## 6 Milestone Ages of Special Needs Planning

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### **About**

#### The 6 Milestone Ages of Special Needs Planning

If you're reading this, you most likely have or know someone who is caring for a family member with special needs. We understand that the efforts to ensure your loved one is well cared for now and in the future can be daunting. It's natural to worry about all the potential financial issues or care needs that you and your loved one may face in the future. You may wonder where to start or be overwhelmed by all the issues you need to consider.

**First of all, know you are not alone.** We have worked with so many families who have been right where you are today. That's why we've put together this special ebook for you. Think of *The 6 Milestone Ages of Special Needs Planning* as an overall roadmap of the topics you'll need to consider for your loved one at key age points throughout their life. Although this by no means covers every issue in-depth, it is our goal is to equip you with basic knowledge of important planning areas such as healthcare, financial, and public benefits, so that you will feel better prepared to enter the planning process armed with this information.

**How you read this is up to you.** If your focus is on a minor special needs child, it may make sense to start from the beginning to get an idea of the different factors you'll need to consider as your child ages. If you are caring for an adult, you may want to start with the milestone just before their current age.

**We're here to help.** Our attorneys are strong client advocates who have helped individuals and families navigate these waters for over 20 years. As a compassionate and knowledgeable resource, we are here to provide you the support and information you need to make the best care decisions for your loved ones.

**Our sincere hope** is that this ebook will give you both encouragement and valuable planning information. As with any other major undertaking, it starts with the first step. If we can help you take that step, let us know. We'd be happy to help.

# I B EIGHTEEN

In New Hampshire, an individual legally becomes an adult at age 18. As a result, there are a number of issues that require consideration well in advance of a family member's 18<sup>th</sup> birthday.

#### **Health Care Decisions**

Medical information is subject to strict confidentiality rules and once a patient turns 18, medical information is only provided to the patient. A patient may sign a release to allow family member(s) or other selected individual(s) to have access to protected health care information. Also, a patient may designate a family member, friend or interested person to make health care decisions for the patient as an agent under a health care power of attorney when the patient becomes mentally incapacitated to make his or her own decisions. If the patient does not have the capacity to sign a health care power of attorney, individuals could become the patient's health care decision maker under the surrogacy or guardianship laws.

- Health Insurance Portability and Accountability Act ("HIPAA") Release If an individual has the mental capacity to do so, a HIPAA release may be signed by such individual at age 18, thereby providing the designated individual(s) with access to confidential medical information. Medical information such as medical records and direct communication with health care providers may be accessed, however an executed HIPAA release does not provide the designated individual with any decision-making authority. A HIPAA release may be revoked at any time by the patient.
- Durable Power of Attorney for Health Care ("HCPOA") Upon reaching age 18, an individual may execute a durable care power of attorney for health care ("HCPOA") that allows named person(s), referred to as agent(s) or attorney(s)-in-fact, to make health care decisions if/when the individual lacks the capacity to do so. The individual may express any preferences for medical care or place limitations on the agents in the document. In order to execute a HCPOA, an individual must be able to understand the document and the consequences of signing the document. If the individual is physically unable to sign the document, another can sign for the individual upon instruction. The document must be formally executed before two witnesses or a Notary Public/Justice of the Peace.
- An agent has no authority to make health care decisions for the patient until the HCPOA is "activated." A
  HCPOA is activated when a physician or advanced practice registered nurse certifies in the medical record
  that the patient is not capable of making or communicating decisions regarding medical treatment. A
  HCPOA likewise can be "deactivated" if the individual regains mental capacity.
- In New Hampshire, a "living will" is a separate section of the HCPOA document, and may be executed at the same time as the HCPOA. a living will specifically expresses an individual's wishes regarding end-of-life procedures.

#### 4

- Surrogacy If a patient loses capacity to make health care decisions after the age of 18 and there is no individual with legal authority to make health care decisions (for instance, the patient never executed a HCPOA), a physician or advanced practice registered nurse may identify a surrogate from a statutory list of prioritized eligible individuals. A surrogate may not be appointed over the patient's objection and the surrogate's authority terminates after 180 days.
- Guardianship of the Person Another option when an individual reaches the age of 18 is to become that individual's guardian. A guardianship may be over the person, the finances (see guardianship of estate below), or both. Guardianship over the person provides the appointed guardian with decision making authority over areas such as health care, education, and living arrangements.
- A guardianship requires filing a court petition which sets forth factual examples that show the individual's health or safety would be at risk without the guardianship. The factual examples must be events that have occurred within 6 months of filing the petition and one instance must be within 20 days of filing. There is a court hearing and the individual filing the petition is required to put forth evidence and establish the need for guardianship "beyond a reasonable doubt." The court always appoints an attorney to represent the potential ward. Court appointed counsel is required to represent the client's wishes, not the client's best interests.



#### **Financial Decisions**

Financial decisions may be made by an individual named under a financial durable power of attorney document or by becoming guardian over the estate. As with the HCPOA, the individual who is named to make financial decisions is known as the agent or attorney-in-fact; the person who signs the document is known as the principal. It is important to note that certain public benefit agencies, such as the Veterans Administration and the Social Security Administration, do not recognize FPOAs or guardianship, but require the appointment of a representative through the agency's internal process.

- Financial Power of Attorney ("FPOA") A FPOA may be executed by an adult (i.e., someone who is at least age 18) who understands the terms of the document and the consequences of signing the document. A FPOA may be drafted to provide the agent with broad authority over the principal's finances. A FPOA can be drafted so that it is effective immediately, allowing an agent to assist with financial matters even though the principal still has mental capacity. Alternatively, a FPOA can be drafted so that it is "springing," that is, that the agent would not have authority to act until the occurrence of a triggering event, such as a doctor's determination of incapacity as with a HCPOA. If a FPOA is "durable" it means that the document is still valid even if the principal no longer has mental incapacity. The principal always retains the power to revoke the FPOA, or to discharge the agent, even if incompetent.
- Guardianship of the Estate Guardianship over the estate involves the same type of court filing and hearing as discussed above under guardianship over the person. A guardian of the estate is necessary if
  - an individual over the age of 18 has assets in his or her own name, and thus requires assistance with managing the assets. If the individual's sole asset flows from a monthly check through the Social Security Administration, a family member or interested individual may apply to be appointed Social Security Representative Payee, thus generally avoiding the need for guardianship over the estate. A person appointed as guardian of the estate most likely will be required to obtain a corporate surety bond, and will be required to file an inventory, and annual accounting of assets.



#### **Public Benefits**

Certain public benefits become available when an individual turns 18, including Supplemental Security Income and Aid to the Permanently and Totally Disabled benefits. Generally, Medicaid eligibility does not change until an individual reaches age 19 or 20, if the individual continues to be enrolled in a school program.

- Supplemental Security Income ("SSI") SSI is a federal cash assistance program for individuals who have a disability which is expected to last at least 12 months. Additionally, these individuals must meet certain income and resource standards to qualify for SSI. Prior to the age of 18, a parent's income and resources are "deemed" to the child, and thus are counted when determining financial eligibility, which often prevents a child under the age of 18 from being able to qualify. Upon reaching 18, however, only the individual's income and resources are counted. The maximum cash benefit for an individual is \$967 per month in 2025, which amount generally increases on an annual basis with a cost -of -living adjustment. The amount of cash awarded is also based on the recipient's living situation and whether the recipient receives in-kind support for food or shelter expenses. If the recipient receives in-kind support for food or shelter, the amount of the cash award may be reduced by a maximum of one third. For example, if an individual is living in a parent's household and does not pay rent and/or is provided with food, the SSI payment will be reduced by up to one third. Therefore, it may be beneficial for a parent to consider charging a child a proportional share of household expenses for room and board.
- Medicaid Individuals receiving Home Care for Children with Severe Disabilities (HC- CSD), also known as Katie Beckett benefits, Expanded Children's Medicaid or Children's Medicaid for Children with Severe Disabilities (CSD) may receive benefits until age 19. Individuals on HC-CSD and CSD programs are notified 3 months prior to the child turning 18 that an application for Aid to the Permanently and Totally Disabled ("APTD") must be filed to prevent the automatic termination of Medicaid and allow Medicaid benefits to continue until age 21. Both HC-CSD and APTD are specific to New Hampshire.
- Aid to the Permanently and Totally Disabled ("APTD") Some states, including New Hampshire, supplement the federal SSI payments with additional payments the program in New Hampshire is APTD. APTD is a cash assistance program with associated Medicaid benefits. In order to qualify for APTD, an individual must be at least 18, have a disability which is expected to last for at least 48 months, and also meet certain income and resource standards. Eligibility for APTD is required in order for an individual to be eligible for certain types of Medicaid benefits, such as Medicaid Waiver program benefits. As noted above, establishing eligibility for APTD at age 18 is important in order for certain individuals to retain Medicaid coverage after age 19.

#### **Child Support and SSI**

New Hampshire law generally allows a court to order child support to be made payable until your child turns eighteen or finishes high school, whichever is later. If your child has disabilities, however, a court may order that support payments continue beyond the age of eighteen even if your child is not in high school. These support payments cannot continue past the child's twenty-first birthday.

If you are receiving child support on behalf of a disabled child, and your child receives Social Security Insurance (SSI) cash benefits, it is important to understand how such payments can affect your child's eligibility for SSI. Child support payments are counted as unearned income to your child, not to you.

If your child is under the age of eighteen, or if your child is under the age of twenty-two and enrolled in school or college, then SSI will exclude one-third of the child support amount from countable income. However, if you are receiving child support for a disabled child who is between the ages of eighteen and twenty-one, but is not enrolled in school, SSI will count the full amount of any child support payments as countable income to that child.

Therefore, because the amount of child support counted as income will increase, a child with disabilities who turns eighteen, and who is not enrolled in school, may have a change in his or her eligibility for SSI cash benefits.



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# 2 TWENTY ONE

#### Transition to Adult Medicaid

Children who are enrolled in a Medicaid program are entitled to robust medical services, some of which are mandated by the federal Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) law. Services may include physician and hospital services, diagnostic and screening services, home health services, prescriptions, and dental, vision, and hearing care. In New Hampshire, children's Medicaid typically ends when your child turns age 19. Children who retain Medicaid coverage past their 19th birthday will be eligible for EPSTD services until turning age 21. Therefore, if your child has a severe health condition or disability and qualifies for Aid to the Permanently and Totally Disabled (APTD) or Aid to the Needy Blind (ANB) at age 18, children's Medicaid coverage will continue until your child turns 21 and the comprehensive coverage provided to children will continue.

When children's Medicaid benefits end, your child will transition to an adult Medicaid program, which generally does not include the same comprehensive set of benefits as children's Medicaid. For example, your child will only receive coverage for acute dental issues, such as tooth extractions, and will no longer be eligible for coverage of routine maintenance of dental health. Therefore, it is recommended that, prior to your child's 21st birthday, you work with your child's health care providers to identify and treat any issues that may not be covered under an adult Medicaid program, and that you ensure your child receives a full vision exam and a full dental check-up and cleaning.



#### **Special Education Services**

During K-12 schooling, your child may be entitled to services under one of two federal laws, either the Individuals with Disabilities Education Act (IDEA) or Section 504 of the Rehabilitation Act of 1973. Elementary and high schools are responsible for identifying students with disabilities, screening them, and providing services designed to allow students to be successful in school according to each student's individual needs and abilities. However, these mandates are not imposed on colleges providing post-secondary education.

IDEA provides special education services for children starting at age 3 by requiring the development of an Individualized Education Plan (IEP) that modifies the school curriculum, information delivery, or testing to meet each child's individual needs. IDEA covers children through high school graduation or through age 21, whichever comes first.

Section 504 protects individuals with disabilities from discrimination while attending a school or college that receives federal funds. However, Section 504 has different requirements for K-12 schooling than it does for post-secondary education. During K-12 schooling, the school must provide children with disabilities with a "free appropriate public education" (FAPE) that adequately meets their needs. During this time your child may have a "504 plan" that offers modifications to the physical environment or learning process. In contrast, Section 504 requires that a post-secondary educational institution provide appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability. In addition, if the postsecondary school provides housing to nondisabled students, it must provide comparable, convenient, and accessible housing to students with disabilities at the same cost.

Colleges do not have the same legal obligations as elementary and high schools, although they are subject to certain portions of Section 504, mentioned above, and the Americans with Disabilities Act. The focus shifts from ensuring your child's academic success to providing equal access to education, and the responsibility for obtaining the protections offered under these laws shifts from the school to the student. Colleges are not required to identify students with disabilities, nor are they allowed to speak with parents about a student's performance unless the student gives the school permission. Therefore, your child will need to self-identify as disabled, may need to pay for their own screenings, and will need to advocate for reasonable accommodations, as they are needed. Services available vary from college to college, and may include receiving materials in large print or in Braille, having a note taker for lectures, receiving a single dormitory room, or taking exams in a quiet room alone.

# 22 TWENTY TWO

## For individuals who've acquired a disability prior to reaching age 22

Age 22 is relevant because there are many public benefit programs that require proof that a person's disability arose before reaching age 22 in order to establish eligibility. While it may be tempting to toss or destroy yellowing medical records and other papers because they're more than three, seven, or 37 years old, you should resist the urge to purge, since it may be impossible to recreate the records years later! Professionals who have helped a person in the past may have retired, moved, changed jobs or even passed away. Schools or non-profit agencies can merge with other organizations, evolve or even become extinct making record recreation a nightmare, if not impossible. Tracing back through the years to track down the people who might still remember enough details to verify that the disability arising before age 22 may prove futile, even in the age of Facebook and Google. It also is important to recall that professionals like attorneys and physicians, and even some government programs and public schools, may not be required to keep records indefinitely



A person might need documentation of an early disability to acquire appropriate accommodations in vocational training or college. Others may need to document that a condition originally discovered during childhood was exacerbated in adulthood, putting substantial gainful employment on hold and qualifying for various benefits necessary. Some of the most important documents that may be useful throughout a person's lifetime would include the following:

- Individual education plans (IEPs), multi-factored evaluations (MFEs), 504 plans, and recommendations for accommodations
- Results of medical exams, particularly by specialists such as neurologists and psychologists
- Medical records documenting the "before and after" picture if an acute illness, accident or trauma resulted in permanent changes in the individual's cognitive skills or physical abilities
- Documentation that the individual received services from agencies that serve individuals with special needs or disabilities
- Records from job training programs or workshop employment documenting supports provided
- Letters from employers preserving the story of how your child got the job, whether the job was created or tailor-made for your child, whether any supports were provided to make employment possible, and whether there were any problems or issues on the job
- Letters from coaches, camp counselors, neighbors, religious or community leaders whose observations may someday help to establish how different or special your child was
- Court documents regarding guardianship/conservatorship, settlements for personal injuries or orders concerning legal capacity

Having clear documentation may become necessary for a person to qualify for invaluable public benefits in the future, including many of the following:

- Social Security Disability Insurance (SSDI) based on the individual's own work record, or adult Childhood
  Disability Benefits (CDB, formerly Disabled Adult Child (DAC)) based on the earnings of a parent who is
  permanently disabled, retired, or deceased
- Supplemental Security Income (SSI)
- Medicare
- Medicaid
- Income and health insurance benefits available through a parent's employer for dependent adult children
- Supported living and other benefits through public Developmental Disability boards
- Medicaid Waiver programs
- Military Survivor Benefits Plans



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#### **Childhood Disability Benefits**

Childhood Disability Benefits (CDB) is an important public benefit that often is overlooked. CDB benefits allow a disabled adult child to receive monthly income based on a parent's social security earnings record. To qualify for CDB, the adult child must be able to prove the following:

- (1) The child must be 18 years of age or older and have a disability that arose before reaching the age of 22;
- (2) The child must be disabled as defined by the Social Security Administration;
- (3) The child may not be married, unless the adult child's spouse also is disabled; and
- (4) At least one of the child's parents is receiving Social Security retirement or disability benefits or is deceased and had an adequate work history.

To apply for CDB, you may contact the Social Security Administration by phone or go to one of the SSA field offices. CDB benefits essentially are Social Security Disability Insurance payments, but through a parent's work history rather than through the child's work history.

#### Military Survivor's Benefits

A child who became disabled before age 18, or before age 22 if enrolled full-time in school, and is incapable of self-support, is considered a dependent child for life and parents in the military may undertake special needs planning for the child.

To qualify as a dependent child of a military member, the child must be unmarried and also be: (1) younger than age 18; (2) older than 18 but younger than age 22, and enrolled in a full-time course of study or training at a defined educational institution; or (3) incapable of self-support due to mental or physical incapacity which existed before age 18, or arose after age 18 but before age 22, while the child was enrolled in a full-time course of study or training.

Any child whose incapacity arose on or after a 22nd birthday is not considered "dependent" under the law and thus, the military parent is unable to use the special planning option of directing the payment of Military Survivor's Benefits to a qualifying special needs trust. A child not only must be a "dependent," but also must be "disabled" under the same standard used to determine eligibility for Supplemental Security Income benefits.



# 26 TWENTY SIX

Parents of a child with special needs continually look for ways to enrich the quality of their child's life and ensure his or her future health and wellbeing. These goals can be achieved using a variety of planning tools, some of which are driven by whether the child's disability either arose before age 26 or is expected to continue past that age.

#### Age 26 and Private Health Insurance Benefits

The Affordable Care Act (ACA) became effective in 2010, and if it continues in its present form, it requires group health plans and health insurance issuers that offer dependent child coverage to make that coverage available for an adult child until age 26. Employers are not required to offer dependent coverage but if they do, coverage must be provided to a participating parent's children under age 26. A child is considered a dependent under the ACA solely based on the child's relationship to the parent. As a result, dependent coverage under a parent's private health insurance is available to a child who has not attained age 26 regardless of whether the child lives with the parent, is disabled, married, a student, employed or financially independent. The extended availability of health insurance to a child with disabilities is complimented by the fact that the ACA also prohibited insurance companies from denying coverage based on a child's pre-existing medical conditions.

In New Hampshire, dependent coverage also must be extended to a child who is incapable of earning his or her own living. Although the ACA would permit a policy to terminate coverage when a child reaches age 26, New Hampshire requires that family-member coverage under the policy continue for an insured child who is mentally or physically incapable of earning a living on the date the child's dependent status as a covered family member would expire due to age. The coverage under the policy continues as long as the child remains chiefly dependent on the parent who is the policy holder, employee or his or her estate charged for the care of the dependent.

#### Age 26 and Federal Employee Health Benefits

Following the health care reforms in 2010, Federal Employee Health Benefits now are available to family members up to age 26. In addition, coverage is available to a child who is age 26 or older if the child is incapable of self-support because of a physical or mental disability that existed before the child turned age 26. A child is considered incapable of self-support only if his or her physical or mental disability is expected to continue for at least one year and, because of the disability, he or she is not capable of working at a self-supporting job. The cash and health insurance benefits available to special needs children of federal employees are complex, and families should work with an attorney focusing in this area.

# 55 FIFTY FIVE

Because ABLE accounts are owned by the person with disabilities personally, they can offer a means of maximizing the financial independence for those individuals with the ability to manage their own finances. Given the complimentary nature of ABLE accounts and special needs trusts, parents may wish to consider opening and funding an ABLE account for a child whose disability arises before age

26, while still creating a third-party special needs trust to hold other inheritance assets long term.

New Hampshire has partnered with STABLE Account, a national ABLE plan, to make ABLE accounts available to residents of New Hampshire. ABLE Accounts under the NH STABLE program can be opened at <a href="mailto:stablenh.com">stablenh.com</a>. For general information regarding ABLE programs, see <a href="www.ablenrc.org/">www.ablenrc.org/</a> and <a href="www.thearc.org/what-we-do/public-policy/issues/able-program-implementation">www.thearc.org/what-we-do/public-policy/issues/able-program-implementation</a>.

#### A State's Right to be Reimbursed for Cost of Medicaid Assistance

The age of 55 is relevant because it limits a State's right to seek reimbursement for Medicaid benefits paid on an individual's behalf. Some people decide not to apply for help because they are concerned (a) they might have to pay the government back for the help received if they later inherit money or obtain a good job, (b) that a lien might be placed on their home, or (c) that the government will seek reimbursement from their estate at their death. However, some of these concerns are misplaced.

#### **Medicaid Recovery During Life**

#### **Benefits Correctly Paid**

In general, federal law prevents the government from demanding reimbursement for help it provided while an individual is still living if the individual was, in fact, entitled to the help received. For instance, if you accurately reported all of your income and resources when you applied for assistance and were found eligible for Medicaid, then you would not have to pay the government back during your lifetime, even if you later inherited a significant sum of money or became gainfully employed. The one exception to this, described in greater detail below, applies to certain individuals who are at least age 55, not living in their home, and receiving Medicaid long-term care benefits.

#### **Benefits Incorrectly Paid**

If you did not report all of your income or savings, however, your eligibility for future benefits might be affected, and the government might have the right to request reimbursement. It therefore is highly important to provide complete and truthful information when applying for assistance, and to then inform the relevant agency when your circumstances change.

#### Liens on Real Estate

You may have been told that the government will put a lien on your home if you receive Medicaid. For the most part, however, that is not true.

The Medicaid program will not force you to sell your house to pay it back for help to which you were entitled. Your house cannot be "taken away" from you simply because you needed and received medical assistance from the government. Moreover, there are significant restrictions on when the State is allowed to file and enforce a lien on a home.

#### Specifically,

- A lien cannot be placed on the home for most types of Medicaid benefits, but only for nursing facility level of care benefits (nursing home, or benefits under a home and community-based care waiver);
- Even if an individual is receiving nursing facility level of care Medicaid benefits, a lien cannot be placed on the home unless the individual is not living in the home, and only if it is determined that the individual cannot reasonably be expected to be discharged from the facility and return home;
- A lien also may not be placed on the home if any of the following people live in the home:
  - The individual's spouse; or
  - The individual's minor or disabled child; or
  - The individual's sibling, if the sibling had lived in the home for at least a year prior to the individual's nursing home admission and who has some type of claim to the property.

#### Medicaid Recovery upon Sale of Real Estate

If a lien was properly placed on a home under the rules listed above, then the State can enforce its lien and seek recovery from the sale of the home for Medicaid nursing facility benefits paid on that individual's behalf, but only for those benefits paid on behalf of the individual after the age 55.



#### **Medicaid Recovery After Death**

Although the State cannot seek reimbursement for Medicaid benefits that were paid correctly while the individual is living, it might have the authority to seek reimbursement after the individual's death. First, if a lien properly had been placed on the home during the individual's lifetime, the State generally can seek recovery upon the sale of home.

However, it may not seek recovery if:

• There is an adult child living in the home, and had been living in the home for at least two years before the individual was admitted to the nursing home, and provided care to that individual that resulted in a delayed nursing home admission.

Second, the State has the right to seek recovery against the individual's "estate," but only if none of the following individuals then are living:

- The individual's spouse; or
- The individual's minor, disabled or blind child.

An individual's "estate," for Medicaid recovery purposes, includes probate assets as well as life estates and joint tenancies in real estate, and property held in a revocable trust.

#### Medicaid Benefits Received Before Age 55

Why is the age 55 significant? Because, generally, federal law prohibits a State from seeking reimbursement for Medicaid benefits that were correctly paid prior to an individual reaching the age of 55. Therefore, if an individual dies prior to reaching the age of 55, there would be no Medicaid recovery regardless of how much was paid on that individual's behalf.

There are two very significant exceptions to this rule, however:

- The State can seek recovery against assets remaining in a self-settled special needs trust i.e., a special needs trust that holds assets previously owned by the individual – and its claim can include any type of Medicaid benefits paid on the individual's behalf, even if paid prior to the creation of the special needs trust.
- The State can seek recovery for assets remaining in an ABLE account. ABLE stands for Achieving a Better Living Experience, and is an advantage savings account for certain individuals who became disabled prior to age 26. Medicaid recovery against an ABLE account includes Medicaid benefits provided after the date the ABLE account was established.

#### Not all Resources (such as a home) are 'Countable'

To be eligible for Medicaid or Supplemental Security Income ("SSI") you may have only a limited amount of "countable" resources in your own name, such as bank accounts, stocks, bonds, etc. If you are eligible for Medicaid or SSI, receiving a significant amount of money from a personal injury settlement or an inheritance could present a true dilemma if retaining eligibility for this benefit is important. One option is to use the money to purchase assets that are "non-countable," such as a house, vehicle, furniture or other household goods and personal effects; another option is to deposit the funds into a self-settled special needs trust, and then the trust later could purchase a house, vehicle, etc. It also is possible to use both of these options — i.e., to purchase certain items, and then deposit the excess funds into a special needs trust.

Therefore, if a person were to die prior to reaching the age of 55, the State may not have a right to seek Medicaid reimbursement from the individual's estate, but the State must be reimbursed from any assets remaining in a self-settled special needs trust or cash held in an ABLE account. Since valuable assets, such as a home, may be titled in a self-settled special needs trust it is important to consider whether such assets should be titled in the name of the trust or in one's own name.

## Should a Home be Owned by a Special Needs Trust? There are a number of factors to consider:

#### If Titled in Your Name:

#### **Pros:**

Owning a home in your own name can bring a sense of pride and independence. You can decorate the house to your liking. You will have the right to borrow against the equity in the home in order to make repairs or improvements, and to determine who will live in the home with you. You alone can decide whether to sell the home and how to use the sale proceeds. Were you to pass away before the age of 55, the equity in your home will not be subject to Medicaid recovery.

#### Cons:

If you have creditors, or are likely to have creditors, your housing could be at risk if you own the home in your individual name. While having the ability to mortgage a house might be appealing, this may not be the best option for someone who tends to be irresponsible with money, or who is vulnerable to being taken advantage of by others. Further, if you have limited income, you may not always be able to pay the monthly mortgage, which also will put your housing at risk. If your special needs trust or a family member helps you pay the real estate taxes or other costs associated with owning a home, such assistance will be treated as your "unearned income" for both SSI and Medicaid eligibility purposes. However, funds taken from an ABLE account and used to pay housing expenses are not treated as income by SSI or Medicaid.



#### If Titled in the Name of a Special Needs Trust:

#### **Pros:**

If a special needs trust owns a home, the home will be protected from any future creditors. The trustee becomes responsible for all costs associated with the home. If the trust pays property taxes and other carrying costs associated with the home, SSI will still treat such payments as unearned income to you, but, in NH, such trust expenditures will not be considered your income for Medicaid eligibility purposes. You will not be able to take out a mortgage, which could be beneficial if you have a tendency to act irresponsibly or impulsively, or simply cannot afford a monthly mortgage payment.

#### Cons:

If a special needs trust owns the home, the Trustee ultimately makes all decisions, not you – including whether you may decorate the house in a particular way, whether certain improvements will be made, and whether the house will or will not be sold. Assets titled in the name of a special needs trust at the time of your death might have to be paid to the State as reimbursement of Medicaid paid on your behalf over the course of your lifetime and will not be restricted to assistance provided after the age of 55.

# GG SIXTY FIVE

#### **Medicare Benefits**

Medicare is a health insurance program offering coverage to individuals who are over the age of 65 and eligible to receive Social Security Retirement or Railroad Retirement benefits. Medicare also provides health insurance coverage to persons under the age of 65 who have received Social Security Disability Insurance benefits for two years or more. An individual who is receiving coverage under Medicare Parts A, B, and D generally will receive health coverage for in-patient hospital care, skilled nursing facility care (but not long-term custodial nursing home stays), home health care, hospice care, physician visits, certain preventative services, lab tests and prescriptions. There are no preexisting condition exclusions for persons entitled to receive Medicare. General information concerning Medicare benefits can be found online at www.medicare.gov, an informational website managed by the U.S. Centers for Medicare & Medicaid Services.



## When do Social Security Disability Insurance benefits automatically change to Social Security Retirement?

Social Security disability benefits automatically change to retirement benefits when the person on SSDI reaches the full retirement age set by the Social Security Administration. Many folks receiving Social Security Disability Insurance ("SSDI") often think their SSDI benefits automatically convert to Social Security Retirement Benefits when they turn age 65. However, because the Social Security Administration periodically adjusts the full retirement age, anyone born after 1937 does not reach "full retirement age" at age 65.

Anyone born after 1960 will not reach full retirement age until age 67, and only then will their SSDI monthly cash benefit convert to Social Security Retirement Benefits. If you were born after 1937, but before 1960, you can determine your full retirement age on the Social Security Administration's website: https://www.ssa.gov/planners/retire/ageincrease.html.

#### Self-Settled Special Needs Trusts and Age 65

Many government benefits programs that are available to persons with disabilities, like Supplemental Security Income ("SSI") and Medicaid, limit the amount of monthly income an individual may receive, and the value of certain countable assets the individual can may own if applying for benefits. These federally-mandated limits often prevent someone from being eligible in the first instance, and sometimes may result in individuals losing some or all of their essential public benefits. The asset limits for SSI cash assistance is \$2,000, and is a varying and modest limit for many Medicaid programs. Therefore, persons with disabilities who depend upon these essential public benefits based on financial need continually must monitor their "countable" assets, as well as their income, to ensure they never exceed the allowable limits.

There are some planning options available for individuals to set aside their own assets and remain eligible for SSI and Medicaid. Generally, a person with disabilities cannot transfer assets out of his or her name, especially to an irrevocable trust, without causing a period of disqualification for SSI benefits and some Medicaid programs, unless the transfer either (a) occurred before a time period commonly known as the "look-back period" or (b) the assets were placed into a certain type of irrevocable trust that contains specific provisions and restrictions. These unique trusts commonly are referred to as "self-settled" special needs trusts ("SNTs"), since they hold assets which previously belonged to the trust beneficiary. Assets transferred to a qualifying SNT are exempt from the usual asset transfer penalties for SSI and Medicaid eligibility. However, these irrevocable trusts must be drafted very carefully to satisfy strict federal guidelines.

Using a self-settled SNT to hold countable assets or to receive unearned income is a favored planning technique when the goal is to preserve financial eligibility for public benefits programs like SSI and Medicaid. Self-settled SNTs can be created to benefit a person with disabilities who is about to receive an unexpected inheritance, settlement of a personal injury claim, alimony or child support, or who has personal savings and unexpectedly becomes disabled.

Again, a self-settled SNT holds funds that previously belonged to the person with disabilities who later becomes the beneficiary of the SNT. Self-settled SNTs differ from "third-party" SNTs, which are trusts that benefit a person with disabilities but hold assets that originally belonged to someone else. A third-party SNT often is used by family members or friends who want to plan for the future care of a loved one by setting aside an inheritance as part of an overall estate plan. Although third party and self-settled SNTs both help to preserve eligibility for public benefits which are based on financial need, like SSI and Medicaid, the two types of SNTs have very different requirements because self-settled SNTs are defined by federal law.

For instance, while third-party SNTs have no age restriction whatsoever, the person creating a self-settled SNT under federal law, must be under the age of 65 at the time the SNT is established (this type of self-settled SNT is often called a "(d)(4)(A) SNT"). A (d)(4)(A) SNT must be irrevocable, and must be created either by the person with disabilities, a parent, grandparent, guardian or a court. Also, any assets remaining in a (d)(4)(A) SNT at the beneficiary's death must be used first to reimburse the state or states for Medicaid benefits paid for the person with disabilities during his or her lifetime. This feature of self-settled SNTs is known as the "Medicaid payback" and only self-settled SNTs have this requirement, third-party SNTs do not. Any funds remaining in a (d)(4)(A) SNT, after paying back the state(s), can be paid to whoever is named as successor beneficiaries.

A "pooled" SNT is another type of self-settled SNT that complies with a different sub-section of the same federal law, and often is used for more modest estates or when an individual needs to spend assets quickly to remain eligible for government benefits. Pooled SNT programs operate in many states, including New Hampshire.

Although federal law does not impose an age restriction on who can create and fund a Pooled SNT, New Hampshire follows guidance issued by the Center for Medicare and Medicaid Services (CMS) which states that if the person with disabilities is age 65 or older, a penalty for Medicaid eligibility will be imposed for any transfers of assets to a Pooled SNT. There is on-going litigation in certain states to clarify whether a transfer to a Pooled SNT after age 65 should be a disqualifying transfer that disrupts certain needs-based public benefits.

A Pooled SNT also must be irrevocable, used for the sole benefit of the trust beneficiary who is a person with disabilities, and created by the individual beneficiary, his or her parent, grandparent, guardian, or a court. Further, like the (d)(4)(A) SNT, a self-settled Pooled SNT also must contain a Medicaid payback provision. Under the Pooled SNT design, separate sub-accounts belonging to multiple beneficiaries are managed by a non-profit entity. These funds then are "pooled" for management and investment purposes, but each sub-account is used for the sole benefit of the individual account beneficiary — which is why (this type of self-settled SNT also is referred to as a Pooled SNT. Since some financial institutions either do not handle small SNTs or charge fees that may be cost-prohibitive for smaller amounts, Pooled SNTs offer beneficiaries access to skilled investment and trust administration services. Finally, any assets remaining in the Pooled SNT after the beneficiary's death typically are divided in some proportion between the state(s) for Medicaid recovery and the non-profit entity.

If a person with disabilities expects to receive a settlement, an inheritance or any other monies that would increase his or her countable assets to more than \$2,000 for SSI, or the varying and modest asset limits for many Medicaid programs, it is important that the individual or family members meet with an attorney who specializes in disability and public benefits planning so that proper planning can be done to protect the person's continued eligibility for essential programs.



#### 6 Milestone Ages of Special Needs Planning

## All Ages

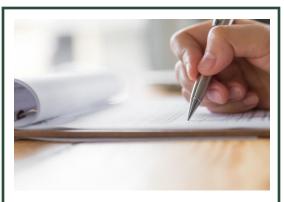
## All Ages

#### **Public Benefits Based on Financial Need**

Public benefits for individuals meeting certain financial eligibility requirements fall within several general categories:<sup>1</sup>

- Food assistance (commonly referred to as "food stamps" or "SNAP" (Supplemental Nutrition Assistance Program))
- Housing assistance (subsidies through Section 8 vouchers or public housing)
- Cash assistance (Supplemental Security Income ("SSI")
   through the federal government, and Aid to the Permanently
   and Totally Disabled ("APTD") and Old Age Assistance
   ("OAA") through the State of NH)
- Medical assistance (Medicaid)

Some people decide not to apply for help because they are concerned (a) they might have to pay the government back for the help received if they later inherit money or obtain a good job, (b) that a lien might be placed on their home, or (c) that the government will seek reimbursement from their estate at their death. However, many of these concerns are misplaced.



<sup>1</sup> As mentioned above under age 22, eligibility for Social Security Disability Insurance ("SSDI") and Medicare are based upon work history and not financial eligibility (except for income from working which must remain under a certain threshold or you are presumed not to be permanently and totally disabled). The discussion in this section therefore does not relate to those programs.

You may have been told that the government will put a lien on your home – or "take your home away" – if you receive public benefits assistance. For the most part, that is not true.

First of all, there are no public benefits programs that allow the government to force you to sell your house to pay it back for help to which you were entitled. Your house cannot be "taken away" from you simply because you needed and received assistance from the government.

Second, the law does not allow liens to be placed on a home for the receipt of SSI, food stamps or housing assistance.

Special Needs Planning requires a working knowledge of a broad range of legal and financial issues.  Bringing knowledge and skill in both areas, our team of attorneys and paralegals assist disabled clients and their families with navigating this complex legal area.
The information in this guide is general in nature.
For more information or to speak with one of our attorneys contact us at 603.668.0300, or visit us at www.sheehan.com.

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