

Autism Society of America: Future Planning

The 10-Step Process

In order to prepare a plan 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. 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.

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