

WHO WILL BE THERE for my child?

By Joel Mendler



Many pioneering parents during the 1950s and 1960s shunned the well-meaning advice of physicians to institutionalize their child with a disability. Instead, they elected

to provide loving and nurturing care at home at great personal sacrifice and expense. However, recent medical strides mean that both you and your child are living longer than previous generations. If you are in your mid to late 50s or older, you are part of the first generation whose child with a disability may well outlive you. Likewise, as you grow older, you may begin to feel your age, lose your strength and vitality or suffer medical issues. Thus, every parent, particularly those with adult children with disabilities living at home, must confront the painful and difficult dilemma: Who will take care of my child when I am too old or frail to do so or when I die?

One thing is certain. You need a plan. You should start your plan now, while you are healthy. Tough decisions should not be made under the pressures of a crisis situation, especially

at a time when you may not be able to make such decisions. Yet few parents develop a timely plan. A recent survey conducted by Massachusetts Mutual Life Insurance Company and Easter Seals of parents of adult children with a disability found that 70% had not designated a guardian, 74% had not developed an estate plan, and 94% had no life care plan for their child. Marie Hartwell-Walker, a noted Massachusetts psychologist, has aptly stated:

You have given your child the gift of a loving family life well into adulthood. Now it's time to give that child, and you, the security that comes with having some idea of what the future will bring. You don't have a choice about eventually dying. You do have at least some choices about how to best provide care for the adult child left behind.

You are not alone if you find this enormously difficult even to think about. Your life has been entangled with your child's for so long that it's hard to sort out whose needs are whose. Maybe it breaks your heart to think about how difficult it will be for your child to adapt to a new situation. Maybe you worry whether any program can provide enough protection or can see to your child's complicated medical and emotional needs. Then again, maybe you don't want your child to move out because you will lose each other's company or you have so centered your life around your child's needs that it's hard to imagine what you will do next if he or she leaves home. Or, like many parents, you are so overwhelmed by the thought of dealing with the bureaucracy called human services you are finding it hard to get up the energy to put plans in motion.

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Nonetheless, your job as a parent isn't over. Without a plan, your child could be emotionally traumatized by losing everything at once (parent, home, and all that is familiar) if you suddenly become disabled or die. Loving your child now means beginning the process of letting go. Your child needs your support

bers or that some family members may not be willing to accept the responsibilities after you are no longer able or die.

Explore alternative housing options, such as independent living, group homes, supportative living facilities or with the family members who will have the ultimate care responsibilities for your child. Many government-funded residential services have long waiting lists so it's important to plan early.

Contact a life care planner and/or local agencies which oversee services for people with disabilities for assistance on available housing, transportation, equipment, special services and therapies, and other community services.

Continue fostering your child's independence to whatever extent possible, even as to such mundane chores as doing laundry.

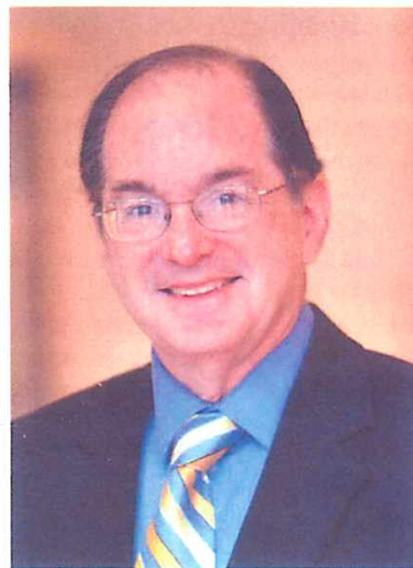
Consult with a qualified attorney to get your legal affairs in order. Consider obtaining a legal guardianship and/or conservatorship for your child. Although you made personal care and financial decisions for your adult child while your child lived with you, the next caregiver will not have such legal authority without court appointment. If your child has sufficient legal capacity, a power of attorney appointing an agent and successor agent may suffice. Even if you have a modest estate, drafting a Will leaving your assets to a trust for your child can provide for financial management of inherited assets by your designated Trustee and, if your child is or may qualify for means-tested governmental benefits, such as SSI and/or Medicaid, a special needs trust can preserve your child's eligibility for such benefits.

Prepare a Letter of Intent.

A Letter of Intent is a non-binding document that describes your child's history and background and your hopes and desires for your child's care when you are gone. It gives future caregivers some insight on medical care and treatment, names of professionals (physicians, caseworkers, attorney, etc), housing options, daily living skills, edu-

cation, religious upbringing, personal needs, social and recreational needs, the likes and dislikes of your child (including foods) and the rights and values which you want accorded to your child. Although not a legal document, it provides guidance and information which future caregivers vitally need.

Again, as Ms. Hartwell-Walker has noted: "You've supported your child, cared for your child, advocated for your child, and loved your child into adulthood. You're probably exhausted. You may be scared. Taking the next step is a lot to think about. But worrying about the future won't help you or your child. Embracing the challenge of planning for the future will." Or, stated another way: A failure to plan is a plan for failure.



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in transitioning to whatever will come next. You need the peace of mind, and the relief, that can come with knowing that your child will be safe and cared for.

What are some of the planning options?

Determine whether there are other family members who have the desire and capability of caring for or monitoring your child's care and needs. Perhaps you can get family gradually involved in care now, if possible. But also accept the reality that there may be no family mem-