



# Planning for a Person with Disabilities

## Traditional and Emerging Planning Considerations

By Michele P. Fuller

**T**raditionally, the only way for many persons with disabilities to receive financial support and healthcare coverage has been through government programs like Supplemental Security Income and Medicaid. To qualify for these programs, a person with a disability is required to have a very modest estate—typically below \$2,000 for an individual and \$3,000 for a married couple.

To allow persons with disabilities to access these government programs, it was an unfortunate common practice for these individuals to be disinherited so they would not receive money from parents or others that would disqualify them from government programs. Money was then sometimes left to a relative to care for the person with a disability. The flaws in this planning were many. For example, what happened if the relative died and the money went elsewhere? What if the relative divorced and the money was lost during the divorce? What happened if the relative decided to spend money on other things? What if the relative declared bankruptcy or had creditor problems? Thus, because of the need for access to healthcare and the inability to find employment, many

persons with disabilities remained impoverished.<sup>1</sup> A planning tool was required to keep benefits preserved for persons with disabilities that did not disqualify them from access to healthcare.

Special-needs trusts became the primary planning tool. But proposals have been made for new planning tools, including an Achieving a Better Life Experience account. Also, because of the passage of the Affordable Care Act, special-needs planners now have a valuable tool to access healthcare that is not dependent on government benefit eligibility.

The future of special-needs planning will be much like it has been in the past: finding ways to access healthcare, protect and grow assets, and enhance the quality of life for people with disabilities.

### The special-needs trust

Previously, special-needs planners created myriad ways to allow persons with disabilities to lead more than a subsistent existence. This included a variety of trusts to hold money for the

benefit of persons with disabilities. These trusts came of age in 1993 when the government passed the Omnibus Budget Reconciliation Act. The act provided exceptions to the general rule of counting trusts as resources and income for Medicaid and exempted transfer penalties to fund them for three unique trusts:<sup>2</sup>

- (1) A trust that contains the assets of a disabled individual under age 65, established for his or her benefit by a parent, a grandparent, a legal guardian, or the court, if the State Medicaid agency will receive all amounts remaining in the trust on the beneficiary's death up to the amount of benefits paid.<sup>3</sup> This trust is commonly known as a "(d)(4)(A) SNT."
- (2) A trust that is composed only of pension, Social Security, and other income in a state that does not allow income spend-down.<sup>4</sup> These trusts are commonly known as "Miller Trusts" (after *Miller v Ibarra*, 746 F Supp 19 (D Colo, 1990)). [not recognized in Michigan]
- (3) A trust that contains the assets of a disabled individual if
  - (a) the trust is established and managed by a nonprofit corporation and maintains separate accounts of pooled assets;
  - (b) the accounts are established by a parent, a grandparent, a legal guardian, the individual beneficiary, or the court; and
  - (c) the state will, on the beneficiary's death, receive all amounts remaining in the beneficiary's account (unless the account is retained by the nonprofit corporation) up to the amount of Medicaid benefits paid.<sup>5</sup> These trusts are commonly known as "pooled SNTs."

The same trust exceptions were expressly adopted for Supplemental Security Income.<sup>6</sup> The statute also made an exception for a trust established using other people's assets, typically from an inheritance; this is commonly called the third-party special-needs

trust.<sup>7</sup> This third-party trust has become the primary tool for the special-needs planner because it allows the attorney to address (in a legally binding fashion) the management of the assets for the benefit of a person with a disability in such a manner as to preserve eligibility for Supplemental Security Income and Medicaid as well as ensure that the individual receives all of his or her education, healthcare, access to employment, housing, voting rights, and other benefits.

While the special-needs trust has been an extraordinarily useful and powerful tool that enhances the quality of life for thousands of persons with disabilities, certain issues have made it an unattractive option for some. Because of establishment requirements, the cost of setting up a special-needs trust may be more than some can afford. The trust can also be expensive to administer. Additionally, per a requirement of the trust, the person with a disability loses control over his or her assets. This loss of control is problematic for those who have capacity to manage their own financial affairs. Finally, because of the complicated rules surrounding the trust's administration, many persons with disabilities end up losing eligibility for their benefits even when assets are placed into an otherwise qualifying trust, unless professionally administered.

Given these issues, some lawmakers and disabled individuals are looking at alternatives to the special-needs trust, such as the creation of other types of accounts that will benefit persons with disabilities without some of the trust's limitations. Does this mean there is no room for the special-needs trust in the future? Absolutely not. It will still be an important tool for the special-needs planner. The ability to set aside assets with written instructions in a legally binding format will still be required for many persons with disabilities. The trust will still be valuable because it protects a beneficiary with special needs who is susceptible to undue influence from financial predators. It still protects the beneficiary who does not have capacity to manage his or her own affairs. It can provide written instructions from a parent or loved one on the best ways to provide housing, education, and living arrangements for the family member with special needs. It can describe a system of advocacy in which the funds in the trust may be used to assist the person with a disability. Thus, the future of the special-needs trust is bright. However, there is a concern that its use is limited to obtaining or preserving Medicaid or Supplemental Security Income. There also has been a steady erosion of its protection by decisions made by state Medicaid programs and the Social Security Administration. The good news is that the Affordable Care Act may take away some of the concerns regarding the loss of Medicaid.

## FAST FACTS

Traditionally, the only way for many persons with disabilities to receive financial support and healthcare coverage has been through government programs like Supplemental Security Income and Medicaid.

Special-needs trusts became the primary planning tool to keep benefits preserved for persons with disabilities that did not disqualify them from access to healthcare. However, certain issues have arisen that make these trusts impractical.

The Affordable Care Act will directly affect many aspects of special-needs planning because so much of it is focused on the needs of individuals with chronic, long-term physical or cognitive conditions.

## Affordable Care Act

The passage of the Affordable Care Act will profoundly shape the future of special-needs planning. Implemented on January 1, 2014, the act provides healthcare coverage for many persons with disabilities. The act was able to clear its first obstacle when the United States Supreme Court held that it was constitutional.<sup>8</sup>

The Affordable Care Act will directly affect many aspects of special-needs planning because so much of it is focused on the

needs of individuals with chronic, long-term physical or cognitive conditions. The act provides:

- (1) Extension of private health coverage to those with pre-existing conditions, removal of lifetime limits, and guaranteed renewal—and subsidized premium costs;
- (2) Coverage of children on their parents' health care plans until age 26 regardless of their student or marital status;
- (3) Extension of Medicaid to non-institutionalized, non-disabled poor individuals under age 65—that is, no “categorization” of persons eligible to get insurance versus those who are not, based on age or disability or pregnancy; and
- (4) Care coordination efforts between home, facility, and hospital to reduce expensive hospital re-admissions.<sup>9</sup>

The act allows persons with disabilities to have access to private healthcare. This is important because people with disabilities have options they did not previously have. Before the act's passage, persons with disabilities had to use the special-needs trust to become impoverished in order to qualify for Medicaid, which was generally the only healthcare available to them. With the passage of the Affordable Care Act, persons with disabilities can now enroll in private healthcare plans. This means that a special-needs trust will not be necessary to provide access to healthcare except for long-term skilled nursing home care or other Medicaid paid-only programs, but may be a good choice to provide protection and financial management.

Will the Affordable Care Act cause the death of special-needs planning as predicted by some? No. Persons with disabilities will still require planning to cover financial issues if they do not have legal capacity to manage their affairs. Private insurance plans provide limited coverage for long-term care. Plus, some state Medicaid plans cover the cost of in-home caregivers, support for independent living, and activities such as sheltered workshops not covered by the act. Special-needs planners will have to prepare trusts so that the trustee may use funds to pay for a private health plan rather than limit their coverage to Medicaid. The Affordable Care Act is a boon for persons with disabilities. Special-needs planners must understand its intricacies so their clients can take full advantage of this law for persons with disabilities.

The primary goal of special-needs planning will remain the same: to provide persons with disabilities the best legal, personal, and financial planning that enhances their quality of life and allows them to reach their full potential. The historical treatment of persons with disabilities has generally been poor. The disability rights movement brought forth many positive changes. These advances have always been hard fought but easily watered down by later events. Thus, the special-needs planner will be required to remain ever vigilant to defend the gains made on behalf of persons with disabilities.

The special-needs planner will continue to use the special-needs trust as a tool to aid in planning. However, it may be only one of many tools. New planning tools may arise to help the person with a disability achieve financial stability. This may include

the Achieving a Better Life Experience account or a similar account that allows a person with a disability to keep more than \$2,000 in assets without jeopardizing eligibility for public benefits. However, the passage of the Affordable Care Act may have the most profound effect. The act allows persons with disabilities the right to buy private healthcare. This may lead many people to choose not to participate in public benefit programs to access healthcare. Perhaps the days of planning for a person with a disability to continue to receive public benefits for the sole purpose of obtaining healthcare will diminish or become extinct.

While many things look bleak for the person with a disability, there are many positive changes to look forward to, and the successful special-needs practitioner will be there to meet those challenges. ■



*Michele P. Fuller's law practice focuses exclusively on estate planning, elder law, special-needs planning, Veteran's Administration planning, and settlement planning. Her articles on special-needs planning have appeared in national publications such as Estates and Trusts Magazine, the NAELA Journal, and BiFocal, a journal of the ABA Commission on Law and Aging. She has been quoted in*

*The New York Times and was named Top Special Needs Child Advocate in 2013 by Parenting Magazine.*

## ENDNOTES

1. Nearly 28 percent of those with disabilities aged 18 to 64 were in poverty in 2010, according to statistics released from the U.S. Census Bureau. Meanwhile, the poverty rate for their peers in the general population reached 12.5 percent. DeNavas-Walt, Proctor & Smith, *Income, Poverty, and Health Insurance Coverage in the United States: 2010* (September 2011), available at <http://www.census.gov/prod/2011pubs/p60-239.pdf> (accessed October 13, 2014).
2. The safe-harbor trust exceptions in the Omnibus Budget Reconciliation Act of 1993, 42 USC 1396p(d)(4), apply to Medicaid eligibility rules. The federal special-needs trust statutory exception was the first expression by Congress stating a congressional policy permitting special-needs trusts and continuing eligibility for Medicaid for persons with disabilities. Before such time, there was much litigation with common-law special-needs trusts between applicants and the states. Many states opposed such trusts on policy grounds.
3. 42 USC 1396p(d)(4)(A).
4. 42 USC 1396p(d)(4)(B).
5. 42 USC 1396p(d)(4)(C).
6. 42 USC 1382b(e)(5) (Supplemental Security Income financial eligibility will be preserved if assets are held in a qualifying trust). Title 42 USC 1382b(e)(5) refers to the Medicaid safe-harbor trust rules in 42 USC 1396p(d)(4).
7. For Medicaid, a third-party special-needs trust established on or after August 11, 1993, is not affected by the Omnibus Budget Reconciliation Act trust rules. See 42 USC 1396p(d)(2)(A). For Supplemental Security Income purposes, the regulations allow third-party special-needs trusts. See 42 USC 1382b(e)(3)(A); 20 CFR § 416.1201(a)(1) (2003). Some people use the phrase “supplemental needs trust” to distinguish between a third-party trust and a first-party trust.
8. See *National Federation of Independent Business v. Sebelius*, \_\_\_ US \_\_\_, 132 S Ct 2566; 183 L Ed 2d 450 (2012). The case was heard together with *Florida v. Dep't of Health and Human Services*, 780 F Supp 2d 1256 (ND Fla, 2011). Note, however, that the court struck down the federal government's plan to enforce the expansion of Medicaid by withholding all Medicaid funding from states choosing not to broaden their programs.
9. See Lillesand, *The Impact the Affordable Care Act Will Have on Our Practices*, presentation at the 6th Annual Conference of the Academy of Special Needs Planners (2012).