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You're Not in This Alone: A Guide to Resources for Special Needs Families

Anyone who has a relative with special needs knows how demanding, uplifting and at times, draining, the situation can be for a family, both emotionally and financially. Thankfully, there's a wide range of planning techniques, professional services and benefits programs available to help everyone involved.

The first step to accessing them is also perhaps the most important step a family can take on a special needs person's behalf: proactive planning and goal-setting. "It starts with a family meeting," says Suzanne Krasna, a CFP® in Walnut Creek, Calif., to assess the support roles people in the family



are going to play, to set out a vision for how the special needs person and family members want their lives to be, and to script a plan for realizing that vision.

Consider these six elements in shaping such a plan:

- 1. Providing the best care possible to the special needs person, given financial and other constraints.
- 2. Affording the special needs person a chance to pursue his or her goals and dreams.
- 3. Providing additional income to improve the person's quality of life.
- 4. Protecting assets left or gifted to a special needs beneficiary.
- 5. Preserving the person's access to benefits, and pursuing those benefits diligently.
- 6. Preserving the standard of living for the person if his or her guardians (such as parents) die.

For help drafting and executing such a plan, it's vital for families to tap into a strong network of professionals and peers for insight, advice, and services. "There are plenty of resources out there. You just need to know how to access them," Krasna said.

First, for help determining what it's going to cost to carry out your family's plan and the best options for covering those costs, consult a financial planner with special needs experience. To find one, get referrals from peers or search the Financial Planning Association's national database at www.FPAnet.org/PlannerSearch/PlannerSearch.aspx.

In many cases a financial planner will recommend establishing a special needs trust, which, done properly, can provide a special needs person with financial resources and tax benefits, without curbing their access to benefits. This isn't a do-it-yourself endeavor; consult an attorney with expertise in this area.

Next, leave no stone unturned in seeking out benefits programs, public and private, that provide resources for special needs situations such as yours, including programs like Supplemental Security Income (www.ssa.gov/ssi/) and Medicaid/Medicare (www.cms.gov). Beside those federal programs, also look for benefits offered at the state and local levels (such as through regional/local SNAP programs). For help, talk to a social worker or adviser with special needs expertise.

Get involved in peer groups for families in special needs situations. Peers might be the best source you have for professional referrals and service recommendations, plus good old-fashioned advice and reassurance.

Draft a "Letter of Intent," essentially a document that communicates a family's vision, desires and concerns for the special needs person to his or her current and future caretakers. Again, turn to an attorney, adviser, or social worker with special needs expertise for help drafting the document.

Identify a guardian to step in should their current guardian(s), such as parents, die.

Hold family meetings periodically to assess current and future needs, care, and other issues in light of changing circumstances, and revise the special needs plan accordingly.

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