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## **Planning for the Future**

A 1996 survey conducted by the ICR Survey Research Group showed that at least one individual in 20 percent of U.S. households is a caregiver - either part-time or full-time. Planning for the future of people with disabilities is something they and their families/caregivers must tackle - and the sooner the better.

Whether the person with special needs is 4 or 40 years old, it is imperative that families create a plan. Despite the growing number of persons with developmental disabilities in this country, less than 20 percent of families have done any planning.

Whether people with disabilities function entirely on their own or need assistance, a written directive can provide instruction for daily care, as well as unexpected and sudden contingencies.

- How would these individuals like to be bathed and dressed?
- What music do they enjoy, and when do they want to listen?
- Do they have special dietary needs and requirements?
- Who monitors their medication?
- What activities do they enjoy?
- How can they live with dignity, quality, self-esteem, and security?

Family members/caregivers should discuss information regarding the needs and desires of people with disabilities and compose a directive document addressing the lifestyle, financial, legal, and government-benefit issues.

Most people realize they need to plan and want to do something, but they fail for a variety of reasons. Some believe the task is overwhelming - they don't know where to find qualified professionals who understand their needs and how to resolve their concerns. And, too, the cost of professional services can be prohibitive. Families are also concerned with privacy issues. How do they overcome these obstacles and begin planning for the future?

As families begin their plan, they should first identify the people that can assist in the planning process. This should include, when possible, the family, the person with a disability, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, anyone involved in providing services, and a lifetime assistance planner to act as a "team" advisor to make sure that all parts of the plan are coordinated and complete.

The planning process that financial planner Barton Stevens, ChLAP, recommends addresses four key issues affecting the life of the person with special needs. They are:

1. Lifestyle
2. Legal
3. Financial
4. Government Benefits

**Lifestyle.** Lifestyle planning is where the family records what they want for the future of their loved one. This information is recorded in a document called the "Letter of Intent." Although not a legal document, it is as important as a Will and a Special Needs Trust. Lifestyle issues require decisions regarding where the person will live, continued education programs, employment, social activities, religious affiliation, medical care, behavior management, advocacy and/or guardianship, trustees, and final arrangements.

In addition, detailed instructions are provided for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting. Perhaps the person has a special way of communicating that only the immediate family knows and understands. It is important that this information be included. Rather than write hundreds or thousands of words describing how to do these things, it is recommended that families videotape them performing the activities of daily living, communicating, and in different social settings such as the home, school, a day care center, and so on.

Imagine how much easier and less traumatic it will be for the person with special needs and the care providers if they have detailed instructions immediately available to them rather than having to figure things out on their own. What could take weeks or months to adjust to could be shortened to a few days. The ultimate goal is to make the transition from parental care to independent living, residency in a group home, or moving in with other family members as easy as possible, bearing in mind the comfort and security of the person.

**Legal.** Legal planning provides for the family to state their wishes as to the distribution of their assets and appointing executors to settle their estate. In conjunction with this, a trust is usually executed to provide professional money management, trustees, guardians, maintain government benefits, and protect the assets left for the individual.

The "Irrevocable" Special Needs Trust is the most commonly used document to provide, supplemental funds for the exclusive benefit of the person with a disability. The assets are not in the name of the person, so they will not cause the loss of SSI (Supplemental Security Income) health care benefits. This Trust has proven invaluable to families regardless of the size of their estate or the amount of assets they are leaving.

**Financial.** Financial planning is used to determine the supplemental needs of the person. First, a monthly budget is established based on today's needs while projecting for the future. Then, by using a reasonable rate of return on principal, the family identifies how much money is needed to fund the trust. In addition, the life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must now identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, your home, life insurance, etc. Professional management for investing the assets may be done by the Trustee, or the Trustee may hire advisors.

**Government Benefits.** Government entitlements play a key role in the lives of many persons with special needs by providing cash and health care benefits under SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, and Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that the person gets all that they are qualified to receive, and that assets received from family members through gifts, inheritance, and litigation do not result in the disqualification and termination of government benefits or the government claiming reimbursement for benefits provided from assets received by the person.

It should be clear that each of these issues is interrelated and requires they be coordinated in the planning process. Those persons who provide advice in one particular area should be made cognizant of what others are doing. This emphasizes the importance of an organized plan.

The result of a comprehensive plan should be that it: provides lifetime supervision and care; maintains government benefits; provides supplementary funds to help ensure a comfortable lifestyle; provides management of funds; provides dignified final arrangements; and avoids family conflict.

### **The 10-Step Process**

In order to prepare a plan in a simple step-by-step procedure without feeling overwhelmed by the process, Barton Stevens recommends that families commit to know the 10 life planning steps. If these steps are followed, the family will create a directive that addresses the lifestyle and care needs of the person.

There are 10 steps you follow to help you create a directive that addresses the lifestyles and care needs of people with disabilities. The information recorded depends on the type and severity of the disability.

1. **Prepare a life plan.** Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.
2. **Write informational and instructional directives.** Put your hopes and desires in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.
3. **Decide on a type of supervision.** Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Individuals or institutions manage the estate of people judged incapable (not necessarily incompetent) of caring for their own affairs. Guardians and conservators are also responsible for the care and decisions made on behalf of people who are unable to care for themselves. In some states, guardians assist people and conservators manage the estate of individuals. Many parents who have kids with disabilities do not realize that when their children reach 18, adults may no longer have legal authority. Choose conservators/guardians for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.
4. **Determine the cost.** Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will be needed to provide enough funds to support his or her lifestyle. Don't forget to include disability income, Social Security, etc.
5. **Find resources.** Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.
6. **Prepare legal documents.** Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.

7. **Consider a "Special Needs Trust."** A Special Needs Trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. If drafted properly, assets are not considered income, so people do not jeopardize their Supplemental Security Income or Medicaid. And, too, they don't have to repay Medicaid for services received. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks).
8. **Use a life-plan binder.** Place all documents in a single binder and notify caregivers/family where they can find it.
9. **Hold a meeting.** Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.
10. **Review your plan.** At least once a year, review and update the plan. Modify legal documents as necessary.

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. "Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. Solutions are available. The next step is up to you.

*Note: The previous section was provided by Barton Y. Stevens, ChLAP, founder and Executive Director of Life Planning Services in Phoenix, AZ, who has been providing estate and financial planning services since 1972.*