

The costs of caring for children with special needs are high, relative to those for typically developing children. Approximately 12.3 percent of the population of children ages 5 to 17 in the United States has a disability. Because the vast majority of public financial resources for developmental disabilities are devoted to residential services, families receive very limited financial support to care for their child with developmental disabilities. Research has revealed:

- The direct costs to families, indirect costs through reduced family labor supply, direct costs to children with disabilities, as they age into the labor force, and the costs of safety net programs for children who have disabilities average \$30,500 a year per family. (Stabile & Allin, 2012)
- 28% of children with disabilities lived in households with income below the federal poverty level compared with 16% of children who do not have disabilities (Fujiura & Yamaki, 2000).
- Income of parents with children who have disabilities averaged 32 percent or \$12,000 below that of other parents, and savings were 36 percent or \$48,000 lower (Parish, Seltzer, Greenberg, & Floyd, 2004).

Basic Financial Tips for Caregivers:

1. **Plan for future medical, educational, employment, and housing needs for your child.** Start by thinking about what your dependent's needs will be in the future – and develop your financial strategy based on these projections. Will they need weekly/daily medical treatments? Will they need funds for college? Would they live in a group home or need their own space? Adults who have disabilities increasingly are living independently, marrying, and going to college. Discuss expectations as early as possible with your child.
2. **Review beneficiary designations.** To continue to receive federal aid, dependents with special needs cannot have any assets in their name (cash, art, jewelry) that is worth more than \$2,000. Check with close friends and family to see if they have designated your child to receive any inheritance or insurance benefits from their estate– if they have, it's important that they leave this amount to your child's special needs trust (see number eight on this list for information on trusts).
3. **Have a family meeting to discuss your children's future needs.** Just as caring for a child with special needs is a family affair, so is the related planning. Although you facilitate your child's care when young, siblings or other relatives may be more involved with caring for your child in adulthood. Meet with your family members to discuss their

concerns and options for future care. This is also a good time to broach the beneficiary designation issue discussed above.

4. **Speak with a special needs financial professional and create a team of professionals to assist you in planning.** Once you have determined the current and future financial needs of your child, it's important to pull together a support team that can help guide you through the variety of options available to you and your family. The composition of the team may vary depending on your unique situation, but it should include an attorney, and perhaps a health professional and a school social worker, among others.
5. **Contact local nonprofit organizations for additional resource support.** Your local nonprofit that serves individuals with disabilities may be able to provide resources that can help with planning or that supplement services provided by government agencies. A good starting place is to first contact a nonprofit dedicated to your child's diagnosis.
6. **Apply for government benefits.** Government benefits – such as Medicaid and Social Security (www.ssa.gov) – may help provide for your dependent's needs in the form of medical treatments and supplies, equipment, financial assistance and more. Visit your local Social Security Office or department of social services to find out what benefits your child may qualify for; call or visit their website first to find out what documents you should have with you for your visit.
7. **Prepare your Last Will and Testament (review and update periodically).** A will declares how you want your estate to be distributed and allows you to select a guardian for your dependent when you pass away. Speak to your attorney for additional information.
8. **Consider setting up a Special Needs Trust.** This allows caregivers a way to provide for their dependent's care and quality of life, without disqualifying them for federal assistance. Trusts can be set up either funded or unfunded, and must be overseen by a trustee – often the dependent's caregiver and/or a bank trust officer. Funds can be contributed gradually over the years, or the trust can be designated as a beneficiary of an inheritance or life insurance policy. The money in the trust must be used to enhance the dependent's quality of life, and can help to supplement services and benefits provided by government agencies. Speak to an attorney experienced in special needs planning for more information.
9. **Apply for guardianship and conservatorship, if appropriate.** Caregivers must apply for a guardianship or conservatorship to maintain legal control over financial and healthcare decisions once a dependent reaches the age of 18. This can take up to a year in some states, so it's maybe best to start this process early. There are different levels of guardianship and conservatorship available, depending on the dependent's capabilities and needs. For example, a limited guardianship could be solely for financial or healthcare-related decisions.
10. **Prepare a Letter of Intent.** Although not legally binding, this document is important for providing direction for the person or persons who will care for your child with special needs and should be stored with other vital documents, such as your will. Think of it as a "letter to the caregiver" – it can cover day-to-day care routines such as what medical

assistance is needed, as well as guidance about activities and supports to enhance your child's independence and quality of life.

These tips and more information can be found on the special needs planning site at www.metlife.com.

For more information please also see:

Fujiura, G. T., & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Children, 66*, 187–199.

Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2004). Economic implications of caregiving at midlife: Comparing parents of children with developmental disabilities to other parents. *Mental Retardation, 42*, 413–426.

Stabile, M., & Allin, S. (2012). The economic costs of childhood disability. *The Future of Children, 22* (1, Children With Disabilities), 65-96. Retrieved from <http://www.jstor.org/stable/41475647>