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ADMITTED IN MISSOURI AND KANSAS

Do I Need a Guardian for My Family Member Who Has Down Syndrome?

Written for the
Down Syndrome Guild of
Greater Kansas City by
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I. Introduction: One of the critical issues facing parents, siblings or other concerned family members of an adult who has Down Syndrome is how to best assist and protect him or her when it comes to making legal, financial and medical decisions. Just because an individual has Down Syndrome does not mean that he or she lacks the mental capacity to make and communicate appropriate decisions. The individual may have sufficient mental capacity to adequately make decisions and protect himself. If so, then he or she should consider signing Durable Powers of Attorney so someone can step in and assist if the mental capacity is ever lost. This is no different than for any other adult.

However, if a person does not have sufficient mental capacity to be able to make and communicate appropriate decisions such that he or she may be taken advantage of or not be able to manage his or her affairs, then guardianship should be considered. This is a court proceeding where it must be proven that the person lacks sufficient mental capacity and needs the appointment of a guardian to make personal decisions (such as medical and housing) and a conservator if there are sufficient assets to manage.

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These materials will provide an overview of this process and its results for residents of Kansas and Missouri. These materials are current as of December 2011. As we all know, laws change over time, so be sure to verify that the information in these materials are current before relying on them.

1. Minor Person (Less than 18 Years Old): A parent has a legal duty to support and care for their minor child, whether naturally born or legally adopted. Therefore, the parent's income and resources are counted as "available" to the child for Medicaid and SSI purposes. This is why the child typically will not be eligible for benefits from those programs while a minor.

Parents of a minor child can legally make decisions for their minor child and can talk to educators, physician, police and others on behalf of the child. Since the parents have this authority, they do not need to go to court to be appointed as the child's guardian. In fact, most states refer to a parent as a "natural guardian."

However, if the minor child inherits money or receives an award from a personal injury lawsuit or insurance settlement, the parents will have to go to court to be appointed as their child's conservator. This allows the parents to manage their child's money, subject to court oversight. This is true whether or not the child has a disability. Any money held in a conservatorship for a minor will be turned over to the child when he or she attains age 18.

Missouri statute §475.024 allows a parent of a minor child to sign a power of attorney that delegates to another adult person the authority to make decisions on behalf of the child while the parent is temporarily away. These can include medical or housing decisions. This authority cannot be for a period longer than one year. Kansas does not have any specific statutory authority to do this. Neither state allows a court appointed guardian or conservator to delegate their authority to another person without court approval.

2. Adult Person: When a child reaches the age of 18 years, the child is no longer a minor, even if he or she is totally disabled. Since the child is now legally an adult, he or she is treated differently by the law in a variety of ways, some of which are discussed below.

A. The parents no longer have a legal duty to support the child, even though they are still the child's parent;

1) This means the parents' income and resources will <u>not</u> count as being available to the child for Medicaid and SSI purposes, and

2) If the child's income and resources are low enough, and the child is sufficiently disabled, he or she may qualify for SSI and Medicaid. (In Missouri, Medicaid is referred to as “MO HealthNet”).

3) This may not apply to a parent who is required by a court order to pay child support for a child past age 18. However, any child support paid after the child is 18 will be treated as income to the child for SSI and Medicaid eligibility. This will have an adverse effect on these public benefits unless there is a court order requiring the child support to be paid into a self-settled special needs trust.

B. If the adult child marries, his or her spouse has a legal duty to support the child (and vice versa). Therefore, for Medicaid and SSI purposes, the income and resources of the spouse are deemed to be available to the child and may cause the child to not be eligible for these benefits, even if otherwise qualified.

C. But, even though a parent is still the parent, and any spouse of the parent’s child is legally required to support the child, neither the parent nor the spouse can legally make decisions for the adult child. There are only two ways someone can have authority to make decisions on behalf of an adult and manage the adult's assets and income.

1) The adult appoints someone as attorney-in-fact (sometimes referred to as an “agent”) under a Durable Power of Attorney. This means the adult must have the mental capacity to execute a Durable Power of Attorney; or

2) The local probate court appoints someone as guardian (to make personal decisions) and/or conservator (to handle property and financial assets) for the adult. This means the adult person has been found by the court to be sufficiently mentally disabled that he or she needs this oversight. Physical disability does not cause the need for the appointment of a guardian; only mental incapacity does.

II. Should My Family Member Who Has Down Syndrome Have a Durable Power of Attorney? In order to adequately answer this, it is first necessary to understand what a durable power of attorney is and what is needed to sign one.

1. Definitions:

A. Power of Attorney: A Power of Attorney is a written instrument which authorizes someone designated in the document (the "attorney-in-fact" or "agent") to act on behalf of the person granting the power (the "principal").

Once performed, the acts of the attorney-in-fact become legally enforceable acts of the principal. The concept of a power of attorney comes from our common law, although under the common law the authority granted to the attorney-in-fact stops if the principal loses mental capacity.

B. Durable Power of Attorney: In contrast to a common law power of attorney, a Durable Power of Attorney is a power of attorney that stays in full force and effect even if the principal becomes mentally incapacitated. Usually it must contain words that make it clear that the principal intends the authority conferred on the attorney-in-fact to continue to be exercisable notwithstanding the principal's subsequent incapacity. The authority to establish a durable power of attorney is found in the state statutes, and every state has different requirements that must be followed. It is important that a durable power of attorney comply with the laws of the State where the principal resides.

2. Scope of Authority: The authority granted to the attorney-in-fact is limited to the authority held by the principal. If the principal cannot perform a certain act, then he cannot give the authority to do so to his attorney-in-fact. In addition, the principal may further limit the authority given to the attorney-in-fact.

In essence, this means that the principal must have the mental capacity and legal authority to make any decisions and perform any acts he or she is delegating to the attorney-in-fact in the durable power of attorney. Therefore, if your family member with Down Syndrome has sufficient mental capacity to make appropriate decisions concerning his or her money management, health care and living arrangements, then he or she should be able to execute a durable power of attorney. In fact, a court will not appoint a guardian to act for a person if he or she has sufficient capacity to execute a durable power of attorney. However, the opposite is also true: your family member who has Down Syndrome cannot execute a durable power of attorney if he or she does not have sufficient mental capacity to make the same decisions that are being delegated to another person by a durable power of attorney.

3. What Does Signing a Durable Power of Attorney Accomplish? By signing a durable power of attorney, your family member is not giving up any legal rights; they are merely being duplicated in the attorney-in-fact. This means you, as attorney-in-fact, can check your family member into a medical facility, but he or she can immediately check out. What your family member instructs the physicians will be followed, not what you, the attorney-in-fact, says, unless the family member is at that time mentally incapacitated. Your family member will be legally bound by any contracts he or she signs, and you will not be able to intercede on your family member’s behalf for any civil or criminal legal actions.

4. How Guardianship Differs from Durable Power of Attorney: If, on the other hand, you were appointed as the guardian for your family member who has Down Syndrome, none of the above-described examples would be true. As guardian, you would make medical decisions for your family member. If you checked your family member into a medical facility, she could not check out without your permission. If your family member signed a legal contract, he would not be bound by the provisions of the contract and could not be sued. The contract would be void because only you, as guardian, can sign contracts on behalf of your family member. If your family member had any issues with school or police authorities, they are required to notify you as his or her guardian and allow you to intercede on your family member's behalf.

5. General Rule: If your family member who has Down Syndrome has sufficient mental capacity to live on his or her own, make appropriate decisions and manage his or her money, then a durable power of attorney should be signed by your family member to forestall the necessity of appointing a guardian if your family member loses this mental capacity. This is no different than for every adult, including you. If, on the other hand, your family member does not have sufficient mental capacity, then guardianship should be pursued in order to make sure your family member is adequately protected.

6. Durable Power of Attorney Forms: There are two types of durable powers of attorney: one is for health care and the other is for legal and financial matters. Although they are occasionally combined into one document, usually they are separate documents. It is easier to find adequate forms for health care decisions than for financial matters. For example, the Center for Practical Bioethics has a Caring Conversations section of its website that can contains forms (www.practicalbioethics.com). Also, in Missouri, the Missouri Bar Association has such a form on its website (www.mobar.org). However, use these forms with caution.

A durable power of attorney is a technical legal document that must comply with the laws of the State where the person executing the document resides. Although there are many sources for forms, such as computer programs, internet sites and office supply stores, usually those forms are inadequate, especially for legal and financial matters. They may cover the broad strokes of typical powers granted, but they will almost never get into the details required when the principal (your family member) has a disability and may be receiving or eligible for public assistance. Durable powers of attorney are usually strictly construed, which means that in order to take certain actions on behalf of your family member there must be express authority granted in the document. If it is not there, then often the attorney-in-fact will not be allowed to act on behalf of your family member.

The better source for durable powers of attorney is an attorney who practices elder law. Not only will the durable powers of attorney comply with local law and be customized to your family member's situation, but the attorney who prepared the documents will be the best witness if anyone ever challenges the document based on your family member's disability and presumed lack of mental capacity to execute the document.

III. The Legal Process Required to Appoint a Guardian: It requires a court proceeding to establish a guardianship. Each county has a courthouse and one of the courts is designated as the "probate" court. This is where guardianship cases are heard - in the probate court of the county where the proposed ward (your family member who has Down Syndrome) resides.

If it is decided to petition for the appointment a guardian for your family member who has Down Syndrome, then the judicial process will pass through three phases: (1) adjudication of incapacity; (2) appointment of guardian and (3) administration. These will be briefly described below.

For ease of reference, these materials will usually only refer to guardianship and the appointment of a guardian. Unless otherwise indicated, the process is essentially the same for the appointment of a conservator.

1. Phase 1 - Adjudication of Incapacity: Guardianship proceedings are initiated by a person (the "petitioner") filing a petition in the probate court of the county where your family member who has Down Syndrome resides. Normally a parent, sibling or other close relative of your family member will be the petitioner, and will be asking the court to be appointed as guardian. If both parents are living, they may ask to be appointed as co-guardians. It is also possible for siblings or other close relatives to ask to be appointed as co-guardians. This is further discussed later in these materials.

The court will appoint an attorney to represent your adult family member for whom guardianship is proposed (for ease of reference, this person will be referred to as the "proposed ward" for the remainder of this section). The proposed ward can also hire his or her own attorney. The proposed ward's attorney cannot be the same as the guardian's attorney. The job of the proposed ward's attorney is to protect the legal rights of the proposed ward. This includes making sure that the proposed ward is not being taken advantage of and has the opportunity to challenge the proceedings. In Missouri, the court automatically chooses this attorney. In Kansas, it is usually the responsibility of the petitioner to find an attorney to represent the proposed ward.

A hearing date is set and notice of the hearing is served on the proposed ward. In Kansas, the hearing must be held between seven and twenty-one days following the date the petition is filed. In Missouri, it is set on the next available court date, but it is often less than a month after the petition is filed.

Just as with any legal action, notice of the filing of the petition to appoint a guardian and the hearing must be served on the proposed ward. In Kansas, this is often accomplished by the attorney appointed to represent the proposed ward. In Missouri, it is usually a sheriff who serves the petition and notice of the hearing. In addition, notice of the hearing is mailed to close family members. In Missouri, this includes the proposed ward's parents (unless they are the petitioner), spouse (if there is one), adult children, anyone who is already appointed guardian or conservator for the proposed ward, anyone who has "power to act in a fiduciary capacity" with respect to the proposed ward's assets (such as an attorney-in-fact under the proposed ward's durable power of attorney), and anyone who is caring for or has custody of the proposed ward. Kansas also requires notice to the proposed ward's adult grandchildren and adult siblings. If there are none, then at least one adult who is nearest in kinship must be notified of these proceedings.

At the hearing, evidence is presented by the petitioner to establish that the proposed ward is sufficiently mentally impaired to need a guardian and, if the proposed ward has sufficient property or income, a conservator. If the proceeding is not contested, then this evidence is often satisfied by the written opinion of a physician who has recently examined the proposed ward. If the proceeding is contested, then there are often multiple physicians who render opinions and other people who have worked with, lived with, or just spent time with the proposed ward to testify for one side or the other. If the proposed ward wishes to challenge the proceedings, his or her attorney can cross-examine all of the petitioner's witnesses and present evidence favorable to the proposed ward. The proposed ward can also request a jury trial; otherwise the judge will hear the case.

At the conclusion of the proceedings, the judge (or jury, if it was a jury trial) will decide whether the evidence presented is enough to establish that the proposed ward is sufficiently mentally impaired to meet the definition as set forth in the statute.

In Missouri, the standard that must be met before a guardian is appointed is "unable by reason of any physical or mental condition to receive and evaluate information or to communicate decisions to such an extent that the person lacks the capacity to meet essential requirements for such person's food, clothing, shelter, safety or other care such that serious physical injury, illness, or disease is likely to occur." R.S.Mo. §475.010(9). Missouri refers to this person as "incapacitated." If a person also "lacks the ability to manage his or her financial resources," they are referred to as "disabled."

In Kansas, the standard is, "A person 18 years or older, ..., whose ability to receive and evaluate relevant information, or to effectively communicate decisions, or both, even with the use of assistive technology or other supports, is impaired to such an extent that the person lacks the capacity to manage such person's estate or to meet essential needs for physical health, safety or welfare, and who is in need of a guardian or a conservator, or both." K.S.A. §59-3051. Kansas refers to this person as "an adult with an impairment in need of a guardian or a conservator, or both."

If it is determined that the proposed ward is not sufficiently mentally impaired to meet these standards, then no guardianship will be imposed and the proposed ward is free to go. If the judgment is that the proposed ward is sufficiently impaired, then the judge will proceed to phase 2, which is described below.

2. Phase 2 - Appointment of a Guardian: If the court finds the proposed ward is sufficiently mentally impaired to need a guardian, the next step is to appoint one. This usually takes place in the same court hearing. All interested persons can present evidence in favor of or against any potential guardians. The court will then decide who will serve. If the proposed ward has sufficient income and/or assets that a conservatorship is needed, then both a guardian and a conservator will be appointed. Usually the same person is appointed to both positions, but this is not required.

The people, organizations, social service agencies, or corporations that can be appointed guardian and/or conservator are set by statute. In Kansas these are, in order of priority (K.S.A. §59-3068):

- Any eligible person nominated in a valid Durable Power of Attorney previously signed by the proposed ward;
- The nominee of a parent ("natural guardian") of the proposed ward;
- The nominee of the proposed ward if he or she is over 14 years of age;
- The nominee of the spouse, adult child, or other close family members of the proposed ward; or
- The nominee of the petitioner.

In Kansas, any adult person, or a private, non-profit corporation organized under Kansas law can serve as guardian and/or conservator if it qualifies.

In Missouri these are, in order of priority (R.S.Mo. §475.050):

- Any eligible person chosen by the proposed ward;
- Any eligible person nominated in a valid Durable Power of Attorney previously signed by the proposed ward;
- The spouse, parents, adult children, adult brothers and sisters, and other close relatives of the proposed ward; or
- Any eligible person nominated in a Will of such spouse or other relative that was probated within five years before the guardianship hearing.

In Missouri, any adult person who is not a "habitual drunkard", does not have a guardian or conservator appointed for them, or has not previously had letters of guardianship or conservatorship revoked may serve as a guardian and conservator. A social service agency may be appointed as guardian (not conservator) if it employs a licensed professional with expertise and primary responsibility for providing guardianship services. A corporation authorized to do business in Missouri or chartered as a national bank may serve as conservator (not guardian). Only charitable organizations that were incorporated as a not-for-profit corporation in Missouri prior to January 1, 1902, can serve as a guardian. (R.S.Mo. §475.055)

In both Kansas and Missouri the court will appoint a guardian if one is needed even if there is no close relative willing to serve. In Missouri, the court will usually appoint the Public Administrator of the county where the proposed ward resides. This is a person who has been appointed or elected to a county government position. The Public Administrator is appointed as guardian and conservator for people who need one and there is not a relative or friend who the court is willing to appoint. The Public Administrator also handles probate estates. Usually the Public Administrator has a staff who assists in preforming the functions of the job. Kansas does not have a Public Administrator. Instead, local attorneys or other persons the court trusts are appointed as guardian, conservator or to handle probate estates if no one else is willing or able to do so.

Rather than just one person acting as sole guardian, it is also possible to appoint more than one person as co-guardians. If the guardianship proceeding is in Missouri, then the court will order that the co-guardians must always act together. If the guardianship proceeding is in Kansas, then the court usually allows each guardian to act independently of each other.

After the guardian satisfies the court that he or she will faithfully perform their duties as guardian (in Kansas this requires the filing of an Oath; in Missouri the filing of a consent to act), the court will issue Letters of Guardianship. With this piece of paper the guardian can make decisions on behalf of the ward (which is the name used to refer to a person who has a guardian appointed to act on his or her behalf). If there are sufficient assets for the appointment of a conservator, then once the conservator posts a bond and otherwise satisfies the court, the conservator will receive Letters of Conservatorship and can then begin handling the ward's property.

Although rarely used, it is also possible to appoint a "standby guardian". In Kansas, this is a person who is appointed to automatically take over upon a temporary absence of the guardian. In Kansas and Missouri, the standby guardian will also assume the role of guardian upon the death or resignation of the guardian, but a court hearing will be needed shortly after this occurs to confirm the appointment of the standby guardian as the new guardian.

3. Phase 3 - Administration: If you are appointed guardian of your family member who has Down Syndrome, you are responsible for personal living and health care decisions for your family member. The court continues to oversee your actions as guardian, however, and any proposed change in circumstances or living arrangements must be approved by the court, usually in advance. This requires filing a motion and obtaining a court order. Often a court hearing is held to determine if the proposed change is in the best interest of your family member. In addition, annual reports must be filed by the guardian with the court.

If you are appointed as conservator for your family member who has Down Syndrome, you are responsible for the management and spending of your family member's income and assets. An inventory of all of your family member's assets must be filed with the court within thirty days after being appointed. Annual accountings (referred to as "settlements") must also be filed, and these are reviewed by the court. Usually the person appointed conservator must purchase a corporate surety bond, or all of the conservatorship funds must be placed in a restricted account at a bank, before the court will authorize the person to begin acting as conservator.

As a practical matter, if your family member is receiving SSI or Medicaid assistance, he or she will not have a large enough amount of assets to require the appointment of a conservator. In such a case the guardian will manage the family member's income and assets and, in most courts, will not have to post a bond or account to the court.

IV. Powers, Duties and Responsibilities of the Guardian:

1. Generally: If you are appointed as guardian for your family member who has Down Syndrome, you become responsible for the physical care of your family member, who is referred to as a "ward". All of your decisions must be based on what is in the "best interest" of your family member. You must also make sure that your family member is in the "least restrictive environment." This responsibility includes making health care decisions, choosing who your family member's care providers and doctors are, and decisions concerning where your family member lives. All of your decisions are subject to review, and often prior approval, of the court.

2. How the Statutes Describe a Guardian's Powers: Missouri Statute R.S.Mo. §475.120.3 describes the guardian's powers as follows: "The general powers and duties of a guardian of an incapacitated person shall be to take charge of the person of the ward and to provide for the ward's care, treatment, habilitation, education, support and maintenance; and the powers and duties shall include, but not be limited to, the following: (1) Assure that the ward resides in the best and least restrictive setting reasonably available; (2) Assure that the ward receives medical care and other services that are needed; (3) Promote and protect the care, comfort, safety, health, and welfare of the ward; (4) Provide required consents on behalf of the ward; (5) To exercise all powers and discharge all duties necessary or proper to implement the provisions of this section." The Kansas statute is essentially the same.

3. Practical Effect: Your family member loses certain legal rights when a guardian is appointed. Generally, this means any ability to make his or her own decisions. These include such things as the ability to sign a contract, determine where to live, decisions about health care treatment, the right to hold a drivers license and the right to vote. Occasionally an exception will be made if the family member can demonstrate to the Judge that he or she has the capacity to perform the task, such as voting in general elections.

For many of these removed powers, the guardian is empowered to make the decisions for your family member; although sometimes it is necessary to get prior court approval. For others, such as the right to vote, the guardian does not have the power to do so on your family member's behalf.

Even if your family member takes some legal action, such as sign a contract or a lease, it is not binding on the family member since the guardian is the only person who has the legal authority to act on behalf of your family member. Any contract or lease signed by a ward is void and can be easily set aside by the guardian. In addition, the guardian can take legal actions on behalf of your family member without your family member's prior consent or approval; provided such action is within the scope of the guardian's authority or approved by the court overseeing the guardianship.

4. Selected Duties and Restrictions: Some of the more common duties and restrictions on your authority if you are appointed guardian for your family member who has Down Syndrome are as follows:

A. Duties: As guardian you are required to -

- take charge of your family member and to provide for his or her care, treatment, habilitation, education, support and maintenance;
- consider and either provide or refuse to provide necessary or required consents on your family member's behalf;
- assure your family member resides in the least restrictive setting appropriate to the needs of your family member and which is reasonably available;
- assure your family member receives any necessary and reasonably available medical care and non-medical care or other services that may be needed to preserve the health of your family member or to assist your family member to develop or retain skills and abilities;
- promote and protect the comfort, safety, health and welfare of your family member; and
- make necessary determinations and arrangements in regard to your family member's funeral arrangements, burial or cremation.

B. Restrictions: If you are appointed a guardian in Kansas you do NOT have the authority to -

- prohibit the marriage or divorce of your family member;
- consent to the termination of your family member's parental rights; and
- consent to the performance of any experimental biomedical or behavioral procedure on your family member, or for your family member to participate in any such experiment, without prior review and approval by a review committee.

C. Limitations Requiring Court Approval: As guardian you do NOT have the authority to do the following unless the Court approves

- consent to the adoption of your family member;
- consent to any psychosurgery, removal of bodily organ, or removal or amputation of any limb, unless it is an emergency and necessary to preserve the life or prevent serious and irreparable impairment to your family member's physical health;
- consent to the sterilization of your family member;

- admit your family member to a mental health facility for more than thirty days; and
- consent to the withholding or withdrawal of life-saving or life-sustaining medical care, treatment, services or procedures. Most states, including Missouri, have a flat prohibition against this unless the ward signed a health care directive prior to becoming incapacitated. However, the Kansas guardianship law contains a procedure where a hearing can be held and, if sufficient evidence is submitted to establish that the ward is in a persistent vegetative state or suffering from some other illness or medical condition where the ward is merely being kept alive by artificial means, then the court can order that life support be withheld or withdrawn from the ward.

D. No Requirement to Use Your Own Money: As guardian you are NOT required to use your own money or assets to provide for your family member. Nor are you required to allow your family member to live in your home. Also, you do NOT become personally responsible for your family member's debts merely because you are serving as your family member's guardian or conservator. This is one of the major differences between being the parent of a minor child and merely serving as guardian and/or conservator for your adult child.

V. Powers, Duties and Responsibilities of the Conservator:

If you are appointed as conservator for your family member who has Down Syndrome, you are responsible for the management of your family member's property. A person who has a conservator appointed for him or her is referred to as the "conservatee" in Kansas and the "protectee" in Missouri. As conservator you must act in a fiduciary capacity. This means you must invest your family member's conservatorship assets prudently, cannot place yourself in a position in which your interests conflict with your family member's, and cannot profit or gain from your family member's assets. Typically, the court will only allow conservatorship assets to be invested in an FDIC insured bank account or certificate of deposit, rather than in the stock market. As conservator you are given broad power to manage your family member's conservatorship assets, but you are personally liable for any damage to or wasting of the conservatorship assets. You must keep track of all expenditures and file an accounting (referred to as a "settlement") with the court annually.

If your family member is participating in the SSI or Medicaid programs, he or she will not have many assets. Therefore, most courts will not require that a conservator be appointed. For those that go ahead and appoint you as conservator, you will be excused from filing any settlements with the court unless your family member receives sufficient money to disqualify him or her from the SSI and Medicaid programs. This is referred to as placing the conservatorship on "no further process."

Both Kansas and Missouri laws authorize the guardian and/or conservator to ask the court to establish and fund a self-settled special needs trust with your family member's conservatorship assets. Since your family member has a guardian and/or conservator appointed to act on his or her behalf, it requires court action to establish this type of trust. Assuming your family member is otherwise eligible (which essentially means he or she is under the age of 65 and sufficiently disabled to qualify for SSI), this will allow your family member to qualify for Medicaid and/or SSI and the former conservatorship assets will be held in a trust that can be used to supplement the public assistance benefits your family member is receiving. Since this trust is holding assets that formerly belonged to your family member, it is the type of special needs trust that must repay Medicaid when your family member is no longer living. It is not the same type of trust that a parent would use when leaving the parent's assets in a special needs trust for the benefit of a child who has a disability.

VI. Other Thoughts Relating to the Guardianship Proceeding:

1. How Do I Find Out Whether a Guardian Has Already Been Appointed? If you are unsure whether a guardian has already been appointed to act on behalf of your family member who has Down Syndrome, you should contact the probate court of the county where your family member resides. They will be able to tell you whether a guardianship has been established for your family member. If your family member has moved, then you should check with the probate court located in each county where your family member has resided since age eighteen.

2. What Will Be Required of Me if I become a Guardian? You should not ask to be appointed guardian for your family member who has Down Syndrome unless you truly want to be involved in his or her life. Although you are not responsible to use your own money for your family member's support, or allow him or her to live with you, you will be responsible for making sure your family member lives in the least restrictive environment, is receiving appropriate medical care, is not being taken advantage of, and is receiving the care and assistance to which he or she is entitled. This will require you to spend time and energy overseeing and being with your family member. It is you who will be contacted when the emergency happens, and you need to be ready, willing and able to immediately step in and act on behalf of your family member. You need to be genuinely concerned about your family member's well being. The law does not require that you live in the same community as your family member, but it is certainly easier if you do. If you live far away, it will be your responsibility to arrange for someone to be able to check up on and be on call for your family member's immediate needs.

3. Do I Need an Attorney to Represent Me? Although not required except in Jackson County, Missouri, it is recommended that you hire an attorney to represent you if you are petitioning to be appointed as a guardian for your family member who has Down Syndrome. The appointment of a guardian for another person is treated very seriously by the courts. The process and formalities that must be adhered to can be confusing. Also, each county has different local rules and procedures that must be followed, and the judges have little time or patience for mistakes.

4. What Information Do I Need for the Petition? When you decide to hire an attorney to help you obtain guardianship for your family member who has Down Syndrome, the attorney will need certain information from you. At the least, the following should be gathered for your appointment with the attorney:

- Full name, address, birth date and Social Security number for your family member;
- Full name, address, birth date and Social Security number for each petitioner, and anyone else proposed to be appointed as a guardian;
- Full name and address of all of the people who must be given notice of the proceeding (see Section III. 1, above);
- What public benefits, if any, your family member is receiving;
- Details about your family member's income - where it is coming from, how much is being received and whether anything is being withheld. A copy of the pay stub or benefit statement is helpful.
- List of all assets owned by your family member, including how each asset is titled, its current value, whether there is beneficiary named who will receive the asset upon your family member's death, and the account number, if applicable. A copy of the most recent statement for any bank or investment accounts is helpful.
- Medical information relating to your family member's disability.
    - This could include any written evaluations that are still applicable, the most recent IEP and anything else you think would be helpful;
- A description of your family member's functional abilities.
    - For example, your family member's communication skills, dressing and self-feeding skills, ability to prepare meals or take medications without assistance, ability to manage money, ability to make and communicate decisions, and so on;
- The name, address and telephone number of your family member's physician who will provide the medical information that the court will use in its determination of whether your family member is sufficiently incapacitated to need a guardian;

- Whether your family member will agree with the appointment of a guardian, or will contest this action; and
- For Missouri, the full name, address, telephone number and relationship of three adults who are not living in your house and who will know how to contact you.

5. How Long Will This Take? From the filing of the petition to the appointment of a guardian, an uncontested guardianship proceeding will usually take less than a month to accomplish. A contested proceeding, especially if there is a jury trial, can take much longer. If there are valid reasons, it is possible to also petition the court for an emergency guardian or a guardian-ad-litem to be appointed immediately and serve until the full hearing can be held.

6. When Should the Petition Be Filed? Normally a petition for guardianship is not filed until the your family member for whom a guardianship is sought is an adult, i.e., at least eighteen years old. However, it is possible to file the petition shortly before that age so the family member can be served a copy immediately after reaching age eighteen.

7. How Much Will This Cost and Who is Responsible for the Costs? The costs for an uncontested guardianship proceeding consist of the court filing fee, attorney fees for the attorney representing the petitioner and attorney's fees for the attorney representing your family member. In addition, the physician may charge for the opinion letter used as evidence of your family member's incapacity in the court proceeding. Although not common, some physicians may charge twenty to fifty dollars for this letter.

Each court has a different filing fee, but generally they will be around or less than $200. If your family member does not have any assets, in Missouri some courts may order the county to pay your family member's attorney's fees; otherwise, your family member is responsible for those fees. The costs of the proceedings, including attorney fees for the petitioner, are usually the responsibility of your family member (although, as a practical matter, parents who are petitioning for guardianship usually pay them because the child does not have sufficient income or assets). However, if your family member is found to be competent and not in need of a guardian or conservator, the petitioner's costs and attorney's fees must be paid by the petitioner.

Some attorneys will charge by the hour, while others will charge a fixed fee. Currently, it is not unusual to see total costs, including the petitioner's attorney fees, for an uncontested guardianship fall into the one to two thousand dollar range. However, this is merely an observation; it is important that you discuss all charges, expected costs and payment arrangements with your attorney before you hire one.

8. How Does A Successor Guardian Get Appointed? Only a court can appoint a guardian or conservator. However, certain relatives of a person for whom a guardianship is established can nominate other people to serve as a guardian.

In Missouri, the spouse, parents, adult children, adult siblings and other close adult relatives may nominate a person to serve as successor guardian in their last will and testament if it was admitted to probate and executed no more than five years before the guardianship hearing. (R.S.Mo .§475.050.2(4)) In Kansas, this is limited to the parents of a minor child. (K.S.A. §59-3054) However, another statute (K.S.A. §59-3068) allows a parent, spouse, adult child or other close family member to nominate a guardian, presumably by appearing in court.

If a person serving as a guardian or co-guardian dies or becomes unable to serve, the court overseeing the guardianship must be notified. The court will remove the guardian who can no longer serve and either appoint the existing co-guardian or a new person as successor guardian. As with the original proceedings, the court can also appoint more than one person as co-guardians.

VII. How to Decide Whether to Pursue Guardianship:

1. Reasons Against: The decision to file guardianship proceedings is not one to be made lightly. Not only are the proceedings somewhat expensive and time consuming, but once a guardianship is in place, it is difficult to terminate. Your family member who has a guardian appointed for him or her will lose many basic legal rights, such as the right to decide where to live, to sign a contract, to vote, to hold a drivers license, to make decisions about his or her health care, and so on. The court essentially takes control of the life of your family member, and the guardian is appointed to handle many of the day-to-day dealings for your family member. The restrictions and limitations imposed by the guardianship and conservatorship statutes are much more restrictive than those imposed by a broad Durable Power of Attorney. Therefore, in most circumstances, if it is at all possible, a Durable Power of Attorney should be used instead of a guardianship.

2. Reasons for: However, in some situations it is necessary to file for guardianship.

A. Your family member may be too mentally impaired to execute a valid Durable Power of Attorney.

B. Even if a Durable Power of Attorney exists, it may not be broad enough or enforceable.

C. If your family member is refusing necessary treatment or institutionalization, acting out uncontrollably, being unduly influenced by people trying to take advantage of your family member, or signing contracts and agreeing to purchases or commitments that clearly are not in your family member's best interest, then guardianship may be the only method of legally gaining control of your family member and being able to help him or her.

Keep in mind that a Durable Power of Attorney does not restrict the authority of your family member to act on his or her own behalf. Instead, it merely duplicates the power to make legally binding decisions that affect your family member, and gives such power to the attorney-in-fact appointed in the Durable Power of Attorney.

3. Summary of Items to Consider: In summary, listed below are items to consider when making the decision about whether to file a guardianship and/or conservatorship proceeding for your family member who has Down Syndrome.

A. Reasons Against Filing For Guardianship/Conservatorship:

1) Cost of proceedings:
- **a.** Court costs;
- **b.** Attorney fee for your attorney;
- **c.** Attorney fee for your family member's court-appointed attorney;
- **d.** Cost for physician's opinion of incapacity; and
- **e.** Cost of bond for conservator, if one is appointed.

2) Annual reports you as guardian must file with court.

4) Time needed to comply with court requirements.

5) Restrictions imposed on your family member and you as guardian.

6) Annual accountings that must be filed with court if you are appointed conservator.

B. Reasons in Favor of Filing For Guardianship/Conservatorship:

1) A sufficient Durable Power of Attorney does not exist, and your family member is too impaired to sign one.

2) To have the authority to make decisions for your family member and to prevent your family member from making certain decisions that may not be in his or her best interest.

Example: To decide where your family member lives, what health care treatment should be administered, etc.

3) To have the authority to talk to educators, physicians, police and others on behalf of your family member. Also, it is important to remember that being appointed guardian for your family member requires that these people talk to you about your family member. Since you are appointed guardian it is you, not your family member, that has all of the authority and power to make decisions concerning your family member.

This does not occur if your family member signs a Durable Power of Attorney. In that event your family member has merely authorized you to make certain decisions on your family member's behalf. It does not take anything away from your family member. This means that your family member's educators and physicians, the police and others can still talk to your family member alone without you being present, and you cannot require them to talk to you instead of your family member. Only guardianship accomplishes that.

VIII. In Conclusion...

This handout is an attempt to provide some insight into the factors a parent, sibling or other close relative of a person who has Down Syndrome should take into account when considering whether or not to petition a court to become a guardian when the person turns eighteen years old. It is not meant to be a definitive source for all information relating to this decision. Only by consulting with an attorney who is familiar with the laws and procedures relating to guardianship in the community where the person who has Down Syndrome resides can all of the nuances of your particular situation be appropriately factored into this decision.