

# Understanding Governmental Benefit Programs in Utah to Assist People with Special Needs

by Kathie Brown Roberts and Allison Barger

In our previous article in the July/August 2023 *Utah Bar Journal*, entitled “Drafting a Special Needs Trust in Utah, A Primer,” we discussed both first-party and third-party special needs trusts and other planning tools available to preserve eligibility for means-based benefits for individuals with disabilities. This article focuses on the characteristics of common benefits available to individuals with disabilities from both the Social Security Administration and Utah Department of Health and Human Services, the administrator of both Medicaid and the Division of Services for People with Disabilities (DSPD). This article will also address appropriations in the 2023 legislative session for respite care and caregiver compensation, which are currently available to caregivers of individuals with disabilities in Utah, and the need for additional funding for the state Home & Communitied-Based Services (HCBS) Waiver programs.

As attorneys, understanding which benefits a person is receiving (or will likely be receiving in the future) is one of first steps in planning for them. Receipt of a settlement or inheritance by individuals with disabilities who are currently receiving means-based benefits may wreak havoc on their qualification for such benefits. Also, understanding the programs available in Utah gives hope and support to those people and families who need it most. This article is organized to provide threshold questions for planning attorneys and an explanation of how those questions impact planning considerations.

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**In special needs planning, like other estate planning, knowing the questions to ask makes all the difference.**

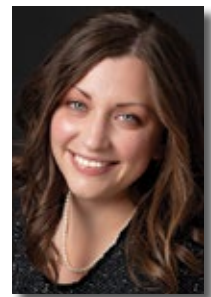
The following queries are threshold questions when planning for people with disabilities:

## **Are you planning for an individual or contingent beneficiary who is “disabled” or likely to need public benefits?**

All of the benefits discussed in this article have “disability” as a condition precedent to receipt of the benefit. An estate planner should consider implementing some of the tools described in our previous article if there are beneficiaries of an estate plan who are disabled or if other contingent beneficiaries of a plan are disabled (or likely to need public benefits in the future). Nobody has a crystal ball when it comes to knowledge of future health. For that reason, it is also prudent to include contingent special needs provisions which toggle-on, in case any beneficiary becomes disabled in the future.

The definition of “disabled” according to the Social Security Administration found in 42 U.S.C. § 1382c(a)(3)(A) is when an individual is “unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected . . . to last for a continuous period of not less than twelve months.” Even if there has not been a formal determination of disability by the Social Security

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Administration, in Utah, disability may be independently established by the Medical Review Board (MRB) in cases where there has not been an application for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) or where there has been a denial by the Social Security Administration for reasons other than “disability.” According to Marcel Larsen-Jones, Policy Coordinator at the Utah Department of Health & Human Services, the MRB in Utah follows the same criteria as the Social Security Administration to make the disability determination. The procedure to obtain an MRB determination of disability in Utah can be found in the Utah Medicaid Policy Manual. *See* UTAH MEDICAID POLICY MANUAL § 303-3, <http://hepmanuals.health.utah.gov/medicaidpolicy/DOHMedicaid.htm>.

### Which benefits is the individual currently receiving or likely to need?

#### Is the individual with a disability receiving SSDI?

The SSDI is an example of an “entitlement benefit,” which provides for payment of disability benefits to disabled individuals under Title II of the Social Security Act (Act) 42 U.S.C. Ch. 7. SSDI is an “entitlement benefit” because an individual becomes eligible to receive the benefit if “insured” under the Act by virtue of their work record. In order to qualify for SSDI, a disabled individual must have worked at least forty quarters, with twenty quarters earned in the ten years immediately preceding an application. *See* <https://www.ssa.gov/benefits/disability/qualify.html#anchor3>. Each element of this definition is strictly construed by the Social Security Administration (SSA). For example, the element of “substantial gainful activity” (SGA) cannot be met if the disabled individual earns more than an average of \$1,470.00 per month in 2023 (SGA Cap). *Id.* If an individual qualifies for SSDI, the individual automatically becomes eligible for Medicare parts A and B in the twenty-fifth month of eligibility. *See Medicare Information*, SOCIAL SECURITY ADMINISTRATION, <https://www.ssa.gov/disabilityresearch/wi/medicare.htm#work> (last visited Aug. 14, 2023).

Because an individual with a disability is entitled to receive SSDI based on his/her work record, receipt of inheritance or a settlement will have no bearing on the continuation of the benefit. SSDI could, however, be jeopardized if the individual is working and the average monthly earnings of the individual exceed the SGA amount of \$1,470.00/month. Even if the disabled individual is receiving SSDI, consideration should be given to the odds that the individual will need long-term care in the future and how will that care be funded. If Medicaid long-term care looks like a reality, should special needs planning be incorporated into the disabled individual’s plan?

#### Is the individual with a disability entitled to Social Security Derivative Benefits?

Social Security derivative benefits are also entitlement benefits derived from a worker’s work record and based on a worker’s eligibility by working at least forty quarters and paying into the Social Security Trust Fund. Examples of derivative benefits include benefits available to a surviving disabled spouse, an adult disabled child, a disabled veteran (benefits in addition to compensation benefits through Veterans Affairs), blind or low vision individuals, and disabled children. Generally, such individuals are entitled to a portion of the worker/wage earner’s primary insurance amount. *See How You Qualify: Disability Benefits*, SOCIAL SECURITY ADMINISTRATION, <https://www.ssa.gov/benefits/disability/qualify.html#anchor7> (last visited Aug. 14, 2023). As with SSDI, these benefits are not affected by inheritance or settlement but would be affected by exceeding the SGA cap.

#### Is the individual with a disability receiving Supplemental Security Income (SSI)?

In contrast to SSDI or benefits derivative from SSDI, SSI is a means-based benefit and not an entitlement benefit. Title XVI of the Social Security Act provides SSI payments to aged, blind, and disabled individuals (including children under age eighteen) who have limited income and resources. *See* <https://www.ssa.gov/ssi/?tl=0>. Individuals with disabilities receiving SSI will likely lose all or part of their benefits if an inheritance or settlement is not protected by a special needs trust or other planning tool.

In 2023, the maximum amount of SSI that an individual can receive is \$914.00 monthly (the Federal Benefit Rate). *See* <https://www.ssa.gov/oact/cola/SSI.html>. Additionally, an individual’s assets may not exceed \$2,000.00 (\$3,000.00 per couple). *See* <https://www.ssa.gov/ssi/spotlights/spot-resources.htm>. Slightly different rules apply if the SSI recipient has earned income. *See* <https://www.ssa.gov/ssi/?tl=0>. The Social Security Administration will reduce the SSI dollar for dollar if the recipient receives gifts of income directly. *See* POMS SI 00830.520.

If food or shelter is paid *indirectly* on behalf of the SSI recipient (such rent paid by a third party to an SSI recipient’s landlord), the federal benefit rate will be reduced by 1/3 plus \$20.00, not dollar for dollar. *See* POMS SI 00835.200. The Social Security Administration refers to such indirect gifts of as “in-kind support and maintenance” (ISM). POMS SI 00835.001. Regardless of the actual value of the food or shelter paid on behalf of the SSI recipient, 1/3 plus \$20.00 of the Federal Benefit Rate is the Presumed Maximum Value (PMV) that SSA will deduct from the

SSI recipient's benefits. POMS SI 00835.300. The SSI recipient can rebut the amount of reduction, if he/she has proof that food or shelter gifted is less than the PMV. *Id.* If the recipient lives in someone else's home and receives both food and shelter, the value of one-third reduction (VTR) applies, not PMV. *See* POMS SI 00835.200. VTR is not rebuttable. *See* POMS SI 00835.320.

A proposed rule introduced by the Social Security Administration on February 15, 2023, proposes to eliminate food from the calculation of ISM. *See* <https://www.federalregister.gov/documents/2023/02/15/2023-02731/omitting-food-from-in-kind-support-and-maintenance-calculations>.

### Is the individual with a disability receiving Medicare?

Medicare is an entitlement program that is available to individuals age sixty-five or older and to individuals who have been receiving Social Security Disability for at least two years. It is primarily a method of health care insurance. It does not cover nursing home stays unless it is a short-term stay related to rehabilitation after discharge from a hospital. Like other entitlement benefits, Medicare is not affected by receipt of inheritance or a settlement.

### Is the individual with a disability receiving Medicaid Benefits or an HCBS/1915(c) Waiver?

#### Overview of Medicaid Benefits

Medicaid is a means-based program that provides a variety of healthcare services to those who qualify. Receipt of the Medicaid long-term care benefit can be critically impacted by either the outright receipt of inheritance or settlement proceeds. Moreover, after the death of the Medicaid recipient, the Utah Office of Recovery Services "may recover from the [Medicaid] recipient's estate and any trust, in which the recipient is the grantor and a beneficiary, medical assistance correctly provided for the benefit of the recipient when the recipient was fifty-five years old or older." Utah Code Ann. § 26B-3-1013(1)(a). However, estate recovery is prohibited while the deceased recipient's spouse is still living or if the deceased recipient has a surviving child who is under twenty-one years old or is blind or disabled, as defined in the state plan. *Id.* § 26B-3-1013(1)(b).

As mentioned in our previous article, estate planners should be familiar with the use of a spousal third-party special needs trust arising under the pour-over will of the predeceased spouse, as a possible planning technique to preserve an surviving spouse's eligibility for benefits and avoid estate recovery on certain assets. *See* 42 U.S.C. § 1382b(e)(2). Additionally, certain types

of asset protection trusts or techniques such as gifting and/or annuities may similarly be considered to seek eligibility and avoid estate recovery in Utah.

Medicaid, however, administers many programs, each with eligibility requirements that vary depending on the program and, consequently, planning may vary based on the type of program an individual is receiving. When Medicaid is referenced, most people typically think of what is referred to as ABD or Community Medicaid. "ABD" refers to Aged, Blind, or Disabled. This is a method of healthcare insurance and has strict asset and income requirements: \$1,215.00 of income and \$2,000.00 of assets (for a single individual). *See Utah Medical Programs Summary*, UTAH DEPARTMENT OF HEALTH, <https://medicaid.utah.gov/Documents/pdfs/medicalprograms.pdf> (last visited Aug. 6, 2023).

It is important to remember that there are several types of assets that are not countable for purposes of qualifying for Medicaid, such as one vehicle and a home up to certain equity limit (currently \$688,000.00). *See* UTAH MEDICAID POLICY MANUAL § 521, generally. Qualifying for ABD Medicaid often is the gateway to receive services through a variety of waiver programs that provide home and community-based services.

In 2018, Utah opted into a limited Medicaid expansion program. Like ABD Medicaid, Utah's limited Medicaid expansion program is a method of healthcare insurance for people with low incomes. However, unlike ABD Medicaid, there is no asset limit.

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Income limits for various family sizes can be found in the UTAH MEDICAID POLICY MANUAL. [https://bepmanuals.health.utah.gov/Medicaidpolicy/Tables/TABLE\\_VII\\_-\\_Income\\_Limits\\_for\\_Medical\\_Medicare\\_Cost-Sharing\\_Programs.htm](https://bepmanuals.health.utah.gov/Medicaidpolicy/Tables/TABLE_VII_-_Income_Limits_for_Medical_Medicare_Cost-Sharing_Programs.htm). Money is treated as income in the month in which it is received, but the month following receipt, it is considered an asset and no longer countable toward eligibility. *See* UTAH MEDICAID POLICY MANUAL § 413-1. Beneficiaries still have an obligation to report the receipt of the asset within ten days of the date of receipt, but as long as they were unaware of the asset at the time of application for benefits, there will be no penalty against the beneficiary for receipt of the asset. *See* UTAH MEDICAID POLICY MANUAL §§ 107-4, 815. For example, if a beneficiary who is on Medicaid expansion receives an inheritance of \$100,000 on April 10, they must report that receipt to Department of Workforce Services (DWS) within ten days of the date of receiving the inheritance. As long as it is reported, the beneficiary will not experience a disruption in their Medicaid expansion benefits. Failing to report could result in overpayments or other disruption to benefits.

### Long-Term Care Medicaid

While Medicare does not provide long-term care benefits, Medicaid does cover long-term care. Long-term care Medicaid covers two types of long-term care venues: skilled nursing facilities (SNFs) and assisted living facilities (ALFs). The asset and income requirements are the same for both; however, care in an ALF is administered through Utah's New Choices Waiver program and has a separate application process and other qualification requirements. *See* Tables II and II-A of the UTAH MEDICAID POLICY MANUAL.

Not all facilities accept Medicaid or New Choices Waiver. Qualification for Medicaid Long-Term Care is nuanced and many rules apply. For example, qualification for Medicaid long-term care requires a knowledge of countable and exempt assets. Additionally, part of the review process for an application for long-term care Medicaid involves a sixty month look back period. *See* UTAH MEDICAID POLICY MANUAL 575. DWS will request sixty months of bank statements and information on any asset transfers from the time of application and conduct their own

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review of assets to determine whether any transfers for less than fair market value have been made. *See* UTAH MEDICAID POLICY MANUAL § 575-2. After determining whether an individual's income and assets are within the allowable limits, residents of a nursing facility must pay a cost-of-care contribution, unless they only receive Supplemental Security Income, or their income after allowed deductions, including the personal needs allowance, is zero. *See* Table II-A UTAH MEDICAID POLICY MANUAL for income and asset limits. The cost-of-care contribution helps pay for the services they receive in the institution and, consequently, reduces the payment the Medicaid agency makes for their care. *See* UTAH MEDICAID POLICY MANUAL § 463.

### Home and Community Based Services (HCBS) Waivers

Section 1915(c) of the Social Security Act, 42 U.S.C. 1396a, authorizes the "waiver" of certain Medicaid statutory requirements so that Medicaid dollars may pay for services in a community setting/outside of an institutional nursing home. The federal Medicaid website summarizes the requirements for state HCBS Waiver programs must:

- Demonstrate that providing waiver services won't cost more than providing these services in an institution.
- Ensure the protection of people's health and welfare.
- Provide adequate and reasonable provider standards to meet the needs of the target population.
- Ensure that services follow an individualized and person-centered plan of care.

Home & Community-Based Services 1915(c), <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> (last visited Aug. 4, 2023).

States can make an application to the Center for Medicare Services (CMS) to waive certain Medicaid program requirements under HCBS Waivers, including targeting certain geographic areas within a state, targeting certain groups within

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a state, and providing Medicaid to people who would otherwise be eligible only in an institutional setting, often due to the income and resources of a spouse or parent. *Id.*

According to the Utah Department of Health and Human Services website: <https://medicaid.utah.gov/ltc-2/>, Utah has nine Medicaid 1915(c) HCBS Waivers, each with their own qualifications and often very lengthy waiting lists for benefits. According to Utah State Rep. Raymond Ward, the time equivalent of some program wait lists is twenty years. Most of the below waivers are administered by the Division of Services for People with Disabilities (DSPD):

- Acquired Brain Injury Waiver
- Aging Waiver (For Individuals Age Sixty-Five or Older)
- Community Supports Waiver for Individuals with Intellectual Disabilities or Other Related Conditions
- Medicaid Autism Waiver
- Medically Complex Children’s Waiver
- New Choices Waiver
- Physical Disabilities Waiver
- Waiver for Technology Dependent Children
- Limited Supports Waiver

See Home and Community Based Services (HCBS) Waiver Programs, <https://medicaid.utah.gov/ltc-2/> (last visited Aug. 4, 2023); Waivers – Division of Services for People with Disabilities, <https://dspd.utah.gov/services/waivers/> (last visited Aug. 4, 2023).

### Great Need for Funding HCBS Waivers

Recently, Utah legislators have been attempting to increase funding to DSPD and help get services to more people who are on the wait list. These attempts were recently highlighted in a KSL.com article entitled, *Here’s What the Legislature Is Doing – and not Doing – to Care for Utah Caregivers*. Jenny Carpenter, *Here’s What the Legislature Is Doing – and Not Doing – to Care for Utah Caregivers*, KSL (July 16, 2023, 12:17 pm), <https://www.ksl.com/article/50686126/heres-what-the-legislature-is-doing--and-not-doing--to-care-for-utah-caregivers>.

The authors spoke with Utah State Representatives Jennifer Dailey-Provost and Raymond Ward about the KSL.com article and the legislation they sponsored. In the 2023 legislative session, Rep. Jennifer Dailey-Provost sponsored SB106: Caregiver Compensation Amendments, which expanded the definition of “caregiver” to include parents or guardians and allowed them to receive compensation for caregiving for their child if they meet specific qualifications. Parent caregivers can now receive compensation for up to eight hours per week for a year. This is now part of the general budget and will continue to be funded as part of the state plan. This was added onto an existing CMS waiver under the Home and Community Based Waiver programs through Medicaid. Compensating parental caregivers can help alleviate the financial burdens they experience in caring for a loved one, particularly after already having met the strict financial requirements to receive Medicaid benefits.

Rep. Raymond Ward also sponsored HB242: Services for People with Disabilities Amendments, which was overwhelmingly supported by the legislature but ultimately was not approved for funding. The bill would have given funding to DSPD for 200 more people who are currently on the DSPD waitlist. The DSPD waitlist is ranked by need, so some people wait years for services even though they otherwise qualify. The current number of people on the waitlist for services through DSPD is approximately 4,700, which roughly equates to a twenty-year-long wait. Although this bill was ultimately not funded this year, over the prior two years, similar efforts have been able to provide funding for services to at least 350 people and remove them from the wait list. Funding these services is a long-term commitment, and it requires a long-term plan to support it.

### Conclusion

Planning for individuals with disabilities requires at least a basic understanding of what benefits the individuals are receiving and the complexity of how those programs function, whether administered federally or in partnership with Utah. With that knowledge in hand, there are many planning opportunities for beneficiaries with disabilities and their families. Moreover, awareness of the demand for these services, particularly those provided by the HCBS Waiver programs in Utah, should also bring awareness to the need for funding these programs by our legislature.