

Preparing a Life-Planning Document for Your Disabled Family Member

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A “life-planning document” for your disabled family member does more than preserve and protect his or her safety and security. It is also to help him or her enjoy a better quality of life.

Producing a life-planning document for your disabled family member is not a legal imperative. It is, rather, a moral one.

Preparing a life-planning document will give you peace of mind. Knowing that you have memorialized critical information regarding the needs of your disabled family member, is important for his or her future in the event you are suddenly unable to care for him or her.

COMMUNICATE YOUR ENCYCLOPEDIA KNOWLEDGE

A life-planning document, sometimes called a “letter of intent” or “letter of instructions,” aims to provide critical information about your disabled family member to future care providers and trustees.

Such a document can contain the following information about your disabled family member:

- His or her personality characteristics and personal-care preferences.
- His or her family members as well as the trustee of his or her special needs trust.
- His or her medical history, physician and other individuals and organizations providing support and services to him or her.
- His or her friends, pets, favorite foods, likes and dislikes, and hopes and expectations.

You should develop a life-planning document when your disabled family member is going to live outside your home sometime in the future and will require a good deal of support and services to maintain and enhance his or her quality of life. While a life-planning document applies to such a person of any age, we encourage all parents of disabled children, from school age up to adulthood, to have a such letter of intent. We further recommend that you update the life-planning document on an annual basis, to incorporate changes in current information about your disabled family member.

A life-planning document is important to have because many people with cognitive or psychological impairments may be unable to accurately convey pertinent facts and information about themselves to others. The life-planning document gives you an opportunity to communicate your perspective on and knowledge of him or her regarding a wide range of topics. Combined with

your disabled family member’s self-determination, the life-planning document contains the core considerations that care-providers should heed when providing support and services to him or her.

CONSIDERING THE PAST, PRESENT AND FUTURE

Classically, you can think of a life-planning document in three time frames:

1. The past, which can include, among other things, the educational and medical background, residential placements, living arrangements, family and religion.
2. The present, which can include, among other things, the upcoming medical appointments and evaluations as well caregivers for your disabled family member.
3. The future, which can include, among other things, the hopes, dreams and wishes of your disabled family member, as well as the people whom he or she wants to be involved in his or her care. For example, he or she may want a board of advisors to the trustee of his or her special needs trust.

You should annually update this past/present/future orientation with the idea in mind that you are your disabled family member’s encyclopedia. That is, you know them best. It is also important to memorialize the knowledge you have of his or her needs while you are alive, well and able to do so.

Typically, the quantity and quality of personal information in a life-planning document is much greater than that found in either an “individual education plan” (for children) or an “individual support plan” (for adults). IEPs and ISPs tend to be sterile documents that are often bureaucratic in nature, using behavioral and measurable terms in order to meet regulatory requirements.

In contrast, a life-planning document is individual-driven rather than regulatory-driven. As such, it is based on the day-to-day needs and desires of your disabled family member.

NOT A LEGAL, BINDING DOCUMENT

You do not need a special form in order to prepare a life-planning document.

Plenty of sample forms exist, including those produced by Fletcher Tilton PC, which operates as The ARC of East Middlesex, MassMutual and MetLife. (The form that Fletcher Tilton PC uses was presented at a conference of the National Academy of Elder

Law Attorneys in 2004 and has since been replicated and cited nationally in several settings. Our form is a derivation of one from Vancouver, British Vancouver that we came across in 1994.)

Once you produce or update a life-planning document, you should give a copy to the trustee of a special needs trust for the benefit of your disabled family member, as well as to other family members and anyone else who is going to be involved in the life and care of him or her.

As we noted above, a life-planning document is not a legal, binding one, so you do not need to file it with the courts. Instead, you prepare a life-planning document in conjunction with, and as an adjunct, to the special needs planning process for your disabled family member.

As such, you would not face legal liabilities if you fail to produce or update a life-planning document. However, the peace of mind offered as a result of this document often supports the many reasons for writing one.

COMMUNICATE EFFECTIVELY ON PAPER

You also do not need an attorney in order to prepare a life-planning document.

Indeed, most attorneys would not know how to fill out such a form, which needs to read more like a social history than a legal record. The most important qualification is having the ability to communicate effectively on paper and to future care providers your encyclopedic knowledge of your disabled son, daughter or sibling.

That being said, it is a wise idea to let your attorney know that such a document exists when that attorney is going to be involved in administering the trust of your disabled family member. For example, when we at Fletcher Tilton PC are successor trustees of a special needs trust, we highly recommend that the parents or siblings provide to us information about their disabled family member.

A special needs trustee must be actively engaged in ensuring that the ideas and thoughts contained in the life-planning document are continually recognized and respected in the life of your disabled family member.

AMOUNT OF TIME AND ENERGY VARIES WIDELY

The amount of time and energy required to prepare a life-planning document varies widely, depending on how much information you want to include and whether you plan to write it by hand or on a computer. Generally speaking, count on it taking six to eight hours.

The initial effort can be considerable and daunting as you try to think of everything to include. Rest assured that updates are usually much easier. We recommend that you update the life-planning document at least once a year – perhaps around the birthday of your disabled family member. Using his or her birthday may help you to remember that it is time to update the document. Time has a way of flying and without a trigger date to help you remember, you may forget to update the plan.

If you find it difficult to write a life-planning document, we recommend that you tell the life story about your disabled family member to a qualified person who can facilitate a discussion and help to write the document. This person can be a certified life planner, certified care manager, or someone with a social services, educational or journalistic background.

In short, rely on someone who can listen well and empathetically to the story you tell and write it in coherent, understandable terms.

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