Comparative Perspectives on Adult Guardianship

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Chapter 20

Alternatives to Guardianship and Supported Decision-Making

James H. Pietsch

Introduction

There are two not necessarily opposing or competing, but also not quite supporting or complementing, aspects of the evolving question of how best to address the decision-making needs and rights of individuals who may have diminished physical or mental capacity. First, in many jurisdictions, a guardianship of the person or a guardianship of the estate can involve actual or potential loss of control, autonomy, and privacy for the respondent (also known as the subject of the proceeding or the individual for whom the appointment of a guardian is sought), as well as significant time delays and costs for the petitioner who is seeking to be a guardian for the potential ward or protected person. Second, there is an increasing realization that persons with disabilities should be entitled to adequate levels of assistance and support to protect them from abuse and to help them exercise their rights to retain their own capacity to make decisions and to take action on

1. This chapter will provide examples of legal mechanisms used in various jurisdictions to authorize and perhaps encourage alternatives to guardianship and supported decision-making. Since virtually every jurisdiction will have different laws, practices and terminology, and while making citations to particular provisions of the law may not seem to be very meaningful to many, such citations are meant to serve as examples of laws applicable to the topic. I will cite periodically to some of the “uniform” acts drafted by the National Conference of Commissioners on Uniform State Laws (NCCUSL) intended for use in all jurisdictions in the United States. See Uniform Law Commission Home Page, http://www.nccusl.org (last visited Mar. 17, 2012). The NCCUSL, in partnership with Biddle Law Library at Penn Law, is making these drafts and final acts of Uniform Laws and Model Acts available online to help fulfill its mission to distribute information to the public. See Pennsylvania Law School, NCCUSL Drafts and Final Acts, http://www.law.upenn.edu/bill/archives/ucl/ucl.htm (last visited Mar. 17, 2012). I will also cite to Hawaii law since I am most familiar with this jurisdiction. Hopefully the listing of selected alternatives to guardianship and the supported decision-making concepts themselves will be of value and the reader can link the concept to the applicable laws of the local jurisdiction.

2. These terms will collectively be called “guardianship” throughout this chapter. Guardianship of the property is called “conservatorship” in many jurisdictions. Sometimes these negative aspects of guardianship can be more hypothetical than real. For example, the question of expenses may or may not be an issue in jurisdictions or in selected segments within jurisdictions that provide free legal services, and the question of time may be of no significance to individuals who are permanently unconscious and who are being cared for but require guardians to assume legal responsibility for their continuing care.
their own behalf, including representing themselves in court, deciding where they should live, entering into contracts, voting, and making health care decisions. Utilizing alternatives to guardianship and supported decision-making frameworks may help address these concerns.

In general, courts may appoint a guardian only if it finds that the respondent is incapacitated and that the respondent's needs cannot be met by less restrictive means, including use of appropriate technological assistance. Further, in many jurisdictions, guardianship laws require that courts grant to a guardian only those powers necessitated by the ward or protected person's limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward or protected person's maximum self reliance and independence. On the other hand, there is a growing movement that suggests that guardianship marginalizes the individual and imposes a form of segregation violating basic principles of supporting autonomy and delivery of services in the most integrated and least restrictive manner. This chapter will be primarily focused on alternatives to guardianship but will also include a limited insight into the emerging and still evolving concept of supported decision-making.

Alternatives to Guardianship

Alternatives to guardianship can be viewed from both the perspective of the respondent and from the perspective of the petitioner. Guardianship can be a complicated process that can take a long period of time to pursue. Obtaining the required documents (such as birth certificates, marriage certificates, and a doctor's assessment), going through the judicial process, giving notice to the interested parties, and attending the court proceedings normally takes several months. Filing fees and attorneys' fees and costs are normally incurred with each proceeding. Further, guardianship documents, proceedings, and reports are often matters of public record. Accordingly, the financial affairs of the ward or protected person may become public knowledge.

With proper advance planning, guardianship proceedings may not be necessary if less restrictive alternatives can serve the purpose of providing the necessary assistance to an incapacitated adult. Broadly, alternatives can be categorized as those that support the individual as the decision-maker, those in which decision-making responsibility is shared with the individual, and those in which the individual or an appointing authority delegates decision-making authority. As will be discussed in this chapter, there are distinct advantages and disadvantages to the use of alternatives to guardianship. There are also distinct advantages and disadvantages within the variety of potentially available alternatives to guardianship. Finally, more than one alternative to guardianship may be required to perform tasks that a guardian may normally be empowered by a court to take on behalf of an incapacitated person.

Powers of attorney, advance directives for health care, trust arrangements, representative or fiduciary payeeships, and joint financial accounts to pay bills are a few of the frequently used alternatives. In the broadest sense, limited guardianship and "co-decision making" can be considered alternatives to guardianship. Each alternative comes with its attendant costs and trade-offs, advantages and disadvantages, benefits and risks, positives and negatives. In a practical sense, setting up effective alternatives to guardianship requires careful thought and a bit of guessing since sometimes one will never really know if all the personal, health care, legal, and financial needs of an individual are actually covered until the individual becomes incapacitated. In this sense, obtaining a guardianship could be considered an "alternative to alternatives to guardianship," thus, completing the circle.

Powers of Attorney

A power of attorney is an important legal tool that can be used in planning for incapacity and, as such, it can be an important alternative to guardianship. Powers of attorney are probably the most popular and utilized alternatives to guardianship; however, they are probably the most abused of the alternatives. Accordingly, a significant portion of this chapter is devoted to this topic. A power of attorney is a written instrument through which a person (called the "principal") designates another person to be his or her agent (or "attorney-in-fact") and grants the agent authority to perform certain acts on the principal's behalf.

Powers of attorney can be drafted to take effect immediately or on a future date or upon a future contingency. Accordingly, for purposes of serving as an alternate to guardianship a "springing" or contingent power of attorney can be drafted to take effect upon some subsequent future event such as the principal's disability or incapacity. A power of attorney can be effective for a specific period or can be effective indefinitely or until death, which normally terminates a power of attorney. Powers of attorney for personal financial and legal matters will be discussed in this section while powers of attorney for health care decisions will be discussed in the section dealing with health care decision-making alternatives to guardianship. It is most important to know that in most jurisdictions, mental disability or incapacity of the principal terminates a power of attorney unless the instrument contains a provision that states that the power will not be affected by such disability or incapacity. There are usually certain specific words that need to be included in the power of attorney for it to be considered "durable or enduring."  

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4. See Linda Whitton, Durable Powers as an Alternative to Guardianship: Lessons We Have Learned, 37 Stetson L. Rev. 7 (2007).
5. In some jurisdictions powers of attorney can continue to be effective after death for certain purposes, for example, for organ donation. This is true in jurisdictions of the United States that have enacted the latest version of the Uniform Anatomical Gifts Act (UAGA) drafted for potential use in all of the states by the National Conference of Commissioners on Uniform State Laws. See Revised Unif. Anatomical Gift Act (2006) §§ 1 et seq., 8A U.L.A. 42 (Supp. 2011), available at http://wwmlaw.upenn.edu/bll/archives/ulc/uaga/2009final.htm (last visited Mar. 19, 2012).
7. In the United States, the term "durable" is used but in Canada, e.g., the terms "enduring" or "continuing" have been used to express the concept that the powers granted to the agent continue to be effective during periods of disability or incapacity of the principal. Phrases such as "these powers will not be affected by my disability or incapacity" or "these powers will only be effective upon my incapacity or disability" would serve to create a durable power of attorney. The latter phrase would create a springing durable power of attorney which can be useful for individuals who do not want to grant powers effective immediately but who do want someone to have power in the event of inca-
Powers of attorney, including durable powers of attorney, come in two basic types: “general” and “special.” A general power of attorney is a very broad and sweeping grant of authority and is normally intended to grant virtually all of the powers that the principal possesses to an agent. This is the reason general powers of attorney are most often utilized as alternatives to guardianship—the attorney-in-fact or “agent” theoretically can handle any personal, legal, or financial situation that may come up in the future. For the principal, the general power of attorney should be used with extreme caution since, unless prescribed by law or regulation, this instrument authorizes the agent to do any legal act that the principal might do. In contrast, a special power of attorney grants authority to an individual to act in specific matters. A special power of attorney is often used to allow an agent to handle specific situations when the principal is unavailable or unable to act. For example, the principal may be traveling outside the state or country, or may be unable to handle a specific situation because of other commitments or health reasons. Since it is limited in scope, the use of a special power of attorney reduces some of the risks involved in giving another person power but it is not always very helpful as an effective alternative to guardianship.

Powers of attorney are probably the most commonly used and popular of all the alternatives to guardianship. First of all, they are relatively simple to draft and to execute and do not require any court involvement. While some guardianship proceedings take weeks and months to pursue, powers of attorney can be accomplished very quickly. Very often powers of attorney are “do-it-yourself” types of documents that are as easily found over the Internet as they have been easily found in stationery stores for years. Accordingly, they are usually inexpensive to procure, even if drafted by an attorney. This easy access directly leads to some of the inherent danger, namely abuse of powers of attorney, which will be discussed later in this section.

In addition to the inexpensive nature of powers of attorney, these documents can be tailored in accordance with the known intentions and desires of the principal who can empower an agent of choice and who can put into place safeguards, accountability standards, and limitation of powers as the principal may deem appropriate. Unlike a guardian, whom a court appoints and who is usually given plenary powers, the agent is selected by the principal prior to incapacitation and, presumably, is someone that the principal knows and whom the principal feels can be trusted. Accordingly, it is possible to grant powers to an agent that the court may be reluctant to grant to a guardian. For example, an agent may grant powers to the agent to self-gift under various circumstances. Even if the principal has doubts about the potential agent but still wishes to grant that person certain powers, the principal can take those concerns into account and have an attorney draft safeguards into the document. These safeguards can include periodic reports, much like those generally required for guardians by the court. While the reports would not be submitted to a court, at least there could be some mechanism to assure that the powers are utilized in a fiduciary capacity. In the same vein, as long as the principal is still competent, the principal can revoke or modify the power of attorney at any time. Guardianships would need to be revoked or terminated by court order.

Powers of attorney can also be revoked or modified at any time. The agent’s powers are essentially subject to any revocation by the principal or by a court when the principal is incapacitated and the powers are abused.

8. The difference between self-gifting and self-dealing can be difficult to differentiate and can also include built-in adverse tax, estate planning and self-support problems.
There are also distinct dangers or disadvantages to powers of attorney. Powers of attorney can be dangerous in the wrong hands. Across the United States, Canada, and the world, there are increasing reports of financial abuse, exploitation, and theft by the use of powers of attorney. There have been efforts to combat such issues, but the problems seem to be increasing, perhaps due to hard economic times. The principal should be especially careful when giving a power of attorney to someone to handle real estate matters. While it is difficult to ascertain, the principal should make every effort to be certain that the agent is trustworthy and, of course, the principal should make sure to read and understand the document when signing it. If the principal has any doubts, the principal should not sign the document until the trustworthiness of the agent is assured or, assuming a lawyer is involved, until the lawyer drafting the document has built in sufficient protections in the document. Nevertheless, the potential for fraud exists in every power of attorney arrangement, through self-dealing, embezzlement, and unlawful gifting. When an agent acts with the apparent authority granted by the power of attorney, it may be impossible to undo what the agent has done, especially if the principal is no longer capacitated and is unable to provide testimony one way or another about the principal’s intentions in granting the authority.

In addition to the potential for abuse, there are also certain drawbacks to relying on a power of attorney as an alternative to guardianship. Generally, there is no requirement for an individual or organization to accept a power of attorney. Many organizations have their own forms or required formats. The principal should also be aware that some institutions do not accept powers of attorney at all or may require a more detailed and formal property description before a power of attorney can be accepted in a real estate transaction. Some institutions may require the agent to have a specifically delegated power rather than just broad general powers to act on behalf of the principal. To help the principal make a determination whether a particular organization or financial institution or individual would accept a power of attorney, it would be wise for the concerned party to verify this in advance. This can be accomplished by the lawyer, principal, or agent and usually involves presenting the document to the particular institution or individual to whom it will be presented in the future for use.

Much like guardianships and with just a few exceptions, as previously mentioned, death automatically terminates the power of attorney. In jurisdictions that have adopted provi-

9. See J. Bueno, Reforming Durable Power of Attorney Statutes to Combat Financial Exploitation of the Elderly, 16 The Journal of the National Academy of Elder Law Attorneys 20 (2003). To partially safeguard against abuse, some people include a “self-executing revocation date,” which specifies an expiration date. However, this provision would not make the document one that would be considered to be very effective as an alternative to guardianship. Of course, it is wise to keep track of to whom the power of attorney is given and where the document is located. In most jurisdictions, the principal has the right to revoke, terminate, or modify the power of attorney at any time. Although it can be revoked either orally or in writing, to be safe, the revocation should be in writing and given to the agent and to any person or organization where it may have been used.

10. As previously mentioned, powers of attorney forms are readily available over the Internet as they have been in stationery stores over the years. In some jurisdictions there are statutory forms which are available free of charge and are required forms. Examples of statutory forms are found in the Uniform Power of Attorney Act drafted by the National Conference of Commissioners of Uniform state Laws. See sources cited supra note 7.

11. In the United States, the Internal Revenue Service has its own Power of Attorney Form 2848 that allows a person to authorize an agent to represent him or her before the IRS, receive and read confidential tax information and correspondence, sign returns and perform other actions related to tax returns. The Internal Revenue Service, Form 2848 Power of Attorney and Declaration of Representative (2012), http://www.irs.gov/pub/irs-pdf/f2848.pdf (last visited Mar. 19, 2012).
sions similar to those found under the Uniform Anatomical Gifts Act an agent under a health care power of attorney may donate a decedent's body or body parts even after death. It should be noted that in most jurisdictions durable powers of attorney can include health care powers but only if such powers are specifically stated in the document, even if the document states that it is a general power of attorney and grants "all authority" to the agent. Information about "Durable Powers of Attorney for Health Care" will be discussed in detail in the section on health care decision-making alternatives to guardianship.

**Trust**

Trusts are used to manage assets and, sometimes in the broadest sense of the term "trusteeship," the authority to manage other aspects of a person by another person or an entity. In this section, the term "trust" will be used in a more narrow sense, specifically as a legal mechanism to help manage assets of one person by another as an alternative to guardianship. For simplicity, a trust will be simply defined as an arrangement a person (sometimes called the "settlor" or "trustor") makes to give control of his or her property to a trustee (who could also be the settlor). A trustee holds the property for the benefit of the settlor and/or other beneficiaries. As with powers of attorney, there are a variety of types and characteristics of trusts. Living trusts are very useful as estate planning tools but should be used with great caution in "Medicaid Planning" as practiced in the United States.

An individual who is planning for incapacity can use a trust as an effective alternative to guardianship. If a person should become incompetent or incapable of handling his or her own affairs, the trust can be drafted to go into effect when needed and to utilize assets placed in the trust for the benefit of the person, thus avoiding the need to appoint a guardian of the property. The trustee (or successor trustee) can be given instructions on how to utilize the property for the benefit of the beneficiary in accordance with the desires of the settlor. If the settlor and the beneficiary are the same person, that person's autonomy and self-determination can be preserved even during periods of incapacity through the instructions incorporated into the trust.

As with powers of attorney, trusts are generally less expensive than guardianships, although trusts are generally more expensive than powers of attorney. Also like powers of attorney, trusts can be set up to avoid issues relating to the privacy of the individual setting up the trust, the persons or entities managing the trust, and the person benefitting from the trust (i.e., for purposes of this chapter, the incapacitated person). Trusts are

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13. In this sense the terms "conservatorship" or "guardian of the property" are most commonly used.
14. Testamentary trusts are established in wills and are thus generally not very useful as alternatives to guardianship since the trust only becomes effective upon death. Usually a testamentary trust would only go into effect after an estate has been probated. Of course if a trust is established through the will of one party for the benefit of an individual who is or may become incapacitated, such a trust can be considered an alternative to guardianship since a trustee can manage the assets included in the trust for the benefit of the incapacitated person. Trusts established by a settlor while alive are called "living trusts" and can be established by an individual for the specific purpose of management of assets in the event of incapacity. Living trusts can be either revocable or irrevocable.
15. While living trusts can be very effective as alternatives to guardianship, they can also be very effective estate planning tools and can help individuals avoid some of the difficulties involved with probate of their estates. Effective use of trusts can also result in favorable tax benefits.
generally more accepted than powers of attorney but do not have the full effect of a court order obtained through a guardianship.

One of the most important considerations in setting up a living trust is to properly transfer into the trust the property that is to be managed. This can include a home and rental properties, vehicles, bank and savings accounts, stocks and bonds, and virtually anything that is tangible and can be legally owned. Transferring title of the property to the trust is not automatic and often involves the services of an attorney. Once property is transferred into a trust, the trustee can use and manage the property in accordance with instructions in the trust. Unlike guardianships, in a trust there is no court order that authorizes the transfer of authority over the property of the incapacitated person. Trusts that are not funded, that is to say that they do not include property to be managed for the benefit of the incapacitated person, are ineffective.

Although a trustee and guardian share commonalities, such as fiduciary responsibility for the property entrusted to them, there are marked differences. A guardian is appointed by the court; and must follow the rules of the probate code and the court, such as making yearly reports. In contrast, the individual settlor selects the trustee as well as the successor trustee and decides under what conditions the successor trustee will serve, what the terms of the trust are, whom the beneficiaries are, and what if any reports are made. As previously mentioned, trusts are generally more readily accepted than powers of attorney. In many countries a trust is a well-established financial mechanism in commerce. In contrast to powers of attorney, courts are more readily petitioned to intervene in cases where fiduciary responsibilities have been violated and often jurisdictions have well-established mechanisms for oversight, intervention and resolution of conflicts. Although it is not uncommon for a court to intervene in cases of fraud or exploitation perpetrated by an agent under a power of attorney, such intervention is more often prescribed under a jurisdiction’s penal code or adult protective services statutes.

As with powers of attorney there are increasing reports of financial exploitation involving trusts but, unfortunately, the same can be said of guardianships. In the past, trusts were primarily used as estate planning tools but are now seen as both an effective tool for estate planning as well as for planning for incapacity and avoiding guardianship.

Representative Payees and Appointed Fiduciaries

When a person has memory loss, is incapacitated, or does not understand the process of paying bills or money management, a representative payee can be appointed to handle his or her government benefits. For example, in the United States, upon appointment, the representative payee receives checks (or direct deposit of funds) from the Social Beneficiaries Act.

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Security Administration, the Department of Veterans Affairs, or other agencies. A representative payee must use the money for the needs of the beneficiary. As each agency has its own procedures for designating or appointing a representative payee, the potential representative payee must apply to the particular agency to be appointed.

Once a representative payee is appointed, he or she will need to decide how best to use the funds for the beneficiary’s personal care and well being. The Social Security Administration requires that any money left after meeting the beneficiary’s current and reasonably foreseeable needs must be saved and maintained for the beneficiary. Periodically, the Social Security Administration will ask the representative payee to complete a form to account for funds received. A representative payee is also required to keep Social Security informed of changes that may affect the beneficiary’s eligibility for benefits.

Money Management and Informal Financial Arrangements

One of the most common reasons that an older adult becomes the subject of guardianship and conservatorship proceedings is that the individual has difficulty handling his or her financial affairs and needs help with money management. “Money management,” a catch-all term for a wide range of services provided by individuals and organizations to help people manage their financial affairs, includes check writing, bill paying, depositing money, reconciling checkbooks, filing taxes, and even financial counseling. Financial institutions and professional or otherwise skilled money managers such as accountants, including certified public accountants, for profit and nonprofit organizations among others, offer professional money management services. Such individuals and organizations can be insured and bonded, thereby adding a level of protection for clients. Fees are normally charged; however, lower income individuals may be able to obtain free or reduced fee services. In order to plan for periods of future incapacitation, often such individuals or organizations will request powers of attorney or suggest setting up a trust or otherwise establish a financial management arrangement by means of a contract.

To start off with, in order to manage a person’s account, there needs to be some money in the account. The use of direct deposit for wages, pensions, and public benefits is nearly universally accepted but not all persons participate. For example, in the United States, even though the direct deposit program has been widely publicized by the Social Security Administration and other major payees, many persons in the United States may be unfamiliar and distrustful of how it works. The United States Treasury announced that it is phasing out paper check payments and requiring federal benefit recipients to get their money electronically. If a person does not choose to receive an electronic payment option by March 1, 2013, the recipient will receive payments via a "Direct Express®" card. The Treasury Department's "Go Direct®" public education campaign is helping educate federal benefit recipients about the new electronic payments requirement and what it means for them.19

Once a direct deposit account is set up, an automatic payment system to pay for recurring bills such as electricity, water, mortgage and insurance payments can be set up. Automatic payment systems take the worry out of forgetting to make payments and simplify the task of paying bills. On the other hand, receiving checks electronically and having another person manage the account through the Internet or through use of ATM

machines can completely shield the transactions from any review or oversight and, accordingly, subject the owner of the account to potential financial exploitation. An increasingly popular tool for very informal money management is the use of bank cards in automatic teller machines (ATMs) through the use of personal identification numbers (PINs) to obtain cash on behalf of a disabled person to buy groceries, to pay rent and to make other purchases and payments. This type of informal money management can last well beyond the capacity of the disabled person once the individual secures the PIN number. This mechanism can also be fraught with dangers of potential financial exploitation and theft.

Another simple alternative to guardianship for financial purposes is the establishment of joint checking, savings, or other financial accounts. Joint accounts are established when one or more persons are added to such accounts the primary account holder or as persons authorized to access the account, usually by means of a contract and signature cards executed by the parties with the financial institution. Having a joint account with another person can be useful for someone who needs help writing checks, making deposits, or withdrawing cash because it gives the assisting person access to the funds. While it may be simple and convenient, this alternative can also be very risky because the person whose name is added to the account is generally considered a co-owner of the account, thus, enabling the co-owner to withdraw any or all of the money at any time.

While many people still pay bills and manage their investments through checks and other paper transactions, computers and the Internet have dramatically changed the way people manage their finances. Electronic banking makes it possible to manage and access funds through electronic funds transfer, direct deposit, pay-by-phone systems, personal computer banking, debit card purchases, and to perform many other functions.

Close family members can provide basic money management services, and much of the work can be done electronically over the Internet even if they are separated geographically. For example, the state of Hawaii in the United States comprises numerous islands with no bridges in between. A daughter living on one island can easily make bill payments (including utility and credit card payments) for her parents on another island just the way she makes her own bill payments. She can also manage savings accounts, mutual funds, stock portfolios and other financial assets, and can file federal and state tax returns over the Internet.

As with other alternatives to guardianship in the area of money management, there are many schemes and scams that can be perpetrated, especially since Internet and telephone transactions do not occur face-to-face. Individuals should be warned about entrusting their ATM bank card to others, especially to people or companies they do not know. They should also be advised to make sure that the money managers are insured and bonded to protect them from theft or loss.

**Health Care Decision-Making Alternatives to Guardianship**

The process for making medical treatment decisions revolves around the concepts of informed consent and a person's right to accept or refuse medical treatment. In general and with few exceptions, an individual with decision-making capacity has the right to consent to or refuse any suggested medical treatment, even if refusal may result in death.\(^\text{20}\)

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When an individual is no longer mentally capacitated most jurisdictions require that a legally authorized representative make such decisions for the individual, except in an emergency. A guardian is a legally authorized representative for an individual but there are several alternatives to guardianship in the area of health care decision-making.

The use of advance directives as alternatives to guardianship has been an integral part of health care planning for years; however their effectiveness is questioned and compliance to patients' desires may still be somewhat inconsistent. In the United States, as with other issues confronting the nation as a whole, the National Conference of Commissioners on Uniform State Laws (NCCUSL) has addressed the area of health care decision-making, including decision-making for incapacitated individuals, by drafting the Uniform Health Care Decisions Act (UHCDCA). Under the UHCDCA, an adult or emancipated minor may make an advance health care directive by giving an "individual instruction" orally or in writing and/or by executing a power of attorney for health care, which may authorize the agent to make any health care decision the principal could have made while having capacity. An individual may revoke the designation of an agent only by a signed writing or by personally informing the supervising health care provider, but an individual may revoke all or part of an advance health care directive, other than the designation of an agent, at any time and in any manner that communicates an intent to revoke. The UHCDCA even provides an optional sample form (and explanation), which may be duplicated or modified to suit the needs of the person. Alternately, one may use a completely different form that contains the substance of the sample form found in the statute.

The UHCDCA places the so-called "living will," the durable power of attorney for health care, and a surrogate consent law together in one statute. As mentioned in a previous section, powers of attorney for health care may be included in a general power of attorney. It can also be included in an advance health care directive or as a stand-alone document. No matter what form the designation takes, drafting a health care power of attorney needs to comply with the health care decision-making law of the jurisdiction. This leads to one of the potential drawbacks of this document, namely "portability"—will the document be recognized in other jurisdictions? The UHCDCA seeks to make such documents portable from one jurisdiction to another, but this is not guaranteed and legal practitioners often create multiple documents for individuals who live for extended periods in different jurisdictions.

An "individual instruction," which takes the place of what is commonly called the "living will," applies to a wide range of health care decisions, not just end-of-life decisions. An individual instruction permits an individual to provide information to health care providers about health care decisions in the future, including desires with respect to artificially-provided nutrition and hydration (tube feeding), other life-sustaining treatments, pain management, mental health treatment, and virtually any other health care decision.

21. For example, in 2008, the U.S. Secretary of Health and Human Services provided a comprehensive report to Congress entitled "Advance Directives and Advance Care Planning." The report focused on (1) the best ways to promote the use of advance directives and advance care planning among competent adults as a way to specify their wishes about end-of-life care; and (2) addressing the needs of persons with disabilities with respect to advance directives. See United States Department of Health and Human Services, Advance Directives and Advance Care Planning: Report to Congress (2008), http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm (last visited Mar. 20, 2012).
23. Some jurisdictions still use the term "living will." Most jurisdictions in the United States now use the term "individual instructions" as used in the uniform act.
that an individual could make if capacitated. The residual decision-making portion of
the Act is usually included in hierarchical or “family consent” provisions that have been
adopted in a majority of the states of the United States. This section of the Act applies only
if there is no applicable individual instruction, guardian, or appointed health care agent.

Under the UHCDA, a surrogate may make a health care decision for a patient if the pa-

tient lacks capacity and no agent or guardian has been appointed or neither the agent nor
guardian is available. 24 A patient may designate or disqualify any individual to act as a sur-
rogate by personally informing the supervising health care provider. In the absence of such
a designation, or if the designee is not reasonably available, a surrogate may be appointed
to make a health care decision for the patient. In the absence of a designation, or if the de-
signee is not reasonably available, any member of the following classes of the patient’s fam-

ily who is reasonably available, in a descending order of priority, may act as surrogate. 25

There are a variety of other approaches to who can make decisions for an incapacitated
person if there is no guardian, agent, or designated surrogate. For example, Hawaii has

established a unique framework for appointing or selecting surrogates. Hawaii provides

no established hierarchy for surrogates but instead provides for decision making by sur-
rogates selected by consensus from a group of “interested persons.” 26 In some jurisdic-
tions, when an adult does not have the capacity to make a decision and does not have a

 guardian or personal directive, a health care provider (a physician, nurse practitioner, or
dentist for dental care only) may choose a relative to act as a specific decision-maker and

make the necessary decision on behalf of the adult.

As with other alternatives to guardianship that already have been discussed, since ad-

vance directives do not involve court oversight and are often cloaked in privacy, there

may be problems involved with implementation of such alternatives. There are also con-

 tinuing issues regarding health care providers refusing to follow the directions of author-
ized decision-makers, such as agents and surrogates, but such reluctance can also apply
to decisions made by guardians. Further, there is evidence that health care professionals

may not have adequate knowledge about advance health care directives, including durable
(enduring) powers of attorney. 27

24. “Capacity” as an individual's ability to understand the significant benefits, risks, and alterna-
tives to proposed health care and to make and communicate a health care decision. Unif. Health

25. The order prescribed in the UHCD A is as follows:

(1) the spouse, unless legally separated;

(2) an adult child;

(3) a parent; or

(4) an adult brother or sister.

(c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably avail-
able, an adult who has exhibited special care and concern for the patient, who is familiar with the pa-
tient’s personal values, and who is reasonably available may act as surrogate.


27. See F. Matthews, Doctors, Elder Abuse, and Enduring Powers of Attorney, 117 The N.Z. Med.
Journal 1, 1202, (2004). See also Unif. Health Care Decisions Act § 8, 9 Part IB U.L.A. 120 (2005), which
provides immunities for health care providers or institutions acting in good faith and in accordance
with generally accepted health-care standards applicable to the health-care provider or institution.
They would not be subject to civil or criminal liability or to discipline for unprofessional conduct.
On the other hand, section 9 of the UHCDA provides that a health care provider or institution that
intentionally violates this act is subject to liability to the aggrieved individual for damages resulting
Co-Guardianship and Limited Guardianship

If an adult’s ability to make decisions is diminished but the adult is still able to make decisions with adequate support, a court may order the appointment of a co-guardian (in some jurisdictions called a "co-decision-maker") to serve with the respondent. This may or may not be considered as an alternative to guardianship since the process still involves a court order, but it helps maintain the respondents autonomy by allowing the respondent to continue to make decisions but with the assistance of another. Such orders require the consent of the respondent and the proposed co-guardian. Co-guardianship is usually considered appropriate for spouses, family members and close friends. Likewise, a limited guardianship involves court intervention and an order, but it limits the powers of a guardian to those needed to address the particular disabilities of a respondent while preserving the residual powers of the respondent.

Supported Decision-Making

Supported decision-making mechanisms may be informal or formal. In some jurisdictions, if an adult has the capacity to make decisions but the individual desires some formal assistance, the individual may sign a document that authorizes another individ-

from the violation plus reasonable attorney’s fees. Note that advance healthcare directives under the UHCD Act are not very useful when a patient suffers cardiac or respiratory arrest. In a hospital or other healthcare facility setting, a patient who suffers an arrest is routinely resuscitated, unless there is a written do-not-resuscitate (“DNR”) order in the medical record. The DNR order is only an instruction to withhold the otherwise automatic initiation of cardiopulmonary resuscitation and it should not affect other forms of treatment. Outside of a healthcare facility, emergency response personnel normally attempt to resuscitate an individual who suffers a cardiac or respiratory arrest. This may or may not be the course of action that the individual would request if he or she still could make and express a choice. Use of out-of-hospital or rapid identification documents and Physician Orders for Life Sustaining Treatment (POLST) forms are effective means of supplementing advance healthcare directives.


29. The Uniform Guardianship and Protective Proceedings Act (UGPPA) supports such limitations by requiring judges to enquire into the abilities as well as the disabilities of the respondent.

Findings: Order of Appointment

(a) The court may appoint a limited or unlimited guardian for a respondent only if it finds by clear and convincing evidence that:

(1) the respondent is an incapacitated person; and

(2) the respondent’s identified needs cannot be met by less restrictive means, including use of appropriate technological assistance.

(b) Alternatively, the court, with appropriate findings, may treat the petition as one for a protective order under section 401, enter any other appropriate order, or dismiss the proceeding.

(c) The court, whenever feasible, shall grant to a guardian only those powers necessitated by the ward’s limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward’s maximum self-reliance and independence.


30. In the broadest sense, provided services and assistance may range from companion, telephone assurance, transportation, medication management, home health, nutrition, housekeeping, respite and case management, services to the assignment of dedicated supporters. The supported individual may have full or limited capacity.
ual to be the individual's "supporter." This supporter may be given permission to access the individual's private information, including personally identifiable health care information normally protected under privacy laws. The supporter could be granted permission to assist the individual in making and communicating complex decisions about the individual's health care, personal, legal, and financial matters. Such an alternative is appropriate for those individuals with mild cognitive impairments, including impairments due to mental disorders, those who have difficulty communicating, or those individuals whose first language is not that of the particular jurisdiction.

There is increasing momentum in the world community for supported decision-making and the United Nations has been at the forefront of this movement. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) obliges signatory countries to replace guardianship systems with a more rigorous system of alternatives, including systems and methods of supported decision-making for individuals with disabilities. Article 12 also recognizes that persons with disabilities have legal capacity on an equal basis with others but may require assistance to exercise this capacity. Accordingly signatory states are required to support individuals with and to provide safeguards against abuse of that support.

The supported decision-making framework under Article 12 is distinguished from more entrenched substituted decision-making mechanisms, such as guardianship or traditional alternatives to guardianship such as powers of attorney, advance health care directives, and health care surrogates where the person acting on behalf of the disabled person is granted the power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in conformance with the wishes of the individual best interests of the disabled person.

There can be practical issues in supported decision-making frameworks, especially if an individual cannot identify or agree upon a trusted person or group of people to provide assistance. In addition, supported decision-making generally requires more resources to assure that personal autonomy and self-determination are respected. Accordingly,

31. "With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. This distinguishes supported decision-making from substituted decision-making, such as advance directives and legal mentors/friends, where the guardian or tutor has court-authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interest or according to his/her wishes. Paragraph 4 of Article 12 calls for safeguards to be put in place to protect against abuse of these support mechanisms.

Supported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity."


32. Support could take the form of one trusted person or a network of people; it might be necessary occasionally or all the time. With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. Id.
chances for successfully implementing such programs may be limited unless jurisdictions mandate a supported decision-making framework for disabled persons.

Conclusion

Often guardianship allows guardians to ignore or to supersede actions and desires of the incapacitated person, much like a parent's actions over a child. Since traditional guardianships may seriously limit a person's self-determination, rights, and freedoms, it is becoming increasingly recognized that a less restrictive framework must be considered in order to safeguard the principles of autonomy, independence, and self-reliance. The effective use of alternatives to guardianship and supported decision-making can help balance the right to self-determination with the need for society to protect vulnerable adults.