

# WHAT THE FAMILY NEEDS TO KNOW ABOUT PLANNING FOR A LOVED ONE WITH A DISABILITY

By

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## I. Estate Planning in General

A. Every estate plan must include:

1. Review of your family's needs;
2. Examination of the resources available to meet those needs; and
3. Decision concerning the appropriate structure to handle the resources which will meet those needs.

B. Facts of life in planning for a person with a disability:

1. Persons with disabilities are living longer and often outliving their parents.
2. The needs and cost of care for a person with a disability are likely to be greater than those of non-disabled family members.
3. Although children with special needs will require costly care after their parent or parents have died, few parents have provided for such costs. Those who have a plan often make mistakes by leaving money directly to their special needs children, thereby jeopardizing

means-tested governmental benefits, such as SSI and/or Medicaid, upon which the child now depends or for which the child may be eligible in the future.

4. The potential resources available include governmental assistance which should not be jeopardized by the estate plan in most cases. However, there is:
  - a. No assurance public benefits will provide adequate care for life.
  - b. No guarantee that public agencies will provide lifetime services and advocacy.
5. There are generally unique and continuing financial management and personal care considerations for family members with a disability.

## **II. Personal Care Alternatives**

### **A. Minors**

1. Tutorship (Guardianship)
  - a. For children under the age of 18 who have not been legally emancipated, parents are the “natural” tutors of their minor children with full decision-making authority, including, but not limited to, health care decisions.
    - i. If a parent dies, the surviving parent has the right of tutorship.

- ii. If parents divorce, tutorship belongs to the parent who is awarded custody of the minor child. If joint custody is awarded, co-tutorship belongs to both parents, equally, unless the court order or the parents provide otherwise.
- b. The right of appointing a successor tutor belongs exclusively to the parent dying last. However, if parents are divorced, the parent awarded custody has the right to appoint a successor tutor. In joint custody, the parent dying last has the power to appoint the successor tutor for the minor child.
- c. Tutor has the custody of and is required to care for the person of the minor and to preserve and administer the minor's property, if any. The tutor is required to obtain prior court approval for all actions with respect to the minor's property.

## 2. Continuing or Permanent Legal Tutorship

- a. Applies to mentally retarded or deficient children. Permits continuation of tutor's limited authority over child beyond age 18 until court terminates the tutorship.
- b. Requirements of simplified court procedure.
  - i. Child must be above age 15 and under age 18.
  - ii. Child must possess less than 2/3rds of the average mental ability of a normal person of the same age,

measured by standard testing procedures administered by a competent person, such as a child psychologist.

c. Procedure.

- i. A petition is filed in the proper court by the tutor (and undertutor), together with an Affidavit from the competent person who administered the mental test and the written concurrence of the parish coroner.
- ii. Tutor must file necessary qualification papers and descriptive list and valuation of minor's property, if any.
- iii. Court issues decree of continuing tutorship and letters of continuing tutorship.
- iv. If a child has assets, general mortgage exists over the tutor's property, unless a special mortgage or bond is substituted, as security for and protection of the minor's assets. This means that there may be a mortgage on your family home and any other real estate you may own which would have to be removed if you wanted to sell your real estate.

d. Continuing tutor has same power as tutor of a minor, including authority to give consent to any medical treatment, to give consent to any educational plan and to obtain medical,

educational or other records. However, after age 18, the child generally has full administration of his or her estate unless interdicted (as discussed below).

B. Adults

1. Once your child is 18, he or she is entitled to make all decisions affecting his or her person and property, including but not limited to, healthcare decisions, unless your child voluntarily delegates decision making authority to you or someone else pursuant to a Power of Attorney or is judicially deprived of some or all of his or her rights through an interdiction (guardianship) proceeding.
2. Only your adult child or his or her authorized personal representative has the right to inspect, review and receive a copy of his or her medical records under the federal and state HIPPA Privacy Rules.
3. Once your child is 18 and assuming your child has legal capacity (can understand the nature and consequences of the legal document being signed), consider having your child execute a healthcare power of attorney, a financial power of attorney and an “education” power of attorney. Your child can designate one or more persons (including a parent or parents) as Agent to make decisions and can provide for a back-up Agent. Although a Power of Attorney is more desirable than an interdiction (which can be expensive, time consuming and emotionally draining), the disadvantage with a

Power is that your child can revoke it at any time. Furthermore, granting an Agent authority under a Power of Attorney does not deprive your adult child of making his or her own decisions. It only authorizes the designated Agent also to make decisions, but it is unlikely that a third party, such as a healthcare provider or financial institution, would follow an Agent's direction if your child directs otherwise and the third party believes your adult child is competent to make his or her own decision.

4. The Louisiana Medical Consent Law does provide a priority of individuals who can consent to surgical or medical treatment or procedures if your adult child is not willing and competent to act. Special rules apply in determining whether a developmentally disabled child has capacity to consent in cases of emergency care.
5. Limited Interdiction
  - a. Applies to a person incapable by reason of an infirmity of consistently making reasoned decisions as to his or her care or of administering his or her financial affairs, or any aspect of either.
  - b. Procedure.
    - i. Formal court proceeding.

- ii. Person sought to be interdicted has right to choose legal counsel or legal counsel will be appointed by the court.
  - iii. Judge may appoint an expert to examine the person sought to be interdicted.
  - iv. Curator and undercurator are appointed after qualification.
- c. The rights of a limited interdict can be infringed only in the least restrictive manner consistent with the interdict's incapacities. Limited interdiction cannot deprive the incapacitated person of any civil right or the right to contract unless specifically set forth in the judgment of limited interdiction.

## 6. Total Interdiction

- a. Applies to a person who due to an infirmity, is unable consistently to make reasoned decisions regarding his or her care and property, and whose interest cannot be protected by less restrictive means, such as a Power of Attorney, trust or limited interdiction.
- b. Procedure is identical to limited interdiction.

## 7. Civil Commitment

- a. Voluntary admission.

- b. Noncontested admission.
- c. Emergency admission.
- d. Coroner's commitment.
- e. Judicial commitment.

### **III. Financial Decision Making**

- A. As previously stated, the parents, as natural tutor(s) of a minor child, make decisions with respect to their minor's property, if any, during minority, but your child makes his or her own decisions upon reaching age 18, unless your child has granted someone a financial Power of Attorney to act as his or her Agent or your child has been deprived of financial decision making as a result of a judgment of limited or full interdiction. A child may have assets in his or her own name, such as by virtue of an inheritance, personal injury award, gifts from parents or other family members, U.S. savings bonds, or property held in a Uniform Transfer to Minors Act account which becomes payable to your child at age 18.
- B. Louisiana inheritance rights
  - 1. If you die without a Will, your children inherit your property outright and equally. A surviving spouse may have a "usufruct" (the right of use and income) over the deceased spouse's share of community property, but not over any separate property. The survivor's usufruct over the deceased spouse's share of community

property automatically terminates upon the surviving spouse's remarriage if there is no Will.

2. With a properly drafted Will, you can:
  - a. Achieve greater flexibility as to how you want to dispose of your assets, both separate property and your share of community property, including to your surviving spouse.
  - b. If your spouse is granted a usufruct, you can have it last until remarriage, for a term of years or for your surviving spouse's lifetime. In addition, the usufruct can apply to both your interest in community and any separate property.
  - c. Designate tutors for minor children.
  - d. Provide special bequests (cash, personal property such as jewelry and household items, guns, collections, etc.)
  - e. Provide for estate tax planning in larger estates.
  - f. Provide trusts for children, including "special needs" trusts to preserve a child's eligibility for means-tested governmental benefits, such as SSI and Medicaid.
  - g. Provide bequests to other family members, friends or charitable organizations which have been important in your life and your child's life.
3. Certain assets pass outside of your Will ("nonprobate" assets). These assets include life insurance, IRAs, retirement plans (such as

governmental or private pensions and 401k plans), annuities, and bank accounts or U.S. savings bonds which are “payable on death” (POD). Death benefits are paid to your designated beneficiary (or contingent beneficiary) on the latest beneficiary form on file with the payor.

4. In Louisiana, children under age 23 and “handicapped” children, regardless of their age, are forced heirs of their parents, entitled as such to demand a “forced share” of their parents’ estates. A “handicapped” child is one who, because of mental or physical incapacity, is permanently incapable of taking care of his or her person or administering his or her estate at the time of his or her parent’s death. The “forced share” is based upon the number of forced heirs (not necessarily the number of children).
  - a. If there is one forced heir, the forced share is  $\frac{1}{4}$ th;
  - b. If there are two or more forced heirs, the forced share is  $\frac{1}{2}$ , divided equally among all of the forced heirs.
  - c. However, in no event is the forced share more than an intestate portion (that is, what a child would have inherited if the parent had died without a Will). For example, if there are 5 children and only one is a forced heir, that child’s forced share is  $\frac{1}{5}$ th, not  $\frac{1}{4}$ th.

- d. Life insurance and retirement benefits payable on account of a parent's death are not counted in determining the value of the parent's estate in calculating forced share, but to the extent such assets are, in fact, paid to the forced heir (or a trust for the forced heir's benefit), they can be counted in determining if the child's forced share has been satisfied.

#### **IV. Financial Care Alternatives**

##### **A. Outright gifts or bequests to the disadvantaged child - Disadvantages**

1. Persons with disabilities may not have the capacity to manage money properly.
2. Outright control may jeopardize qualification for governmental assistance programs, such as SSI or Medicaid (\$2,000 resource limit).
3. Assets are subject to creditors' claims, including state reimbursement claims for public assistance.
4. Once ownership vests, it may be impossible to divest ownership, if the person with a disability lacks or is likely to lack the competence to make a Will.

##### **B. Gifts or Bequests to Third Parties**

1. Instead of outright gifts or bequests, some persons desire to make gifts or bequests to others, such as non-disabled children, coupled

with instructions that they are to care for a disadvantaged brother or sister.

2. Advantages.

- a. Easily understood.
- b. Simple to accomplish.
- c. Inexpensive.
- d. May be very appropriate in small estates where the family is willing to shoulder the burden.

3. Disadvantages.

- a. Morally responsible sibling may have additional tax problems.
- b. If assets are inadequate, morally obligated child may feel obligated to use his or her own resources, even where his or her own family needs may be sacrificed.
- c. Obligated child's own disability, bankruptcy, or family or business problems could interfere with ability to care or aid the sibling with a disability.
- d. If the obligated child dies first, he or she may have failed to effectively provide for the sibling's care.
- e. Still must contend with Louisiana "forced heirship" rules, if applicable.

## V. Trusts

- A. Offer several advantages over other forms of personal and financial care alternatives.
1. Unlike tutorship or interdiction proceedings, there is no inquiry into the person's competency. May be very important to the emotional needs of the family by avoiding the initial court proceeding and constant judicial and legal involvement in decisions affecting the person with a disability.
  2. A carefully drafted trust instrument which grants sufficient discretion to a capable Trustee affords a significant degree of flexibility to assure the trust beneficiary's needs will continue to be met, even in face of changing and perhaps unforeseen personal, social or legal conditions.
  3. Persons with disabilities may not be competent to make Will. A trust can provide distribution of principal to other beneficiaries in certain circumstances. For example, the child with a disability is named income beneficiary of the Trust with discretionary power in the Trustee to invade principal for his or her benefit. Upon the child's death, the trust assets would be distributed to other beneficiaries, such as other children, thereby completely avoiding probate proceedings for the child with a disability. Even as to the

child's forced portion, a trust can provide that the forced portion will shift to others if the child dies without a Will and without children.

4. Trust may avoid disallowance of governmental benefits and avoid state reimbursement claims.

B. What is a trust?

1. Legal document - created during lifetime or at death (in a Will) - appointment of one or more Trustees (individuals, banks, or both) who act as fiduciaries and are required to preserve, manage, invest, and distribute the trust funds for the sole benefit of one or more designated beneficiaries in accordance with the terms of the trust instrument.
2. One of the most difficult decisions involves the selection of the Trustee, particularly if there is no surviving spouse - someone who is capable of managing the trust assets and who also is willing and able to assume an active role in the provision of proper personal care for the child with a disability.
  - a. Are there brothers or sisters who are willing to assume this responsibility?
  - b. Would the appointment of another child as Trustee create animosity and friction between the Trustee and the child with a disability?

- c. What about a bank? Sadly, very few banks are willing to manage assets under \$100,000 or become involved in the child's life as you would wish.
- 3. Trust instrument can be as flexible as you desire. You can specify:
  - a. Powers and duties of Trustee.
  - b. When income distributions are to be made.
  - c. When and if principal distributions are to be made.
  - d. Investment limitations.
  - e. Advisors to the Trustee.
  - f. You can provide as many restrictions or limitations that you desire or give the Trustee unbridled discretion.

## **VI. Coordination of the Estate Plan with Governmental Assistance Programs**

- A. If the family does not need to rely on governmental assistance programs or is not concerned about potential state reimbursement claims for goods or services furnished to the person with a disability, a different estate plan can be considered.
- B. However, if eligibility for governmental assistance is desired, parents with other children face certain moral dilemmas:
  - 1. Treat all children equally;
  - 2. Leave more to the disadvantaged child because of the child's special needs and the ability of the other children to provide for their own needs;

3. Leave as little as possible to the child with a disability to qualify for governmental assistance. Many parents are reluctant to minimize bequests to a child with a disability in view of the child's needs and dependence as well as the uncertainty of continuation and funding of governmental programs.

#### C. Governmental Benefits

##### 1. SSI (Supplemental Security Income)

- a. This is a federal benefit payable monthly for individuals with a disability who meet certain eligibility requirements. The maximum monthly benefit in 2013 is \$710 for a single individual to assist the individual in purchasing food and shelter.

##### b. Minors

- i. The benefit is available to a child who is considered "disabled" under Social Security rules for minors, and who has countable income and resources below the financial eligibility limits. The countable resource limit in 2013 is \$2,000. A minor child is considered "disabled" if the child has "marked and severe functional limitations" for at least twelve months.
- ii. However, as long as a child is under age 18, the income and resources of the parents(s) with whom the

child lives is “deemed available” to pay the costs of the child’s food and shelter. Therefore, many minor children with a disability do not qualify for SSI unless the parent(s) is poor.

c. Adults

i. Once a child with a disability attains age 18, parental deeming of income and resources ceases for SSI eligibility determination, even if the child continues to live with the parents. SSI looks only to the child’s countable income and countable resources.

ii. Also, once a child attains age 18, Social Security uses the adult definition of “disability” in determining eligibility, that is, whether the individual, due to a recognized physical or mental condition, is unable to engage in a substantially gainful activity (SGA), which is measured by how much the individual could earn. The SGA monthly limit in 2013 is \$1,040 for non-blind individuals. However, earnings can affect the amount of SSI monthly benefit, even though under the SGA dollar limit.

d. If a child has been disabled since before age 22, he or she may be entitled to Social Security benefits (a/k/a SSDI or

DAC benefits) based upon his or her parent's work history when the parent dies or the parent becomes eligible for Social Security due to disability or reaching retirement age. This benefit is not means-based, that is, eligibility is not based upon the child's limited income or resources. Thus, a child who starts with SSI (a means-tested program) may convert in the future to SSDI (which is not a means-tested program).

2. Medical Coverage

- a. In Louisiana, an individual who receives any SSI benefit (even only \$1) is automatically covered by Medicaid. For minor children who do not qualify for SSI (for example, due to parental deeming of income and resources), there may be other available Medicaid programs, such as LaChip, Children's Choice and Home and Community Based Medicaid Waiver Services.
- b. If an individual with a disability receives SSDI benefits, he or she will be eligible for Medicare, which is not a means-based program. However, if the individual meets the financial eligibility criteria, he or she also may receive Medicaid as a back-up to Medicare.

3. Other Means-Tested Benefits

- a. SNAP (food assistance)

- b. HUD housing
- 4. The receipt of countable assets, by inheritance or otherwise, in excess of \$2,000 will cause the loss of SSI and SSI-linked Medicaid. The failure to access assets, such as the failure of a forced heir to demand his or her forced share, will trigger a period of ineligibility for SSI and for long term Medicaid benefits. Proper planning is necessary to preserve means-tested government benefits, especially due to Louisiana forced heirship laws.

#### **IV. Planning Strategies**

##### **A. Applying for SSI**

- 1. If your child would meet the Social Security definition of disability but has more than \$2,000 of countable resources (for example as a result of an inheritance, retroactive payment of governmental benefits, personal injury award, support payments, prior gifts, etc.), the assets can be placed in a qualified special needs trust for your child's sole benefit. The assets will not be counted in determining SSI and Medicaid eligibility, regardless of the amount.
- 2. If your child is living with you and Social Security asks if your child pays you rent, you should respond affirmatively and actually use part of the SSI benefit to pay rent and a share of household expenses. Otherwise, the SSI monthly benefit may be reduced by as much as one-third (1/3rd ) of the maximum applicable SSI benefit amount on

the assumption that your child doesn't need the full benefit since you are providing food and shelter at no cost.

- B. If your child qualifies for SSI/Medicaid, make sure there are no family members (divorced spouse, grandparents, aunts or uncles, etc.) who would gift or bequeath assets to your child which would disqualify your child for such benefits, except through a special needs trust. This is critical if your child receives Medicaid Waiver Services. The receipt of a gift or inheritance from you or others could make them immediately ineligible for continued benefits, but more importantly, the loss of a Medicaid Waiver slot may mean your child has to wait 8-10 years on a waiting list once countable resources fall below the resource limit.
- C. Prepare a properly drafted Will incorporating a trust or a special needs trust, especially if your child is or is likely to receive means-tested governmental benefits.
  - 1. A trust can be a very flexible planning device.
  - 2. You can designate the Trustee and successor Trustee who will have investment and distribution powers in accordance with whatever provisions you incorporate into the trust.
  - 3. Assets generally are protected from claims of your child's creditors.
  - 4. Special needs trust provisions will preserve eligibility for means-tested governmental benefits. The funds in the special needs trust

can be used to improve your child's quality of life by providing for those items and services which the government will not provide.

5. Trusts are appropriate for minor children (even those without a disability) as well as children who will not have sufficient maturity to handle funds when they become adults at age 18.
- D. Coordinate beneficiary designations (primary and secondary) on all non-probate assets, such as life insurance, retirement benefits and IRAs, with your overall planning, including payment to a special needs trust for a child with a disability.
  - E. Consider life insurance to provide an immediate source of liquidity for the benefit of a family member with a disability, particularly a child who may not be able to be self-supporting and whose needs may be greater than other children. Life insurance can be paid into a special needs trust.

### **VIII. Consider a Letter of Intent**

- A. A Letter of Intent is a document written by you or other family members that describes your child's history and background, your child's current status and your wishes, hopes and desires for your child's future care when you are gone. It gives future caregivers some insight on medical care and treatment, names of professionals (physicians, caseworkers, attorney, etc.), housing options, daily living skills, education, religious upbringing, personal needs, social and recreational needs, and the rights and values which you want accorded to your child. Even though it is not a legal

document, it provides guidance and information which future caregivers vitally need.

- B. Start by writing it out in longhand. Don't worry about grammar. Later you can type it.
- C. Put the Letter of Intent where it can be found. Tell close relatives or friends why you have written the Letter, what type of information it contains and where it can be found.
- D. Update the Letter on a regular basis.

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