

Five Planning Pointers for Parents with Disabled Children

1. Buy enough life insurance.

A parent is irreplaceable. However, someone will have to fill in. It may be siblings or other relatives. In all likelihood, that family will have to pay for at least some services the parent or parents had provided when able. If the estate is not large enough for this purpose, it can be made large enough through life insurance proceeds. Premiums for second-to-die insurance (which pays off only when the second of two parents passes away) can be surprisingly low.

2. Set up a trust.

Any funds left for a disabled child, whether from an estate or the proceeds of a life insurance policy, should be held in trust for his or her benefit. Leaving money for anyone with a disability jeopardizes public benefits. Many people with disabilities cannot manage funds—especially large amounts. Some families disinherit disabled children, relying on their siblings to care for them. This approach is fraught with potential problems. Siblings can be sued, get divorced, disagree on their responsibilities, or run off with the funds. It can also cause tax problems for siblings. The best approach is a trust fund set aside for the disabled child.

3. Record a Will and Appoint a Guardian.

While a will and the appointment of a guardian is important for anyone with minor children, it is doubly so if the child is disabled. Finding the right guardian can be difficult. In some cases, the care needs of the child may be so demanding that he or she will need a different guardian from his or her siblings. The parents need to make these determinations while they can. The will is the vehicle for the appointment of a guardian.

An adult child may also require a guardian when the parent can no longer serve in this role (whether officially appointed or not). It will probably not be legally possible to officially appoint a successor guardian. So, it may make sense to begin making the transition to a new guardian while the parent is able to assist in the process. This can be in the form of a co-guardianship, or passing the baton to a successor guardian.

4. Document a Care Plan.

All parents caring for disabled children are advised to write down what any successor caregiver would need to know about the child and what the parent's wishes are for his or her care. Should the child be in a group home, live with a parent, be on his or her own? Usually, the parent knows best, but needs to pass on the information. The memo or letter can be kept in the attorney's files with the parent's estate plan.

5. Coordinate with other family members.

A well-meaning relative who leaves money directly to the child with a disability can sabotage even a carefully developed plan. If a trust is created for the benefit of the child, grandparents and other family members should be told about it so that they can direct any bequest what they may like to leave to that child through the trust.