

## **Special Needs: Financial Costs and Financial Planning Challenges**

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*Individuals with special needs, particularly young people, face a multitude of financial planning challenges relative to those without disabilities. The challenges include navigating through complex laws and rules which impact the financial resources and support (if any) available to the young with special needs. These complexities, in addition to the difficulty in obtaining economic opportunities, can create costs and obstacles for effective financial planning. This paper will provide an overview and discussion of these issues, in an attempt to identify both the economic challenges faced by the disabled and the unique financial planning issues that must be considered.*

### **INTRODUCTION**

Individuals with special needs typically face a myriad of unique financial planning challenges relative to those without disabilities. This paper will provide an overview of some of the major issues faced by those with special needs, including 1) how “disability” is defined, and how the definition can differ in determining eligibility for federal educational and financial support, 2), the programs of Social Security and eligibility requirements given the importance of Social Security in possibly providing financial assistance for the disabled, 3) financial costs of disabilities, with a focus on how disabilities affect earnings, family income, and employment, and 4) financial planning challenges for those with disabilities, including saving, retirement planning, and transfer of wealth considerations.

Financial planning for the disabled features various complex laws, rules, and regulations. These complexities, in addition to the economic opportunities (or lack thereof) afforded to the disabled, can create costs and obstacles for effective financial planning. This paper will provide an overview and discussion of these issues, in an attempt to identify both the economic challenges faced by the disabled and financial planning issues that must be considered when determining how to appropriately plan for the disabled’s benefit.

### **DEFINING SPECIAL NEEDS AND DISABILITY**

The *Merriam –Webster* dictionary defines special needs as “the individual requirements (as for education) of a person with a disadvantaged background or a mental, emotional, or physical disability or a high risk of developing one”. The terms “disability” and “special needs” often go hand-in-hand. The presence of a disability may translate into special needs – individual requirements, accommodations, or assistance that helps the individual achieve desired goals.

However, exactly what constitutes a disability, and if the disability is severe enough to warrant special accommodations or assistance, is not always easy to determine or uniformly judged. The term

“disability” does not have a uniform definition. The definition of disability may differ between medical and social models (Altman, 2001). Medical models view disability as resulting from a physiological condition that requires treatment or therapy. Social models view disability as resulting from societal forces on impairment, and imply that social norms affect disability restrictions. Federal laws differentiate the definition of disability for receiving federal educational assistance and federal financial assistance. The U.S. Census Bureau collects information across a range of defined disabilities in the communicative, mental, and physical categories (Brault, 2012). The *National Center for Learning Disabilities* focuses on and categorically classifies learning disabilities, which are defined as neurological disorders that can make it difficult to acquire certain academic and social skills.

## **STUDENTS WITH SPECIAL NEEDS**

The diagnosis and determination of a disability for students may impact the ability to receive assistance through federal programs on two fronts: 1) educational assistance, and 2) financial assistance. These two areas are summarized below because in each case, the disability may impact the future earning power and the financial challenges faced by the disabled individual. Comparing federal programs that provide educational assistance and financial assistance to students with disabilities also demonstrates how the definition of disability and requirements for program eligibility can change, based on the goals and services provided by the program. This has particular implications for young students, as the diagnosis and determination of a disability resulting in eligibility to receive educational assistance does not automatically translate into eligibility to receive financial assistance.

There are two primary federal laws that serve the special educational needs of students with disabilities. The Individuals with Disabilities Education Act (IDEA) has specific eligibility criteria and serves students with learning disabilities through age 21. Students not eligible under IDEA may qualify for disability services under section 504 of the Rehabilitation Act, providing requirements are met. In each case, the focus of the legislation is to provide additional educational resources to help the learning disabled student in academics.

Government programs for financial assistance to the disabled include Supplemental Security Income (SSI), Social Security (retirement, survivor, and disability benefits), Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP) benefits (formerly called food stamps), and public or subsidized housing. However, for the young and disabled, federal financial assistance through Social Security plays a pivotal role in determining ongoing income supplementation and benefits, and access to Medicare. Financial benefits to the disabled are primarily provided by two programs under Social Security: 1) Social Security Disability Insurance (SSDI), and 2) Social Security Supplemental Income (SSI).

An extremely point is that there are different laws and criteria that regulate the determination of a disability for education, and for Social Security eligibility. Because the focus of each is different, the determination of a disability for education does *not* mean the individual is disabled for Social Security purposes. The focus of disability eligibility for education is identifying and determining if a disability impacts a student’s ability to learn significantly enough to warrant accommodations and additional educational resources. The focus of disability determination for Social Security is identifying and determining if a disability impacts an individual’s ability to work significantly enough to warrant financial assistance. The criteria determining the presence and significance of a disability are different; consequently a student may be found to be learning disabled and receive special needs educational benefits but not found to be eligible under Social Security. In addition, although there are distinct laws and guidelines regarding eligibility criteria for special needs educational assistance and Social Security assistance, there may be significant judgment applied in determining if educational and/or financial assistance is warranted. However, even if a learning disabled individual is not classified as disabled according to Social Security, the learning disability may have a significant negative impact on earnings potential and standard of living.

## **DISABILITIES AND EDUCATIONAL ASSISTANCE**

The Individuals with Disabilities Education Act (IDEA) requires that public schools serve the educational needs of students with disabilities, and that services will be provided to eligible students as outlined in a student's Individualized Education Program (IEP). The IEP is a jointly created document with input from teachers, parents, administrators, health care providers, and potentially the student. The IEP will stipulate the specific accommodations that are to be made to the student to enable an effective learning environment that will help the student maximize their learning potential. It serves as the building block for providing a quality education to a child with learning disabilities. The IEP can specify room, exam, and coursework accommodations.

Before an IEP is created, it must be determined that the student is eligible for services under IDEA, and consequently an IEP. Eligibility for services under IDEA begins with the parent or school district initiating a request for an evaluation to determine if the student meets the criteria for learning disability and needs special education. A learning disability is defined by IDEA as "a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written that may manifest itself in the imperfect ability to listen, speak, read, write, spell or do mathematic equations."

IDEA requires that assessment of the student involve various tests and measures to determine whether the child qualifies as having one of thirteen disabilities specifically identified as a qualifying condition for special education. In order to qualify for special education services, the IEP team must determine that a child has at least one of the following thirteen disabilities: 1) autism, 2) blindness, 3) deafness, 4) emotional disturbance, 5) hearing impairment, 6) intellectual disability, 7) multiple disabilities, 8) orthopedic impairment, 9) other health impairment, 10) specific learning disability, 11) speech or language impairment, 12) traumatic brain injury, or 13) visual impairment.

If a student is not eligible under IDEA, a section 504 plan may be developed if a student has a disability that "substantially limits one or more major life activities such as: learning, speaking, listening, reading, writing, concentrating, or caring for oneself. 504 plans are developed by school teams and parents to support the educational needs and provide appropriate support to a student with learning disabilities. Similar but distinctly different, section 504 does not require an IEP but it does require a documented plan. Similar to the IEP process, parents can request their child be evaluated for eligibility for services under section 504. The law requires that assessment includes a variety of tools to determine the child's specific areas of educational need. Different from the IEP process, section 504 has broader classes of disability, does not specifically mention learning disabilities, and does not require an IEP.

The determination of a disability for educational purposes resulting in greater access to resources may be crucial to the educational success of a disabled student; however, the disability process for financial support is separate and distinct. It should be noted that educational success, the ability to advance through grades and graduate, does not guarantee employment success – the ability to get and retain meaningful work at a livable wage. Financial support may be necessary for a learning disabled individual to reach the poverty line.

## **DISABILITIES AND SOCIAL SECURITY FINANCIAL ASSISTANCE**

Federal financial assistance to the disabled is primarily provided by two programs under Social Security: 1) Social Security Disability Insurance (SSDI), and 2) Social Security Supplemental Income (SSI).

### **Social Security Disability Insurance (SSDI)**

The SSDI program is designed to provide benefits to people who cannot work because they are disabled, with the benefit amount a function of work history and earnings. Benefit eligibility requirements include: 1) a long enough work history to meet requirements, 2) the medical condition that resulted in a disability must be expected to last at least one year or result in death, and 3) meeting the definitional requirements of disability and its impact on work.

In general, to get disability benefits, two different earnings tests must be met:

1. A *recent work* test, based on age and the time the disability occurred, and
2. A *duration of work* test, to show that work history was long enough to meet Social Security requirements.

The following table indicates the Social Security rules for how much work is needed under the *recent work* test based on the age of the worker and when the disability began. The rules are based on calendar year quarters.

**TABLE 1  
RECENT WORK TEST**

<i>Age When Disability Occurred</i>	<i>Amount of Work Needed</i>
In or before the quarter the age of 24 was reached	1.5 years of work during the three-year period ending with the quarter the disability began
In the quarter after turning age 24 but before the quarter in which age 31 was reached	Work during half the time for the period beginning with quarter after turning 21 and ending with the quarter the disability began.
In the quarter age 31 was reached or later	Work during five years of the 10-year period ending with quarter the disability began

The following table indicates the Social Security rules for how much work is needed under the *duration of work* test.

**TABLE 2  
DURATION OF WORK TEST**

<i>Age When Disability Occurred</i>	<i>Years of Work Generally Needed</i>
Before Age 28	1.5 years
30	2 years
34	3 years
38	4 years
42	5 years
44	5.5 years
46	6 years
48	6.5 years
50	7 years
52	7.5 years
54	8 years
56	8.5 years
58	9 years
60	9.5 years

The above earnings tests are necessary conditions that must be met, but an applicant for SSDI must also meet the definition of “disabled.” The Social Security Administration uses a five-step process to determine if an applicant meets disability criteria. State agencies, operating under federal guidelines,

make the determinations (both medical and vocational) for the Social Security Administration about whether an applicant meets the test of disability in the law. The state agency is directed to use and evaluate medical records, work history, and the applicant's age and education in making the disability determination.

*1. Current Employment and Earnings*

For an applicant to be working and be eligible for SSDI, monthly earnings (substantial gainful activity) cannot average more than \$1,070 in 2014 for a non-blind individual (\$1,800 if blind). The amount is generally adjusted each year according to a national average wage index. If monthly earnings exceed the specified limit, then an individual can become ineligible for SSDI.

*2. Severity of Medical Condition*

As determined by the Social Security Administration, the applicant must be unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or is expected to last for a continuous period of at least 12 months. The Social Security Administration, in conjunction with state agency Disability Determination Services, will gather information from the applicant, health care professionals, and medical records to determine an applicant's eligibility.

*3. Listing of Impairments*

A specified Listing of Impairments, as well as the definition of the impairments, has been established by the Social Security Administration for both Adult and Child applicants. The state agency will use the Listing of Impairments in determining if an applicant is automatically deemed disabled by the law. If an applicant's condition is not on the Listing of Impairments, the severity of the condition will be evaluated and compared to conditions on the list. If the severity of an applicant's condition is equal to or greater than a listed impairment, the state agency will deem an applicant disabled.

*4. Can the applicant do the work previously performed before the disability?*

The state agency decides if an applicant's medical condition prevents them from doing work that was done before the disability occurred. If the state agency feels that the same work could be done, the applicant is not considered disabled. If the same work could not be done, step 5 is considered by the state agency.

*5. Can the applicant do any other type of work?*

The impairment or combination of impairments must be of such severity that the applicant is not only unable to do his or her previous work but cannot, considering his or her age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy. A person is considered to be involved in substantial gainful activity if he or she earns more than \$1,070 (\$1,800 if blind) in monthly earnings in 2014.

Adults who have a disability that began before they became 22 years old may be eligible for SSDI benefits, even if they do not meet work requirements. An important point, this SSDI benefit is considered a "child's" benefit because it is paid on the parent's Social Security earnings record. For the disabled adult to receive this "child" benefit, one of the parents 1) must be receiving Social Security retirement or disability benefits; or 2) must have died and have worked long enough under Social Security. Once the child turns 18, the child must meet the Social Security disability rules for adults. The benefits will continue as long as the disabled adult "child" continues to meet the Social Security disability rules. The "child" does not have to work to get these SSDI benefits.

## **SUPPLEMENTAL SECURITY INCOME**

The SSI program pays benefits to the elderly and disabled adults and children who have limited income and resources. The program, which is funded from general tax revenues rather than Social Security taxes, is designed to provide cash for basic needs. To be eligible for SSI, an applicant must be 1) 65 or older, 2) be totally or partially blind, or 3) have a medical condition that meets the Social Security definition of disability. In addition, there are significant restrictions on income and assets in order to actually receive SSI.

In general, the income limit is determined by the Federal Benefit rate, although the calculation of income is subject to certain exemptions and inclusions. Income includes wages or any other kind of money received from working, unemployment compensation, Social Security retirement, and the value of any free food or shelter provided. Social Security has exemptions to income that include: 1) the first \$20 of income, 2) the first \$65 of earned income and one-half of all earnings over \$65 a month, 3) Supplemental Nutrition Assistance Program benefits (food stamps), 4) shelter received from private nonprofit organizations, and 5) home energy assistance.

In 2014, the monthly Federal Benefit rate is \$721 for an individual and \$1,082 for a couple. The monthly benefit is reduced by the income of an applicant subject to income exclusions. For example, if an eligible person made \$1,005 per month, the first \$20 of income is excluded as is the first \$65 of earned income. This leaves \$920 of earnings, of which one-half would be excluded. The remaining earnings of \$460 would be deducted from the Federal Benefit rate of \$721 for a monthly benefit of \$261. The annual Federal Benefit rate is adjusted by changes in the Consumer Price Index, and some states supplement the Federal SSI benefit.

The limit on assets is strict. Assets include real estate, bank accounts, cash, and financial securities such as stocks and bonds. There are limited exclusions to assets, including a home and the land it is on. Social Security requires SSI recipients to have less than \$2,000 in assets, for a single person, and \$3,000 for a couple.

## **DISABILITIES AND COSTS**

The U.S. Census Bureau estimates the number of people with various types of disabilities in its report *Americans with Disabilities: 2010* (Brault, 2012). Disabilities are also classified as severe or non-severe, with severe disability generally indicated by the impact on the person's physical or mental capabilities. The estimates are based on questions asked of representative samples of the civilian non-institutionalized population living in the United States. The population living in institutional group settings, such as correctional facilities and nursing homes, and those living in military barracks are not included in the estimates.

It is estimated that approximately 56.7 million people living in the United States had some kind of disability in 2010, which accounted for 18.7 percent of the 303.9 million people in the civilian non-institutionalized population. Approximately 12.6 percent or 38.3 million people had a severe disability, which included disabilities that made it difficult to find a job or remain employed. For children under age 15, 8.4 percent had some kind of disability with 4.2 percent of the age group having a severe disability. For young people aged 15 – 24 years, 10.2 percent had some kind of disability with 5.3 percent of the age group having a severe disability and 1.4 percent needing assistance with daily living skills. The report provides a wide variety of information on the prevalence of specific types of disabilities; employment, earnings, and family income among individuals by specific measure of disability, and public assistance information and educational attainment information. Table 3 provides a summary of the data from the *Americans With Disabilities: 2010* report that focuses on financial costs for the disabled.

**TABLE 3**  
**DISABILITIES AND FINANCIAL COSTS**

	<b>Severely Disabled</b>	<b>Non- Severely Disabled</b>	<b>No Disabilities</b>
<i>Employment</i>			
Percent Employed	27.5	71.2	79.1
Consistently Employed - Percent	19.9	54.8	61.1
24 mo. Period of Unemployment - Percent	49.9	14.1	9.2
Employment Limitations - Percent	74.2	24.1	3.1
<i>Earnings and Income</i>			
Employed - Median Monthly Earnings	\$1,577	\$2,402	\$2,724
Employed - Median Monthly Family Income	\$2,376	\$3,959	\$4,771
<i>Individual Income Distribution - Percent</i>			
Less than \$5,000	28.0	25.9	25.0
\$5,000 - \$14,999	37.3	21.5	16.8
\$15,000 - \$24,999	16.4	14.6	14.8
\$25,000 - \$49,999	12.5	22.7	23.3
\$50,000 - \$74,999	3.8	9.1	10.8
\$75,000 - \$99,999	1.3	3.3	4.6
Greater than \$100,00	0.8	2.8	4.3
<i>Family Income Distribution - Percent</i>			
Less than \$25,000	45.6	27.8	22.2
\$25,000 - \$49,999	25.0	26.2	23.5
\$50,000 - \$74,999	14.2	18.8	18.7
\$75,000 - \$99,999	7.3	11.8	13.6
Greater than \$100,00	7.9	15.3	22.0
<i>Poverty Status</i>			
Percent in Poverty	28.6	17.9	14.6
Percent in Poverty for at least 12 mo.	10.8	4.9	3.8
Percent in Poverty during 24 mo. period	53.1	41.7	38.1
<i>Educational Achievement- Percent</i>			
Less than High School	18.4	11.7	8.8
High School Diploma	32.1	26.3	22.9
Some College or Associate's Degree	35.9	38.5	34.2
Bachelor's Degree or Higher	13.5	23.6	34.1

Source: M. Brault, "American With Disabilities: 2010," *Current Population Reports*, P.70-131, U.S. Census Bureau, Washington D.C. 2012.

## **Employment**

The overall employment rate for disabled individuals aged 21 to 64 was 41.1 percent. Employment was particularly problematic for those with severe disabilities, with only 27.5 percent of severely disabled adults being employed compared to 71.2 percent of adults with non-severe disabilities. The employment rate was 79.1 percent for adults without disabilities. In addition, adults aged 21 - 64 years with a severe disability were less likely to remain employed consistently over longer time periods. The percentage of adults aged 21 - 64 years with a severe disability that were employed consistently over a 24-month period of time was 19.9 percent compared to 54.8 percent for adults with non-severe disabilities and 61.1 percent for adults with no disability. Conversely, people with severe disabilities were more likely to experience longer periods of unemployment. Almost half, 49.9 percent, of adults with severe disabilities were not employed for all 24 months, compared with 14.1 percent of adults with a non-severe disability, and 9.2 percent of adults with no disability.

## **Earnings and Income**

Not surprisingly, earnings of the disabled were significantly below that of non-disabled workers. The median monthly earnings for adults aged 21 – 64 years with a disability were \$1,961 compared to \$2,724 for a non-disabled adult. The median monthly earnings for severely disabled adults were only \$1,577; those with non-severe disabilities had median monthly earnings of \$2,402. The median monthly family income for a disabled adult was \$2,856, approximately 60% of the median income of \$4,771 for a family without a disabled adult. Median monthly family income for a severely disabled adult was only \$2,376; families of adults with non-severe disabilities had a median family income of \$3,959.

## **Individual Income Distribution**

Nearly two-thirds, 65.3 percent, of adults aged 21 to 64 years with severe disabilities had annual income less than \$15,000. This compares to 47.4 percent for adults with non-severe disabilities and 41.8 percent of adults without disabilities. Only 5.9 percent of adults with severe disabilities had income greater than \$50,000, compared to 15.2 percent of adults with non-severe disabilities and 19.7 percent of adults without disabilities. The bottom three percentiles had greater percentages of adults with severe disabilities than either adults with non-severe or no disabilities. The top four percentiles had greater percentages of adults without disabilities than either adults with severe or non-severe disabilities.

## **Family Income Distribution**

Not surprisingly, family income distribution patterns were similar to individual income distribution patterns. The percentage of families with less than \$50,000 with a severely disabled adult was 70.6 percent; this compares to 54.0 percent for families with a non-severely disabled adult and 45.7 percent with families without a disabled adult. Almost half, 45.6 percent, of families with a severely disabled adult had family income less than \$25,000 compared to 27.8 percent of families with a non-severely disabled adult and 22.2 percent of families without a disabled adult.

## **Poverty**

Poverty rates were twice as high for people aged 15 to 64 with severe disabilities compared to those with no disability. Approximately 28.6 percent of people aged 15 to 64 with severe disabilities were in poverty compared to 14.3 percent of people with no disability. The poverty rate for people aged 15 – 64 years with non-severe disabilities was 17.9 percent.

Poverty rates can change over time, given the flux of employment and earnings over time. When poverty was measured over a 24-month timeframe, people with severe disabilities experienced the greatest difficulties. The percentage of people aged 15 – 64 years with severe disabilities that were in poverty for at least 12 months over a 24-month period was 10.8 percent. This compares to 4.9 percent for people aged 15 – 64 years with non-severe disabilities and 3.8 for people with no disabilities. More than half of people aged 15 – 64 years with severe disabilities, 53.1 percent, were in poverty during some point



over the 24-month timeframe. This compares to 41.7 percent for adults aged 15 -64 years with non-severe disabilities and 38.1 percent for adults with no disabilities.

### **Education**

Education is listed as a financial cost, because the inability to achieve educational levels can have an adverse impact on earning power. The percentage of adults with severe disabilities able to obtain a bachelor's degree or greater was 13.5 percent, compared to 23.6 percent of adults with non-severe disabilities and 34.1 percent of adults without disabilities. Over half of adults with severe disabilities, 50.5 percent, maxed out their educational achievement at high school or less, compared to 38.0 percent for adults with non-severe disabilities and 31.7 percent for adults without disabilities.

## **FINANCIAL PLANNING CHALLENGES**

The financial planning challenges for the disabled and their families can be significant and varied. While the list below is not all inclusive, it does contain some of the major challenges faced by the disabled and their families.

### **Saving**

It is extremely difficult to save when earnings are at a low level and employment is difficult to find or maintain. Particularly for those adults with severe disabilities, saving can be extremely difficult. In terms of family income, severely disabled adults had 50% less in financial resources than families without a disability. The median monthly earnings for severely disabled adults were only \$1,577 (\$18,924/yr.). The family income of severely disabled adults, which takes into account income from various sources, was only \$2,376 (\$28,512/yr.). Saving can be challenging at any income level, but extremely challenging at these levels. The median monthly earnings for a non-severely disabled adult were \$2,402 (\$28,824/yr.) and \$2,724 (\$32,688/yr.) for an adult without disabilities. Median monthly family income with a non-severely disabled adult was \$3,959 (\$47,508/yr.) and \$4,771 (\$57,252/yr.) for families with no disabilities.

Earnings are relatively low and saving difficult for the disabled, particularly severely disabled, *if* the disabled can find and maintain employment. Employment was particularly problematic for those with severe disabilities. Severely disabled adults were less likely to be employed (27.5 percent vs. 79.1 percent of adults without disabilities), less likely to be consistently employed (19.9 percent vs. 61.1 percent of adults without disabilities), and more likely to be unemployed for long periods of time (49.9 percent vs. 9.2 percent of adults without disabilities).

### **Retirement Planning**

Supplemental Security Income may be option for disabled adults and children who have limited income and resources, and meet the Social Security definition of disabled. In addition, there are significant restrictions on income and assets in order to actually receive SSI. Generally, Social Security requires SSI recipients to have less than \$2,000 in assets, for a single person, and \$3,000 for a couple. Retirement benefits may be included in this asset calculation.

The treatment by SSI of retirement plans varies. Social Security treats defined benefit plans different from self-directed Individual Retirement Accounts (IRAs). For SSI recipients who have a defined benefit plan and are receiving benefits from that plan, those pension benefits are countable income and reduce SSI payments. For SSI recipients who have a defined benefit plan but are not yet receiving benefits under the plan, the present value of expected future benefits has no current impact on receiving SSI benefits. The funds cannot be immediately accessed by the SSI recipient; consequently they do not currently impact receiving SSI benefits. However, funds in Individual Retirement Accounts could be accessed by the recipient, even though tax penalties may apply. As a result, Social Security considers the funds in IRAs to be assets of the recipient and count against the SSI asset limitation.

Consequently, although IRAs could provide increased wealth at retirement, they can be a detriment to a possible SSI recipient.

### **Transfer of Assets - UTMA/UGMA (Uniform Trust or Gift to Minors) Account**

The UTMA/UGMA account has the purpose of allowing a transfer of funds to a minor, with a reduction in taxes on the earnings because a minor is the beneficiary. Up to \$14,000/year can be contributed into the UTMA/UGMA account, which is controlled by a custodian for the benefit of the minor. When the minor comes of age (either 18 or 21; varies by state) the minor can take control of the account and use the funds as they wish. This type of account can allow parents to prudently transfer funds to their child in an effort to gain the tax advantages of the account and allows savings to be built up for needed asset purchases by the minor in the future.

However, UTMA/UGMA accounts may be a detriment for a disabled child potentially eligible to receive SSI. Once again, the asset limitation of SSI comes into play. Generally, Social Security requires SSI recipients to have less than \$2,000 in assets, for a single person, and \$3,000 for a couple. The UTMA/UGMA accounts assets will count as assets when the beneficiary becomes of eligible age to take ownership of the account.

### **Transfer of Assets - Special Needs Trusts**

There are two kinds of special needs trusts: Self-Settled (also called First-Party) and Third Party Special Needs trusts. The Self-Settled Trust is funded with the assets of the disabled person; the Third Party Trust allows a transfer of assets to the disabled person. In each case, the disabled beneficiary must meet the Social Security Administration's definition of "disabled" before the trust is implemented (see Mattleman, Weinroth, & Miller).

A Self-Settled Trust is funded with the assets of the disabled (although other family members and friends can contribute) and subject to significant federal and state law requirements. The assets are the assets of the disabled person, the beneficiary, and managed by a trustee in the best interests of the disabled person. A disabled person under age 65 may place assets in a Self-Settled Trust to preserve Medicaid or SSI eligibility. Even though the funds of the disabled person are used to create the trust, the trust must be established by a parent, grandparent, guardian, or a court. The beneficiary cannot be the trustee of a self-settled special needs trust. The trustee should have sole discretion to determine what distributions are appropriate. A Self-Settled Trust contains a payback provision - any money left in the trust after a person dies must be used to reimburse the government for Medicaid benefits the person received before any money can pass on to the person's heirs.

Third-party Special Needs Trusts are designed to allow a transfer of assets to those of any age that have disabilities and qualify for SSI and Medicaid Benefits (Elias and Urbatsch, 2013). Funds within the trust are *not* counted against the asset limit for SSI. Basically, the funds allow a transfer of assets to a disabled person, while retaining that person's eligibility to receive financial assistance (SSI) and medical assistance (Medicaid). The trustee will manage the funds in a fiduciary manner (in the best interests) for the disabled person. Third-party Special Needs Trusts can offer a variety of advantages to the disabled person: 1) a transfer of assets to be used in their best interests, without loss of eligibility for federal financial assistance through SSI, 2) financial management facilitated by the trustee, including money management and overseeing appropriate expenditures, and 3) protection of assets in a divorce or from creditors. Third-Party Special Needs Trusts are primarily designed to protect assets that will be gifted or willed to a disabled person, rather than protecting the personal assets of the disabled person.

Third Party Trusts are considerably more flexible than Self-Settled Trusts. Third Party Trusts can be created during life or through a Will; Self-Settled Trusts are created during life. Third Party Trusts can be revocable or irrevocable; Self-Settled Trusts must be irrevocable. Third Party Trusts do not repay Medicaid benefits; Self-Settled Trusts do. There is no age restriction with Third Party Trusts; once the beneficiary of a Self-Settled Trust becomes 65 years old contributions to the trust are no longer allowed. In each case, the trustee must not use the trust funds to provide food or shelter for the beneficiary, because

this would result in a reduction of government benefits. In each case, it is the trustee, and not the beneficiary, that will make decisions on how to use trust funds appropriately.

An extremely important point is that both trusts require the disabled beneficiary meet the Social Security Administration's definition of "disabled" before the trust is implemented. The Social Security test of disability is designed to be detailed and strict. However, in certain cases, it can also be viewed as somewhat subjective. To use a baseball analogy, the rules of baseball specify when a pitch should be called a strike. However, the interpretation of the rules, and exactly if a pitch should be called a strike, can differ on a given day between pitchers, batters, managers, fans, and umpires. The listing of impairments specifies and defines what is considered a disability. However, the interpretation of the severity of a condition, and an applicant's ability to be involved in substantial gainful activity, can differ between an applicant, the Social Security Administration, judges, attorneys, and physicians. The final determination, as to whether an applicant meets the definition of "disabled" for Social Security purposes, can take well over a year. An applicant denied benefits has a right to go through the Social Security appeals process but the process can increase the time and cost involved with the attempt to obtain Social Security benefits.

### **Transfer of Assets – Pooled Trusts**

Pooled Trusts use the pooled resources of different disabled individuals. Assets are combined and collectively managed, with each disabled individual having a sub-account within the trust. Funds are spent on beneficiaries in proportion to their share of the trust. Pooled Trusts can offer a variety of services, including money management and investment management services in exchange for fees. State laws apply to pooled trusts; as a result, most pooled trusts accept only beneficiaries in their own state. Pooled trusts are generally nonprofit organizations that work closely with a financial institution to provide money management and investment management services.

There are both advantages and disadvantages to using a pooled trust for a disabled person. Potential benefits of Pooled Trusts include: 1) the Pooled Trust can be valuable when a responsible individual cannot be found to act as trustee for another type of trust; the Pooled Trust acts as the trustee for the disabled beneficiary, including appropriate financial decisions, 2) the Pooled Trust offers services in which it has expertise or access to expertise, 3) rather than having to set-up their own trust, Pooled Trusts generally handle the paperwork and legal expertise to set up a beneficiary's participation in the trust, and 4) compared to other trust forms, the death of a trustee is not a concern for the ongoing nature of the Pooled Trust. However, there are also disadvantages to Pooled Trusts, including 1) fees and costs of a Pooled Trust may be significantly higher than what would be incurred with alternative trusts, reducing the available funds for the beneficiary, 2) financial decisions made for the benefit of the beneficiary will likely be made by someone not knowing the beneficiary as well as a family member or friend, who could serve as trustee in an alternative trust, 3) withdrawal of funds may incur a fee, 4) certain pooled trusts may keep a portion of the funds after the beneficiary dies.

The advantages and disadvantages must be clearly weighed in deciding if a particular Pooled Trust is applicable for a disabled person. Once again, the disabled person must meet the definition of disabled for Social Security purposes and assets in the trust will not count as financial resources for the disabled person for SSI and Medicaid purposes.

### **SUMMARY**

Individuals with Special Needs face unique financial challenges and costs. The paper attempts to increase the awareness of certain costs, and some of the financial issues that must be considered when financial planning for the disabled.

Individuals with disabilities, particularly severe disabilities, are at an economic disadvantage relative to individuals without disabilities in terms of earnings, family income, and employment. Poverty is more likely, employment more difficult to obtain and retain, and educational advancement more difficult. These economic and educational challenges create financial planning challenges in the form of appropriately planning for saving, retirement, and transfer of assets.

A unique challenge for an individual with a disability is to have the disability meet the definitional requirements of Social Security to be eligible for financial assistance through the programs of Social Security. Meeting the disability definitional requirement also opens up the opportunity to consider trust options that require the disability definition to be met. Although sometimes a disability may obviously meet the "Listing of Impairments" severity requirements of Social Security, sometimes whether a disability meets the definition will lead to legal proceedings, as there can be a difference of opinion between Social Security and an applicant as to whether the disability definition has been met.

Additional challenges can be created when disabled individuals are limited economically by their disability, but are not classified as disabled by Social Security. This limits trust options and negates federal financial assistance, and may increase legal costs in pursuing Social Security benefits. The challenge is to somehow provide the greatest financial opportunity for someone whose economic opportunities may be limited.

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