

Estate Plan Guide for Parents;

If you have a child with a disability, the need to plan for your future, as well as your child's, is important and the time to plan is now! The reality is that something could happen at any moment to leave you or your child at risk. It could be your death, or a chronic or debilitating illness or catastrophic injury that impairs your ability to care for yourself and your child. These events cause emotional and often financial hardship, so why not create a plan now while you can be clear-headed and thorough? Planning early may seem expensive upfront but will save a lot of money in the long run. Planning gives everyone peace of mind: you, your friends, your family, and your child.

Planning ahead seems daunting - but if you take it step by step, it is really not so bad! First you organize, then you decide what you want, and then you sign the appropriate documents.

Get Organized!

Below are some specific strategies for gathering and keeping the information you need to make a thorough plan. If you don't gather this information, it can take weeks if not months for someone else to make sense of your organizational system (or lack of a system). Some of this information you need to make a plan and some of this information you will have only after your plan is adopted. The point is to get organized enough to make a plan - and then keep the information in one place for future reference. If you keep these key pieces of information handy, there is a greater chance your plan will be followed.

Step One-Creating the Receptacle: Get a file cabinet and folders, or an accordion-type folder that you can label. If you are more comfortable with computer folders and files, set this up on your personal computer. If you choose the digital route, keep the information secure but make sure to let someone know your usernames and passwords so that the information is accessible. There should be one file for your information and one file for your child's.

Step Two-Important Personal Information: Create a document with all of your and your child's personal information (name, nicknames, date and place of birth, phone numbers, Social Security number, Medicare number, addresses, etc.). You should also keep a separate folder with copies of birth certificates, military service records, deeds, insurance policies, stock certificates, spouse's death certificate, marriage certificates, social security cards, automobile titles, divorce decrees, usernames, and passwords.

Step Three-Emergency Contacts: Create a document for emergency contacts for you and your child. Include contact information for your spouse, partner, significant other, children, siblings, and parents. If you have trusted service people who help with the home or lawn, these names and numbers should be included here. For your child you should have the name of the person you want to care for your child in case of an emergency.

Step Four-Medical Providers and History: Create a document for you and for your child with a list of medical providers and medical history. This list should include the names and numbers for primary care providers and specialists, medications, allergies, significant family history, insurance companies and policy numbers, your employer retiree coverage, health insurance, and any Medicaid or Medicare information. If you have prepaid your or your child's funeral or burial, keep this information here as well. If your child is still in school, include information about his or her individual education plan and counselors at the school who work with your child.

Step Five-Financial Information: Create a chart for financial information. This includes the gross and net amount of each source of income (employment, social security, supplemental security income, etc.) and current value of each asset, the death benefit (if any), and all beneficiary designations associated with the asset. Include on the chart policy numbers and contact information, the name of any financial advisors you work with, a copy of your most recent tax statement, and a section on recurring bills, including whether the bill is paid on-line or by an automated payment. For your child, you should include all information concerning his or her representative payee accounts and special needs trust accounts. Copies of statements should be kept in the file cabinet or scanned in and stored on line.

Step Six-Legal Information and Documents: Collect any legal information you already have, such as the names and numbers for attorneys, health care agents, attorneys-in-fact, beneficiaries, trustees, and personal representatives. Make sure to also collect a copy of your will, health care directive, and power of attorney.

Step Seven-Accounts and Passwords: If you use on-line banking or bill-pay, or have any other accounts (email, Facebook, photo storage, etc.), collect a list of usernames, passwords, and answers to security questions to these accounts. Keep these in a secure place and make sure someone you trust knows where to find them! Make sure you have log-in and password information for internet accounts and sites your child may be using.

Step Eight-Letter of Intent: As a parent of a child with disabilities, you will also need to create a letter of intent. An upcoming issue of The Voice will discuss in more detail the importance of a letter of intent.

If these organizational tasks seem daunting, tackle them one at a time, and enlist a friend, family member, or financial advisor to help. You want this information to be protected yet accessible. Consider keeping the folder in a locked safe or file cabinet, a safety deposit box, or in a password-protected space on your computer. Then, let the important people in your life know how to access this information.

Make a Plan

Step Nine-Future Planning for Your Child: How do you want to provide for your child with disabilities if you die or are too ill to provide the care? You can't make any plans if you don't have any idea what you want. If it's too difficult to think about your own death or loss of capacity, there are two ways to combat this: 1) consider what you don't want (I don't want my children to have to decide if I should be kept on life support if I am dying), and 2) consider what you would not want to have to do for someone else. For example, would it break your heart to have to figure out where your friend's children would live if your friend died? By not planning for your own future, these are the kinds of decisions other people will have to make for you and your child if you are no longer able. Take some time to consider these issues, talk with friends and family, and pause and then come back to it if it becomes overwhelming. Remember that as a parent of a child with a disability, your planning will ensure that he or she will be cared for in the best way possible when you are no longer able to do so.

Step Ten-Meeting with a Special Needs Attorney: Meet with an attorney. Not only can an attorney draft the necessary documents for expressing how you want your property, finances, health care, and care of your children handled following your death and/or incapacity, but your attorney can also help you set up financial strategies, such as trusts, to ensure that your child with a disability can continue to maintain a quality life when you are gone. Make sure this attorney is familiar with Medicare, Medicaid, Social Security, and Supplemental Security Income (SSI) and the unique challenges that a disability brings to the estate planning process.

Develop your Plan

Step Eleven-Planning for Your Own Disability or Incapacity: Determine how your finances and health care will be managed if you are no longer able to manage them. How your finances will need to be handled, depends upon your situation. Here are the options:

Informal Arrangements for Finances: You can ask a trusted friend, or relative, or hire someone on a part-time or one-time basis to help manage your money and property. You could rely on automatic banking, direct deposit, or naming someone on your bank accounts to allow him or her to sign checks, pay bills, and transfer money between accounts. If you are the representative payee for your child's Social Security benefits you cannot formally name someone to fill this role should something happen to you, but you can include your preference in your letter of intent (see Step Eight, above). Most important, you should think about potential representative payees for your child's Social Security benefits and approach those individuals to see if they are willing to assume that role if needed.

Power of Attorney to Manage Finances. A power of attorney is a written document that appoints someone to handle financial matters in whatever way you spell out. For instance, the person you appoint could pay your bills, manage your bank accounts, and make sure that you are getting your income. Make sure you get a durable power of attorney, that is, one that continues to be effective after you lose capacity. The person you name as your attorney-in-fact or agent should be someone you trust, as you are giving this person an immense amount of power over you and your finances. If your child is disabled but has capacity (i.e., the child can manage his or her own affairs), then at 18 the child should also execute a power of attorney to appoint an agent to help with financial decisions if needed.

Arrangements for Health Care. There are countless informal and creative ways you can have health care and living needs managed. Often friends, family, neighbors, and the community will help provide you with the things you need. To ensure that you have your basic needs met, however, you may want to consider some of the more formal options available:

Advance Health Care Directives. A health care directive is a written document in which you name someone to make decisions about your care. By putting your health care wishes in writing, you give your family and loved ones a gift: they will know your health care preferences and to whom you choose to make decisions for you. Some states provide standard forms for powers of attorney for health care which you can use to nominate agents to manage your health care for you.

DNR/DNI/DNH. You may also choose to limit the scope of emergency medical care, through a “do not resuscitate/do not intubate/do not hospitalize” directive by you to your physician. Because of the limited scope of this directive, a health care directive should be completed as well.

Step Twelve-Your Child's Conservatorship or Guardianship: Review your child's conservatorship or guardianship. A conservatorship or guardianship is a court proceeding to designate a person to handle the financial or health care decisions for an incapacitated person. If your child has a guardianship or conservatorship, you should identify who should succeed you if you are no longer able to serve. Your state may have a procedure for you to designate your preference for who should replace you if needed. If you do not have a guardianship or conservatorship for your child but believe it may be needed after your death, you should discuss this with your attorney and get advice on the steps to take to be sure your child will be protected. Your planning should include identifying possible guardians or conservators if needed for your child and making sure those individuals understand the steps they will need to take to have the court appoint them for that role.

Step Thirteen-Decisions and Arrangements upon Death: Determine what arrangements should be made for you or your child at death.

Organ and Tissue Donation. To most people's surprise, organ and tissue donation can be valuable no matter what the age of the donor! There are multiple ways you express your wishes to donate or not, which include: through your health care directive, driver's license, written statement, or donor registry. Unless you expressly state that you do NOT want to donate organ or tissue upon your death, your health care agent or relatives (in order of preference) can make the decision to donate your organs at the time of your death. A parent may consent to the donation of a minor child's organs.

Funeral Planning. In many states, you may name the person who you want to be in charge in a health care directive, or you can fill out an advance funeral directive. The funeral directive gives the person you name the power to make funeral arrangements, and can be helpful if you believe that people in your life may disagree about how to carry out your wishes regarding your funeral and the disposition of your body after death. You can prepay funeral expenses for both you and your child. If your adult child does not have the capacity to make his or her own funeral arrangements, you will need to see what steps your state laws provides for how a parent or guardian can make those arrangements in advance.

Step Fourteen-Your Own Estate Plan and Child's Special Needs Trust: Have your attorney prepare a will or revocable trust that specifies what will happen to your property at your death. This document directs what portion of your estate should go to your child. Because Medicaid and the Supplemental Security Income (SSI) program impose special rules about how much money a person with disabilities can have to remain eligible, your estate plan may include a special needs trusts (SNT). A SNT can ensure a quality life for the child without affecting your child's ability to continue to receive Medicaid and SSI, as long as the trust is drafted and administered properly. If you have specific goals or preferences for how your child should be cared for after your death, they can be specified in your will or living trust.

Review and Update your Plan

Step Fifteen-Updating Your Plan: Remember that planning for the future is a process, not a one-time task. As circumstances change for you and your child, you will need to revisit your plan. Sometimes this will mean updating your documents on your own, but usually you will need an attorney to guide you. You should update your information every year.

Consulting with an attorney who is familiar with special needs trusts and disability benefits will help ensure that you have done everything possible to provide for your child with disabilities.

The above 15 steps are not easy, but they will bring you peace of mind knowing that you have planned in advance for the time when you may no longer be able to manage your own or your child's financial and health care matters.

About this Newsletter: We hope you find this newsletter useful and informative, but it is not the same as legal counsel. A free newsletter is ultimately worth everything it costs you; you rely on it at your own risk. Good legal advice includes a review of all of the facts of your situation, including many that may at first blush seem to you not to matter. The plan it generates is sensitive to your goals and wishes while taking into account a whole panoply of laws, rules and practices, many not published.

Reprinted from Special Needs Alliance Newsletter; May 2013;