

Special-Needs Adult Children Need a Plan For Their Future

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After a lifetime of caring for their child at home, parents of children who are intellectually and/or developmentally challenged don't want to give up their authority to strangers, but what happens if they haven't established plans for when they are too sick to provide care or have passed away?

For decades in their homes, many families have provided full-time care for family members who are severely disabled, without accessing in-home social services. They may have resisted tapping into government programs or didn't trust others to help. Some have cared for children with multiple disabilities who don't fit into supported housing scenarios. Whatever the case may be, parents should not hesitate to find out what they can do to provide for their adult child with special needs when they are gone.

With a 10-year wait for home and community-based programs in Texas, it often takes a crisis such as the death of a parent, a medical emergency or another tragic event to get priority on the waiting list.

Establishing a decision-making process during the parents' lifetime reduces distress for the adult child who is disabled when transitioning from home to community services.

If an adult child who is disabled has capacity, then it's important to put advance directives in place, including a Durable Financial Power of Attorney, Medical Power of Attorney, HIPAA Authorization, Physician's Direct-ive or "Living Will," and a Declaration of Guardian to allow trusted decision makers to step in when parents are no longer able to.

If the adult child does not have the requisite capacity to execute advance directives, then a guardianship will need to be established for decision making. Putting a guardianship in place ahead of time, during the parents' lifetime, eases the transfer of decision-making.

Elder law attorneys can help with these pre-planning steps. They focus on the legal needs of the older individuals and on persons (of any age) with disabilities. They have knowledge about legal issues arising from old age, financing long-term care, planning for incapacity and leaving money to persons with special needs without jeopardizing their eligibility for public benefits such as Medicaid and SSI.

They also network with others in the special needs community and are able to pair appropriate services with caregivers in need.

Parents who wish to leave an inheritance to a child with disabilities should discuss the matter with an elder law attorney because any money received by a person on SSI or Medicaid as a result of an inheritance (or a personal injury award settlement) will incur a penalty period, during which time Medicaid will not pay for medical care. To avoid this costly mistake, parents should include special needs trusts (SNTs) in their wills as an essential part of the pre-planning process.

SNTs supplement the income of a person with disabilities for things such as housing, food, clothing and additional medical care, but do not supplant his or her Medicaid benefits. A trustee is appointed to manage the trust for the beneficiary and should be someone with considerable financial experience or close family member.

These delicate matters are too important and complex to leave to chance. Forming a working relationship with a qualified elder law attorney can open many doors for families with special needs adult members.

Contact the National Academy of Elder Law Attorneys at www.naela.org for a referral to a Certified Elder Law Attorney (CELA) near you.