It is imperative that families touched by viral hepatitis make careful estate plans. Viral hepatitis may prevent children from supporting themselves later in life or they may find themselves with cirrhosis and in need of a liver transplant with its huge medical bills.

A financial legacy specifically tailored to these possibilities will be extremely helpful.

Define and Refine Your Goals

It is important to think about the legacy that you would like to leave all your children, including your child with unique medical needs. This planning is challenging work.

Will your child require special care throughout his or her life? If so, who should provide this care after you die? If you have more than one child, how can you take care of the child with special medical needs, as well as leave a legacy to his or her siblings?

There are a number of strategies and solutions, but they will vary based on your income and where you live. For example, families with more than one child can take out life insurance to provide for siblings, and they can make specific bequests so a financial gift is provided to everyone. In some states, probate is extremely complicated and expensive while in other states it's inexpensive and quite straightforward.

Each family will make decisions based on its own circumstances; no estate plan will be identical to another family’s. But parents must be prepared to work through the sometimes conflicting objectives in planning their estate.

Where There's a Will

A simple will may not be enough to protect children whose illnesses could impact their daily lives at some future point. Some parents are also ill with liver disease themselves and carry the additional burden of worrying about their own physical and mental capacities.

A will does not protect assets if parents become incapacitated. It goes into effect only after they die. This means that important decisions regarding the welfare of children
may be left to the courts if ill parents are unable to make decisions.

If there is only a will, the estate must go through probate after a parent’s death. This legal process in some states, depending on the size of the estate, can be expensive and time-consuming. While the courts are busy ensuring that a parent’s debts are paid and accounts of assets are valid and in order, these assets could be frozen. If children need money to live on during this period (or to bury a parent), they must go through the courts to get it, and it’s possible that the courts could deny their request.

Seek Professional Assistance

To make sure the right plan is made, it is important to consult an attorney and also a financial planner. There are many options to consider depending on each family’s situation. An attorney will help sort through them and will most likely recommend placing a parent’s assets in a trust.

It’s best to select an attorney experienced in living trusts and possibly Supplemental Needs Trusts. The type of trust that is best depends on the needs of the children and the extent of their disability, but a good place to begin for most people is with a living trust.

Many estate planning attorneys have considerable experience with living trusts but have limited knowledge and experience with trusts for disabled individuals. The right estate planner will be familiar with the concept of a Supplemental Needs Trust, what it pays for, its limitations, and coordination with various public benefits programs including SSI, Medicaid, SSDI and public housing assistance.

How Does a Living Trust Work?

At the time a living trust is created, a parent transfers assets from his or her name to the name of the trust. Parents can control the trust while they’re alive and can specify the distribution or management of assets in the trust after their death. As a trustee, a parent can change or cancel the trust and do anything with the assets in the trust that they could before (e.g., buy or sell the assets).

They may choose to name a successor trustee such as a close friend or relative to handle the estate after their death. They also have the option of hiring a bank or trust company as corporate trustee if they prefer. These institutions charge a fee but can manage assets if a parent desires professional help, becomes incapacitated or dies.
What Are the Benefits of a Living Trust?

A living trust:

- Allows assets to be distributed more quickly to beneficiaries. (A parent can also specify that assets remain in the trust until he or she wants them distributed.)
- Prevents court control of assets should a parent become incapacitated.
- Prevents court control of a minor’s inheritances.
- May reduce estate taxes.
- Makes it difficult for other parties to contest a parent’s wishes because they are specified and legally documented.
- Protects dependents with special needs.
- Maintains control of assets and keeps them together in one plan.

A parent doesn’t have to be rich to set up a trust; for example, a house may be the sole asset a parent has to ensure a child will have a place to live. If a child’s illness causes him or her to depend on the government for support at some point, without proper planning he or she could be forced to sell the house in order to qualify for those benefits.

Assets such as real estate, stocks, certificates of deposit (CDs), bank accounts, insurance, jewelry and furniture can be included in the trust. Laws are revised constantly and vary by state, so only an attorney can advise parents about the best way to plan for their family.

There are various types of government benefits available to dependents who need long-term or life-time care. Parents should have some familiarity with this subject if they face the possibility that their child's illness could disable him or her at some future time. In particular, trusts should be specially designed to cover these needs or to be easily changed to cover them at the point the child becomes disabled.

Regulations affecting eligibility for public benefits vary from program to program and sometimes from year to year. A family member who acts as a trustee under a Supplemental Needs Trust must work closely with a knowledgeable trust and estates lawyer to ensure continuing compliance with the applicable rules for distributions from this type of trust.
The trustee should therefore be prepared to approach his or her obligations and duties with the understanding that compliance will require continuing review and an exceptional degree of discipline.

**What About Government Benefits?**

There are various types and levels of government benefits and a multitude of laws governing definitions and eligibility. As a brief overview, the most common benefits are:

- **Pension or insurance-type benefits** such as Social Security Disability Income and Medicare. These benefits are entitlements based on contributions and are not dependent on a person's financial need.

- **Welfare or needs-based benefits**, which require a person to be disabled (strictly defined by the government) and to meet financial criteria. Included in this type of benefit are Supplemental Security Income, Medicaid, food stamps and Section 8 housing subsidies.

- **Sliding scale fee benefits**, which require a disabled person to pay the government for services in accordance with his/her ability to pay. Department of Human Services and Department of Rehabilitation Services are examples of this type of benefit.

**How Do These Benefits Affect an Estate Plan?**

If a child becomes ill and disabled, parents need to make sure he or she does not lose governmental benefits eligibility. In this case, a primary purpose of a trust would be to protect the family’s assets and the individual’s inheritance from being counted as an asset by state or federal governments. For example, Medicaid and SSI programs treat earned income differently than unearned income in determining benefits.

There are two types of trusts to consider:

- **Supplemental Needs Trust.** This trust is best suited for an individual with high medical costs whose food, clothing and shelter are largely addressed by government programs or family support. It will not affect public benefits if properly structured. The trust cannot pay for food, clothing or shelter; those needs should be paid for out of public benefits. The trust supplements those needs by paying for adaptive equipment, training, social support, travel, education, and medical care over and beyond what Medicaid may provide.
• **Discretionary Supplemental Needs Trust.** This special needs trust (or discretionary supplemental needs trust) provides goods and services that would not otherwise be available to a child from local, state or federal government agencies. Ask an attorney about setting up a special needs trust that could be implemented when needed. The assets you place in a properly worded special needs trust for your child would not be considered “countable” assets of the child (beneficiary), and are thereby protected.

**Not an Easy Solution**

A Supplemental Needs Trust is not an easy or inexpensive estate panacea. A good iron-clad trust from a knowledgeable planner will generally cost between $1,500 and $2,000 to complete, provided there is a real commitment on the part of the family to stick to a timetable to make decisions and work through the conflicts.

The proper drafting of a Supplemental Needs Trust and family counseling (selection of trustee, income tax implications, estate tax implications, life insurance coordination) are time consuming, complex and require a serious level of commitment by the family to the planning process and a commitment to understanding the benefits and obligations entailed in the proper implementation and administration of the trust.