DISABILITY RIGHTS PENNSYLVANIA

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CONSENT, CAPACITY, AND SUBSTITUTE DECISION-MAKING

DISABILITY RIGHTS PENNSYLVANIA

To make decisions for oneself is a core human and civil right, and for too long too many people with disabilities have had that right unnecessarily infringed. When someone needs help making decisions, such assistance must be tailored to that person's unique needs and abilities so that their right to self-determination is honored to the maximum extent possible. It is DRP's hope that, by providing the information in this manual, people with disabilities, their family members, service providers, and others will be better informed about the important issues related to decision-making and thus assure that this right is protected for all.

This manual has been made possible by the generous support of the Pennsylvania Developmental Disabilities Council, and DRP is grateful for their ongoing assistance in making this publication a reality. To learn more about PaDDC and its work, please visit www.paddc.org.

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.

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CONSENT, CAPACITY, AND SUBSTITUTE DECISION-MAKING

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CHAPTER 1: DECISION-MAKING BY PEOPLE WITH INTELLECTUAL DISABILITIES: THE IMPORTANCE OF SELF-DETERMINATION

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Until relatively recently, individuals with intellectual disabilities in this country usually lived their entire lives in institutions, segregated from their peers, families, and society as a whole. There were few, if any, issues concerning **consent** and decision-making in institutions. It was generally presumed that institutionalized individuals were unable to make decisions regarding their own lives due to their disabilities. Beyond this patronizing assumption, the very nature of institutional care undermined individuals' decision-making abilities. Prolonged, pervasive denials of the opportunity to make even basic decisions simply exacerbated the institutionalized persons' dependence on others to make decisions for them.

In the past 40 years, however, the model of care for people with intellectual disabilities has substantially evolved, thanks to the concerted efforts of self- advocates, families, lay advocates, and concerned professionals. Today, most individuals with intellectual disabilities live in their own homes in integrated communities. As integration has become the norm, there has been increased focus on the ability of individuals to participate in community life to the fullest extent possible.

As for all human beings, community life for people with intellectual and other developmental disabilities involves daily decision-making. Many of these decisions are quite basic. What should I eat? Should I go to the store? What should I wear? Other decisions, though, can have important and long-lasting consequences. Where should I live? Should I get treatment for an illness? Should I get married?

The freedom to make decisions -- even decisions that might have adverse consequences -- is fundamental to personal autonomy and self-determination. This right, however, is not unlimited. In some situations, **substitute decision-makers** may be necessary and appropriate. Yet, in determining what role, if any, substitute decision-making should play in the life of an individual with an intellectual disability, there are several considerations to bear in mind.

I. DISABILITY VARIATION

The presence of a developmental disability, including an intellectual disability, by itself does not tell us anything about a particular individual's decision-making **capacity**. Decision-making abilities are not the same for all people with developmental disabilities. People with developmental disabilities are individuals whose abilities and disabilities are subject to wide variation. Obviously, individuals with physical disabilities who have no cognitive limitations will rarely, if ever, need a substitute decision-maker.

Many individuals with autism or an intellectual disability have expressive and receptive language abilities to communicate many of their needs and desires and have sufficient comprehension and reasoning skills to understand their choices. Some individuals with autism or an intellectual disability might not have strong expressive language skills, but can still communicate their desires through a variety of means and understand their choices.

There are, however, other individuals with cognitive disabilities whose decision-making abilities are compromised, at least to some extent, and they may need some form of assistance, guidance and education, or perhaps a substitute decision-maker. Adolescents and young adults with severe emotional disorders might be able to make decisions some of the time, but not other times. In short, the ability to make decisions must be determined on an individual basis, and based on the situation and circumstances, without resort to assumptions and stereotypes.

II. VARIATION IN TYPES OF DECISIONS

There are wide varieties of decisions that affect the lives of individuals with disabilities, including everyday living decisions; decisions about disability-related services and supports (housing, day programs, therapies); decisions about medical and mental health care; decisions about finances; and decisions about marriage, sexuality, and procreation. The fact that an individual is unable to make some decisions does not mean that she is unable to make any decisions. The type of decision that is at issue can be as important as the type and extent of an individual's disability in

determining whether a substitute decision-maker is necessary, appropriate, or lawful.

III. DECISION-MAKING EXPERIENCE AND TRAINING

One of the key deterrents to people with intellectual disabilities making decisions is the extent to which they have been previously denied the choice to make important decisions. Even outside the institutional context, people who are "integrated" have too often been the subject of decisions rather than an active participant in them. This is changing as we recognize the importance of people having as much control as possible over their own lives. It is important to provide decision-making training to individuals with disabilities as well as opportunities to make decisions that affect their lives to the maximum extent possible.

IV. NATURAL SUPPORT SYSTEMS

Substitute decision-making is often thought to be necessary to protect individuals from making decisions that are harmful to their health and well-being. Although there are many types of formal substitute decision-making (such as **powers of attorney** and guardianship), it is important to bear in mind that such formal arrangements are often unnecessary if the individual has an adequate **natural support** system. A circle of family members, friends, or lay advocates can work with the individual to assist him to make decisions.

In sum, decision-making is part of daily life and a key element of self determination and community integration. People with intellectual disabilities should be encouraged to make decisions and choices that affect their lives, whether major or minor, to the maximum extent that they can do so. Substitute decision-making should be the option of last resort and should be narrowly tailored to assure that individuals with intellectual disabilities are not stripped of their right to make choices when they can do so.

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CONSENT AND CAPACITY TO MAKE DECISIONS

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"Consent" and "capacity" are key concepts that affect issues relating to substitute decision-making. The standard by which it is determined whether a person can make decisions for himself or herself, rather than needing a substitute decision-maker, is whether the person is able to provide consent (either "simple consent" or "informed consent" depending on the context). Whether a person can provide consent often requires an assessment of the person's capacity (capacity is sometimes called "competence").

I. BACKGROUND OF THE DOCTRINE OF CONSENT

The doctrine of consent stems from legal cases in which physicians were sued after performing a medical procedure that did not go well. The courts initially held that physicians were entitled to make decisions as to what treatment was in the best interests of the patient, regardless of whether the physician provided any information to the patient or whether the patient understood the procedure and its consequences. The law subsequently changed. Now, patients are entitled to make treatment decisions for themselves in non-emergency situations. Physicians must provide the patient with information sufficient to allow the patient to understand the proposed procedure and its benefits, risks, and consequences.

II. SIMPLE CONSENT VS. INFORMED CONSENT

Simple Consent -- Simple consent requires the individual to be informed about the matter and to make a decision. It does not require that the individual actually have full knowledge of the issue, options, and consequences of the decision.

Simple consent generally is sufficient for a number of decisions relating to routine matters that pose no risk of harm greater than that which is normally encountered in daily living. These types of decisions include:

- choosing what to eat;
- choosing what, if any, religious activities in which to participate;
- choosing what, if any, recreational activities in which to participate;

- participating in routine physical examinations, tests, and treatment;
- choosing whether to vote and, if so, for whom to vote.

The vast majority of people with intellectual disabilities are readily able to provide simple consent for these day-to-day decisions. An individual may be able to make these decisions on his or her own or with the assistance of his or her natural support system. Even if an individual has a substitute decision-maker, such as a guardian, his or her simple consent to everyday decisions should be respected.

Informed Consent -- Decisions which have greater risks and consequences than those generally encountered during daily life require informed consent. These types of decisions include:

- whether to undergo medical treatments for complex illnesses;
- whether to undergo invasive tests;
- whether to have surgery;
- how to spend Social Security benefits or other funds.

Informed consent requires the provision of information relating to the decision. This information should identify the proposed action and explain its purpose, the possible adverse consequences, the anticipated benefits, and any alternatives.

Informed consent requires not only that the individual receive adequate information about the proposed action, but, also, that the individual have "competence" or "capacity" to consent to the action. Individuals who are not competent or lack capacity to provide informed consent will generally need some form of substitute decision-maker to make the decision.

III. CAPACITY/COMPETENCE

Competence to consent means that a person: (1) possesses an ability to understand the situation, the alternative options, and the risks and benefits; possesses the ability to use the information in a logical and rational way to reach a decision; and (3) is able to communicate the

decision (either verbally or through other effective means).

Persons age 18 and older are presumed to have capacity to make their own decisions until they are shown not to have such capacity (though Pennsylvania law provides that parents or guardians of persons in the special education system remain the educational decision-makers for persons aged 18 to 21). Minors, for the most part, are deemed to be incompetent as a matter of law, regardless of disability, and their parents are their decision-makers.

A person who has capacity is able to make his or her own decisions. It does not matter that the decisions made by a person with capacity appear **irrational or wrong to others.** A diagnosis of an intellectual or other developmental disability does not automatically mean that a person is not competent to provide informed consent for some or all of the types of decisions that require that consent.

It is vital to understand that a person may be competent to make some decisions but not others. For example, a woman with an intellectual disability may be able to consent to take aspirin for a headache, but not to heart surgery. This is because it is much easier to understand an immediate treatment to relieve a current pain than it is to understand the potential risks and complications of major surgery. Even with respect to more invasive procedures, like heart surgery, individuals with intellectual or other developmental disabilities have the capacity to consent until they are shown not to have such capacity. Information should be offered in a form that they may understand (for example, drawings) and, if possible and if the individual consents, should be offered in the presence of people in his or her circle of natural supports. These individuals can help to relay the information to the individual and can help assess whether he or she understands it and, if so, consents.

IV. BEYOND CONSENT AND CAPACITY

Although consent and capacity are important to determine when, if at all, a substitute decision-maker should be involved, it is not the standard used in all situations. For example:

- **Medical emergencies** -- When a person is unconscious or not capable of giving consent and delay will threaten the person's life or health, a physician can perform an emergency medical procedure unless it is known that the individual had specifically refused the procedure when conscious or competent.
- **Financial management** -- When a person receives a large payment of money (for example, through a lawsuit settlement or an inheritance), it may be appropriate to place that money in a trust that is controlled by a trustee even when the person has capacity to provide consent to make financial decisions. This is because the direct receipt of money by the individual could jeopardize his or her government benefits. If the individual has capacity to make the decision, the individual decides whether to place the money in a trust.
- **Personal decisions** -- There are some decisions that are beyond the authority of a substitute decision-maker even when an adult lacks capacity to consent. These include marriage, divorce, sterilization, termination of a pregnancy, termination of parental rights, and admission to an institution. In some cases, a court may authorize a guardian to make these decisions if certain criteria are met, but others can never be made by a guardian or substitute decision-maker. For further information on the authority of a guardian, please see Chapter 10: Guardianship in Pennsylvania.

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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. <u>Advantages</u>

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.

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Individuals with and without disabilities are required to make decisions about medical treatment every day. This chapter will address when people with intellectual disabilities can make health care decisions. This chapter will also address substitute decision-making options that can be used when a person cannot make his or her own health care decisions, including when each option can be used and the scope of authority for various substitute decision-makers. Since access to medical records can be important in making health care decisions, this chapter also briefly addresses who can access the records of an individual with a disability.

I. MAKING YOUR OWN HEALTH CARE DECISIONS

Adults generally have the right to make their own decisions.[1] When a person has an intellectual disability, he or she still has authority to make his or her own decisions, including health care decisions, if he or she has "capacity" (also called "competence") to do so.

Many individuals with intellectual disabilities have capacity to make health care decisions that require only "simple consent" (rather than "informed consent"). Decisions for which simple consent is adequate are those that do not pose a risk of harm greater than that normally encountered in daily life, such as whether to participate in routine physical exams, tests, and treatment.

Health care decisions that might have greater risks and consequences than those generally encountered in daily life, however, can only be made by individuals who have capacity to give "informed consent." These types of decisions can include whether to take part in invasive testing, surgery, or treatment for chronic or complex illnesses. Capacity or competence to give informed consent requires that the individual: (1) have an ability to understand the decision, the alternative options, and the risks of benefits; (2) have the ability to use the information in a logical and rational way to

[1] For a fuller discussion of this right, see the chapter on "Consent and Capacity to Make Decisions."

reach a decision; and (3) be able to communicate the decision verbally or through other means.

Some individuals with intellectual or other developmental disabilities have the capacity to make health care decisions, including those that require informed consent. Some individuals with intellectual or other developmental disabilities have capacity to make some medical decisions but not others, depending on the complexity of the issue. Even when individuals do not have capacity to make health care decisions, it is vital to involve them as fully as possible in the decision-making process.

Finally, it is important to remember that a person who has the capacity to consent to health care also has the capacity to refuse health care. A person's decision to refuse health care which most people would authorize does not suggest that a person lacks capacity to make decisions. All people who have capacity to consent to health care have the corollary right to refuse treatment.

II. SUBSTITUTE DECISION-MAKING IN HEALTH CARE

While individuals with intellectual or other developmental disabilities often can make some types of health care decisions, there may be situations in which they will be unable to do so. Moreover, most individuals who do not now have disabilities may reach a point in their lives when they are no longer able to make their health care decisions. Under Pennsylvania law, various devices are available to allow substitute decision-makers to act for individuals who lack capacity to make some or all of their health care decisions.

A. Guardianship

"Guardians of the person" can be appointed by a court to make some or all decisions for persons who are determined to lack capacity. "Plenary" guardians of the person have authority to make medical decisions for the persons in their care. "Limited" guardians of the person have only those powers specified by the court, although such powers can include the authority to make some or all medical decisions for the persons in their

care. "Guardians of the estate" deal solely with financial matters and have no authority to make medical decisions.

The chapter on guardianship describes more fully when guardians can be appointed, the duties of guardians, and alternatives to guardianship. Two alternatives to guardianship -- advance health care directives and health care representatives -- are further detailed in this chapter.

Although guardians of the person may have authority to make medical decisions, they do not have the authority to withhold or refuse life-preserving treatment for individuals who do not have end-stage medical conditions or are not permanently unconscious.

Note: The phrases "end-stage medical condition" and "permanently unconscious" are used repeatedly in this chapter. Pennsylvania law defines an "end-stage medical condition" as an incurable and irreversible medical condition in an advanced state, caused by injury, disease, or physical illness that will, to a reasonable degree of certainty, result in death. It does not include permanent and irreversible physical, mental, or intellectual conditions where treatment can provide a benefit that does not merely prolong the process of dying, such as cerebral palsy or quadriplegia. Pennsylvania law defines "permanently unconscious" to mean total and irreversible loss of consciousness and capacity for interaction with the environment, such as a permanent vegetative stage or permanent coma.

B. Advance Health Care Directives

1. Advance Health Care Directives, Health Care POAs, and Living Wills

An "**advance health care directive**" is a health care power of attorney (POA), a living will, or a combination of those two documents.

- A **"living will"** is a document that expresses the wishes and instructions of an individual, known as the "principal," when the individual becomes incompetent and has an end-stage medical

condition or is permanently unconscious. Unlike a health care POA, discussed below, it is not necessary to appoint a "health care agent" in a living will to make decisions, though it is often wise to do so. A living will usually just sets forth specific types of end-of-life care (such as mechanical ventilation, dialysis, and supplying water and nutrition through tubes) and states whether the individual desires or does not desire such care at that stage. If, however, the instructions are more ambiguous (such as stating that the person desires a particular treatment only if necessary to alleviate pain), then it may be best to designate a health care agent to make those decisions.

- A "**health care POA**" is a document in which an individual, known as the "principal," designates one or more persons, known as "health care agents," to make health care decisions for the individual if she or he is determined to be incompetent to make those decisions. Unlike a living will, a health care POA can apply to all health care decisions that arise after a person becomes incompetent -- not simply to those decisions that arise at the end of life. For example, if a person is in a car accident resulting in a serious brain injury, but not in an end-stage medical condition or permanent unconsciousness, a health care agent acting under a health care POA will be able to make necessary health care decisions for her. If she only has a living will, a guardian may be needed to make her health care decisions.

Health care advance directives are important for everyone, regardless of disability. They allow individuals, while they have capacity to do so, to put in writing their wishes about the types of treatment they want and factors that should be considered in making treatment decisions in the event that they become unable to make those decisions for themselves. Health care advance directives thus assure that individuals' health care treatment wishes will be respected. These directives also have the benefit of relieving families and friends of the pressure of determining what the individuals would want in specific situations since the individuals have given them guidance.

As used in this section, the term "advance health care directive" will mean both living wills and health care POAs unless otherwise noted.

2. Ability to Make Advance Health Care Directives

Any individual who is of "sound mind" can make an advance health care directive as long as he or she meets one of the following criteria: (1) he or she is 18 years of age or older; (2) he or she has graduated from high school; (3) he or she has married; or (4) he or she is an emancipated minor.

The law does not explicitly define "sound mind," but, in essence, it means that the individual is able to make an informed decision about the matters in the advance health care directive. Again, it is important to remember that **a diagnosis of an intellectual or other developmental disability does not mean that a person cannot make an advance health care directive.**

Moreover, to the extent that an individual with such a disability can make an advance health care directive, he or she should be encouraged to do so to assure that their health care wishes are followed in the event that they become unable to make health care decisions in the future. Family, friends, advocates, case managers and other involved persons may be able to encourage and, where necessary, assist individuals with disabilities to create advance health care directives.

3. Creating Advance Health Care Directives

An advance health care directive must be made in writing. The document must be signed and dated by the individual who makes it (the principal). If an individual cannot write his signature, he can make a mark. If the individual is unable to sign or mark the document, another person can sign the document on his or her behalf if the individual specifically directs him or her to do so. Neither a health care provider who provides services to the individual nor the provider's agents, however, can sign the health care directive on behalf of the individual.

To be valid, a health care advance directive must be signed by at least two witnesses who are at least 18 years old. A witness cannot be the same person who has signed the document on behalf of an individual who is unable to sign the document.

The form of an advance health care directive can vary, although it is required that a health care POA identify the principal and the health care agent and declare that the principal authorizes the health care agent to make decisions on behalf of the principal. Although lawyers can draft advance health care directives, it is not necessary to hire a lawyer to do so. Pennsylvania law includes a statutory form for an advance health care directive that combines a health care POA and living will. This form can be completed and modified as needed to create a valid advance health care directive.

If family, friends, or the individual's physician is not aware that a person has created a health care advance directive, it may be meaningless. It is important that the individual make others aware of the document and where it can be found so that, in the event the individual becomes suddenly incapacitated, his or her wishes as expressed in the document will be followed. Accordingly, at a minimum, an individual should give copies to his or her primary physician and to any health care agent who is named in the document. Family and friends should also be aware that the document exists and where it can be located.

4. Health Care Advance Directives' Effective Dates

A living will becomes operative when: (1) a copy is provided to the individual's attending physician; and (2) the attending physician determines that the individual is both incompetent to make decisions and has an end- stage medical condition or is permanently unconscious.

A health care POA becomes operative when: (1) a copy is provided to the individual's attending physician; and (2) the attending physician determines that the individual is incompetent, regardless of whether the person has an end-stage medical condition or is permanently unconscious.

For purposes of determining whether a living will or health care POA is effective, "incompetent" means that the individual, despite receiving appropriate medical information, communication supports, and technical assistance, is unable to do any one of the following: (1) understand the potential benefits, risks, and alternatives involved in a particular health care decision; (2) make that decision on his or her own behalf; or (3) communicate that health care decision to any other person.

5. Termination and Revocation of Health Care Advance Directives

Unless the living will or health care POA has a termination date or has been revoked by the individual, it will remain in effect regardless of how long ago it was made.

An individual can revoke a living will at any time and in any manner regardless of his or her physical or mental condition. The decision to revoke must be communicated to the attending physician by the individual or someone who witnessed the individual's decision to revoke the living will.

In contrast, a health care POA can be revoked only when the individual is of sound mind and the revocation either must be in writing or communicated by the individual to the attending physician, health care provider, or health care agent. Although an individual must be of sound mind to revoke a health care POA, an individual who is incompetent has the authority to overrule a health care decision made by his or her agent that would withhold or withdraw life-sustaining treatment (treatment that merely prolongs dying for a person with an end-stage medical condition or that merely prolongs an unconscious state for a person who is permanently unconscious). The individual can overrule such a decision simply by personally informing his or her attending physician. An individual who is incompetent cannot overrule a health care decision made by his or her agent to provide life-sustaining treatment, however, as long as the agent’s decision is consistent with the POA.

6. Selection of Health Care Agents

As described above, a health care agent is a person who is designated by the individual to make decisions in accordance with his or her health care advance directive in the event that he or she becomes incompetent to make those decisions. Health care agents must be identified in health care POAs, but they are optional in living wills.

One of the key parts of creating an advance health care directive, particularly a health care POA, is the selection of a health care agent who will make decisions when the individual becomes incompetent. It is important for individuals to ask potential health care agents whether they are willing to serve in that capacity and, most importantly, whether they are comfortable following the individuals' wishes for health care treatment. Individuals should explore with potential health care agents their views about treatment to assure that, if the time comes when the individual can no longer make his own health care decisions, the person chosen as a health care agent will comply with the individual's stated wishes for treatment.

The individual's physicians, health care providers, and employees of the individual's health care providers cannot serve as health care agents. The only exception to this rule is if the physician, provider, or employee is related to the individual by blood, marriage, or adoption.

More than one person can be appointed as the individual's health care agent. Unless stated otherwise in the advance health care directive, multiple agents will be required to act jointly (that is, they must make decisions together). A health care advance directive also can (and probably should) identify one or more individual who will act as "successor" health care agents in the event that the health care agent is not available or refuses to act.

7. Health Care Agents' Authority

Unless otherwise provided in the health care advance directive, a health

care agent has authority to make any health care decision and to exercise any right and power regarding the individual's care, custody, and health care treatment the individual could have made and exercised when competent to do so. The health care agent's authority also can extend beyond the individual's death, allowing him or her to make anatomical gifts, dispose of the individual's remains, and consent to autopsies.

The health care agent's decisions, however, must comply with the individual's instructions in the health care advance directive. In the absence of specific instructions, the health care agent must consider the individual's preferences and values, including his or her moral or religious beliefs. If the health care agent does not know enough about those preferences and values, he or she should take into account what is known about the individual's preferences and values and consider the individual's best interests, taking into consideration the goals of preserving life, relieving suffering, and preserving or restoring functioning. In making these decisions, the health care agent should gather information on the individual's prognosis and acceptable medical alternatives regarding diagnosis, treatment, and supporting care.

8. Relationship Between Health Care Agents and Guardians

A guardian may be appointed for a person who becomes incapacitated even if he or she has a validly executed health care advance directive. An individual can nominate someone in his or her health care advance directive who should be appointed as a guardian, if necessary, and the court will honor that request absent good cause or disqualification.

If the guardian is different than the health care agent, the health care agent is accountable to the guardian as well as the individual who made the advance directive. The guardian has the same power to revoke or amend the appointment of a health care agent, but does not have the authority to revoke the advance directive or to amend its terms or instructions without judicial authorization.

C. <u>Health Care Representatives</u>

Individuals who have not made health care advance directives -- including those who never had capacity to execute such documents -- may have some health care decisions made for them by "health care representatives" without the necessity for guardianship or court approval.

1. Health Care Representatives' Authority & Duty

A health care representative can make health care decisions for an individual if all of the following circumstances are met: (1) the individual's attending physician has determined the individual to be incompetent to make a health care decision; (2) the individual is at least 18 years old or has graduated from high school or is married or is an emancipated minor; (3) the individual does not have a guardian who is authorized to make health care decisions; and (4) the individual either does not have a health care POA or he or she does have a health care POA but the appointed health care agent is not willing to act and there is no alternative health care agent previously designated by the individual.

There is a debate as to the types of health care decisions that a health care representative has authority to make. Although the Pennsylvania law creating health care representatives, known as Act 169, can be read to allow health care representatives to make decisions only for individuals with end-stage medical conditions or who are permanently unconscious, many hospitals and physicians, as well as others, interpret the law more broadly to allow health care representatives to make any health care decisions for individuals who meet the criteria set out in the preceding paragraph.

It may be a good idea for the family and friends of an individual with an intellectual or other developmental disability who has not made and cannot make a health care advance directive to discuss with the individual and his or her doctor the use of a health care representative to make decisions.

This will allow friends and family to explore whether and to what extent they will be permitted to make health care decisions for the individual, if necessary, without going to court to obtain legal guardianship.

2. Selecting a Health Care Representative

An individual who is of sound mind can identify the person or persons who he or she wants to serve as his or her health care representative. To make such a designation, the individual either must write and sign a document that designates the health care representative or personally tell his or her attending physician or health care provider.
If the individual has not designated a health care representative, the law provides that the following individuals can act as the health care representative in the following order of priority:

- the individual's spouse (unless a divorce action is pending) and adult children of the individual who are not the spouse's children;
- the individual's adult child;
- the individual's parent;
- the individual's adult sibling;
- the individual's adult grandchild;
- an adult who has knowledge of the individual's preferences and values, including religious and moral beliefs.

The individual's attending physician, his or her health care provider, and any service provider's employees cannot serve as the individual's health care representative unless they are related by blood, marriage, or adoption to the individual.

An attending physician or health care provider can require a person claiming the right to act as a health care representative to provide a written declaration made under penalty of perjury. This declaration should set forth facts and circumstances that are sufficient to establish that the person has authority to act as the health care representative.

3. Countermanding a Health Care Representative's Decision

Regardless of the individual's physical or mental capacity, he or she has authority at any time to countermand (that is, to overrule) a decision by a health care representative that would withhold or withdraw life-sustaining

treatment (that is, treatment that will merely prolong dying for a person with an end-stage medical condition or that will merely prolong an unconscious state for a person who is permanently unconscious). The individual can overrule such a decision to deny life-sustaining treatment simply by personally informing his or her attending physician. An individual who is incompetent cannot overrule a health care decision made by his or her health care representative to provide life-sustaining treatment, however.

D. MH/ID Providers

For individuals who do not have living relatives or legal guardians, Section 4417(c) of the Pennsylvania Mental Health and Intellectual Disability Act provides that mental health and intellectual disability facility directors (including, for example, group home operators) have the authority to consent to "elective surgery" when two physicians who are not employed by the facility determine that it is necessary. The Pennsylvania Department of Human Services has historically construed this law to permit providers to make health care decisions beyond "elective surgery" for individuals in their care who do not have living relatives or legal guardians.

This law, however, is limited. It does not permit the facility director to consent to psychiatric treatment, to AIDS/HIV testing, or to medical treatment that the individual is refusing. It does not permit facility directors to authorize Do Not Resuscitate Orders or refuse life-preserving treatment for someone who is not at the end-of-life. Moreover, facility directors cannot make end-of-life decisions for persons with end-stage medical conditions or who are permanently unconscious because they would be acting as health care representatives, and Pennsylvania law prohibits health care providers from acting as health care representatives.

***NOTE*:** The Department of Human Services has taken the position that facility directors can make end-of-life decisions for persons with end-stage medical conditions or who are permanently unconscious in the absence of a health care agent, court-appointed guardian, or health care representative. It suggests, however, that the facility director seek judicial

authorization prior to authorizing withdrawal of treatment or life-sustaining care or Do Not Resuscitate Orders for such individuals.

E. Life-Ending Decision-Making

Some issues regarding substitute health care decision-making that would effectively hasten or cause a person's death have been addressed above. Since this is such an important area, however, some further discussion is warranted.

1. Life-Sustaining Decisions for Persons at the End-of-Life

Generally, physicians or health care agents acting pursuant to living wills, health care agents acting pursuant to health care POAs, and health care representatives have authority to make decisions about life-sustaining treatment for persons with end-stage medical conditions or who are permanently unconscious. Life-sustaining treatment is treatment that will simply prolong the process of dying or maintain an individual in a state of permanent unconsciousness.

As noted in Sections II.B.5 and II.C.3 above, however, individuals who have end-stage medical conditions -- regardless of their physical or mental conditions -- can stop the implementation of decisions that would withhold or withdraw life-sustaining treatment to keep them alive by countermanding (that is, overruling) those decisions. This applies to decisions that are otherwise authorized in the individuals' living wills and health care POAs. It also applies to decisions made by health care representatives. (Technically, individuals who are permanently unconscious also have the right to countermand those types of decisions, but as a practical matter cannot exercise it.) In contrast, individuals with end-stage medical conditions who have court-appointed guardians with authority to make medical decisions probably cannot overrule those guardians' decisions to refuse life-sustaining treatment without going to court.

2. Life-Preserving Decisions for Persons Who Are Not at the End-of-Life

Unlike "life-sustaining treatment," "life-preserving treatment" refers to treatment or interventions necessary to save the life of an individual who does not have an end-stage medical condition or who is not permanently unconscious. The general rule is that life-preserving treatment must be provided to individuals.

There are two exceptions to this general rule. First, an individual who is competent can always refuse treatment, including life-preserving treatment. Second, a health care agent appointed under a health care POA can refuse or terminate life-preserving treatment if the individual expressly gave him or her authority to object to such treatment in the health care POA since the individual -- when competent -- effectively made the decision to refuse such treatment himself or herself.

Life-preserving treatment cannot be refused in any other circumstances. Accordingly:

- health care agents cannot refuse life-preserving treatment for individuals whose health care POAs do not explicitly authorize such decisions;
- health care representatives cannot refuse life-preserving treatment; and
- court-appointed guardians -- even those authorized to make medical decisions -- cannot refuse life-preserving treatment for people in their care.

3. Out-of-Hospital DNR Orders

A Do Not Resuscitate (DNR) order is an instruction by an individual that he or she does not want to receive cardiopulmonary resuscitation (CPR). Existing procedures for emergency medical services often require personnel to administer CPR when an individual has been found in cardiac or respiratory arrest, even if the person has an advance health

care directive that indicates that he or she does not want CPR administered.

Pennsylvania law allows individuals who do not want emergency CPR administered under these circumstances to secure written DNR orders and to wear bracelets or necklaces supplied by the Pennsylvania Department of Health that reflect their DNR wishes. When emergency medical services providers know that an individual has a DNR order (by examining the order itself or by seeing the DNR bracelet or necklace), they will not administer CPR to the individual. They will, however, provide other medical interventions necessary and appropriate to provide comfort and alleviate pain unless otherwise directed by the individual or the emergency medical service provider's authorized physician.

Individuals can secure these DNR orders, necklaces, or bracelets from their attending physician only if: (1) the attending physician certifies that the individual either has an end-stage medical condition or is both permanently unconscious and has a living will that directs no CPR to be provided; (2) the individual requests the DNR order, necklace, or bracelet; and (3) the individual is 18 years old, has graduated from high school, has married, or is an emancipated minor. An individual's health care agent or health care representative also can request such out-of-hospital DNR orders, bracelets, or necklaces.

An individual, regardless of his mental or physical condition, can revoke an out-of-hospital DNR order whether it was secured on his or her own request or by his or her health care agent or health care representative. It can be revoked verbally, by destroying it, or by not displaying the order, bracelet, or necklace.

4. Pennsylvania Orders for Life-Sustaining Treatment (POLST)

In addition to advance health care directives, health care representatives, and out-of-hospital Do Not Resuscitate (DNR) orders, Pennsylvania has adopted another way that individuals or their legally appropriate substitute decision-makers can direct their care in end-of-life situations – the Pennsylvania Orders for Life-Sustaining Treatment (POLST) Program.

The intent of the POLST Program is to improve the quality of care that individuals receive at the end of life by turning patient goals and preferences for care into medical orders.

The POLST Program: (1) assists health care professionals to discuss and develop treatment plans that reflect patient wishes; (2) results in the completion of a POLST form; and (3) helps health care professionals, health care facilities, and emergency personnel honor patient wishes regarding life-sustaining treatment in emergency situations. Use of the POLST form is completely voluntary, but it is recommended for individuals who have advanced chronic progressive illness and/or frailty, those who might die in the next year, or anyone of advanced age with a strong desire to further define their preferences of care.

The POLST form is not the same as a DNR order or an advance directive (health care power of attorney (POA) and/or living will), but the use of a POLST form is authorized by the same law that governs DNR orders and advance directives. The POLST form can be used in conjunction with a DNR order and/or an advance directive – it represents and summarizes a patient's wishes in the form of medical orders for end-of-life care. The POLST form is designed to be most effective in emergency situations and can be completed even in the absence of a DNR order or an advance directive.

For an adult with intellectual disabilities, as for an adult without disabilities, a POLST form can be completed based on the individual's own treatment choices as well as those choices expressed by a health care agent, a legal guardian, or a health care representative on the individual's behalf. As noted in Section II.E.2 above, however, neither a health care representative nor a legal guardian may use the POLST form to decline life-preserving treatment for an individual who does not have an end-stage medical condition or who is not permanently unconscious. Only a competent individual or a health care agent expressly authorized to object to such treatment in the health care POA can decline life-preserving care.

The POLST form, at a minimum, must include the patient name, resuscitation orders, and a signature of a physician, physician assistant,

or certified registered nurse practitioner. A physician countersignature is required for physician assistant signed forms within ten days or less as established by facility policy and procedure. The POLST form should be reviewed if: (1) the patient is transferred from one care setting or care level to another; (2) there is a substantial change in the patient's health status; the patient's treatment preferences change; (4) the patient has an emergency room visit and/or inpatient hospitalization; or (5) the patient or his or her substitute decision-maker identifies a reason for a POLST review (e.g., the patient's closeness to death, extraordinary suffering, improved condition, advanced progressive illness, etc.). In general, patients, including patients with intellectual disabilities determined to be incompetent to make their own health care decisions, can revoke a POLST form to the same extent that they can revoke a living will or overrule a health care agent's decision to withhold or withdraw life-sustaining treatment (treatment that will simply prolong the process of dying or maintain an individual in a state of permanent unconsciousness).

The POLST form is specifically designed to assure an individual's treatment choices for end-of-life care are respected whether the choices are for full or limited treatment or comfort measures only. The orders on the POLST form are based on a patient's medical condition and his or her treatment choices. A POLST form may only be completed after a discussion of end-of-life choices between a patient or his or her substitute decision-maker and the patient's attending physician. For more information about the POLST Program in Pennsylvania, visit the Aging Institute of UPMC Senior Services and the University of Pittsburgh website at www.aging.pitt.edu/professionals/resources-polst.htm.

NOTE: Ideally, the values and choices expressed through an advance directive will not conflict with the medical orders on the POLST form. If there is a conflict between these instruments, the one that is not representative of the patient's values and choices for medically indicated treatments should be amended. The attending physician should carefully elicit patient values from the patient and/or his or her substitute decision-maker and make sure that the POLST is consistent with these values. If it is a crisis situation and the goals of care are not clear, then the higher level of care should be provided until more information about the patient's

values and preferred treatment is known.

III. ACCESSING MEDICAL RECORDS

Health care agents appointed under advance health care directives, health care representatives, and court-appointed guardians generally have the same right to control the individual's records and information as the individual would have. Therefore, these substitute decision-makers can see the individual's medical records and discuss the individual's medical conditions with his or her treating physicians and providers. These substitute decision-makers also have authority to determine whether to release that information to third-parties. The only exception would arise if an individual created an advance health care directive that explicitly restricts the right of his or her health care agent to access or control his or her medical information, though such a restriction would be uncommon.

The ability to make a health care decision for a person who lacks capacity to do so often depends upon the decision-maker's ability to review and discuss with the individual's physicians or other providers health care information about the individual, including his or her diagnoses, prognosis, treatment alternatives, and supportive care. Substitute decision-makers -- whether health care agents, health care representatives, providers, or guardians -- should consider this information in light of the individual's express instructions, preferences, or values when making a decision.

CHAPTER 5: CAPACITY, SEXUALITY & FAMILY LIFE

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As people with intellectual disabilities increasingly live in inclusive community environments, they have greater opportunities to develop friendships, engage in sexual relationships, marry, and bear and raise children. The issue of capacity to consent lies at the heart of these often complex issues.

I. CAPACITY AND MARRIAGE

Although historically many states prohibited people with intellectual disabilities from marrying, this is no longer the case. But, this does not mean that people with intellectual disabilities have an absolute right to marry.

In Pennsylvania, the law provides that marriage licenses -- a prerequisite to statutory marriage -- cannot be issued "if either of the applicants for the license is weak minded, insane, of unsound mind or is under guardianship as a person of unsound mind unless the court decides that it is for the best interest of the applicant and the general public to issue the license and authorizes the issuance of the license." Accordingly, a marriage license technically may be denied to a person with an intellectual disability who either has a guardian or who is considered to be of "unsound mind."

Individuals with intellectual disabilities, however, have been able to obtain marriage licenses and to marry in Pennsylvania. Even when license applications are initially rejected, courts have authorized the issuance of licenses for such individuals.

Although Pennsylvania marriage law indicates that persons "under guardianship" cannot secure marriage licenses without court approval, Pennsylvania's guardianship law does not authorize a guardian -- even a plenary guardian of the person -- to prohibit the marriage of the individual who has been adjudicated incapacitated. A guardian of the person can secure the right to prohibit marriage by an incapacitated person only after the court holds a hearing on the specific issue, makes express findings of fact, and issues an order that addresses the issue explicitly.

II. CAPACITY AND SEXUALITY

Many people with intellectual disabilities want to have and do have relation- ships that include sexual expression. Yet, at the same time, it is important to recognize that some individuals with intellectual disabilities are particularly vulnerable to sexual exploitation and abuse. Indeed, people with intellectual disabilities are subject to sexual violence at higher rates than others. The ability of a person with an intellectual disability to participate in sexual activities with another person, however, will depend on his or her social understanding and capacity to consent to such activities.

Appropriate sex education can be a key to providing individuals with intellectual disabilities with the capacity to engage in voluntary sexual activities if they choose, to prevent sexual abuse or exploitation, and to understand appropriate sexual boundaries and behavior to prevent the possibility that they may face criminal charges.

A. Sex Education

It is important for individuals with intellectual disabilities to have access to meaningful, comprehensive sex education. For all people, regardless of disability, education helps to eliminate the vulnerability caused by ignorance, empowers individuals to make informed choices, enables them to recognize and report abuse, and enhances their capacity to express their sexuality in appropriate ways.

Sex education is particularly important to individuals with intellectual disabilities. These individuals may not have access to or be able to take advantage of the other resources through which people can informally learn about sexuality and its proper expressions. Difficulties reading may limit their ability to get information from books or other written materials. Their friends may not have much more knowledge about sex than they do.

There may be few opportunities for them to observe, model, and practice appropriate behaviors. Due to the lack of these positive sexuality

supports and education, individuals with intellectual disabilities may express their feelings in ways that others may deem inappropriate, or out of place for a given situation or location.

Sex education also provides people with intellectual disabilities with the information and language they need to recognize, prevent, report, and avoid sexual abuse and exploitation. Education can help individuals understand the difference between consensual sexual acts and sexual abuse. Education can also help individuals to overcome low self-esteem that might lead them to accept sexual advances from people who want to exploit them. Education additionally can provide them with the understanding that they have the right to say "no."

The goals of sex education for people with intellectual disabilities thus should include:

- providing them with the language resources they need to discuss sex (including anatomy and physiology);
- providing information about forms of romantic and sexual expression;
- teaching about the importance of privacy;
- understanding different types of relationships and what forms of contact or interaction might be appropriate;
- teaching and reinforcing good social skills in both public and private settings;
- providing information on the consequences of sex and how they can be avoided, including unwanted pregnancies and sexually transmitted diseases;
- helping them to understanding and avoid sexual abuse and exploitation and how to report it;
- helping them to reach their own understanding of what role they want sex to play in their lives in light of their own values.

There are various training techniques and curricula that are available (*e.g.*, a "buddy system" that links a student with an intellectual disability with another student who can help teach routine interactions; rehearsal and role playing techniques that allow individuals to practice how they

would behave in different situations; positive behavior supports to reward appropriate behavior). Of course, each individual with intellectual disabilities will have his or her own unique learning needs, and the program of sexual education should be adapted to best meet those needs.

In addition to school-based sex education, families and caregivers can play important roles, too. For instances, families can use "teachable moments" -- from a couple kissing or a wedding or a new baby or a storyline in a television show -- to discuss sexuality informally but with honesty, providing their own views but encouraging the individual to express his own views and to ask questions. Families and caregivers should also encourage their loved ones to ask questions and not react to questions judgmentally or critically. Families and caregivers can reinforce their own beliefs and society's beliefs of what sexual behavior individuals should conduct in private and what is acceptable in public. Perhaps most importantly, families and caregivers should facilitate the participation of the individual in community activities that give them a wide range of experiences and that enable them to have frequent and diverse social interactions and relationships.

B. The Absence of Consent

In Pennsylvania, sexual contact with an individual who has a mental disability which renders the individual incapable of consent constitutes a criminal act that can be prosecuted. It is not necessary to show force was involved; the absence of capacity to consent due to a mental disability can establish criminal liability. Thus, there are serious legal ramifications for sexual activity with an individual with an intellectual disability who cannot give consent.

Neither Pennsylvania's criminal statutes nor the case law clearly define how to measure whether a person with an intellectual disability is capable of consenting to sexual activity. Consent likely will be determined by assessing whether the individual: understands the nature of sexual contact; understands and is able to exercise the right to refuse the activity; and is familiar with the possible risks and consequences of the activity. In

one Pennsylvania case, for instance, the court upheld a rape conviction of a man who had sex with a woman with an intellectual disability who had been babysitting his child. The court credited the testimony of an expert that the woman was incapable of consenting to sexual intercourse because she had an IQ of 58, behaved in a manner "similar to that of a child," had limitations in her daily life, did not have good judgment, was highly influenced by others, and was not able to understand the consequences of her actions.

Often, as in the case discussed in the prior paragraph, professionals will be required to interview the alleged victim to determine if he or she was capable of providing consent to sexual activity. Several authors have identified a number of specific issues that should be considered in making that assessment, including:

- Does the person have an awareness of people, time, places, and events?
- Does the person have basic knowledge of sexual activities?
- Does the person know how to safely participate in sex (*e.g.*, using birth control)?
- Does the person understand the physical consequences and legal responsibilities of pregnancy?
- Is the person aware of sexually transmitted diseases and how to avoid them?
- Does the person understand that they can say "no"?
- Is the person able to call for help or report unwanted sexual advances or abuse?

All individuals are unique and should have the right to assume certain risks, including those relating to their choices regarding sexuality. It is the individual's role to make informed and personal choices about sexual activity in light of his or her own values and abilities. The law, though, does balance the individual's right to control of his or her own body and sexuality against the need to protect the individual from harm.

III. CAPACITY AND REPRODUCTIVE RIGHTS

Generally, people with intellectual disabilities should have the same legal rights to make their own decisions about procreation. Optimally, this decision would be made by each individual with intellectual disabilities, after receiving appropriate sexual education and consulting with his or her sexual partner, family, and a support team and would be based on the individual's personal values, realistic expectations and goals, and consideration of resources and potential legal issues. Questions of capacity, though, can affect the reproductive rights of people with intellectual disabilities. Specifically, the rights of individuals with intellectual disabilities to control their own bodies and make their own reproductive choices can be limited through non-consensual sterilization and limits on access to legal abortion based on the lack of capacity of the individual.

A. Sterilization

Non-consensual sterilization of individuals with intellectual disabilities cannot be authorized by family or providers. Court-appointed guardians also do not have authority to consent to the sterilization of a person who has been adjudicated incapacitated, unless the guardian petitions the court to allow the guardian to consent to the sterilization of the incapacitated person.

Courts can authorize guardians to consent to involuntary sterilization only after a hearing has been held on that specific issue and the court makes specific findings of fact that supports the decision. Since sterilization results in permanent termination of the right of procreation, the Pennsylvania courts will authorize sterilization only if they determine that it is in the best interest of the individual. Courts will look at a number of factors in reaching that decision, including:

- whether the person lacks capacity to make a decision about sterilization and whether that incapacity is unlikely to change in the future;
- whether the person is capable of having children;

- the likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual activity is forced upon him or her;
- whether sterilization is the only practicable means of contraception and that all less drastic contraceptive methods, including supervision, education, and training, are unworkable;
- whether the individual will experience trauma or psychological damage if she becomes pregnant and gives birth or if he fathers a child;
- whether the individual will experience trauma or psychological damage if he or she is sterilized;
- the possibility that the individual will at some point marry and, with a spouse, be able to care for a child;
- the inability of the person to care for a child;
- whether the guardian is acting in good faith and that his or her primary concern is for the best interest of the individual rather than his or her own or the public's convenience.

Individuals with intellectual disabilities whose guardians seek sterilization orders must be provided with court-appointed legal counsel (unless they already have an attorney to represent them) to defend their interests at the hearing. The court also should interview the individual involved to assess his or her physical and mental condition and allow them to express their own views on the subject. An individual's opposition to sterilization should weigh heavily against court authorization of the procedure.

B. Abortion

Generally, a woman with an intellectual disability should be able to make the same decisions about whether to terminate a pregnancy as a woman without a disability. Women with intellectual disabilities who have guardians, however, may see those choices restricted.

Under the "parental notification" provision of Pennsylvania's Abortion Control Law, a woman who has been adjudicated to be incapacitated and has a court-appointed guardian generally cannot choose to terminate a

pregnancy without notifying her guardian, just as a minor is required to notify her parents. A woman who has been adjudicated incapacitated, however, can opt to seek a court order to authorize the abortion if: (1) either the woman's guardian refuses to consent or if she chooses not to seek the guardian's consent; and (2) the court, after a hearing, determines either: (a) that the woman is mature and capable of giving informed consent and does in fact consent to the procedure, or (b) the woman is not mature and able to give informed consent, but an abortion would be in her best interests.

On the other hand, a woman who has been adjudicated incapacitated and who does not want to terminate her pregnancy has greater protections. Under Pennsylvania's guardianship law, a guardian cannot consent to the abortion for a person who has been adjudicated incapacitated without getting specific court approval for the procedure after the court holds a hearing and makes specific findings of fact. Moreover, it is arguable that courts do not have the power to authorize guardians to consent to terminating the pregnancy of an incapacitated person over her objection since Pennsylvania's Abortion Control Law provides that guardians cannot coerce persons who are incapacitated into having abortions.

IV. CAPACITY AND CHILD-REARING

All parents -- including those with intellectual disabilities -- generally have the right to raise their own children as they see fit. This right, however, is not absolute. When parents, including those with intellectual disabilities, are unable to provide for the needs of their children, their right to retain custody may be jeopardized and, eventually, they may be faced with the termination of their parental rights.

Under Pennsylvania's Juvenile Act, the Commonwealth can intervene with the rights of parents to raise a child if it believes that the child is "dependent." A dependent child is one who the court has determined does not receive proper parental care or control necessary for his physical, mental, or emotional health or morals. This can include:

- failing to provide the child with basic necessities, such as food,

clothing, or shelter;
- failing to provide the child with supervision or discipline appropriate to the child's age and capabilities;
- financially exploiting the child;
- not assuring that the child regularly attends school;
- not providing proper medical care and treatment.

A child may not be removed from the family home before the court determines that the child is "dependent" unless it is determined that the child should be taken into "protective custody" because there are reasonable grounds to believe the child is suffering from an illness or injury or is in imminent danger from his or her surroundings. The child can be held in protective custody for up to 72 hours. To hold the child for a longer period of time, the County Office of Children and Youth (OCY) must file a "shelter care" application, and a hearing must be held within 72 hours of the issuance of the protective custody order. Parents have the right to appointed counsel at the shelter care hearing if they are poor. At a shelter care hearing, the court will determine whether to maintain the child in an out-of-home placement or return this child to the home. The court will order the child to remain in an out-of-home placement if it finds that remaining in the home is contrary to the best interests of the child and that the County OCY made reasonable efforts to prevent the child's placement or that the lack of such efforts was reasonable. If continued out-of-home care is ordered, the County OCY must file a dependency petition within 24 hours.

Once a dependency petition is filed -- whether the child has been removed from the home or remained in the home -- the court will schedule an "adjudication hearing" to determine if the child is "dependent." Parents have the right to counsel at the adjudication hearing if they are poor. If the court determines that the child is dependent, it must schedule a "disposition hearing" to decide whether it is in the "best interests" of the child to permit him to remain in the family home with supervision by the County OCY and subject to conditions the court may set or to remove the child from the home and transfer temporary custody to a qualified individual, private agency, or public agency. The court can order removal only if there is "clear necessity" to

separate the child from the parents and must consider whether reasonable efforts were made to prevent placement. For children placed outside the home, the court will subsequently hold periodic "permanency review" hearings to determine the goals for the child (*e.g.*, family reunification or adoption). Ultimately, the County OCY can file a petition to terminate the parent's rights if it concludes that adoption is the goal.[2]

A child cannot be removed from the family home or adjudicated as "dependent" simply because one or both parents have intellectual disabilities. Nor can parents with intellectual disabilities have their parental rights terminated due solely to their diagnosis. On the other hand, a parent's diagnosis of an intellectual disability will not prevent the removal of his or her child, a dependency adjudication, or termination of parental rights if the parent is not able to meet the needs of the child due to the effects of the parent's disability.

Parents with intellectual disabilities should receive services and supports to help them to maintain their children at home. These services can include:

- "Services to Children in their Own Home" (also called SCOH services) are services that are made available to families to reduce the risk of abuse or neglect and to prevent out-of-home placement. SCOH services can include assistance with parenting and household organization, and medical, psychological, or other services or treatment;
- "Family Preservation" services that offer intensive, short-term, home-based intervention to remedy problem situations and avoid placement;
- parenting classes;

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[2] Court-appointed guardians cannot consent to the termination of the parental rights of an incapacitated person nor can guardians even seek judicial authority to provide such consent.

- anger management classes;
- intellectual disability services through the Medical Assistance Waivers that can help support the family (*e.g.*, homemaker or chore services).

It is imperative that parents with intellectual disabilities, their families, or advocates request these services through the County OCY or the County Intellectual Disability Program as soon as it becomes apparent that the parents are having difficulties. These services can help to prevent the removal of children from parents with intellectual disabilities and the termination of their parental rights.

CHAPTER 6:
MENTAL HEALTH ADVANCE DIRECTIVES

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People with mental illness have the same rights as people without mental illness. This includes the right to consent to or refuse health care treatment, including mental health treatment. Mental illness may render people incapable of making mental health treatment decisions at some point in their lives. At these times of crisis, in particular, mental health treatment decisions -- such as the choice of hospital and types of medications -- are critical, but the individual is unable to make his wishes known.

Since 2005, Pennsylvania has authorized individuals to make mental health advance directives. Mental health advance directives are documents that allow people with mental illness to make mental health treatment choices in advance and to have those decisions implemented in the event they later lose capacity to make treatment decisions. Mental health advance directives allow individuals to take responsibility for their treatment and to assure that their treatment decisions will be respected, thus encouraging individuals to seek treatment.

Mental health advance directives do not affect the provisions of Pennsylvania's Mental Health Procedures Act (MHPA) relating to voluntary and involuntary commitment. Thus, an individual who has a mental health advance directive is subject to involuntary commitment if he meets the standards of the MHPA. Mental health advance directives, however, will affect how the individual can be treated after he or she is committed and at other times when the individual lacks capacity to make mental health treatment decisions.

I. TYPES OF MENTAL HEALTH ADVANCE DIRECTIVES

Pennsylvania law recognizes two types of mental health advance directives: (1) a declaration, and (2) a power of attorney. Pennsylvania also allows individuals to make a combined mental health declaration and power of attorney. This allows the individual to make definitive decisions about some treatment issues, while leaving other issues to the discretion of his or her appointed agent.

A. Declarations

A mental health declaration delineates the person's preferences with respect to specific types of treatment. For instance, the declaration can state:

- The name of the facility or facilities where the individual would prefer to be treated in the event involuntary commitment is necessary and the names of any facilities where he or she prefers not to receive treatment. This decision cannot be legally binding because it is possible that there will not be an open bed at the preferred facility, because insurance will not cover the preferred facility, or because the individual is not near the preferred facility at the time of crisis. The individual's physician thus has the authority to place the individual in a facility that is contrary to his or her stated preference.

- Whether the individual consents to the administration of any medications. The declaration can identify any specific medications to which the individual does not consent. In doing so, the individual should explain in the declaration why the medication is refused, such as due to particular side effects, health risks, or because it has been tried and was not effective. It is important to explain the reasons for the refusal of particular medications so that the physician can select appropriate alternative medications that do not risk those side effects. The declaration also can identify which, if any, medications the individual specifically consents to receive and any limitations on that consent. Just because an individual consents to a specific medication, however, does not mean that it will be prescribed. The treating physician or psychiatrist will prescribe the medication only if it is clinically appropriate.

- Whether the individual authorizes electroconvulsive therapy.

- Whether the individual authorizes participation in experimental studies, including drug trials.

- Types of interventions that the individual prefers in the event of a crisis.

- Limitations on the release or disclosures of mental health records.

In the declaration, it is important for the individual to identify treatment that is effective. Mental health declarations also can include information about the individual's mental health history and describe activities that help or worsen symptoms. Declarations also can identify the person nominated by the individual to serve as his or her guardian should guardianship be pursued and determined by a court to be appropriate.

Beyond mental health issues, mental health declarations can also include instructions about dietary requirements, religious preferences, who should have temporary custody of children or care for pets, and who should be notified. These preferences, though, are not generally legally binding. Dietary requirements based on medical conditions or religious beliefs may be binding. Individuals cannot authorize psychosurgery or termination of parental rights through their mental health advance directives.

Since a declaration delineates precise instructions about treatment choices, it does not afford much flexibility. If an individual wants to make precise decisions about some but not all treatment choices, he or she can use a combined declaration and power of attorney that designates another individual to make those mental health treatment decisions for the individual if he or she is unable to do so and the matter is not covered by the declaration.

B. Powers of Attorney

A mental health power of attorney, in contrast to a mental health declaration, requires the individual to appoint an agent who will make mental health treatment decisions in the event the person becomes incapacitated. The agent is authorized to make mental health treatment decisions for the individual once the power of attorney becomes effective. Although the power of attorney can, and usually should, provide guidance to the agent about the individual's preferences and may even impose

limitations on the authority of the agent, it allows more flexibility in the decision-making process than a declaration.

In selecting an agent, the individual should make sure that it is someone he or she can trust to make the same mental health treatment decisions the individual would make for himself or herself. However, the individual's mental health treatment providers, such as doctors or their employees; certified peer specialists; ACT team members; case managers; or the owner, operator, or employee of a residential facility where the individual lives cannot be designated as the individual's agent. Before naming an agent, the individual should discuss with the proposed agent whether he or she is comfortable acting as the agent. The proposed agent should be aware that he or she is not liable for the costs of the individual's care and treatment. If the person agrees to be the agent, the individual and the agent should discuss the individual's feelings about different treatment options that the agent may be required to make. This will help to assure that the agent's decisions are the ones that will be most like those the individual would have made for himself or herself if he or she had capacity.

The mental health power of attorney can also identify one or more successor agents. These are individuals who will have authority to act as the agent in the event the initial agent is unable to act, withdraws, or is removed by a court. An agent may be removed by a court due to death, incapacity, failure to comply with the mental health power of attorney, physical assaults, threats of harm, coercion, or divorce (if the agent is the individual's spouse). If the spouse is the designated agent and either spouse files for divorce, the designation of the spouse as the agent will be considered to be revoked as of the time the action is filed unless the power of attorney makes clear that the designation was intended to continue notwithstanding a divorce action.

Beyond selecting an agent to make mental health treatment decisions, the mental health power of attorney can state:

- The name of the facility or facilities where the individual would prefer to be treated in the event involuntary commitment is necessary and the names of any facilities where he or she prefers not to receive

treatment. Just as with a declaration, this decision cannot be legally binding because it is possible that there will not be an open bed at the preferred facility, because insurance will not cover the preferred facility, or because the individual is not near the preferred facility at the time of crisis. The individual's physician thus has the authority to place the individual in a facility that is contrary to his or her stated preference.

- Whether the individual authorizes the agent to consent to the administration of any medications. Even if medication is authorized, the individual can still identify specific medications for which the agent has no authority to consent. A statement that the individual consents to a particular medication does not mean that the medication will be administered. Medication will be prescribed by a physician only if it is clinically appropriate.
- Whether the agent is authorized to consent to electroconvulsive therapy.
- Whether the agent is authorized to consent to participation in experimental studies, including drug trials.
- Types of interventions that the individual prefers in the event of a crisis.
- Any limitations on the agent's authority to release or disclose the individual's mental health record.

In the absence of specific instructions, the agent will make mental health care decisions after consultation with the individual's treatment professionals and after consideration of the diagnosis, prognosis, acceptable treatment alternatives, and possible side effects of those various alternatives. The mental health agent has the right to request and examine the individual's mental health care information so that the agent can make informed decisions.

Like a declaration, a mental health power of attorney can also include a description of the individual's mental health history and activities that may help or worsen symptoms. The power of attorney also can identify the person who the individual nominates to act as his or her guardian in the event that guardianship is sought and determined by a court to be appropriate. Mental health powers of attorney cannot authorize an agent

to consent to psychosurgery or to termination of the individual's parental rights.

Mental health powers of attorney can include instructions relating to dietary requirements, religious preferences, temporary custody of children or pets, and who the individual would like to be notified about his or her condition, although these preferences are generally not binding. Dietary requirements based on medical conditions or religious beliefs may be binding.

II. PREREQUISITES FOR MENTAL HEALTH ADVANCE DIRECTIVES

To make a mental health advance directive, a person must: (1) be at least 18 years old or an emancipated minor; (2) not subject to a guardianship order; and (3) not currently subject to involuntary commitment under the MHPA. Unless the individual has a guardian or is under an involuntary commitment order, he or she is presumed to have capacity to make a mental health advance directive. It is, however, possible for someone else to challenge the person's capacity to make the advance directive at a later time. To prevent this from happening, the individual might include with the mental health advance directive a letter from his or her treating physician to confirm that the individual had capacity at the time he or she made the advance directive.

In addition, the mental health advance directive must be signed and dated by the individual and at least two witnesses. Notarization is not required. If the individual cannot physically sign the document, another person may sign (though the signer cannot also serve as a witness and cannot be one of the individual's mental health care providers). Witnesses must be at least 18 years old. Witnesses are only responsible to attest that the person signed the document. The witness is not responsible to determine whether the person had capacity to make a mental health advance directive.

III. WHEN MENTAL HEALTH ADVANCE DIRECTIVES TAKE EFFECT

An individual can state in his mental health advance directive when he or

she wants it to take effect. For instance, the directive can state that it will take effect only if and when the person has been involuntarily committed. Alternatively, and more commonly, mental health advance directives are drafted to take effect when it is determined that the individual does not have capacity to make mental health treatment decisions. Lack of capacity is determined by the evaluation of the individual by two mental health care professionals, at least one of whom is a psychiatrist.

Mental health advance directives cannot take effect if people do not know that they exist. Thus, it is important for the individual to give copies of the directive to the person who would be called in an emergency, his or her mental health providers, treating physicians, the designated mental health agent, and family members or other people he or she would want to be notified. The individual should maintain the original in a safe place, but should tell other trusted people where it is located so that it can be retrieved in the event of a crisis and given to the attending physician. Individuals can also carry cards in their wallets that state they have a mental health advance directive and that provide contact information for people to call in the event the individual becomes incapacitated to make mental health treatment decisions.

IV. COMPLIANCE WITH MENTAL HEALTH ADVANCE DIRECTIVES

Once a mental health advance directive becomes effective, a provider must follow the instructions in the declaration or the directions of the appointed agent. The only exceptions are: (1) if the provider cannot comply with the instructions in good conscience because they are contrary to accepted clinical or medical practice; (2) if the provider's policies do not allow compliance (*e.g.*, because the treatment is not covered by the individual's insurance); or (3) if the treatment is physically unavailable.

If a provider cannot comply with the mental health directive for one of the reasons stated above, the provider must notify the individual if he or she is competent, his or her designated mental health agent, and any court-appointed guardian. In addition, the provider must make every reasonable effort to transfer the individual to another provider who can comply with his

or her wishes stated in the mental health advance directive. While a transfer is pending, the provider must treat the individual in accordance with his or her mental health advance directive to the extent possible. If reasonable efforts to transfer fail, the provider can discharge the individual.

V. DURATION OF MENTAL HEALTH ADVANCE DIRECTIVES

A mental health advance directive is valid for two years from the date the individual signs it. If the individual does not have capacity to make treatment decisions at the time his or her mental health advance directive would terminate, the directive will remain valid until the individual is able to make treatment decisions.

The mental health advance directive can terminate before the two-year period ends if: (1) the individual revokes the document; or (2) the individual makes a new mental health advance directive. The individual can revoke the mental health advance directive, in whole or in part, unless he has been determined to lack capacity to make mental health decisions or he has been involuntarily committed under the MHPA. Even when an individual has been involuntarily committed, however, he or she still may revoke the advance directive if a psychiatrist and another physician or mental health treatment professional examine him or her and determine that he or she is capable of making mental health treatment decisions. A revocation can be made orally or in writing, though it is preferable to do so in writing. It is effective as soon as the individual tells his or her physician or other mental health care provider.

An individual can also make changes to a mental health advance directive, without revoking it, at any time as long as he or she has capacity to do so. Any changes to the document must be signed, dated, and witnessed in the same way as the original document. Rather than amending the original document, it is preferable to create a new mental health directive (and revoke the prior one) to assure that the changes are clearly understood.

VI. IMPACT OF GUARDIANSHIP

In some circumstances, guardianship may be sought for an individual whose mental illness makes him incapable to make decisions. An individual can help to assure that a guardian acts in his or her best interests by identifying in his or her mental health advance directive the person who he or she would like to act as his or her guardian if guardianship is necessary. The court will generally appoint the person nominated by the individual to act as his or her guardian unless there is a good reason not to do so.

The individual should consider nominating his or her mental health agent as the potential guardian so that one person makes all important decisions. If a person other than the individual's mental health agent is appointed as his or her guardian, the court should still allow the agent to make mental health treatment decisions. If, however, the court authorizes the guardian to make mental health treatment decisions rather than the agent named in the individual's mental health advance directive, the guardian is still bound to make decisions in accordance with the instructions in the individual's mental health advance directive.

CHAPTER 7:
FINANCIAL POWERS OF ATTORNEY

I. CREATING A FINANCIAL POWER OF ATTORNEY 1

II. TERMINATION OF A FINANCIAL POWER OF ATTORNEY 3

APPENDIX 1: POWER OF ATTORNEY SAMPLE FORM/ NOTICE

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Generally, a "power of attorney" is a document through which an individual confers authority on another person to act on her behalf when the individual is unable or unavailable to make decisions herself. Powers of attorney can include authority to make physical health care decisions, mental health care decisions, financial decisions, or other decisions. For instance:

- An individual travelling to a foreign country for an extended period may create a power of attorney to allow another person to attend to his financial decisions in his absence (*e.g.*, have access to his checking account to pay bills).
- An individual who is in the early stages of a terminal illness may create a power of attorney to allow another person to have access to his finances and make financial decisions in the event that he becomes incapacitated and unable to make those decisions himself.
- An individual can create a health care power of attorney to appoint another person to make health care decisions for him if he becomes unable to make such decisions for himself due to illness, disability, or an accident.
- A young adult with a serious emotional disorder can make a power of attorney to give his parents or another person authority to make post-secondary education decisions in the event that his disability renders him unable to make those decisions himself.

Appointing a substitute decision-maker through a power of attorney can have many benefits. It may help to avoid guardianship proceedings, which can be costly for families. It also helps to assure that the substitute decision-maker is a person who is trusted by the individual and is likely to make decisions that accord with the individual's wishes.

This chapter addresses only financial powers of attorney. Issues relating to health care powers of attorney are addressed in Chapter 4 and issues relating to mental health powers of attorney are addressed in Chapter 6.

I. CREATING A FINANCIAL POWER OF ATTORNEY

Only adults (people age 18 years or older) who are able to make an informed decision can create a power of attorney. It is not necessary to

consult with an attorney to create a power of attorney, but it may be a good idea to do so to assure that the document is technically valid and accurately reflects the wishes and intents of the individual who makes it. A sample power of attorney is attached.

The power of attorney must be in writing. In the power of attorney, the individual (who is called the "principal") identifies another person (who is called the "agent") who will have authority to handle certain facets of the principal's affairs under specified circumstances. The power of attorney may identify more than one agent, but should state whether each agent has authority to make decisions, whether they both must consent to any decision, or whether each agent only has authority to exercise specific powers. The power of attorney may also specify a successor agent or agents in the event that the initial agent is unable or unwilling to act or may authorize the initial agent to designate a successor.

The power of attorney should state with specificity precisely what aspects of the principal's finances the agent will be empowered to handle. These can include:

- power to engage in real property transactions (such as buying or selling property for the principal or collecting rents owed to the principal);
- power to engage in personal property transactions (such as buying or selling furniture, cars, appliances, or equipment for the principal);
- power to engage in stock, bond, or other securities, commodities, or options transactions;
- power to borrow money for the principal;
- power to engage in insurance transactions for the principal (including purchasing or terminating insurance);
- power to engage in retirement plan transactions for the principal (including withdrawal or deposit of funds, making contributions, selecting or changing payment options);
- power to pursue claims and litigation for the principal;
- power to receive government benefits for the principal; and
- power to pursue tax matters.

A principal may also nominate in a power of attorney a person who she

would like to be appointed as guardian of her estate or her person in the event that guardianship proceedings are filed in the future. The court in such proceedings will appoint the person nominated by the principal unless there is good cause not to do so or the person nominated is disqualified from acting.

The power of attorney should also state with specificity when it will become effective. Usually, it will become effective only in the event the principal becomes incapacitated to make financial decisions, but it may become effective immediately or at a specific time chosen by the principal.

The principal must sign and date the power of attorney. If the principal signs using a mark or has someone else sign for him, the power of attorney must also be signed by two witnesses aged 18 or older and neither can be the person who signed the power of attorney for the principal.

The power of attorney must also include a specific notice that appears in the beginning of the document and that must be signed by the principal.

The notice indicates that the principal understands the power of attorney. The agent is also required to sign the document to acknowledge that she recognizes and accepts her responsibilities under the document. The language of the notice and acknowledgement is dictated by Pennsylvania law.

The power of attorney may be filed with the clerk of the Orphans' Court Division of the Court of Common Pleas in the county where the principal resides. The power of attorney also can be recorded in the office for the recording of deeds of the county where the principal resides and in each county where the principal has real property that will be affected by the power of attorney.

II. TERMINATION OF A FINANCIAL POWER OF ATTORNEY

A power of attorney is presumed to be "durable." In other words, the power of attorney will continue in effect indefinitely after the time or event

when the power of attorney becomes effective unless it is revoked by the principal. A principal, however, can include language in the power of attorney that makes it non-durable by stating the circumstances that will result in its termination (such as a specific date). If there is no termination date or event in the power of attorney, it will continue in effect and actions by the agent under the power of attorney will be binding regardless of how long ago it was made.

A power of attorney can be revoked by the principal at any time when the principal gives notice to the agent. The notice can be oral, but it is preferable to put it in writing to document that the agent had actual knowledge that the power of attorney was revoked.

A power of attorney will be terminated upon the death of the principal. However, actions taken by the agent under the power of attorney will be binding until the agent has notice of the principal's death as long as the agent acted in good faith.

If a principal has executed a non-durable power of attorney, it will be terminated upon the principal's incapacity. However, actions taken by the agent in good faith will be binding until the agent has notice of the principal's incapacity and acted in good faith. Incapacity will not terminate a durable power of attorney.

If a principal designates his spouse as his agent and thereafter a divorce proceeding is started, the designation of the spouse as the agent will be revoked as of the filing of the divorce unless it appears from the language in the power of attorney that the principal intended the spouse to continue as his agent even in the event of divorce.

If a principal is adjudicated by a court to be incapacitated in a guardianship proceeding and the court appoints a guardian for his estate, the agent designated in the power of attorney will be accountable to the guardian as well as to the principal. The guardian will have the same power to revoke or amend the power of attorney as the principal would have if he were not incapacitated.

APPENDIX 1

POWER OF ATTORNEY SAMPLE FORM

NOTICE

THE PURPOSE OF THIS POWER OF ATTORNEY IS TO GIVE THE PERSON YOU DESIGNATE (YOUR "AGENT") BROAD POWERS TO HANDLE YOUR PROPERTY, WHICH MAY INCLUDE POWERS TO SELL OR OTHERWISE DISPOSE OF ANY REAL OR PERSONAL PROPERTY WITHOUT ADVANCE NOTICE TO YOU OR APPROVAL BY YOU.

THIS POWER OF ATTORNEY DOES NOT IMPOSE A DUTY ON YOUR AGENT TO EXERCISE GRANTED POWERS, BUT WHEN POWERS ARE EXERCISED, YOUR AGENT MUST USE DUE CARE TO ACT FOR YOUR BENEFIT AND IN ACCORDANCE WITH THIS POWER OF ATTORNEY.

YOUR AGENT MAY EXERCISE THE POWERS GIVEN HERE THROUGHOUT YOUR LIFETIME, EVEN AFTER YOU BECOME INCAPACITATED, UNLESS YOU EXPRESSLY LIMIT THE DURATION OF THESE POWERS OR YOU REVOKE THESE POWERS OR A COURT ACTING ON YOUR BEHALF TERMINATES YOUR AGENT'S AUTHORITY.

YOUR AGENT MUST KEEP YOUR FUNDS SEPARATE FROM YOUR AGENT'S FUNDS.

A COURT CAN TAKE AWAY THE POWERS OF YOUR AGENT IF IT FINDS YOUR AGENT IS NOT ACTING PROPERLY.

THE POWERS AND DUTIES OF AN AGENT UNDER A POWER OF ATTORNEY ARE EXPLAINED MORE FULLY IN 20 Pa.C.S. CH. 56.

IF THERE IS ANYTHING ABOUT THIS FORM THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A LAWYER OF YOUR OWN CHOOSING TO EXPLAIN IT TO YOU.

I HAVE READ OR HAD EXPLAINED TO ME THIS NOTICE AND I UNDERSTAND ITS CONTENTS.

_____ _____

(Principal) (Date)

I, (name) , of (municipality) of (County) , State of Pennsylvania, hereby appoint the following as my lawful agent(s):

- (name of agent) (address)

- (relationship to principal) (phone number)

- (name of agent) (address)

- (relationship to principal) (phone number)

If more than one agent is named above, please check one of the following:

- My agents must act together pursuant to this Power of Attorney.

- My agents may act either alone or together pursuant to this Power of Attorney.

Powers of Agent(s): Consistent with 20 Pa.C.S. Ch. 56, my agent(s) hereby have the authority to exercise the following powers, as appropriate and if in my best interest, when this Power of Attorney becomes effective:

__ Make limited gifts.

__ Create a trust for my benefit.

__ Make additions to an existing trust for my benefit.

__ Claim an elective share of the estate of my deceased spouse.

__ Disclaim an interest in property.

__ Renounce fiduciary positions.

__ Withdraw and receive the income or corpus of a trust.

__ Authorize my admission to a medical, nursing, residential, or similar facility and to enter into agreements for my care.

__ Authorize medical and surgical procedures.

__ Engage in real property transactions.

__ Engage in tangible personal property transactions.

__ Engage in stock, bond, and other securities transactions.

__ Engage in commodity and option transactions.

__ Engage in banking and financial transactions.

__ Borrow money.

__ Enter safe deposit boxes.

__ Engage in insurance transactions.

__ Engage in retirement plan transactions.

__ Handle interests in estates and trusts.

__Pursue claims and litigation.

__ Receive government benefits.

__ Pursue tax matters.

__ Make an anatomical gift of all or part of my body.

[Note -- You do not have to list all of these. Choose only those authorities you want your agent to have.]

Effective Date: This Power of Attorney will become effective (check one):

_____ Immediately

_____ In the event I am out of the country for more than _____ consecutive days.

_____ On (fill in specific date)

_____ In the event I lack capacity to make informed decisions on the matters listed above.

Spouse as Agent: If an agent named above is my spouse, I understand that the Power of Attorney will be revoked as to that agent if either I or my spouse files for divorce unless I indicate otherwise by checking below:

_____ This Power of Attorney shall remain in full force and effect, even if my agent or I file for divorce.

Durable or Non-Durable: I understand that a durable Power of Attorney is meant to continue despite any incapacity or disability I may experience. I also understand that a non-durable Power of Attorney cannot continue if I choose to have it terminated on a specific day or if I become incapacitated or experience a disability. I intend as follows (check one):

_____ This Power of Attorney is durable and will continue even if I become incapacitated or have a disability that impedes my decision-making.

_____ This Power of Attorney is non-durable and will terminate on (date) or in the event I become incapacitated or experience a disability that impedes my decision-making, whichever comes first.

_____ _____

Signature of Principal Date

_____

Principal's Printed Name

If you are physically unable to sign your name, then you may sign this form by making your mark on the Principal's Mark line below. By making this Mark you are also acknowledging that you understand the contents of the Notice on the first page. You must have two witnesses sign their names and write their addresses in your presence.

_____
Principal's Mark

_____
Principal's Printed Name

We, the undersigned witnesses, hereby attest that the principal placed his or her mark above, that we observed the principal make the mark above, that the principal's name was subscribed near the mark in the principal's presence before or after he or she made the mark, and that we then signed our names below in the presence of the principal and in the presence of each other.

1. _____ _____
Witness's Name Address

2. _____ _____
Witness's Name Address

ACKNOWLEDGEMENT OF AGENT(S)

I, (name of agent(s)) , have read the attached Power of Attorney and am the person identified as the agent for the principal. I hereby acknowledge that in the absence of provision to the contrary in the Power of Attorney or 20 Pa.C.S. when I act as agent:

I shall exercise the powers for the benefit of the principal.

I shall keep the assets of the principal separate from my assets. I shall

exercise reasonable caution and prudence.

I shall keep a full and accurate record of all actions, receipts and disbursements on behalf of the principal.

_____ _____

Agent's Signature Date

_____ _____

Agent's Signature Date

CHAPTER 8: EDUCATIONAL DECISION- MAKING UNDER THE IDEA

I. SCOPE OF PARENTAL DECISION-MAKING 1

II. IDENTIFYING THE "PARENT" 1

III. "SURROGATE" PARENTS 2

IV. CHILDREN IN THE CUSTODY OF THE STATE 3

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Generally, **parents** are the **substitute decision-makers** for their children on an array of decisions, including decisions relating to their education. Under the Individuals with Disabilities Education Act (IDEA), parents have the right to make decisions concerning their children who have disabilities. The IDEA is a federal law that requires public schools to provide special education and related services to school-age children with disabilities who need such services to meaningfully access and participate in education. Although in other circumstances parents lose the right to make decisions for their children once they reach age 18, parents retain authority to make IDEA-related education decisions for their children until they graduate from high school or turn 21, whichever happens first.

I. SCOPE OF PARENTAL DECISION-MAKING

There are a number of procedural and substantive decisions under the IDEA that parents have the right to make for their children, including:

- determining whether the child should be evaluated for special education services;
- identifying what services and supports should be included in the child's individualized educational plan (IEP);
- determining whether to approve or challenge the IEP;
- determining whether to pursue dispute resolution processes, like mediation or administrative hearings;
- reviewing the child's education records.

II. IDENTIFYING THE "PARENT"

Under the IDEA, it is the "parent" who has the right to make IDEA-related education decisions. The IDEA, however, recognizes that "parents" are often persons other than the biological parents. Accordingly, the IDEA identifies the following people who may be the "parent" authorized to make education decisions:

- a biological parent;
- an adoptive parent;
- a foster parent;

- a **guardian** who is authorized to act as the child's parent or to make education decisions for the child;
- an individual who acts in the place of a biological or adoptive parent (including a grandparent, stepparent, or other relative) if the child lives with that individual or if that individual is legally responsible for the child's welfare;
- a "surrogate" parent.

There are times when it is possible for a child to have more than one "parent." This can create problems if those parents do not agree on educational decisions. The school must recognize a birth or adoptive parent who is attempting to act on behalf of the child in the special education system as the educational decision-maker unless that person's legal right to make educational decisions for the child has been terminated by a judge or a judge has appointed a different person to make educational decisions. If a birth or adoptive parent has the right to make educational decisions for his or her child but is unable or unwilling to do so, the school can recognize the authority of another person as the "parent" if he or she fits into one of the categories stated above, such as a foster parent or relative with whom the child is living.

In some situations, a child's biological parents may not agree on an education decision. If the parents have joint legal custody, the IDEA allows the school to accept the decision of either parent. For example, one parent may agree to the IEP while the other concludes it is inadequate. The school may implement the IEP based on the authorization of one parent.

The other parent has the right to pursue dispute resolution, such as filing for a due process hearing, to challenge the IEP. If only one biological parent has legal custody of the child, the other parent can participate in the IEP process but cannot make special education decisions for the child.

III. <u>"SURROGATE" PARENTS</u>

Sometimes, a school is legally responsible for appointing a "surrogate"

parent to serve as the educational decision-maker for a child under the IDEA. A surrogate parent has all the rights that a birth or adoptive parent would have related to the provision of free, appropriate public education to the child and the identification, evaluation, and educational placement of the child under the IDEA. A surrogate parent does not have authority to make decisions outside of the special education context. A school must appoint a surrogate parent when:

- there is no other person who can be the "parent" as defined by the IDEA;
- the school cannot locate a parent, as defined by the IDEA, after reasonable efforts;
- the child is a ward of the State, but only if there is no biological or adoptive parent who has the authority to make educational decisions, no foster parent, and no court-appointed guardian; or
- the child is an "unaccompanied homeless youth" as defined by the federal law that protects the rights of homeless youth.

The school must make reasonable efforts to appoint a surrogate parent for a child within 30 days of determining that the child needs a surrogate parent. In identifying a surrogate parent, the school:

- cannot appoint an employee of the school, the local school district, the state education agency, or any agency involved in the education or care of that child (including a children and youth agency);
- must choose a person who does not have a personal or professional interest that conflicts with the interests of the child in getting identified, evaluated, and receiving a free appropriate public education in the least restrictive educational placement; and
- must choose a person who has the knowledge and skills necessary to assure adequate special education services.

IV. CHILDREN IN THE CUSTODY OF THE STATE

If a child is in the custody of the children and youth system because he has been declared "dependent" or "delinquent" and removed from the home, he or she is a "ward of the state." The fact that a child is a ward of

the state does not automatically strip other persons who are "parents" under the IDEA, such as biological parents, from continuing to make educational decisions for the child. The Juvenile Court, however, may appoint a surrogate parent for a child who is a ward of the state unless the child has a foster parent. If the Juvenile Court appoints a surrogate for a child who is a ward of the state, then, for instance, biological parents no longer have the right to make education decisions for their child. In identifying a surrogate, the Juvenile Court must follow the guidelines listed in Section III, above.

Most importantly, the Court cannot appoint the children and youth agency (or any employee of that agency) to act as the surrogate.

When a child has a foster parent, the Juvenile Court may not appoint a surrogate as the foster parent is the child's "parent" under the IDEA. The Court may, however, appoint a guardian and authorize the guardian to make educational decisions for the child, which would make the guardian the "parent" under the IDEA. The guardian cannot be the child's caseworker. The Juvenile Court also can appoint a guardian to make education decisions for a child who has been adjudicated dependent even if he or she remains in the parent's home and is not in the custody of the children and youth agency.

CHAPTER 9:
SUBSTITUTE DECISION-MAKING THROUGH TRUSTS

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Trusts are frequently created to benefit persons with disabilities. While the main purpose is often to assure that the individual with disabilities does not lose essential government benefits, the result is that the individual does not have direct control over the money or other assets in the trust. Instead, a third-person controls those assets and, essentially, is charged with making decisions about how those assets should be used. In this sense, trusts are a form of financial substitute decision-making for individuals with disabilities.

Trusts in general can be a very complex topic. Trusts designed for individuals with disabilities can be even more complex. This is an area in which consultation with an attorney who specializes in this field is essential. Given the important role of trusts for many persons with disabilities, however, this chapter is intended to familiarize people with some of the terminology used in this area, the different types of trusts used to benefit people with disabilities, and the role of the **trustee**.

I. TRUST TERMINOLOGY

It is important to understand the different words and phrases that relate to trusts. Understanding trust terminology, though, can be difficult because multiple words can describe the same thing and because different people sometimes use the same words to mean very different things. Below is a list of some key terms, definitions of those terms, and, when appropriate, a list of alternative terms that can describe the same thing.

"Trust" -- A trust is a property interest where the property is held by an individual or entity called the "trustee," who is designated to use the property for the benefit of another person, known as the "**beneficiary**."

"Grantor" -- A grantor is the individual who creates the trust by providing assets or property to be held for the beneficiary and who creates the terms of the trust that says how it should be invested and spent. A trust may have more than one grantor. A trust can be created by a grantor who is acting through another person if the other person is legally authorized to do so (such as the **parent** of a minor child or the court-appointed **guardian** for

an adult). The grantor is also known as a "**settlor**."

"Trustee" -- A **trustee** is a person who holds the legal title to property for the use or benefit of another person under the terms of the trust agreement. A trustee can be an entity (such as a bank or non-profit association) as well as a person. A trust can have more than one trustee.

"Beneficiary" -- A trust beneficiary is a person for whose benefit a trust exists. A beneficiary does not hold legal title to the property in the trust, but does have an "equitable ownership interest" in it. There can be more than one trust beneficiary.

"Trust Agreement" -- The trust agreement is the document that governs how the trust will be implemented, including: identifying the trustee and beneficiary; stating whether it can be revoked and, if so when; and detailing any specific instructions for how the trustee can invest and spend the trust property.

"Trust Principal" -- The trust **principal** is the property that is placed in the trust by the grantor. The trust principal can consist of cash, stocks, bonds or other personal property, or real property (such as a house or land). The trust principal includes any earnings on the trust that may accumulate, such as interest, dividends, or rent. The trust principal is also sometimes referred to by the Latin word "**corpus**."

"Trust Earnings" -- Trust earnings are the amounts earned by investment or management of assets in the trust. This can include interest, dividends, rent or other returns on investment, depending on how the trust principal has been invested. Trust earnings can also be called **trust income**.

"Discretionary Trust" -- A discretionary trust is a trust in which the trustee is given total discretion as to how, when, or even if to make any distributions to the beneficiary.

"Mandatory Trust" -- The opposite of a discretionary trust, a mandatory trust requires that the trustee pay trust earnings or principal to the

beneficiary at certain times. For example, it may require payment of a specific sum each month or it may require the trustee to pay specific bills for the beneficiary.

"Inter Vivos Trust" -- An inter vivos trust is a trust that is established during the lifetime of the grantor. It is sometimes called a "**living trust**."

"Testamentary Trust" -- A testamentary trust is a trust that is established by the grantor's will and is effective at the time of grantor's death. This is a common estate planning method used by relatives of people with disabilities.

"First-Party Trust" -- A first-party trust is a trust in which the grantor or a person acting on his or her behalf (such as a parent or legal guardian) creates a trust using the grantor's property as the trust property and in which the grantor is also the sole beneficiary. For example, when a person with a disability receives a legal judgment or an inheritance or gift, it may be critical to place that property in a certain type of trust to maintain his or her continued eligibility for government benefits. Note that because a first-party trust is established by an individual for his or her own benefit, this can only be an "inter vivos" trust and never a testamentary trust. A first-party trust is also known as a "**grantor trust**" or a "**self-settled trust**."

"Third-Party Trust" -- A third-party trust is a trust established for the benefit of a person other than the grantor and that is not funded with assets of the beneficiary. For example, a parent may establish a trust for his child using the parent's savings. A third-party trust can be established during the grantor's lifetime (inter vivos) or by his or her will (testamentary).

"Revocable Trust" -- A revocable trust is a trust in which the grantor retains the power to reclaim or take back the property in the trust. Generally, the trust agreement will state whether and how a trust can be revoked.

"Irrevocable Trust" -- An irrevocable trust is one in which the grantor has no authority to reclaim or take back the property in the trust. In some

states, even a trust that is termed an "irrevocable trust" may be deemed revocable under state law.

"Supplemental Needs Trust" -- A supplemental needs trust is a third-party trust that includes language that states that the intent of the trust is to supplement, and not supplant, government benefits such as Supplemental Security Income (SSI) or Medical Assistance (MA) and that limits the trustee's authority to make distributions in a manner that assures that the beneficiary's government benefits will not be jeopardized. This is sometimes called a "**common law trust**" because whether the trust will jeopardize the beneficiary's federal benefits is determined by state judicial decisions and not by federal or state statutes.

"Special Needs Trust" -- A special needs trust is a type of first-party trust that, if it meets the requirements established by federal and state law, will not count as a resource in determining whether the grantor is eligible for SSI or MA. This type of trust is also known as a "**payback trust**." You should be aware that sometimes the terms "special needs trust" or "supplemental needs trust" are used generally to denote any type of trust -- including third-party trusts established by a relative to benefit a person with a disability -- that is intended to protect the person's eligibility for government benefits. The Social Security Administration (SSA), however, tends to refer to "special needs trusts" to mean only those first-party trusts that meet federal criteria to protect benefits. Special needs trusts are discussed further in Section IV.B.1, below.

"Pooled Trust" -- A pooled trust is another type of first-party trust that, if it meets the requirements established by federal and state law, will not count as a resource in determining whether the grantor is eligible for SSI benefits or MA. Pooled trusts are discussed further in Section IV.B.2 below.

II. GOVERNMENT BENEFITS & TRUSTS

Individuals with disabilities often receive government benefits for income, housing, and medical care. Eligibility criteria for these benefits vary based on the type of program.

- *Benefits Available Regardless of Income and Resources* -- Some types of benefits do not have financial eligibility requirements. Key examples of these benefits are Social Security benefits (including Social Security Disability), veterans' benefits, and Medicare.

- *Benefits that Depend on a Person's Income and/or Resources* -- Some types of government benefits will be available only if a person meets certain financial eligibility criteria. Key among these benefits is SSI and MA. Individuals whose income or resources exceed the low thresholds for eligibility set by federal law will lose their SSI and MA benefits.

Many (although not all) people with disabilities receive SSI benefits, which provide a small monthly cash benefit for people with low incomes and resources. Even more importantly, people with disabilities often receive MA, which provides critical health care, benefits, and services necessary to enable them to remain in their own homes and communities.

To be eligible for SSI and MA, an individual's "income" and "resources" cannot exceed set levels, which are fairly low. Accordingly, if a person with a disability inherits money or receives payment as a result of a legal judgment or settlement of a lawsuit, those sums more likely than not will disqualify the individual from continued SSI and MA eligibility.

Simply putting money in a trust for a beneficiary with a disability may not protect that individual's SSI and MA eligibility. Sometimes, trust income will count as income to the beneficiary and the trust property may count as a resource for the beneficiary, either of which might cause the beneficiary to lose his government benefits. If structured and implemented properly, however, these assets can be placed in a trust that will enable the person to maintain his or her eligibility for SSI and MA while providing him or her with the benefit of additional funding to meet needs that may not be met by the government benefits.

III. THIRD-PARTY TRUSTS & FEDERAL BENEFITS

Relatives often choose to create trusts with their own property to benefit a person with a disability. They may create the trusts during their lives (an inter vivos trust) or do so through their wills (a testamentary trust).[3] There are both state and federal guidelines that govern the impact of a third-party trust on SSI and MA eligibility.

A. Third-Party Trusts & SSI Eligibility

The SSA has established internal guidelines that govern when a third-party trust will be counted as a resource for the beneficiary with a disability for purposes of determining his eligibility for SSI. These guidelines are in the SSA's Program Operations Manual (POMS) § SI 01120.200.[4]

SSA will count the trust principal as an available resource to the beneficiary if: (1) the beneficiary has legal authority to revoke the trust (and then can use the trust principal to meet his needs for food and shelter); *or* (2) the beneficiary can direct the use of the trust principal for his support and maintenance under the terms of the trust. POMS § SI 01120.200D.

Generally then, as long as a third-party trust does not authorize a beneficiary to revoke the trust (which almost never occurs) and if the trust is a discretionary trust (rather than a mandatory trust that requires fixed payments to the beneficiary), the trust principal in a third-party trust will not count as a resource to the beneficiary.

While the trust principal of an irrevocable, discretionary third-party trust

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[3] Trusts are one of several estate planning options that may be considered when a relative has a disability. For more information about estate planning in general, review the publication titled "Estate Planning for Families of People with Disabilities" available on DRP's website, http://www.DRPpa.org/publications.

[4] The entire SSA Program Operations Manual is available online at https://secure.ssa.gov/apps10/.

may not count as a resource, the beneficiary's SSI eligibility may be jeopardized by disbursements from such a trust that may count as income depending on who receives the disbursement and the purpose of the disbursement. Specifically:

- Cash disbursements from such a trust directly to the beneficiary will count as unearned income.
- Disbursements to a third-party (that is, a person or entity other than the beneficiary) to pay for the beneficiary's food or shelter will be considered income in the form of in-kind support and maintenance.
- Disbursements to a third-party for items other than food or shelter generally are *not* considered income. Thus, the trustee may be able to use the trust principal to pay for the beneficiary's educational expenses, medical expenses, recreation, and entertainment.

POMS § SI 01120.200E.1.[5]

B. Third-Party Trusts & Medical Assistance Eligibility

If a person loses his eligibility for SSI because his income or resources exceed federal standards, then his continued eligibility for MA benefits also will be jeopardized. Thus, a key prerequisite to the beneficiary of a third-party trust maintaining his or her MA eligibility is to assure that the third-party trust is properly drafted to meet the criteria described above and to assure that disbursements are made in a way that they do not count as income to the beneficiary.

Simply meeting the SSI eligibility standards may not be enough, however. A third-party trust beneficiary's MA benefits may be jeopardized if the trust does not satisfy state law.

The Pennsylvania courts, in a series of decisions, have held that

[5] If the trust principal of a third-party trust counts as a resource to the beneficiary, then the disbursements from the trust to or for the benefit of the beneficiary do not count as income. They will, however, be considered conversion of a resource. POMS § SI 01120.200E.2.

"supplemental needs trusts" established by third parties can be an effective means of providing for the needs of a person with a disability without jeopardizing his MA eligibility, but only if those trusts meet certain standards. The following are brief summaries of the key state court decisions that analyzed different trusts to determine if they counted as "resources" for purposes of determining a beneficiary's MA eligibility.

- *Lang v. Commonwealth, Dep't of Public Welfare* -- The Pennsylvania Supreme Court in 1987 held that a discretionary, testamentary trust created for the benefit of all of the grantor's multiple children would not count as an available resource to one of the children who had a disability, and thus he remained eligible for Medical Assistance services. The Court identified several factors that supported its conclusion: (1) the trust was a discretionary, not a mandatory, trust (and, as such, the trustee had the power -- but not a duty -- to provide support to the Medical Assistance beneficiary); (2) the trust was established for the benefit of all of the grantor's children, not solely for the child with a disability; and (3) during the grantor's lifetime, the child with a disability received government benefits due to his disability, demonstrating that the grantor intended the trust to supplement other resources available to that child only if those government benefits are not adequate or are discontinued.

- *Commonwealth Bank and Trust Co., N.A. v. Commonwealth, Dep't of Public Welfare* -- The Pennsylvania Supreme Court in 1991 held that the trust principal of a testamentary trust was a resource for purposes of determining the beneficiary's eligibility for Medical Assistance. Although the trust was discretionary, the Court cited the following factors to hold that the trust counted as a resource: (1) the grantor, at the time he executed his will and created the trust, had a duty to care for the beneficiary (his mother); (2) there was only one life beneficiary;[6] (3) the trust did not instruct the trustee to consider

[6] A "life beneficiary" is a trust beneficiary who will receive distributions from the trust during his or her life. The trust will also identify one or more "remaindermen" to whom the trust principal will pass when

the impact on government benefits when making distributions; and (4) the bulk of the grantor's estate was not placed in the trust, but, rather, was distributed to other people through the grantor's will.

- *Snyder v. Commonwealth, Dep't of Public Welfare* -- The Pennsylvania Supreme Court in 1991 concluded that the testamentary trust's principal did not count as a resource and, thus, did not jeopardize the beneficiary's Medical Assistance eligibility. The Court focused on the following factors: (1) there were two life beneficiaries (including a Medical Assistance recipient who had a disability), and the trustee was charged with considering the needs of both; and (2) at the time of the grantor's death, the Medical Assistance recipient/beneficiary had been receiving public benefits so the grantor had been aware of the availability of such benefits, and it was unlikely that he intended to deprive him of those benefits.

- *Estate of Rosenberg v. Dep't of Public Welfare* -- The Pennsylvania Supreme Court in 1996 held that the principal of a testamentary trust did count as a resource to the trust beneficiary who was a Medical Assistance recipient. The Court cited the following factors in reaching that conclusion: (1) there was only one life beneficiary (the grantor's widow); and (2) during the grantor's life, the beneficiary received no public benefits.

- *Shaak v. Pennsylvania Dep't of Public Welfare* -- The Pennsylvania Supreme Court in 2000 held that the trust principal was an available resource since the beneficiary was the sole beneficiary and since the beneficiary never received public assistance prior to the creation of the trust.

In sum, there appear to be certain critical factors that must be included in any third-party trust designed for the benefit of a person with a disability to protect it against being counted as a resource and, thus, jeopardizing a

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the life beneficiary dies.

beneficiary's eligibility for MA. These factors include:

- A clear statement of intent that the grantor intends the trust to use the trust principal and income to supplement, not supplant, government benefits.
- More than one beneficiary and language that makes clear that the trustee should consider the needs of all beneficiaries in taking any actions.
- The trustee should have absolute discretion over the payment of income or principal to the beneficiary with a disability.
- Evidence that the beneficiary with a disability received government benefits before the creation of the trust.

Although these seem to be the main factors, there are other trust provisions that might be included to help insulate the beneficiary against loss of government benefits. It is essential that persons who are considering placing assets in a trust for the benefit of a person with a disability consult with an attorney with experience in this field and/or with one of the non- profit organizations listed in Section IV.B.2 that have experience in this field.

IV. FIRST-PARTY TRUSTS & FEDERAL BENEFITS

A. General Rule

There are times when an individual with a disability has or receives assets in his or her own right, such as through an inheritance or as a result of a legal judgment or settlement. These assets can jeopardize the person's continued eligibility for SSI or MA. Congress has enacted strict standards for when a trust funded with the assets of an individual or his spouse (first-party trusts) will count as "income" or "resources" for purposes of determining the individual's eligibility for those federal benefits.

The general rule established by federal law is that first-party trusts will count in determining the grantor/beneficiary's SSI and MA eligibility. 42 U.S.C. §§ 1382b(e)(1)-(3), 1382b(e)(6), 1396p(d)(1)-(3), 1396p(e)(1); *see*

also POMS SI § 01120.201. Specifically:

- If a first-party trust can be revoked by the grantor/beneficiary, then the trust principal is considered to be an available resource and payments to or for his or her benefit will be considered income.

- If a first-party trust is irrevocable, then any portion of the trust principal (including trust income) from which payment could be made to or for the benefit of the individual will be considered a resource and any payments to or for the benefit of the individual will be considered income.

These rules apply regardless of the purpose for which the trust was established, whether the trustees have discretion under the terms of the trust, and whether there are any restrictions on distributions from the trust. *See* 42 U.S.C. § 1382b(e)(2)(C); POMS SI § 1120.201C.2.d.

B. Exceptions

Although first-party trusts, as described above, will generally count as income and resources to the grantor/beneficiary, Congress established two types of trusts that are exceptions to that rule and that enable people with disabilities to protect their eligibility for federal benefits by putting their assets into such trusts.[7] These trusts are known as: (1) special needs trusts (or payback trusts), and (2) pooled trusts. 42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)[8]. In addition, SSA may waive the provisions that count a trust

[7] These exemptions apply only to trusts established after January 1, 2000 (for purposes of establishing SSI eligibility) or to trusts established after January 1, 1993 (for purposes of establishing Medical Assistance eligibility).

[8] Although a special needs or pooled trust may protect the individual's entitlement to benefits, it may not always be the optimal choice. If the funds available to the individual with a disability are sufficiently large and can cover the person's needs for most of his or her life, then the benefit of keeping access to the money without limitations may outweigh

as a resource or income for purposes of determining SSI eligibility to the extent that counting the trust would impose an undue hardship.

1. *Special Needs Trusts (Payback Trusts)*

Congress required that a trust meet all of the following criteria to qualify as a "special needs trust" that will not be counted as income or resources for purposes of determining the grantor/beneficiary's eligibility for SSI and MA:

- The trust must contain the assets of an individual with a disability who is under age 65 or the assets of his or her spouse.
    - The exception will continue to apply after the individual reaches age 65 as long as it was established prior to his or her 65th birthday. Additions to the trust principal after age 65, however, will not be subject to the exception and could jeopardize continued eligibility for benefits.
    - "Disability" means that the individual meets the disability standards of SSI.
- The trust must be established for the individual's benefit by a parent, grandparent, a legal guardian, or a court.
    - The trust must be for the sole benefit of the person with a disability. This means that the trust cannot provide benefits to any other person during the lifetime of the person with a disability (though payments to third-parties for goods or services for the person with a disability are permitted).

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the cost of placing the money in a special needs or pooled trusts where access to it by the individual with the disability is extremely limited. Conversely, if the individual receives only a small sum of money, then it might make more sense to simply spend it quickly. This may result in a short-term loss of benefits, but it may enable the person to purchase certain things he or she needs or to pay off debts and then to resume eligibility for benefits.

- The individual with a disability cannot establish the trust directly; rather, it must be established by a parent, grandparent, legal guardian, or court. If the individual with a disability is an adult who is legally competent, a parent or grandparent can establish a "seed" trust using his or her own money after which the individual with a disability can transfer his own assets into that trust. You should note that the exception will not apply to a trust created by a parent or grandparent acting pursuant to a financial **power of attorney** executed by a legally competent adult.
- A court can only create a special needs trust if it does so by an order. It is not sufficient for the court to merely "approve" a trust.

- The trust must specifically provide that, when the beneficiary dies, the state will receive any amount remaining in the trust up to the amount of MA payments made by the state for the individual.
- The trust must be irrevocable.[9]

In 2005, Pennsylvania enacted a statute that also establishes requirements that must be met for a special needs trust to be exempt from counting as a resource for purposes of determining MA eligibility. 62 Pa. Cons. Stat. Ann. § 1414. Like the federal requirements, the state law requirements apply only to first-party trusts. The state law has somewhat more stringent standards for a special needs trust to be exempt from counting as a resource, including the following:

- The beneficiary must have "special needs" that will not be met

[9] Although the federal statutory standards do not mention the issue of revocability, the SSA has indicated that special needs trusts must still be evaluated under POMS § SI 01120.200D.1.a (which indicates that only irrevocable trusts will not count as resources) to determine if it is a resource. POMS SI § 01120.203D.1.7. 42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)(A); *see also* POMS SI § 01120.203B.1.

without the trust. Special needs are defined as items, services, or products that are not covered by MA or any other third-party for which the individual or his parents are personally liable and that will increase the beneficiary's quality of life and assist in or be related to the treatment of his disability. Special needs include medical expenses, dental expenses, nursing or custodial care, behavioral health services, rehabilitative services, education, and transportation and travel expenses.

- The trust must provide both that all distributions must be for the sole benefit of the beneficiary and that any trust expenditure must have a "reasonable relationship" to the "needs" of the beneficiary.[10]

2. *Pooled Trusts*

Congress required that a trust meet all of the following criteria to qualify as a "pooled trust" that will not be counted as income or resources for purposes of determining the grantor/beneficiary's eligibility for SSI and MA:

- The pooled trust must be established and maintained by a non- profit association. The non-profit association's trust is sometimes called a "**master trust.**"
- Each account must be established solely for the benefit of an individual with a disability. "Disability," for purposes of a pooled trust, means a disability that meets SSI standards. Unlike special needs trusts, there is no age limit.[11]

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[10] While the Pennsylvania law defines "special needs" quite narrowly and seems to exclude needs that are not medical or treatment-related, that definition may only affect whether the beneficiary qualifies to have a special needs trust. In contrast, the Pennsylvania law states that distributions from the trust must have a rational relationship to the individual's "needs" -- not "special needs." Thus, it is arguable that distributions from the trust can be used for items or services that do not meet the definition of "special needs" and are not medical or treatment-related.

[11] Although there is no age restriction, persons over age 65 who

- Each account must be established through the actions of the individual with a disability or his or her parent, grandparent, legal guardian, or a court. Note that, unlike special needs trusts, a competent adult with a disability can directly establish an account in a pooled trust.
- Each beneficiary's assets must be retained in a separate account, but the assets from all accounts are pooled for purposes of management and investment.
- The trust must provide that, to the extent that amounts remaining in the beneficiary's account upon his death are not retained in the pool by the master trust, then the trust must pay to the state the amount remaining in the account up to the total amount of MA paid by the state for the beneficiary.
- The trust must be irrevocable.[12]

42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4)(A); *see also* POMS SI § 01120.203B.2.

Pennsylvania enacted the Pooled Trust Act in 2002, which also establishes standards for pooled trusts that operate in Pennsylvania. 62 Pa. Cons. Stat. Ann. § 1965.1 *et seq.* The Pooled Trust Act provides that the interest of any beneficiary with a disability in a pooled trust will not be considered as a resource for purposes of determining the beneficiary's eligibility for MA. 62 Pa. Cons. Stat. Ann. § 1965.6(a).

More significantly, Pennsylvania's special needs trust statute, discussed in Section IV.B.1 above, also affects pooled trusts. This law places additional restrictions on pooled trusts beyond those in the federal law. Specifically:

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transfer assets to a trust may be subject to a transfer penalty.

[12] Although the federal statutory standards do not mention the issue of revocability, the SSA has indicated that pooled trusts must still be evaluated under POMS § SI 01120.200D.1.a. (which indicates that only irrevocable trusts will not count as resources) to determine if it is a resource. POMS SI § 01120.203B.2, 01120.203D.2.7.

- The beneficiary must be under age 65.
- The beneficiary must have "special needs" that will not be met without the trust, as discussed in Section IV.B.1 above.
- The trust must provide both that all distributions be for the sole benefit of the beneficiary and that any trust expenditure have a "reasonable relationship" to the "needs" of the beneficiary.
- A pooled trust cannot retain more than 50 percent of any trust amounts that remain at the time of the beneficiary's death and that the rest must be paid to the Commonwealth up to the amount equal to the total MA paid on behalf of the beneficiary.

Pa. Cons. Stat. Ann. § 1414.[13]
In *Lewis v. Alexander*, this provision of Pennsylvania law was challenged, and a federal appellate court concluded that it improperly created a more restrictive methodology for determining eligibility for MA benefits and was therefore preempted by federal law.

In Pennsylvania, there are several non-profit organizations that administer pooled trusts, including:

- The Family Trust (412-995-5000 ext. 565), http://www.achieva.info/trustservices.php

- The Arc Community Trust of Pennsylvania (610-265-4788), http://www.arctrust.org.

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[13] Although pooled trusts, unlike special needs trusts, limit the state's right to receive reimbursement for Medical Assistance expenditures (because they allow the pool to retain at least some of the assets), at least one Pennsylvania court has held that the Department of Human Services cannot require a Medical Assistance recipient to place his or her assets in a special needs trust rather than a pooled trust. *Lewis v. Magee Women's Hosp. of UPMC*.

- Securet Trust (866-389-6339), http://www.securettrust.org.

3. *Undue Hardship Exception*

A trust that would otherwise count as resources or income for purposes of determining SSI eligibility may be exempted if counting the trust would result in an "undue hardship." 42 U.S.C. § 1382b(e)(4); POMS SI § C. An individual must apply to the SSA for an undue hardship waiver in order to invoke this exemption. An undue hardship will be found to exist if:

- failure to receive SSI payments would deprive the beneficiary of food or shelter;[14] and,
- the beneficiary's available funds do not equal or exceed the Federal benefit rate plus the federally administered state supplement, if any.

This exception only applies to irrevocable trusts and to trusts that specifically prohibit disbursements that would provide for the beneficiary's support and maintenance.

V. DUTIES OF TRUSTEES & LETTERS OF INTENT

A trustee -- whether a person or an entity -- owes a "**fiduciary duty**" to the beneficiary. This means, that in dealing with the trust property and income, the trustee must act in good faith and with undivided loyalty to the beneficiary. Thus, for example, the trustee probably should not invest the trust **principal** in investments in which the trustee has a personal interest. The trustee's fiduciary duty also requires him or her to use reasonable care and skill to preserve the trust property, to make it productive, and to account for it.

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[14] A person will be considered to be deprived of shelter if he or she would be subject to eviction from his or her current residence without access to SSI and if there is no other affordable housing available or there is no housing available with necessary modifications for the person's disability.

It is important to select a trustee with care since he or she will have the authority to manage the key assets for the individual with a disability that will impact his or her quality of life. In choosing a trustee, it is important to consider whether the person is ready to make a long-term commitment to managing the trust; is sensitive to the needs of the beneficiary with a disability; is willing to take the steps necessary to advocate for the individual with a disability to maintain his eligibility for benefits when appropriate; and has the knowledge and experience necessary to make sound investments. While family members can often serve as the trustee, you might also consider having a professional trustee serve as a co-trustee. In selecting a trustee, you should also compare the fees that different trustees may charge for their services.

Although not a legal document that binds a trustee or anyone else, a **Letter of Intent** may be important. The Letter of Intent reflects what is important to the person with a disability and his family. It may set out the person's routines, likes and dislikes, medical history, habilitation and treatment needs, and future plans. It may also identify people who are important to the person with a disability. This Letter of Intent can help to guide a trustee, as well as the individual with disability's current or future caregivers, to help assure that he or she has a high quality of life and that his or her wishes are respected. A Letter of Intent should be reviewed from time to time to keep it as current as possible.

VI. RESOURCES

Some additional resources and materials related to trusts for people with disabilities are identified below.

Statutes & Regulations

42 U.S.C. § 1382b(e) (trusts under SSI)

42 U.S.C. § 1396p(c)-(d) (trusts under Medical Assistance)

62 Pa. Cons. Stat. Ann. § 1414 (Medical Assistance treatment of special needs trusts & pooled trusts under state law; much of the statute relating to pooled trusts was declared invalid in *Lewis v. Alexander*)

62 Pa. Cons. Stat. Ann. § 1965.1 *et seq*. (Medical Assistance treatment of pooled trusts under state law)

55 Pa. Code 178.4 & 178.7 (Medical Assistance treatment of trusts under state law)

Social Security Materials

POMS SI 01120.200
POMS SI 01120.201
POMS SI 01120.203

Case Law

Commonwealth Bank & Trust Co., N.A. v. Commonwealth, Dep't of Public Welfare, 598 A.2d 1279 (Pa. 1991)

DeBone v. Dep't of Public Welfare, 929 A.2d 1219 (Pa. Commw. Ct. 2007)

Estate of Rosenberg v. Dep't of Public Welfare, 679 A.2d 767 (Pa. 1996)

Estate of Taylor v. Dep't of Public Welfare, 825 A.2d 763 (Pa. Commw. Ct. 2003)

Lang v. Commonwealth, Dep't of Public Welfare, 528 A.2d 1335 (Pa. 1987)

Lewis v. Magee Women's Medical Hosp. of UPMC, 67 Pa. D. & C.4th 362 (Pa. Com. Pls. 2004)

Lewis v. Alexander, _____ F.3d ____, June 20, 2012 WL 2334322 (3d Cir. 2012*Shaak v. Pennsylvania Dep't of Public Welfare*, 747 A.2d 883 (Pa.

1991)

Snyder v. Commonwealth, Dep't of Public Welfare, 598 A.2d 1283 (Pa. 1991)

Articles

Comment, *Supplemental Needs Trusts: A Means to Conserve Family Assets and Provide Increased Quality of Life for the Disabled Family Member*, 32 Duquesne L. Rev. 555 (1994).

Effland, R., and Heckt, M., "*Trusts and Estate Planning*," The Mentally Retarded Citizen and the Law, 116-143 (Kindred, M., Cohen, J., Penrod, D., and Shaffer, T., eds.; Freedom Press, 1976).

Gilfix, M., *Special Trusts for Asset Preservation Planning*, 132 Trusts & Estates 62 (Feb. 1993).

Frolik, L., *Discretionary Trusts for the Disabled Beneficiary: A Solution or Trap for the Unwary*, 46 U. Pitt. L. Rev. 335 (1985).

Nemore, P., Regan, M. and Perkins, J., *Just When You Thought You Had Learned The Rules, They Went and Changed Them: OBRA-93 Provisions Concerning Medicaid Transfers of Assets, Treatment of Certain Trusts, and Estate Recoveries*, 27 Clearinghouse Review 1199 (Feb. 1994).

Scales, K.C. and Anderson L.M., *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, 74 Pa. Bar Assn. Q. 169 (2003).

Schlesinger, S.J. and Scheiner, B.J., *OBRA '93 Makes Sweeping Changes in Medicaid Rules*, 21 Estate Planning 74 (1994).

Tobin, P., *Medicaid Basics and a Review of the Amendments to Medicaid Law under OBRA '93*, 231 P.L.I. 203 (1994).

Van Dolson, R.D., *Medicaid Eligibility Rules and Trusts for Disabled*

Children, 133 Trusts & Estates 51 (Apr. 1994).

CHAPTER 10: GUARDIANSHIP IN PENNSYLVANIA

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When an individual reaches the age of 18, regardless of any functional limitations or disabilities, s/he has the legal right to make decisions on his or her own behalf. Guardianship is one means by which a **substitute decision-maker** can act on behalf of an adult who lacks **capacity** to make some decisions. Only a court, after a legal proceeding, may judge an individual to be **incapacitated** and appoint a **guardian** for him or her. This chapter provides some basic information about alternatives to guardianship and about Pennsylvania's guardianship procedures.

I. ALTERNATIVES TO GUARDIANSHIP

While the appointment of a guardian for a person with limited or impaired mental functioning may in some cases be unavoidable in order to protect the individual's well-being, guardianship proceedings can be costly legal procedures that may be inconsistent with the goal of maximizing a person's independence. Alternatives to guardianship may prove equally effective at a substantially lower emotional and financial cost. The majority of persons with disabilities live in the community with the assistance of their families or a system of support services without the need for guardians. Before initiating guardianship proceedings, it is advisable to fully explore the alternatives.

Many people who cannot independently manage their finances seek the help of family or friends for money management. These voluntary relationships can often avoid the need for legal guardians. Additionally, habilitation programs can increase the degree to which people with disabilities can manage their finances, either independently or with assistance of others. Public benefits, such as Social Security Disability and Supplemental Security Income (SSI), can be managed without a guardian through the appointment of a **representative payee**. Advance planning by families can usually avoid the need for a guardian to manage gifts, inheritances, or other assets.

Many people with disabilities are able to make decisions concerning many or all of the non-monetary aspects of their lives without the assistance of a guardian. In some cases, family, friends, or service providers can assist in this decision-making process. Guardianship may be unnecessary even if a

person is unable to make decisions with the assistance of others. Often existing laws and practices aid in substitute decision-making. For example, medical providers routinely provide medical treatment at the request of families on behalf of persons with disabilities, even when there is a question of whether the individual understands the medical procedure to be undertaken. A family member or friend also can serve as a "**health care representative**" who can make medical decisions. 20 Pa. Cons. Stat. Ann. § 5461. If no family is available, the Mental Health and Intellectual Disability Act of 1966 permits service providers to **consent** to certain medical treatment on behalf of persons in group homes or other residential facilities. 50 Pa. Cons. Stat. Ann. § 4417(c).[15]

[15] This statute states: "The director of any facility may in his discretion and with the advice of two physicians not employed by the facility, determine when elective surgery should be performed upon any mentally disabled person admitted or committed to such facility where such person does not have a living parent, spouse, issue, next of kin, or legal guardian as fully and to the same effect as if said director had been appointed guardian and had applied to and received the approval of an appropriate court therefore." 50 Pa. Cons. Stat. Ann. § 4417(c). This provision has been construed to apply to health care decisions that involve procedures other than "elective surgery." This statute, however, does not permit substituted consent by providers for medical treatment in all cases. For example, it would not permit consent to psychiatric treatment (which is governed by the Mental Health Procedures Act, 50 Pa. Cons. Stat. Ann. § 7101 et seq.), to AIDS/HIV testing (which is governed by 35 Pa. Cons. Stat. Ann. § 7605), or to medical treatment when an individual is refusing treatment. A service provider also cannot consent to the cessation of life- preserving treatment (*i.e.*, treatment to save the life of a person who is not in an end-of-life situation). As of the publication of this chapter, the law was unclear regarding whether a service provider may consent to the cessation of ***life-sustaining treatment*** (*i.e.*, treatment to merely sustain the life of some in an end-of-life situation).

There are circumstances when the appointment of a guardian is unavoidable. Guardianship proceedings should be started, however, only after a problem has been identified for which there is no alternative solution. It is generally not advisable to initiate guardianship proceedings simply because a service provider or other professional recommends guardianship or suggests that guardianship is routinely needed for persons with severe disabilities or persons living in residential facilities.

II. GUARDIANSHIP PROCEEDINGS

A Pennsylvania court may appoint a "guardian of the person" for an individual who lives in Pennsylvania and a "guardian of the estate" for a person who has property in Pennsylvania if it determines after a hearing that the individual is "**incapacitated**" (previously referred to as "**incompetent**"). An incapacitated person is: [A]n adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety.

20 Pa. Cons. Stat. Ann. § 5501.[16]

Any qualified individual, corporate fiduciary, non-profit corporation, or county agency may serve as guardian. 20 Pa. Cons. Stat. Ann. § 5511(f). If no other person is willing or qualified to serve, a guardianship support agency may be appointed by the court. 20 Pa. Cons. Stat. Ann. § 5553(a). If appropriate, the court shall give preference to a person suggested by the incapacitated person. *Id.*; *Estate of Haertsch*, 649 A.2d 719, 720 (Pa.Super. Ct. 1994). The guardian must not have interests that conflict with those of the incapacitated person unless no alternative exists. 20 Pa. Cons. Stat. Ann. § 5511(f); *see also Wilhelm v. Wilhelm*, 657 A.2d 34, 49 (Pa. Super. Ct. 1995) (son of incapacitated person may be inappropriate guardian where son stands to benefit from money remaining

[16] The fact that a person is institutionalized does not create a presumption of incapacity. 20 Pa. Cons. Stat. Ann. § 5512.1(f).

in bank account upon father's death and where there is history of hostile relationship between children and **parents**). For persons residing in state facilities, the guardianship offices located at such facilities may be appointed guardian of the estate. 20 Pa. Cons. Stat. Ann. § 5511(f).[17] In addition, unless no alternative exists, residential service providers and their employees will not be appointed as guardian. *Id.*

A. Starting A Guardianship Proceeding

An interested person may file a petition in the Court of Common Pleas, Orphans Court Division for the appointment of a guardian of a person or the person's estate. The person who files the petition (the "petitioner") must personally serve the individual person for whom a guardian is sought (the "respondent") with a copy of the petition and written notice of the time, date, and place of the proposed hearing at least 20 days prior to the hearing. The notice must be in large type and simple language. The notice must explain the purpose and seriousness of the proceeding and the rights that can be lost as a result of the proceeding. The notice also must inform the respondent of his or her right to request the appointment of counsel and to have paid counsel appointed, if approved by the court. The petition also must give notice to other interested parties, such as family members. 20 Pa. Cons. Stat. Ann. § 5511(a).

B. The Guardianship Petition

All guardianship petitions must be written in plain language and must include the following information:

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[17] As a result of the decision in *Vecchione v. Wohlgemuth*, 377 F. Supp. 1361 (E.D. Pa. 1974), 426 F. Supp. 1297 (E.D. Pa. 1977), *aff'd*, 558 F.2d 150 (3d Cir. 1977), *cert. denied*, 434 U.S. 943 (1977), it is the routine practice of the Commonwealth to seek guardianship over the finances of many people living in state-operated facilities in order to assure that the Commonwealth receives payment for its services. This process can be avoided if an alternate representative payee, such as a family member, can be identified.

- the name, age, residence, and post office address of the respondent;
- the names and addresses of the respondent's spouse, parent(s), and presumptive adult heirs;
- the name and address of the person or institution providing residential services to the respondent;
- the names and addresses of other persons or entities that provide services to the respondent;
- the name and address of the person or entity whom the petitioner asks to be appointed as the guardian;
- a statement that the proposed guardian has no interest that is adverse to the respondent;
- the qualifications of the proposed guardian;
- the reasons why guardianship is sought;
- a description of the functional limitations and physical and mental condition of the respondent;
- the steps taken to find less restrictive alternatives; and,
- the specific areas of incapacity over which the petitioner requests that the guardian be assigned powers.

20 Pa. Cons. Stat. Ann. § 5511(e).

If the petitioner seeks appointment of a guardian of the estate, the petitioner must include (in addition to the information listed above), the gross value of the respondent's estate and net income from all sources to the extent known. 20 Pa. Cons. Stat. Ann. § 5511(e).

C. Respondent's Presence At the Hearing

The respondent must be present at the hearing unless either (a) a physician or psychologist states (under oath) that the person would be harmed by being present, or (b) it is impossible for him or her to be present due to his absence from Pennsylvania. At the request of the respondent or his or her counsel, the hearing may be held at the respondent's residence. 20 Pa. Cons. Stat. Ann. § 5511(a).

D. Right to Counsel

A respondent may hire counsel to represent him or her in a guardianship proceeding. The petitioner has an obligation to determine whether counsel has been retained by or for the respondent and, if the respondent does not have counsel, the petitioner must notify the court at least seven days prior to the hearing. The court, "in appropriate cases," may appoint counsel at no cost to the respondent if counsel has not otherwise been retained to represent the respondent, 20 Pa. Cons. Stat. Ann. § 5511(a), but the statute does not explain what constitutes an "appropriate case" for appointment of counsel. Residents of state psychiatric hospitals and state intellectual disability centers must have counsel appointed to represent them in guardianship proceedings. 204 Pa. Code §§ 29.41-29.42 (provides, in accordance with Pennsylvania Supreme Court orders, that special masters will be appointed to hear guardianship petitions for persons in state psychiatric hospitals and state intellectual disability centers; that such hearings will be held at the institutions; and that the respondent shall be represented by counsel).

E. Right to an Independent Evaluation

The respondent may petition the court for the appointment of an expert to perform an independent evaluation as to his or her capacity. The court will order such an evaluation for "cause." The guardianship law does not explain what constitutes "cause," and a judge will decide each request on a case-by-case basis. If the court chooses to order an independent evaluation, it must give due consideration to the evaluator nominated by the respondent. 20 Pa. Cons. Stat. Ann. § 5511(d); *see also In re Hyman*, 811 A.2d 605, 609 (Pa. Super. Ct. 2002) (holding that the court did not err in refusing the petitioner's request to appoint an independent evaluator where the court found that there was no need for guardianship).

III. DETERMINING WHETHER TO APPOINT A GUARDIAN

Under the guardianship statute, "'[t]he court has the power to place total control of a person's affairs in the hands of another. This great power creates the opportunity for great abuse.'" *In re Hyman*, 811 A.2d 605, 608

(Pa. Super. Ct. 2002) (quoting *Estate of Haertsch*, 609 A.2d 1384, 1386 (1992)). As such, the petitioner must establish by clear and convincing evidence that the respondent is incapacitated. 20 Pa. Cons. Stat. Ann. § 5511(a). In determining whether the respondent is incapacitated, the court must consider, among other things, the nature of the respondent's disability and the extent of his or her capacity to make or communicate decisions. 20 Pa. Cons. Stat. Ann. § 5512.1(a). To prove incapacity, the petitioner must present testimony from an individual qualified by training and experience in evaluating individuals with the respondent's alleged incapacities that establishes the nature and extent of the respondent's incapacities and disabilities; the respondent's mental, emotional, and physical condition; the respondent's adaptive behavior; and the respondent's social skills. 20 Pa. Cons. Stat. Ann. § 5518. In addition, the petitioner must present evidence regarding:

- the services being used to meet the essential requirements for the respondent's physical health and safety;
- the services being used to manage the respondent's financial resources;
- the services being used to develop or regain the respondent's abilities;
- the types of assistance required by the respondent;
- why no less restrictive alternative to guardianship would be appropriate; and,
- the probability that the extent of the person's incapacities may significantly lessen or change.

20 Pa. Cons. Stat. Ann. § 5518.

In determining whether a person is incapacitated, the court must also make specific findings concerning the respondent's need for guardianship services in light of existing alternatives, such as the availability of family, friends, and other supports to assist the individual in making decisions, and in light of the existence of any advance directives such as durable powers of attorney or **trusts**. 20 Pa. Cons. Stat. Ann. § 5512.1(a)(3); *see also In re Peery*, 727 A.2d 539, 541 (Pa. 1999) (a person cannot be incapacitated and in need of guardianship services if his impairment is

counterbalanced by assistance from friends and family or other supports). If the court determines that the respondent is incapacitated and needs guardianship services, it must then determine:

- whether the guardianship should be "limited" based upon the nature of the respondent's disability and his capacity to make and communicate decisions; and,
- the duration of the guardianship. 20 Pa. Cons. Stat. Ann. § 5512.1(a)(4)-(5).

The court will prefer to appoint a "limited guardian" if the respondent is partially incapacitated, but needs guardianship services. 20 Pa. Cons. Stat. Ann. § 5512.1(a)(6) The court may appoint a "plenary guardian" of the person and/or estate only upon specific findings that the person is totally incapacitated and in need of plenary guardianship services. 20 Pa. Cons. Stat. Ann. §§ 5512.1(c), 5512.1(e).

IV. POWERS OF A LIMITED GUARDIAN

If the court appoints a limited guardian, it must identify the powers of the guardian and those powers must be consistent with the court's finding of the respondent's limitations. 20 Pa. Cons. Stat. Ann. §§ 5512.1(b) 5512.1(d). The partially incapacitated person retains all legal rights other than those designated by the court's order as areas over which the limited guardian has power. 20 Pa. Cons. Stat. Ann. § 5512.1(g).

The powers of a limited guardian of the person may include:

- providing general care, maintenance, and custody of the partially incapacitated person;
- designating the partially incapacitated person's place of residence;
- assuring, as appropriate, that the partially incapacitated person receives appropriate training, education, medical and psychological services, and social and vocational opportunities;
- assisting the partially incapacitated person in the development of maximum self-reliance and independence; and,
- providing the required consents or approvals on behalf of the

partially incapacitated person.

20 Pa. Cons. Stat. Ann. § 5512.1(b).

In appointing a limited guardian of the estate, the court (in addition to outlining the guardian's specific powers and authority) must specify the portion of assets or income over which the limited guardian of the estate has assigned powers or duties. 20 Pa. Cons. Stat. Ann. § 5512.1(d).

V. DUTIES OF A GUARDIAN OF THE PERSON

The duties of any guardian of the person include: (1) assertion of the rights and interests of the incapacitated person; (2) respect for the wishes and preferences of the incapacitated person to the greatest extent possible; (3) participation, where appropriate, in the development of a plan of supportive services to meet the person's needs; and (4) encouragement of the incapacitated person to participate to the maximum extent of his or her abilities in all decisions that affect him or her, to act on his or her behalf when he or she is able to do so, and to develop or regain his or her capacity to manage his or her personal affairs to the maximum extent feasible. 20 Pa. Cons. Stat. Ann. § 5521(a); *see also Estate of Rosengarten*, 871 A.2d 1249, 1254-55 (Pa. Super. Ct. 2005) (holding that the guardian violated her duties by disregarding the expressed wishes of incapacitated person).

There are certain powers that a guardian of the person -- even a plenary guardian -- cannot exercise unless specifically authorized to do so by the court after a separate hearing. These are:

- consenting on behalf of the incapacitated person to sterilization, psychosurgery, electroconvulsive therapy, or removal of a healthy body organ;
- prohibiting the marriage or consenting to the divorce of the incapacitated person; and
- consenting on behalf of the incapacitated person to any experimental biomedical or behavioral medical procedure or participation in any biomedical or behavioral experiment.

20 Pa. Cons. Stat. Ann. § 5521(d).

There are certain other powers that a guardian of the person cannot exercise and cannot be authorized by any court to exercise. These are:

- consenting to the incapacitated person's admission to an inpatient psychiatric facility or a state institution for persons with intellectual disabilities;
- consenting to the relinquishment of the incapacitated person's parental rights;
- withholding or refusing to authorize the provision of **life- preserving treatment** for an incapacitated person who does not have an **end-stage medical condition** or is not **permanently unconscious;** and,
- forcing an incapacitated person to consent to an abortion except in an emergency situation.

20 Pa. Cons. Stat. Ann. § 5521(f); 18 Pa. Cons. Stat. Ann. § 3206(g); *In re D.L.H.*, 2 A.3d 505, 515 (Pa. 2010).

VI. DUTIES OF A GUARDIAN OF THE ESTATE

The Pennsylvania guardianship statute details a number of matters that may be handled by a **guardian** of the estate, including insurance, continuation of a business, investments, and sale of personal property. 20 Pa. Cons. Stat. Ann. § 5521(b). In exercising those duties, a guardian of the estate must use the standard of care that a person of ordinary prudence would practice in the care of his own estate. *Estate of Rosengarten*, 871 A.2d at 1256 (indicating that a guardian who charged for services that could have been performed by others free of charge probably violated her duty). A guardian must manage the estate exclusively for the benefit of the incapacitated person and is not permitted to obtain any undue profit or advantage from his position and may not place himself in a position in which his personal interests are in conflict with those of the incapacitated person. *In re Adler,* No. 1144IC, 2003 WL 22053309 at *3 (Pa. Com. Pl. 2003).

VII. INFORMATION THE COURT MUST PROVIDE IF IT APPOINTS A GUARDIAN

If the court determines that the respondent is incapacitated and appoints a guardian, it must assure that the respondent is informed of his or her right to appeal and his or her right to petition to modify or terminate the guardianship. 20 Pa. Cons. Stat. Ann. § 5512.1(h).

VIII. APPOINTMENT OF AN EMERGENCY GUARDIAN

A person may file a petition for appointment of an "emergency guardian" for persons who are present in Pennsylvania and who need the immediate appointment of a guardian. 20 Pa. Cons. Stat. Ann. § 5513. The court will appoint an emergency guardian if, after a hearing, it finds by clear and convincing evidence that (1) the respondent is incapacitated; (2) the respondent needs a guardian; and (3) failure to appoint a guardian will result in irreparable harm to the respondent's person or estate. *Id.* The court must specify the powers, duties, and liabilities of that guardian in its order. *Id.*

The appointment of an emergency guardian of the person can be in effect no longer than 72 hours. 20 Pa. Cons. Stat. Ann. § 5513. If the emergency continues, the order may be extended for 20 days from the date of the expiration of the initial emergency order. *Id.* After the expiration of the extension, the petitioner must institute a full guardianship proceeding in order to continue the guardianship. *Id.* An emergency guardianship of the estate may not exceed 30 days, at which time the petitioner must initiate a full guardianship proceeding. *Id.*

The court must, to the extent feasible under the circumstances, adhere to all of the procedures outlined above -- including those relating to the appointment of counsel for the respondent -- in a proceeding for the appointment of an emergency guardian. 20 Pa. Cons. Stat. Ann. § 5513.

IX. REPORTS A GUARDIAN MUST FILE

Within one year of the appointment and at least once annually thereafter,

a guardian of the person must file with the court a report attesting to the following:

- the current address and type of placement of the incapacitated person;
- any major medical or mental problems experienced by the incapacitated person;
- a brief description of the incapacitated person's living arrangements and the social, medical, psychological and other support services he is receiving;
- the opinion of the guardian as to whether the guardianship should continue, be terminated or modified, and the reasons for that opinion; and,
- the number and length of times the guardian visited the incapacitated person during the past year.

20 Pa. Cons. Stat. Ann. § 5521(c)(1)(ii).

A guardian appointed for an incapacitated person's estate must file with the court within one year of his appointment and on an annual basis thereafter a report attesting to the following:

- the incapacitated person's current **principal** and how it is invested;
- the incapacitated person's current income;
- the expenditures of principal and income since the prior report; and,
- the needs of the incapacitated person for which the guardian has provided since the last report.

20 Pa. Cons. Stat. Ann. § 5521(c)(1)(I).

X. APPOINTMENT OF A SUCCESSOR GUARDIAN

If the court-appointed guardian dies or is otherwise no longer able or willing to serve as the individual's guardian, the court will appoint a new guardian. 20 Pa. Cons. Stat. Ann. § 5514. Before doing so, the court will give notice to interested parties. *Id.*

If the vacating guardian was the parent of the individual and he or she has died, the court, in selecting a new guardian, will give preference to a person nominated by the deceased parent in his or her will to act as the successor guardian. 20 Pa. Cons. Stat. Ann. § 5514. Moreover, although it is not required by law, the court is also likely to consider the nomination in a will of a successor guardian by any guardian who has died, regardless of whether he or she was the individual's parent. Accordingly, if you are a court-appointed guardian for an individual, you should consider who you would want to succeed you as the individual's guardian and to identify that person as the proposed successor guardian in your will.

XI. TERMINATING A GUARDIANSHIP ORDER OR REMOVING A GUARDIAN

An incapacitated person, the guardian, or any interested person may petition the court for a review hearing, or a court on its own may decide to hold a review hearing. 20 Pa. Cons. Stat. Ann. § 5512.2(a). A review hearing may be used to: (1) assert that there has been a significant change in the person's capacity so that guardianship is no longer necessary (or a more limited guardianship order is appropriate); (2) assert that the guardian has failed to perform his or her duties; or (3) assert that the guardian has not acted in the incapacitated person's best interests, including not respecting his or her preferences to the fullest extent possible. *Id.*; *Estate of Rosengarten*, 871 A.2d at 1254-56.

In a review hearing, the incapacitated person has all of the rights he would have at an initial guardianship hearing (including the right to be present and to seek appointed counsel). 20 Pa. Cons. Stat. Ann. § 5512.2(b). The incapacitated person may also be represented by counsel of his or her choosing at any review hearing. *Estate of Rosengarten*, 871 A.2d at 1257. A person need only prove by a fair preponderance of the evidence that he or she has regained capacity so as to no longer need guardianship while the party advocating continued guardianship has the heavier burden of showing by clear and convincing evidence that the person remains incapacitated. 20 Pa. Cons. Stat. Ann. § 5512.2(b); *Estate of Rosengarten*, 871 A.2d at 1255.

XII. CONCLUSION

Pennsylvania's guardianship law is designed to: (1) permit incapacitated persons to participate as fully as possible in all decisions that affect them; (2) assist such individuals to meet the essential requirements for their physical health and safety, to protect their rights, to manage their financial resources, and to develop or regain their abilities to the maximum extent possible; and (3) to accomplish these objectives through the use of the least restrictive alternative. 20 Pa. Cons. Stat. Ann. § 5502. The two most important features of the Pennsylvania guardianship law are: (1) that it permits the appointment of limited guardians to ensure that only those restrictions necessary in the particular circumstances are imposed, and (2) that it provides for certain procedural safeguards to prevent the unwarranted appointments of guardians. Despite these features, **guardianship should be viewed as the option of last resort and used only if other alternatives do not provide an adequate solution.**

CHAPTER 11: GLOSSARY OF IMPORTANT TERMS

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Agent -- A person who has been designated to make decisions for an individual (known as the **principal**) pursuant to a **financial power of attorney**, **health care power of attorney**, or **mental health care power of attorney**. An agent under these documents is sometimes called a **proxy** or an **attorney-in-fact**.

Attorney-in-Fact -- See **agent**.

Beneficiary -- A person who may receive payments of income or property from a **trust**.

Capacity -- The legal ability of an individual to make a decision. Capacity is also known as **competence**. The standard for capacity can vary depending on the circumstances.

Competence -- See **capacity**.

Consent -- A person's agreement, approval, or permission or the act of giving agreement, approval, or permission.

Do Not Resuscitate (DNR) Order -- An instruction by an individual or agent that he or she does not want to receive cardiopulmonary resuscitation (CPR).

End-Stage Medical Condition -- An incurable and irreversible medical condition in an advanced state, caused by injury, disease, or physical illness that will, to a reasonable degree of certainty, result in death. It does not include permanent and irreversible physical, mental, or intellectual conditions where treatment can provide a benefit that does not merely prolong the process of dying, such as cerebral palsy or quadriplegia.

Guardian -- A person appointed by a court to make certain decisions on behalf of another individual who has been determined by the court to be **incapacitated** and, thus, unable to make those decisions. A **guardian of the person** has authority to make personal decisions for the individual

(such as where to live). A **guardian of the estate** has authority only over decisions relating to the individual's finances and property. A **plenary guardian** is authorized to make most decisions for the individual (except those not permitted by law) while a **limited guardian** has only those powers specifically authorized by the court.

Health Care Advance Directive -- A written document by which an individual, while competent to do so, sets forth the parameters for his health care treatment in the event that he becomes incompetent to make his own health care decisions. An advance health care directive can be a **health care power of attorney**, a **living will**, or a **combination health care power of attorney/living will**. See also **mental health advance directive**.

Health Care Agent -- A person designated to make health care decisions for another individual in a **health care advance directive**.

Health Care Power of Attorney -- A document in which an individual (known as the **principal**) designates one or more persons (known as the **health care agents**) to make health care decisions for the individual if she or he is determined to be **incompetent** to make those decisions regardless of whether the individual has an **end-stage medical condition** or is **permanently unconscious**.

Health Care Representative -- A person authorized by Pennsylvania law to make certain health care decisions for an individual who does not have a **guardian**, has not executed an **advance health care directive**, or whose **health care agent** is not reasonably available or is not willing to act.

Incapacitated – A person is incapacitated when a person lacks the ability to make certain decisions. The standard for incapacity can vary depending on the circumstances. A person can be incapacitated to make some decisions, but not others. Incapacitated is also sometimes called **incompetent.**

Incompetent -- See **Incapacitated**.

Informal Supports -- See Natural Supports.

Informed Consent -- A type of consent required to make certain types of decisions, particularly health care decisions that are not routine. Informed consent requires that the decision-maker: (1) have an ability to understand the decision, the alternative options, and the risks of benefits; (2) have the ability to use the information in a logical and rational way to reach a decision; and (3) be able to communicate the decision verbally or through other means.

Life-Preserving Treatment -- Treatment or interventions necessary to save the life of an individual who does not have an **end-stage medical condition** or who is not **permanently unconscious**.

Life-Sustaining Treatment -- Treatment that merely prolongs the process of dying for a person with an **end-stage medical condition** or that maintains an individual in a state of **permanent unconsciousness**.

Living Will -- A document that expresses the wishes and instructions of an individual (known as the **principal**) regarding specific types of health care treatment in the event the individual becomes **incompetent** and has an **end-stage medical condition** or is **permanently unconscious**.

Mental Health Advance Directive -- A document that delineates the person's preferences with respect to specific types of mental health treatment in the event that he or she loses **capacity** due to mental illness to make those treatment decisions. A mental health advance directive can take the form of a **mental health declaration** (which sets out specific treatment decisions the individual does or does not want in the event of incapacity), a **mental health care power of attorney** (which appoints a **mental health agent** to make decisions in the event of incapacity), or a **combination declaration/power of attorney**.

Natural Supports -- Family, friends, or advocates who know an individual

with the disability and can help him or her to make decisions in a variety of contexts.

Parent -- Parents include natural or birth parents, adoptive parents, foster parents, or court-appointed guardians who have legal authority to make decisions for youth under age 18 unless they have been emancipated by the court. For special education decisions, parents can include other types of decision-makers as well and have legal authority to make such decision until the youth is age 21.

Permanently Unconscious -- A person is permanently unconscious when they have a total and irreversible loss of consciousness and capacity for interaction with the environment, such as a permanent vegetative stage or a permanent coma.

Power of Attorney -- A document in which an individual (known as the **principal**) designates another person (known as the **agent**) to make specified financial, health care, mental health care, or other decisions for the individual.

Principal -- An individual who creates any type of **power of attorney** or **advance directive**. **Proxy** -- See **Agent**.

Representative Payee -- An individual or agency appointed by the Social Security Administration to receive Social Security or Supplemental Security Income benefits for someone who cannot manage or direct his or her own money.

Settlor -- A person who creates a **trust** with his or her money or other property.

Simple Consent -- The type of consent granted by someone in order for another person to make everyday decisions or routine health care decisions on behalf of them.

Substitute Decision-Maker -- A person who is authorized by law to make

decisions on behalf of another person in particular circumstances.

Trust -- A legal instrument in which a person (known as the **settlor**) places money or other property (known as **trust assets**) in a special account for the benefit of one or more persons (known as **beneficiaries**). The trust designates a third-person (known as a **trustee**) to control the trust assets in accordance with the specific directions in the trust.

Trustee -- The person designated in a **trust** to make decisions, in accordance with the trust instructions, on how the trust assets will handled and distributed.

CHAPTER 12:
RESOURCES

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SELECT WEB-BASED RESOURCES FOR CONSENT, CAPACITY, AND SUBSTITUTE DECISION-MAKING

Decision-Making by People with Intellectual Disabilities: The Importance of Self-Determination

- Pennsylvania Department of Human Service's Everyday Lives – Making it Happen –

http://www.chesco.org/mhidd/lib/mhmr/pdfs/everyday_lives_boo kl.pdf

- The Pennsylvania Training Partnership for People with Disabilities and Families – Mentors for Self Determination -

http://www.temple.edu/thetrainingpartnership/about/msd.shtml

- American Association on Intellectual and Developmental Disabilities – Joint Position Statement on Self-Determination with The Arc of the United States

http://www.aaidd.org/content_163.cfm?navID=49

- Bazelon Center – Where We Stand: Self-Determination

http://www.bazelon.org/Where-We-Stand/Self- Determination.aspx

Health Care Decision-Making

- Pennsylvania Medical Society:

Facts on Act 169 (Advance Directives) –

http://www.pamedsoc.org/MainMenuCategories/Government/LawsAffectingPhysicians/AdvanceDirectives/Act169facts.html

Decide for Yourself: A Guide to Advance Health Care Directives

http://www.pamedsoc.org/MainMenuCategories/Government/LawsAffectingPhysicians/AdvanceDirectives/Decideforyourself.pdf

- Allegheny County Bar Association – Health Care POA & Living Will (form and pamphlet)

http://www.acba.org/Public/Legal-information/LivingWillPoweroAttyform.pdf

- Pennsylvania Department of Human Services Office of Developmental Programs – Bulletin on Procedures for Surrogate Health Care Decision Making

http://seekthemagic.com/provider/pdf/6000-11-01%20Procedures%20for%20Surrogate%20Health%20Care%20Bulletin.pdf

Capacity, Sexuality & Family Life

- American Association on Intellectual and Developmental Disabilities:
    - Joint Position Statement on Sexuality with The Arc of the United States http://www.aaidd.org/content_154.cfm?navID=40
    - Sexuality and Intellectual Disability http://www.aaidd.org/content_198.cfm
- Better Health Channel (Australia): Sex Education – Young People with Intellectual Disabilities -

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Sex_education_for_children_with_intellectual_disabilities

Mental Health Advance Directives

- Bazelon Center – Where We Stand: Psychiatric Advance Directives -

http://www.bazelon.org/Where-We-Stand/Self- Determination/Advance-Directives.aspx

- Disability Rights Pennsylvania:

Frequently Asked Questions about Mental Health Advance Directives
http://www.disabilityrightspa.org/File/publications/frequently- asked-questions-about-mental-health-directives.pdf

Directions for using the Combined Mental Health Advance Directive Declaration and Power of Attorney form -
http://www.disabilityrightspa.org/File/publications/directions-for-using-the-combined-mental-health-advance-directive-declaration-and-power-of-attorney-form.pdf

Powers of Attorney

- Pennsylvania's Power Attorney Statute (20 Pa. C.S. § 5601 et seq.)

http://law.onecle.com/pennsylvania/decedents-estates-and-fiduciaries/00.056.001.000.html

- Disability Rights Pennsylvania – Power of Attorney

www.disabilityrightspa.org/File/publications/power-of-attorney.doc

Educational Decision-Making Under the IDEA

- Education Law Center – PA:

How Can a Pennsylvania Judge Help a Child in Care Get Needed Special Education Help?

http://www.elc-pa.org/pubs/downloads/english/fos-How%20Can%20PA%20Judge%20Help%20Child%20in%20Care%20Get%20Spec%20Ed%20Help.7-08.pdf

Who Can Make Special Education Decisions for a Child with a Disability in Out-of-Home-Care in Pennsylvania?

http://www.elc-pa.org/pubs/downloads/english/fos-Special%20Education%20and%20Children%20in%20Out%20of%20Home%20Care%207-08.pdf

Substitute Decision-Making through Trusts

- ACHIEVA:

Family Trust http://www.achieva.info/family.jsp

Family Trust Resources and Forms
http://www.achieva.info/family.jsp?pageId=2161392240601292 599520880

Guardianship

- National Guardianship Association, Inc. – What is Guardianship

http://guardianship.org/what_is_guardianship.htm

- Allegheny Court of Common Pleas (sample forms, FAQs, etc.)

http://www.alleghenycourts.us/orphans/guardianship.aspx

Other Resources for Individuals with Intellectual Disabilities

- The President's Committee for People with Intellectual Disabilities

http://www.acf.hhs.gov/programs/pcpid/index.html

- American Association on Intellectual and Developmental Disabilities:

Definition of Intellectual Disability
http://aaidd.org/content_100.cfm?navID=21

FAQ on Intellectual Disability http://aaidd.org/content_104.cfm?navID=22

- National Dissemination Center for Children with Disabilities

http://nichcy.org/laws/idea

- Gold Book – Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services

http://www.temple.edu/thetrainingpartnership/resources/umrspa/goldbook201007.pdf

- Pennsylvania Department of Human Services – Services and Supports for Adults with Intellectual Disabilities

http://www.dpw.state.pa.us/foradults/intellectualdisabilitiesservices/servicesandsupports/index.htm

- The Pennsylvania Training Partnership for People with Disabilities and Families – Waiver Resources

http://www.temple.edu/thetrainingpartnership/resources/waiver/

LEGAL RESOURCES

This section includes some resources that might be helpful for individuals who are interested in additional information on some of the topics covered in this Manual.

General Capacity and Consent

James W. Ellis, *Decisions By and For People with Mental Retardation: Balancing Considerations of Autonomy and Protection*, 37 Vill. L. Rev. 1779 (1992)

Jonathan Herring*, Entering the Fog: On the Borderline of Mental Capacity*, 83 Indiana L.J. 1619 (2008)

Guardianship

Statutes and Regulations

20 Pa. Cons. Stat. Ann. §§ 5501-5554 (Pennsylvania guardianship law)

204 Pa. Code §§ 29.41-29.42 (guardianship procedures for institutionalized persons)

Cases

In re *Adler,* No. 1144IC, 2003 WL 22053309 (Pa. Com. Pl. 2003)

In re D.L.H., 2 A.3d 505 (Pa. 2010)

In re Estate of Haertsch, 609 A.2d 1384 (1992) *In re Hyman*, 811 A.2d 605 (Pa. Super. Ct. 2002) *In re Peery*, 727 A.2d 539 (Pa. 1999)

In re Estate of Rosengarten, 871 A.2d 1249 (Pa. Super. Ct. 2005)

Wilhelm v. Wilhelm, 657 A.2d 34 (Pa. Super. Ct. 1995)

Miscellaneous

Leslie Saltzman, *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157 (2010)

Medical Treatment Decisions

Statutes

20 Pa. Cons. Stat. Ann. §§ 5421-5488 (advance directives for health care, including living wills, health care powers of attorney, and out-of-hospital non-resuscitation orders)

50 Pa. Cons. Stat. Ann. § 4417 (substitute decision-making for people in institutional care)

Regulatory Materials

ODP, *Procedures for Surrogate Health Care Decision Making*, Bulletin No. 6000-11-01 (Jan. 15, 2011), available at http://services.dpw.state.pa.us/olddpw/bulletinsearch.aspx

Cases

In re D.L.H., 2 A.3d 505 (Pa. 2010)

In re Fiori, 652 A.2d 1350 (Pa. Super. Ct. 1995)

Miscellaneous

Eric C. Miller, *Listening to the Disabled: End-of-Life Medical Decision Making and the Never Competent*, 74 Fordham L. Rev. 2889 (2006)

Mental Health Treatment Decisions

Statutes

20 P.S. §§ 5801-5845 (mental health advance directives)

35 P.S. §§ 10101.1-10101.2 (authority of parents to consent to mental health treatment of minors age 14 and older and control of records)

50 P.S. § 7201 (authority of parents to consent to mental health treatment for minors under age 14)

Regulatory Materials

OMHSAS, *Guidelines for Following Mental Health Advance Directives in State Mental* Hospitals, Bulletin No. SMH-06-03 (Sept. 19, 2006), available at http://services.dpw.state.pa.us/olddpw/ bulletinsearch.aspx

OMHSAS, *Administration of Psychotropic Medication to Protesting Patients*, Bulletin No. 99-85-10 (Mar. 11, 1985)

Miscellaneous

Breanne M. Sheetz, *The Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility*, 40 U. Mich. J. L. Rev. 401 (2007)

Financial Decisions

Statutes and Regulations

20 Pa. Cons. Stat. Ann. §§ 5601-5611 (financial powers of attorney)

42 U.S.C. § 1383 (Social Security representative payee)

20 C.F.R. §§ 416.601-416.604 (Social Security representative payee regulations)

Cases

In re Estate of Reifsneider, 610 A.2d 958 (Pa. Super. Ct. 1992)

In re Estate of Slomski, 987 A.2d 141 (Pa. 2009)

In re Weidner, 938 A.2d 354 (Pa. 2007)

Metcalf v. Pesock, 885 A.2d 539 (Pa. Super. Ct. 2005)

Taylor v. Vernon, 652 A.2d 912 (Pa. Super. Ct. 1995)

Miscellaneous

Social Security Administration, *FAQs for Representative Payees*, available at www.ssa.gov/payee/faqrep.htm

Social Security Administration, *Representative Payee Program*, available at http://www.ssa.gov/payee/

Social Security Administration, *A Guide for Representative Payees*, available at http://www.ssa.gov/pubs/10076.html

Trusts

Statutes & Regulations

42 U.S.C. § 1382b(e) (trusts under SSI)

42 U.S.C. § 1396p(c)-(d) (trusts under Medical Assistance)

62 Pa. Cons. Stat. Ann. § 1414 (Medical Assistance treatment of special needs trusts & pooled trusts under state law; currently subject to a court challenge in *Lewis v. Richman*)

62 Pa. Cons. Stat. Ann. § 1965.1 *et seq*. (Medical Assistance treatment of pooled trusts under state law)

55 Pa. Code 178.4 & 178.7 (Medical Assistance treatment of trusts under state law)

Social Security Materials

POMS SI 01120.200, *available at* https://secure.ssa.gov/poms.nsf/lnx/0501120200

POMS SI 01120.20, *available at* https://secure.ssa.gov/poms.nsf/lnx/0501120201

POMS SI 01120.203, available at https://secure.ssa.gov/poms.nsf/lnx/0501120203

Cases

Commonwealth Bank & Trust Co., N.A. v. Commonwealth, Dep't of Public Welfare, 598 A.2d 1279 (Pa. 1991)

DeBone v. Dep't of Public Welfare, 929 A.2d 1219 (Pa. Commw. Ct. 2007)

Estate of Rosenberg v. Dep't of Public Welfare, 679 A.2d 767 (Pa. 1996)

Estate of Taylor v. Dep't of Public Welfare, 825 A.2d 763 (Pa. Commw. Ct. 2003)

Lang v. Commonwealth, Dep't of Public Welfare, 528 A.2d 1335 (Pa. 1987)

Lewis ex rel. Young v. Alexander, _ 2334322 F.3d , 2012 WL (3d Cir. June 20, 2012)

Lewis v. Magee Women's Medical Hosp. of UPMC, 67 Pa. D. & C.4th 362 (Pa. Com. Pls. 2004)

Lewis v. Richman, 276 F.R.D. 421 (E.D. Pa. 2011)

Shaak v. Pennsylvania Dep't of Public Welfare, 747 A.2d 883 (Pa. 1991)

Snyder v. Commonwealth, Dep't of Public Welfare, 598 A.2d 1283 (Pa. 1991)

Education Decisions

Statutes and Regulations

20 U.S.C. § 1415 (surrogate decision-makers under IDEA) 34 C.F.R. §§ 300.30 (definition of parent under IDEA)

34 C.F.R. § 300.519 (appointment of surrogates under IDEA)

237 Pa. Code § 147 (Juvenile Court appointment of surrogate decision-maker for *child* in dependency/delinquency system)

Miscellaneous

Pennsylvania Dep't of Education, Surrogate Parents and Special Education Decision-Making for IDEA Eligible or Thought-To-Be-Eligible Children (Nov. 2009), available at *http://www.pattan.net/category/Resources/PaTTAN%20Publications/Browse/Single/?i d=4dc09560cd69f9ac7fa50000*

Judith C. Saltzman & Barbara S. Hughes, *Planning with Special Needs Youth Upon Reaching Majority: Education and Other Powers of Attorney*, 1-SPG NAELA J. 41 (2005)

Marriage, Sexuality, and Child-Rearing

Statutes and Regulations

18 Pa. Cons. Stat. Ann. § 3206 – (guardian role in abortion decisions)

23 Pa. Cons. Stat. Ann. § 1304 (restrictions on issuance of marriage license based on incapacity)

42 Pa. *Cons*. Stat. Ann. § 6301 *et seq.* (Juvenile Act regarding dependency and delinquency procedures)

237 Pa. Code Ch. 11-18 (Juvenile dependency proceeding regulations)

Cases

In re A.P., 728 A.2d 375 (Pa. Super. Ct. 1999)

Commonwealth v. Thomson, 673 A.2d 357 (Pa. Super. Ct.), *app. denied*, 686 A.2d 1310 (Pa. 1996)

DeMedeo v. DeMedeo, 257 A.2d 290 (Pa. Super. Ct. 1969)

In re Estate of C.W., 640 A.2d 427 (Pa. Super. Ct. 1994)

In re Terwilliger, 450 A.2d 1376 (Pa. Super. Ct. 821)

Miscellaneous

American Ass'n on Intellectual and Developmental Disabilities, *Sexuality and Intellectual* Disability, available at http://www.aamr.org/content_198.cfm

Elizabeth J. Reed, *Criminal Law & The Capacity of Mentally Retarded Persons to Consent to Sexual Activity*, 83 Va. L. Rev. 799 (1999)

Susan Stefan, *Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together*, 2 St. Louis U. J. Health L. & Pol'y 135 (2008)

Clarence J. Sundram*, Sexual Behavior and Mental Retardation*, 17 Mental and Physical Disability L. Rep. 448 (1993)

Leslie Walker-Hirsch, ed., *The Facts of Life – and More: Sexuality and Intimacy for People with Intellectual Disabilities* (2007)