



DOWN SYNDROME GUILD
OF DALLAS

Basic Life Planning Steps

"Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. A well thought out life plan is essential for long-term quality of life for your loved one with Down syndrome. Physical, social, financial and legal issues, among others must be considered. The life plan is evolving and ever-changing; it is a process, not an end result. It will require that different needs be addressed as your loved one ages. Below are some suggested steps to get started in the right direction:

Prepare a life plan. Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.

Write a letter of intent. 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.

Decide on a type of supervision. Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Powers of Attorney are other, less restrictive options. Choose for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.

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.

Find resources. Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.

Prepare legal documents. Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.

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. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks).

Use a life plan binder. Place all documents in a single binder and notify caregivers/family where they can find it.

Hold a meeting. Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.

Review your plan. At least once a year, review and update the plan. Modify legal documents as necessary.