

A Primer for Integrating Futures Planning, Estate Planning and Legal Protections for Persons with Disabilities

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INTRODUCTION

As families plan the future for their son or daughter or sibling with a disability, the considerations of what steps they need to take now can be a most daunting challenge. The future not only holds the high degree of uncertainty faced by all families; families who have a son or daughter with a significant disability face a dizzying array of government services and benefits, legal jargon and often conflicting professional advice. Unfortunately, this conundrum many times results in inaction or, at best, a confusing attempt to plan for the future.

This article is an attempt to identify distinct and concrete elements that a comprehensive plan for the future should contain. As with any endeavor, it is important to identify the underlying principles guiding such a plan. These principles are intended to provide a foundation for decision making that incorporates values that are deeply held by families, individuals with disabilities, and advocates.

GUIDING PRINCIPLES

- Our vision of a good life requires that we confront our own limiting beliefs about what might be possible for enriching the future.
- We become valued members of our communities and families when we have valued roles and respect.
- We need to have committed supports and relevant options in order to make real choices about our lives.
- Everyone's gifts and contributions need to be understood and cultivated.
- While we rely on services to meet many important needs, we rely on relationships to keep us safe.

PLANNING ELEMENTS

A sound and comprehensive plan for the future of an individual with a disability must take into account three separate yet related planning elements. These include a comprehensive person centered plan, a sound estate plan, and a thoughtful financial plan.

FUTURES PLANNING

The person centered plan must be guided by sound principles and involve those who care about and know the individual and family most personally - the network of support. A facilitator guides the network in developing a vision of the future that focuses on the gifts, choices and preferences of an individual. Members

of the network use their personal knowledge, experience, and commitment to design and implement a clear action plan. This plan serves as a roadmap to enriching the person's future and is revised and revisited as often as necessary. Although there are many kinds of person centered planning tools, these components are central to all:

- Understanding of the individual and family;
- Identification of a personal network of support;
- Vision for the future;
- Plan to implement the vision; and
- Review and revision of the plan on a regular basis.

To be effective, this planning effort must value the creativity and collaboration of the informal support network involved in the individual's life. This plan is much more than an individual support plan. There is an attempt to address important concerns in ways that build on the capacity of the individual and the network, and appreciate the importance of relationships in safeguarding one's future.

BASIC LEGAL PRINCIPLES

A common fallacy many parents have is that they are their son or daughter's guardian even after their son or daughter reaches the age of eighteen. This is false. Under Massachusetts law, all individuals are automatically emancipated at the age of eighteen years and presumed competent. In order to be determined to be incompetent to manage one's own affairs or assets, a specific finding must be made by a court of proper jurisdiction.

One of the most enduring principles underlying any solid plan for the future must be the concept of least restrictive alternative to ensure that the plan does not unduly restrict an individual's liberty and choices. A full guardianship for the personal estate of an individual is the most restrictive legal option available under Massachusetts law. Many families over the years have opted for this most restrictive option simply by not considering what other less restrictive alternatives may be available to them. There are many. A guardianship may involve the guardianship of the person only and not of the estate of the individual.

A conservatorship provides for custody of an individual's property yet does not extend to restriction over personal decision making by the individual. The disadvantage to various forms of guardianship and conservatorship is that all of these forms require a proceeding in the Probate and Family Court of Massachusetts. These

proceedings are, by nature, public and can require expenditure of funds for the payment of court appointed guardians, guardians ad litem, and various fees for the initial filing as well as for accountings.

A trustee is responsible for managing trust assets and deciding what should be purchased for the benefit of an individual with a disability. This arrangement can be an appropriate alternative to a conservator. Also, a common legal protective option which is often overlooked is the appointment of a representative payee to manage social security, disability income and supplemental security income payments. A simple though effective legal protective option is for the individual with a disability to appoint an advocate and/or attorney-in-fact to assist them in managing certain aspects of their life. This option has the advantage of involving needed support when necessary, but does not require a specific finding of incompetence and a denial of basic civil rights of the individual.

Finally, under Massachusetts law, each person over the age of eighteen who is not under any legal disability has the right to establish a health care proxy in which a person, called a Health Care Agent, is appointed to make health care decisions in the event the individual can no longer make health care decisions or can not communicate his or her decisions to third parties.

It's very important to recognize that any option which is designed to assist an individual in making choices or decisions is very powerful and can have far-reaching effects (for example, a health care agent can be given the authority to actually refuse potentially life prolonging treatment). For these reasons, such appointments must be made solemnly and with an attitude of great circumspection.

FINANCIAL PLANNING

A necessary element in a future plan for an individual with a disability is the capacity to supplement available government benefits with private funds. Depending solely on government funds to support a family member into the future is a highly risky proposition given the gaps and unpredictability of government funding. More importantly, private funds set aside through insurance, annuities, investments and other resources provide empowerment and a quality of life not typically available

to one totally dependent on government benefits. A future plan without a realistic plan for funding future services through private funds is really not a plan at all. It's simply a wish list with no real hope of becoming a reality. All families who are engaged in the planning process must integrate the person centered planning process and their trust and estate planning with a sound financial plan.

THE ROLE OF A SUPPLEMENTAL NEEDS TRUST

A supplemental needs trust is a cornerstone for futures planning for an individual with a disability. Such a trust can assist a family member with a disability to maintain eligibility for government benefits such as Mass Health, supplemental security income and other means tested benefits into the future. Families are faced then with how best to use the family assets for the benefit of their family member with a disability after the death of both parents. Families are concerned that the family assets not be wasted. There are also significant concerns about those assets being stolen or misused at some point in the future. A fundamental concern is to ensure that future decisions are made by informed and competent individuals who have the best interest of their son or daughter in mind at all times. Properly drafted and administered, a supplemental needs trust can further alleviate these concerns.

CONCLUSION

A comprehensive plan for an individual with a disability should integrate person centered planning and estate planning with a sound financial plan. Families have many options available to them. Through proper planning, the future for their family member with a disability can be viewed with greater confidence, hope, and security.

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