylvania law to act as a principal's health care representative over another individual who may have a greater sense of the principal's values and preferences. Another potential disadvantage is that there is no means to be certain that the health care representative is acting in accordance with the individual's values and preferences, and there are no checks and balances if another person believes that the representative is not acting in accordance with the principal's values and preferences.

IX. MENTAL HEALTH AGENTS

A. Description

A mental health agent is a person who is appointed by an individual under a Mental Health Power of Attorney to make treatment decisions for the

individual in the event of a mental health crisis. While an individual can make a Mental Health Declaration (which provides concrete instructions for specific situations), the Mental Health Power of Attorney allows the agent flexibility to deal with situations as they occur while giving guidance on the individual's wishes and preferences.

B. Circumstances When They Can Act

A mental health agent can only act if he or she has been appointed under a valid Mental Health Advance Directive by a person age 18 or older, who does not have a guardian appointed, and is not currently involuntarily committed.

C. Limits on Authority

The mental health agent's authority is limited by the terms of the Mental Health Advance Directive and the individual's statements about his choices relating to beginning, continuing, or refusing mental health treatment. In addition, the Mental Health Advance Directive (and, thus, the mental health agent's authority) is valid for only two years from the date it is signed unless at the time it would expire, the person does not have capacity, in which case it continues until the individual is competent to make treatment decisions.

D. Advantages

There are several advantages of appointing a mental health agent under a Mental Health Advance Directive, including:

- allowing mental health decisions to be made promptly and without the delay and expense that would be incurred to go to court to secure a guardianship order;

- enabling the individual to identify someone he or she knows and trusts to make important decisions about mental health treatment when the individual cannot do so himself or herself;
- assuring that the decisions made are consistent with the individual's preferences and choices;
- allowing the individual to revoke the Mental Health Advance Directive at any time as long as he or she has capacity.

E. Disadvantages

If providers are not aware that an individual has a Mental Health Advance Directive, it may not be respected. In addition, since the Mental Health Advance Directive is only valid for two years, it may require the individual to continually remake the document, which can be difficult for a person with chronic mental illness.

X. HEALTH CARE PROVIDERS

A. Description

Health care providers include persons who are licensed, certified, or otherwise authorized to provide health care, including physical or mental health care, custodial or personal care, and therapies. This includes doctors, nurses, therapists, habilitation providers and staff, and others.

B. Circumstances When They Can Act

There are several circumstances when health care providers can make health care decisions for persons who are not capable of doing so.

- **Emergencies**-- Physicians, emergency medical staff, and others involved in emergencies generally have authority to consent to a health care procedure for individuals who are unconscious or otherwise not capable of giving consent if the failure to perform the procedure immediately will threaten the person's life.
- **Lack of Other Substitute Decision-Makers** -- If the individual does not have a health care agent, a guardian, or a health care representative, the facility director, mental health and intellectual disability facility directors -- including group home operators -- have authority under Pennsylvania's Mental Health and Intellectual Disability Act of 1966 to consent to "elective surgery" for individuals in their facilities if two physicians have recommended that the surgery be performed. The Pennsylvania Department of Human Services considers the phrase "elective surgery" to mean all types of medical treatment.
- **Forced Medication** -- In emergency situations, psychiatrists in state hospitals can authorize the forced medication of involuntarily admitted patients if it is necessary to protect the health or safety of the individual or others. In non-emergency situations, psychiatrists in state hospitals can authorize the administration of psychotropic

medication to individuals when they refuse the medication if a second psychiatrist, after an independent review, concludes that the medication is necessary. The same procedure applies to state hospital residents under age 14 if the patient or his parents refuse the psychotropic medication.

C. Limits on Authority

There are limits to the authority of providers to make substitute decisions in each of these situations:

- Emergencies -- A health care provider cannot provide emergency treatment if: (1) the provider knows the individual specifically refused the procedure when she or he was conscious and competent to make the decision; or (2) there is enough time to contact another substitute decision-maker.
- Treatment Decisions for Persons at the End of Life -- Facility directors, because they are providers, cannot act as "health care representatives" (described above). As such, facility directors should not be able to make health care decisions for persons who have end-stage medical conditions or are permanently unconscious. The Department of Human Services, however, has taken the position that facility directors do have authority to make health care treatment decisions for persons at the end-of- life who do not have guardians, health care agents, or health care representatives, but has suggested

that facility directors should still request judicial authorization for such treatment decisions.

- Refusal to Authorize Life-Preserving Treatment -- Providers cannot refuse to authorize or withhold "life- preserving" treatment for persons who do not have end- stage medical conditions or are not permanently unconscious.
- Authorization of DNR Orders -- Providers cannot authorize the issuance of Do Not Resuscitate Orders for persons who do not have end-stage medical conditions or are not permanently unconscious.
- Forced Medication -- A state hospital cannot administer medication in a non-emergency situation to a person who has a Mental Health Advance Directive (see above) that indicates his objection to administration of that medication unless a person successfully petitions the court to invalidate that provision based on a finding that the failure to administer the medication may cause irreparable harm or death.

D. Advantages

There are advantages to having a health care provider make substitute health care decisions for persons who are not capable of doing so in several situations:

- Emergencies -- Allowing a provider to authorize emergency medical decisions can be the difference between life and death when a fast decision is critical, the individual is incapable of making the decision, and no preferable substitute decision-maker is available.
- Lack of Substitute Decision-Makers -- Frequently, individuals with disabilities who live in group homes or other types of facilities do not have family or other individuals who are familiar with their values and preferences. In these circumstances, providers may be the closest persons to those individuals and in the best position to act in accordance with their values and preferences in making health care decisions when no one else is available.
- Forced Medication -- Administering medication to a person with mental illness without his or her consent may have a short-term benefit for the hospital, as well as for the individual. In some cases, the forcing of medications can be a lifesaving action.

E. Disadvantages

Conversely, several disadvantages, while usually unintentional, may occur due to a health care provider making a substitute health care decision in the following situations:

- Emergencies -- While decisions made by a health care provider may be necessary in some situations, such decisions, may not reflect the

person's wishes since the provider (e.g., an emergency medical technician) is often not one who will be familiar with the person's wishes.

- Lack of Substitute Decision-Makers -- While many facility directors are likely to act in the individual's best interests and in accordance with their wishes when making health care decisions, there always is the potential for a conflict of interest.
- Forced Medication – Although there may be times when forcing someone to take medications against their will is in the person's best interest, both physically and mentally, it can have a long-term adverse effect on the individual who is likely to become more distrustful of his treatment team, undermining the effectiveness of treatment.

XI. EDUCATION DECISION-MAKERS

A. Description

Under the Individuals with Disabilities Education Act (IDEA), "parents" have the right to make decisions for their minor children who receive special education services. In accordance with the IDEA, Pennsylvania also authorizes parents to make decisions for individuals age 18 and older who continue to receive special education services. "Parents" include natural parents; adoptive parents; foster parents; guardians; and individuals with whom the youngster lives or who are legally responsible for the youngster.

B. Circumstances When They Can Act

Parents have authority to consent or withhold consent with respect to any decisions relating to special education services that their children receive under the IDEA.

C. Limits on Authority

Parents cannot make educational decisions for their adult children outside of the special education system. Thus, teenagers and young adults over the age of 17, in higher education institutions, have the right to make their own educational decisions once they graduate from high school.

D. Advantages

There are several advantages to allowing parents to remain as decision-makers for special education services after children reach 18, including:

- Facilitating continuity since most parents have been making these decisions since their children began school;
- Assuring that school districts do not take advantage of youngsters with disabilities who might be more easily intimidated by the special education procedures than their parents.

E. Disadvantages

It is very important that people with disabilities have the opportunity to make decisions for themselves whenever possible. These opportunities help to build their decision-making skills for the future. Special education, since it continues into young adulthood and affects the daily life of the individual, can be an important arena in which young people with disabilities gain experience in decision-making. Yet, by allowing parents to continue as the sole decision-maker for special education decisions, young people may be deprived of the opportunity to make educational decisions for themselves to the maximum extent possible. Of course, parents can overcome this disadvantage by encouraging their children to participate to the maximum degree possible in making decisions about their special education services. Schools must invite these students to participate and give input in the meetings where these decisions are made.

XII. EDUCATION ATTORNEY-IN-FACT

A. Description

An education attorney-in-fact is a person appointed under a special, limited power of attorney created by an individual with a disability to give another person control over education matters after graduation from high school. Most often, it will be the parent who is appointed as the educational decision-maker.

B. Circumstances When They Can Act

An education attorney-in-fact must be appointed under a valid, special power of attorney created by a competent person. The document sets forth the circumstances under which the attorney-in-fact can make education decisions and which decisions can be made for the individual (including, enrollment, disenrollment, dealing with campus life issues, course selection, and access to records).

C. Limits on Authority

The education attorney-in-fact's authority is limited by the terms of the power of attorney document. Most significantly, it would only extend to issues relating to the individual's education.

D. Advantages

Some young people with disabilities such as autism or mental illness might find that pressures related to dealing with certain education decisions on their own can be so stressful that it interferes with their ability to get the full benefit of a post-secondary education. For these individuals, it might be beneficial to empower a third-person to make decisions that might be difficult or stressful. It can also be useful for the college to have a decision-maker available if the individual periodically may need to ask for leave or other accommodation due to his or her disability, but is unable to do so by himself or herself.

E. Disadvantages

This type of power-of-attorney is novel and may not be recognized as valid by the courts. Moreover, it might undermine the abilities of the individual with a disability to allow another person to make these types of decisions rather than having him or her negotiate the education process and make decisions on his or her own.

XIII. FINANCIAL ATTORNEY-IN-FACT

A. Description

A financial attorney-in-fact is a person who is appointed by an individual in a power of attorney to act as the individual's agent. The attorney-in-fact is authorized by the power of attorney to make certain specified financial and business decisions on behalf of the individuals and they are just as binding as if the individual had made those decisions on his or her own. Financial attorneys-in-fact are often called "agents." A financial power of attorney is the most common form of power of attorney.

B. Circumstances When They Can Act

The power of attorney document sets forth the circumstances under which the financial attorney-in-fact can act. The power of attorney can be written to take affect only if an individual becomes incompetent to make his or her own financial decisions. The power of attorney also sets forth which business or financial decisions the individual is empowered to make (such

as financial or property transactions; creating a trust; applying for government benefits).

C. Limits on Authority

A financial attorney-in-fact cannot exercise any authority that is not set forth in the power of attorney document. In addition, the Social Security Administration does not accept an attorney-in-fact appointed under a valid power of attorney as having any authority to negotiate or manage the individual's Social Security benefits. The financial attorney-in-fact would still need to apply to be appointed as a representative payee (for more information on representative payees, see Section V. in this chapter).

D. Advantages

There are several advantages to drafting a power of attorney to appoint a financial attorney-in-fact in the event that a person becomes incompetent to make his or her own financial decisions, including:

- The expense and delay necessary to have a fiscal guardian appointed is avoided, allowing for prompt financial decision-making if and when the person becomes incapacitated to make his own decisions.
- The individual, when competent, can choose a person he or she knows and trusts to make financial decisions.

- The document can be revoked.

E. Disadvantages

Since only persons who are competent can execute a financial power of attorney, individuals with significant cognitive disabilities might not be able to use this means to appoint a substitute decision-maker.

Contact Information

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). The email address is: intake@disabilityrightspa.org.

The mission of Disability Rights Pennsylvania is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities. Due to our limited resources, Disability Rights Pennsylvania cannot provide individual services to every person with advocacy and legal issues. Disability Rights Pennsylvania prioritizes cases that have the potential to result in widespread, systemic changes to benefit persons with disabilities. While we cannot provide assistance to everyone, we do seek to provide every individual with information and referral options.

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PLEASE NOTE: For information in alternative formats or a language other than English, contact Disability Rights Pennsylvania at 800-692-7443, Ext. 400, TDD: 877-375-7139, or intake@disabilityrightspa.org
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