

CROWDFUNDING IN SPECIAL NEEDS PLANNING

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In 2010, the now popular crowdfunding website GoFundMe was created. To date, it remains among the largest platforms for individuals hoping to raise funds for themselves or others. Let's look back at what, exactly, is crowdfunding, and how it impacts disabled individuals.

Crowdfunding offers an opportunity for individuals or small businesses to raise money without seeking a loan from a bank or contributions from a large donor. Perhaps the individual is undergoing medical treatment and cannot afford the cost, or a business is looking to raise capital but does not have the collateral necessary to secure a loan. In such cases, crowdfunding opens the door for fundraising. Given the prevalence of social media today, such fundraisers are often met with tremendous success. This success can likely be attributed to the old adage that every bit counts.

Consider GoFundMe's "Year in Help" for 2024 (<https://www.gofundme.com/c/gofundme-2024-year-in-help>): two donations were made every second, on average, and more than forty-two million donations were made to individuals (more than twenty-three million were made to charity).

This all sounds fantastic! But, what does it have to do with special needs planning?

Consider Bonnie, an 82 year old woman in declining health. She is undergoing cancer treatment, among other things, and the cost of her medication has become too much for her to afford on a fixed monthly income. Her daughter asked if she can start a fundraiser for her mom to offset some of this cost. The problem is that mom may need a nursing home as a result of her treatment, which will mean an application for Medicaid is looming.

Consider Italo, a young man in his 20s who is confined to a wheelchair due to muscular dystrophy. His mom is able to push his current wheelchair, but wouldn't it be nice for him to ambulate independently? The cost of an electric wheelchair can be as high as \$4,000 (some even

more). How will he afford that? He is on Medicaid and Supplemental Security Income, and the funds for the chair he wants are certainly not coming from the government.

For an individual who is elderly or disabled, access to means-tested government benefits such as Medicaid and Supplemental Security Income are paramount.

Medicaid and Supplemental Security Income (“SSI”) are two programs upon which elderly, disabled and impoverished individuals may rely to meet their daily needs for services and supports.

Eligibility for SSI is based on disability, and the program is structured to provide a monthly stipend to cover shelter costs (42 USC 1381). The current federal stipend is \$967 for an individual who lives alone. Certain states offer a supplement to this, but most are under \$100.

Medicaid is a health insurance program at its core, and is jointly funded by the federal (42 USC 1396, et. seq.) and state governments. This means that while each state is receiving federal funding for its Medicaid program, it is up to the state to determine the rules and regulations that apply (provided that the requirements are not more restrictive than the federal requirements for eligibility). Because the Medicaid programs are governed state by state, the rules are different state to state. Unless a state’s program expanded its Medicaid eligibility rules, an individual is not eligible for Medicaid if he or she has more than \$2,000 in non-exempt resources in his or her name. There are income rules associated with Medicaid eligibility as well, but these vary state to state. Similarly, to establish or maintain eligibility for SSI, an individual cannot have more than \$2,000 in his or her name. Other means-tested programs, such as Supplemental Nutrition Assistance (“SNAP”) or section 8 housing, also have specific rules regarding income and resources.

It is important to remember that for many disabled individuals, their eligibility for Medicaid is directly connected to their SSI benefit. This is because if an individual is eligible for

SSI, he or she has \$2,000 or less in resources and is disabled (as defined by the Social Security Administration). Thus, he or she is categorically eligible for Medicaid. Thus, losing SSI will also mean losing Medicaid and, while the individual can independently qualify for Medicaid, there may be a lapse in coverage.

Ultimately, the role of the elder or special needs law attorney is to ensure that the elderly or disabled individual does not, unintentionally, jeopardize the means-tested benefits upon which he or she relies for medical insurance, housing costs, food or other daily living expenses.

To date, there are no known publications by the Social Security Administration that specifically address crowdfunding, or rules that disregard funds raised on this platform when considering an individual's resources. Medicaid programs across the states have recognized the funds raised as either income or a resource, depending upon whether the funds have been distributed or are held in the account; whether others have access to the funds or if only the disabled individual can access and control the money; and whether the disabled individual began the fundraiser himself or herself or if it was started on his or her behalf. In most cases, a fundraiser will raise more than the permissible \$2,000, thereby jeopardizing the individual's means-tested benefits, and potentially negating the assistance the donors were trying to provide.

There are alternatives, however, that should be considered by anyone seeking to start a fundraiser on behalf of an individual receiving (or anticipated to receive) means-tested government benefits.

A Special Needs Trust is an exception trust permitted under federal law (42 USC 1396p(d)(4)(A)), funded with assets from the beneficiary, such as an inheritance or a settlement from a lawsuit. This type of trust is often called a first party or self-settled trust. A Supplemental Needs Trust is a third party trust funded with assets from someone other than the beneficiary.

In addition to the source of funding, there are distinct differences between the two trusts.

A first party trust must be for the benefit of a disabled individual who is under the age of sixty-five. If the individual has capacity, he or she can establish the trust on his or her own. If not, the trust can be established by a parent, grandparent, legal guardian or the court. The trust must include a payback provision which states that upon the beneficiary's death, any funds remaining in the trust will be used to pay back Medicaid for medical assistance provided during the beneficiary's lifetime. Finally, the trust must be funded with assets held by the beneficiary. Common sources include an inheritance or a legal settlement. As noted, this trust can be established pursuant to federal law, so the trust must be compliant with the federal statute. Certain states also have specific requirements for first party trusts and so compliance with local law will ensure approval and will avoid any gap or delay in coverage as a result of the funding of the trust. If the disabled individual is considering a fundraiser for himself or herself, he or she should consider a Special Needs Trust instead, provided he or she meets the requirements outlined.

A third party trust must also be for the benefit of a disabled individual, but there is no age requirement on the funding because the assets used to fund the trust do not belong to the disabled individual. This trust is most often used in estate planning for a parent or grandparent of an individual with special needs, and can be incorporated so that the disabled individual does not need to be disinherited. There is no requirement for a pay back provision under a third party trust and so it is best practice to avoid comingling the funds held in a third party trust and a first party trust. Thus, if the individual setting up the fundraiser for the disabled individual is a "third party", he or she should consider establishing a Supplemental Needs Trust instead.

In either case, whether the family establishes a first party trust or a third party trust, if the trust is properly drafted and administered then the funds held will not be considered available to

the disabled beneficiary and thus his or her benefits (or eligibility for same) will be maintained. In both cases, the trust must be used for the primary benefit of the disabled individual, and only to supplement, not supplant, the individual's means-tested benefits.

For certain families, the use of a trust is not practical. Perhaps they do not have a trustee to name, or perhaps the amount to be contributed to the trust is too small to warrant the expense of setting up the trust. In these cases, the family can consider a pooled trust or an ABLE account.

Pooled trusts are also considered exception trusts under federal law (42 USC 1396p(d)(4)(C)). These trusts can be first party or third party, but rather than being managed and administered by an individual trustee, the trustee is a not-for-profit organization. Here, too, the funds held will not be considered available to the disabled individual, and can only be used to supplement, not supplant, the individual's means-tested benefits.

The Achieving a Better Life Experience (ABLE) Act was signed into law in 2014 (P.L. 113–295) to provide disabled individuals an opportunity to save their money in order to cover qualified disability expenses. The individual must have been disabled prior to the age of 26¹ and must be disabled at the time the account is established (and when contributions and distributions are made). An ABLE account is subject to annual and cumulative limits. Contributions can be made consistent with the annual gift tax exclusion (\$19,000 in 2025). Each state is able to set its own lifetime maximum for contributions, though for SSI purposes, only \$100,000 is disregarded. Distributions are tax free if made for qualified disability expenses, which include but are not limited to education, housing, transportation, assistive technology, funeral and legal expenses (26 USC 529A(e)(5)). ABLE accounts do include a payback provision.

¹ This will increase to 46 as of January 1, 2026.

Other, possibly more creative, solutions include a (very) carefully timed spenddown which may permit the funds raised to be used to cover a particular cost, or payment to the vendor directly. For example, if Italo's friends raised the \$4,000 needed for his wheelchair by January 15, then purchasing – i.e. paying for – the wheelchair by January 31 may avoid a lapse in his coverage. There are also certain crowdfunding sites that manage the funds directly, and thus bypass any contributions to the disabled individual. It is not immediately clear whether these monies would still be considered “available”, or treated as “unearned income”, for purposes of the individual's benefits.

In most fundraisers, the funds raised can be withdrawn by the person raising the funds and/or by the beneficiary. Once withdrawn, there is no mechanism in place to guarantee that the funds raised are spent for the purpose they were raised. For example, once Italo receives the funds, no one is checking to see that he purchased his wheelchair. Perhaps, instead, he bought his mom a new couch. The beneficiary, or his or her legal representative, must monitor the fundraiser so that any funds raised are deposited into the beneficiary's account and then spent in the month of receipt. Otherwise, what would be considered income is going to be treated as a resource and thus potentially impact eligibility for means-tested benefits such as Medicaid and SSI. In fundraisers where only the beneficiary has access to the funds, the entire fundraiser will likely be considered an available resource, regardless of the timing of distributions. If the beneficiary ultimately decides to establish a Special Needs Trust for the funds raised, it is important that the fundraiser end as soon as the trust is established and funded.

Timing and transparency are critically important when starting or managing a fundraiser for a disabled individual.

Consider Ruth, a disabled woman who was turning 65 when she received a lump sum settlement from a law suit against a nursing home. Because she had not yet turned 65, she was able to establish a Special Needs Trust and direct the proceeds to the trust. Her benefits were preserved. However, she later discovered a GoFundMe account that had been set up for her by a long time friend living in Alaska. The fundraiser was started to raise money for assistive technology that was not covered by Medicaid. Unfortunately, by the time Ruth learned of the fundraiser, she had turned 65. She could no longer contribute the funds raised into her Special Needs Trust. Instead, they had to be released and paid to Medicaid as a partial payment on the lien. Otherwise, Ruth would have lost her Medicaid coverage and would have been personally responsible for her cost of care in the nursing home.

Crowdfunding can, in many cases, enhance the life of someone in need of financial assistance. Whether to start a company, pay for a wedding or funeral, take a trip or go to college, many life events require the support of others. However, for the elderly and disabled, the potential impact on means-tested benefits is enormous, and so proper planning is absolutely necessary. An understanding of the individual's means-tested benefits, and familiarity with federal and state laws pertaining to those benefits, will ensure that funds are properly raised, and properly spent, so that the individual receives the assistance he or she needs and maintains eligibility for crucial benefits.