Life Planning For Families of Special Needs

PACSTX
Tools to Protect Benefits

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TJ Kroehle, AIF

- 5500+ Families in our program
- 60+ Combined Years Serving Special Needs
- 35-Year -Old Life Planning Firm
- Certified Life Planner

"Defining a Reliable Future"

www.txlifeplanning.com

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Life Planning Program Director

- 25-Year-Old Firm

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If There Is One Thing To Remember

Rule #1:

What happens in a typical family is usually wrong for a Family of Special Needs.

Rule #2:

Always Remember Rule #1!

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The System is Designed

The United States Benefit System is designed to fail.

If you follow the typical rules of society, the normal morals, values, instilled in you as a child, everything you hope for in a benefit system is designed to fail.

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What are the Social Benefit Programs in the USA?

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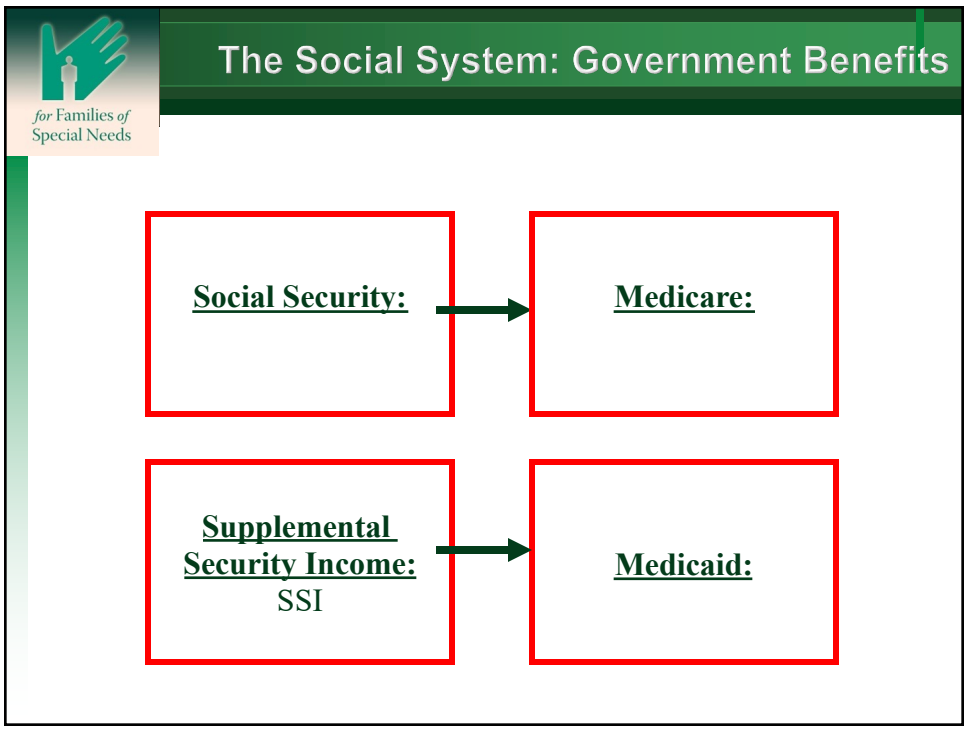
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The Social System: Government Benefits
Social Security:
Medicare:
Supplemental Security Income:
SSI
Medicaid:

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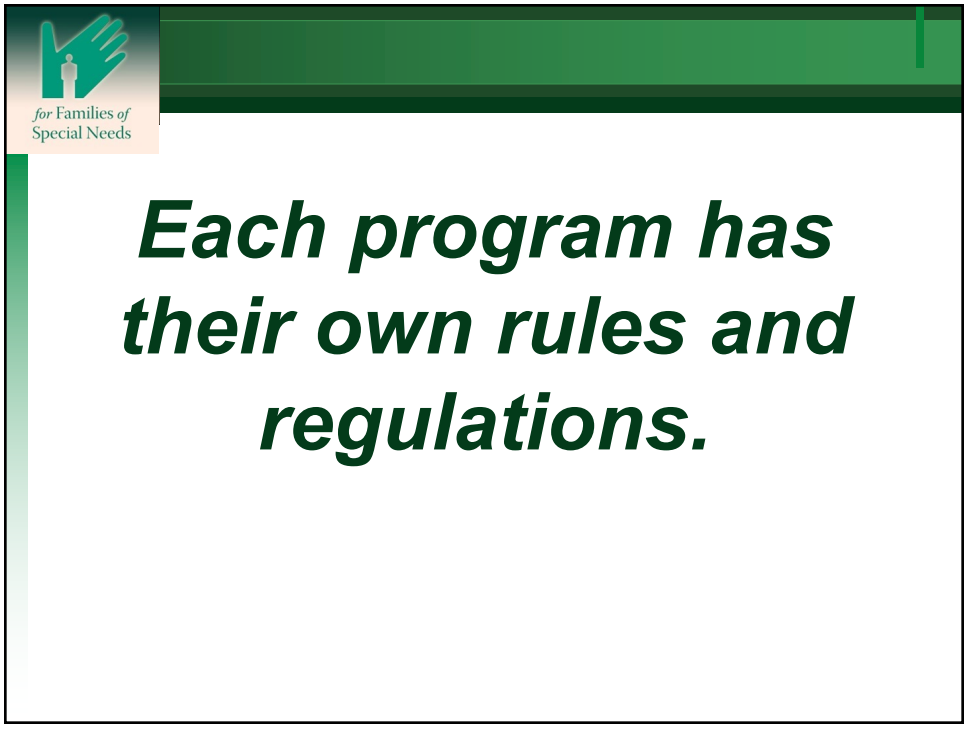
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Each program has their own rules and regulations.

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Medicaid and SSI Assets Rule

$2,000 Asset Limit

Asset: Total balance of all accounts at the close of business any one day. If Medicaid or SSI are requesting a copy of a statement, they are looking at highest daily balance in the month.

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Special Needs Family Estate Planning

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If There Is One Thing To Remember

Rule #1:

What happens in a typical family is usually wrong for a Family of Special Needs.

TYPICAL FAMILIES:

A majority (80%) don't have a will and leave their money intestate! The Texas Probate System gives your money to your kids in equal shares

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How to Protect the Social System

EASY TO LOSE!

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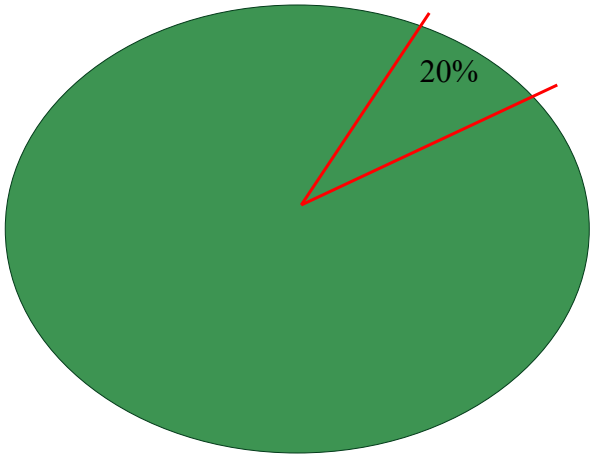
Do You Have a Will?

What Percent of the USA's Population has a will?



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It's More Than A Will And Trust

- *Good News approximately 50% of Special Needs Parents have an Estate Plan*
- *Only 10% of the 50% of Special Needs Families have a proper special needs estate plan in place.*
- *The Balance..*
  - *Have a Typical Estate Plan in Place – giving money to all loved ones equally.*
  - *Some know benefits may be at risk and believe the DAC can't have any money therefore, give all the money to their other kids to take care to the DAC.*
  - *Have what they believe is an effective special needs estate plan that will protect the DAC when in reality, the estate plan was improperly prepared.*

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Estate Planning

If you pass away "Intestate"

This means you have passed away with out any estate planning (will).

In essence you have not communicated who will handle your estate and who will receive your estate.

Therefore: Probate Court is the judicial determination will divide money equally to all children equally.

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The Special Needs Trust: A Key Element in Special Needs Planning

A Special Needs Trust for DUMMIES

"Protects the Child's Social and Medicaid Benefits"

What can it be used for?

If the Social Benefit System (SSI, SSA, Medicare or Medicaid are willing to PAY for it, then the Special Needs Trust CANNOT!

If the Social Benefit System (SSI, SSA, Medicaid or Medicare are NOT willing to PAY for it, then the Special Needs Trust CAN.

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Estate Planning

Types of Special Needs Trusts

Self-Funded Special Needs Trust* (child trust)
Testamentary Special Needs Trust* (parents trust)
In-Vivo Special Needs Trust* (Friends and family)
TRS Special Needs Trust*
Military Special Needs Trust
ARC of Texas Master Pool SNT Trust (4 types)
Structured Settlements "1301"SNT
Structured Settlements "142" SNT
Beneficial Interest SNT
Miller Trust
Mims Pot Trust
Divorce Special Needs Trust
Generation Skipping SNT

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How to Protect the Social System

EASY TO LOSE!

Do you have a process in place to check your families
to determine if they have a proper Special Needs Estate Plan in place to protect your Residential Happy Campers.

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SSI, SSDI and Medicaid Rules

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SSI Assets and Income

Income Rule:

Can't exceed $2011 Income per month

(SSI time 2 plus $85)

$2,000 Asset Limit

Asset: Total balance of all account at the close of business any one day. If Medicaid or SSI are requesting a copy of a statement, they are looking at highest daily balance in the month.

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SSDI Assets and Income

Substantial Gainful Activity (SGA) Rule:

Can't exceed $1,620 of Income per month as this proves the child has capacity to work and they lose their attachment to the parent's record of service.

No Asset Limit

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The Social Security System

Key Points:

In most cases, when the parent collects, the *"Disabled Adult Child"* (DAC) collects.

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Disabled Adult Child (DAC) and SSA

Entitlement

Social Security
Retire = SSA
Disability = SSDI
Die = Survivorship

How Much does it Pay?

SSA = 50% of the Parent's Benefit of the Parents PIA

SSDI = 50% of the Parent's Benefit

Survivorship = 75% of the Parent's Retirement Benefit

Social Security Survivor's Benefit: Paid to minor children and/or qualified Disabled Adult Child at the passing of a parent or qualified step-parent, if the Disabled Adult Child does not qualify for their own benefits.

Social Security Administration: "RETIREMENT BENEFITS" Paid to a qualified Disabled Adult Child at the collection of social security retirement benefits at the onset of the parent's or qualified step-parent's retirement benefits, if the child does not qualify for their own benefits.

Social Security Administration: "DISABILITY BENEFITS" Paid to a qualified Disabled Adult Child at the collection of social security disability benefits at the onset of the parent's or qualified step-parent's disability benefits, if the child does not qualify for their own benefits.

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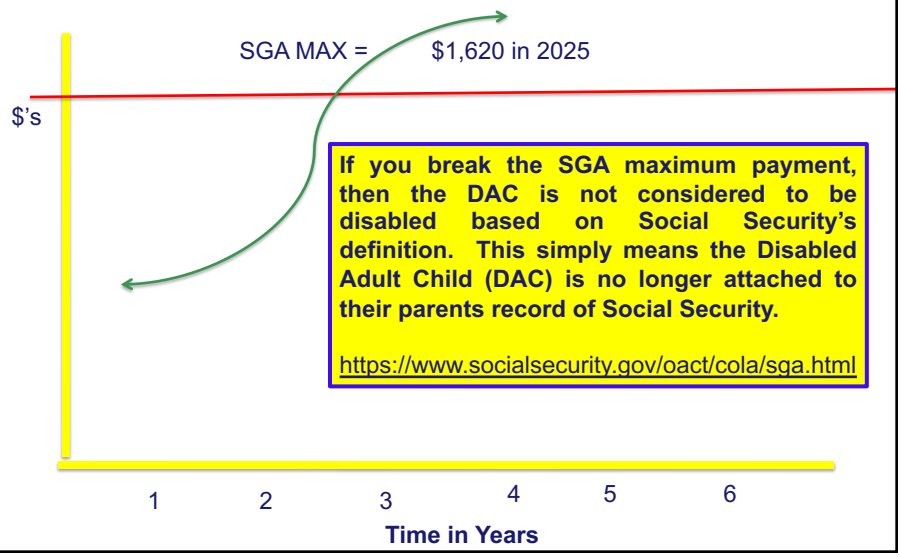
Substantial Gainful Activity (SGA) Rule



If you break the SGA maximum payment, then the DAC is not considered to be disabled based on Social Security's definition. This simply means the Disabled Adult Child (DAC) is no longer attached to their parents record of Social Security.

https://www.socialsecurity.gov/oact/cola/sga.html

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Benefit Payout

What is at Stake?

When a parent retires with a $4,000 retirement income, then the disabled adult child will receive 50% of his parents SSA retirement income, or about $2,000 per month, assuming the child is still eligible for a piece of his parent's benefits.

$2,000 per month, is $24,000 per year.

$24,000 per year is $240,000 over 10 years.

If the child's parent is retired 20 years prior to passing, then the total benefits paid are $480,000.

FOUR HUNDRED EIGHTY THOUSAND DOLLARS IN BENEFITS

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Benefit Payout

What is at Stake?

When a parent passes away with a $4,000 retirement income, then the disabled adult child will receive 75% of his parents SSA retirement income, or about $3,000 per month, assuming the child is still eligible for a piece of his parent's benefits.

$3,000 per month, is $36,000 per year.

$36,000 per year is $360,000 over 10 years.

If the child survives his parents by 30 years, then the total benefits paid are $1,080,000.

ONE MILLION EIGHTY THOUSAND DOLLARS IN BENEFITS

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Benefit Payout

What is at Stake?

ONE MILLION FIVE HUNDRED SIXTY THOUSAND DOLLARS

$1,560,000

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Parents Retirement

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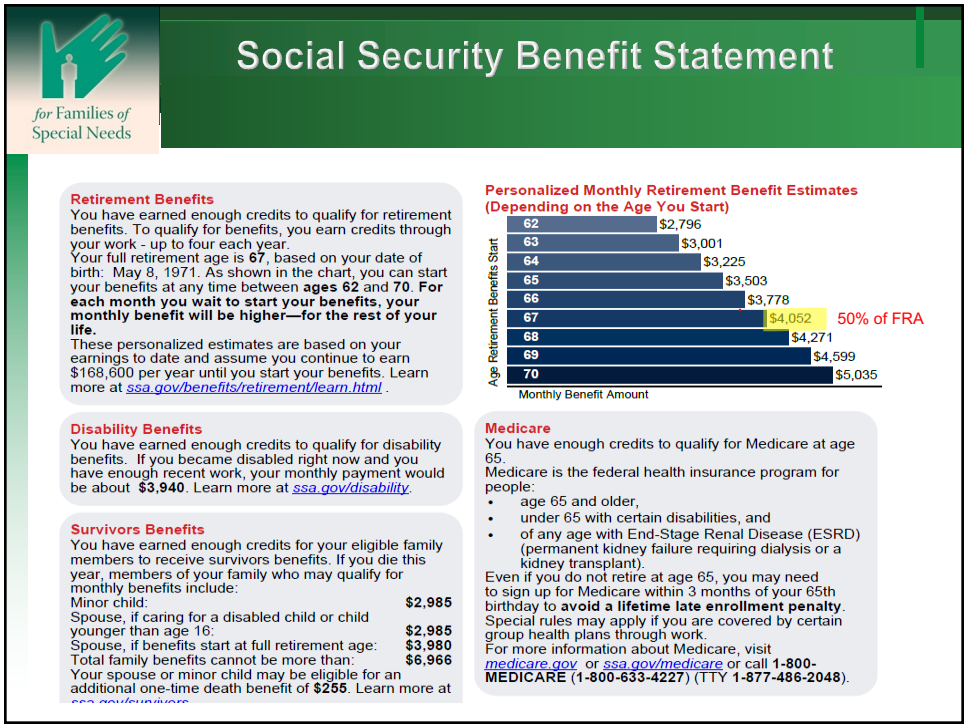

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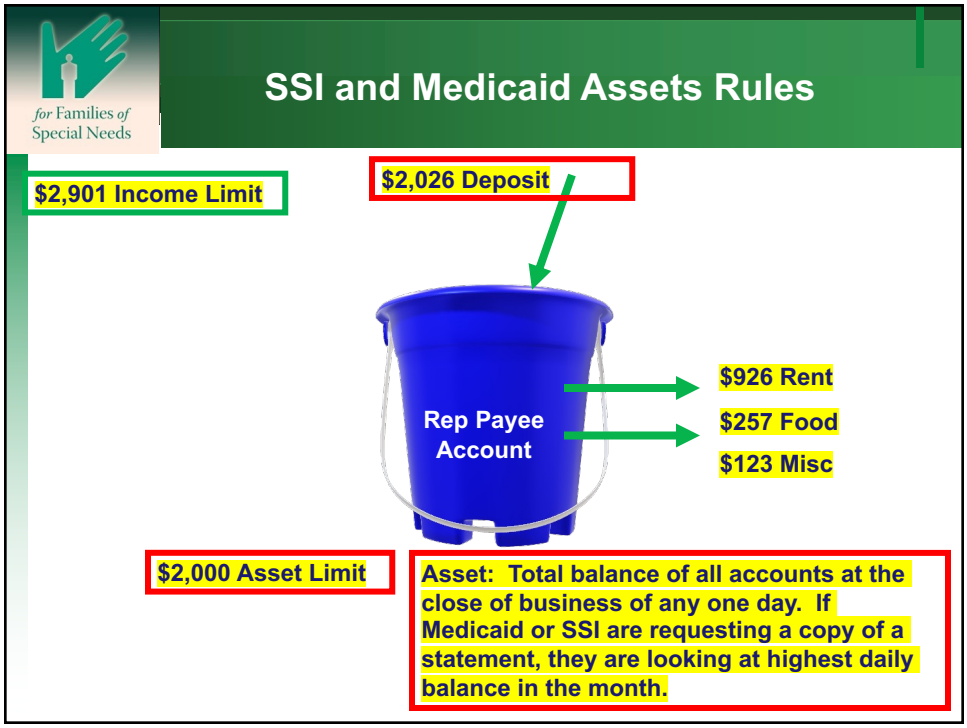

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Special Needs Income Trust

A Self Funded or 1st Party Special Needs Trust

Is a Special Needs Trust designed to allows the Disabled Adult Child (DAC) to make deposits into the trust to protect excess assets from being counted against eligibility for government benefits, MEDICAID. Think "Savings Account"

An Able Account may also support this effort.

We have a "White Paper" on 1st Party Self Funded Trust vs Able Accounts

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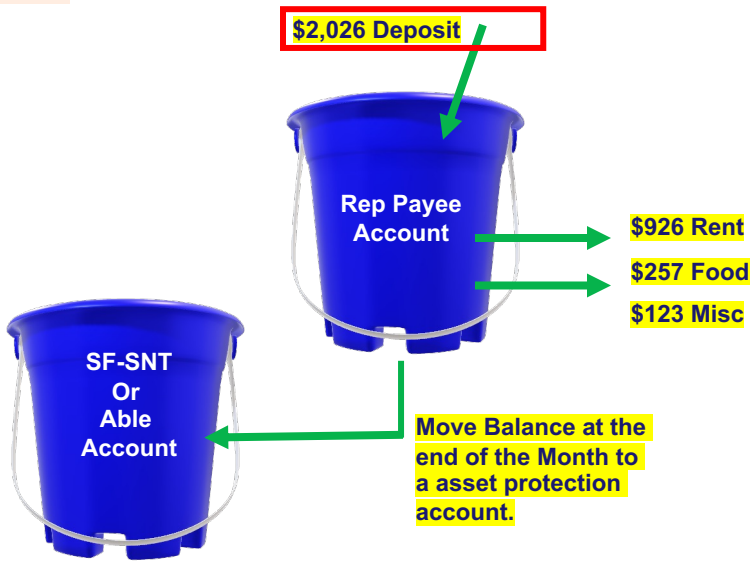
SSI and Medicaid Assets Rules



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Parents Passing

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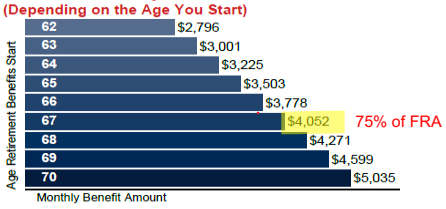
Social Security Benefit Statement

Retirement Benefits
You have earned enough credits to qualify for retirement benefits. To qualify for benefits, you earn credits through your work - up to four each year.
Your full retirement age is **67**, based on your date of birth: May 8, 1971. As shown in the chart, you can start your benefits at any time between **ages 62** and **70**. **For each month you wait to start your benefits, your monthly benefit will be higher—for the rest of your life.**
These personalized estimates are based on your earnings to date and assume you continue to earn $168,600 per year until you start your benefits. Learn more at *ssa.gov/benefits/retirement/learn.html* .

Personalized Monthly Retirement Benefit Estimates (Depending on the Age You Start)



Disability Benefits
You have earned enough credits to qualify for disability benefits. If you became disabled right now and you have enough recent work, your monthly payment would be about **$3,940**. Learn more at *ssa.gov/disability*.

Survivors Benefits
You have earned enough credits for your eligible family members to receive survivors benefits. If you die this year, members of your family who may qualify for monthly benefits include:

Minor child:	**$2,985**
Spouse, if caring for a disabled child or child younger than age 16:	**$2,985**
Spouse, if benefits start at full retirement age:	**$3,980**
Total family benefits cannot be more than:	**$6,966**

Your spouse or minor child may be eligible for an additional one-time death benefit of **$255**. Learn more at *ssa.gov/survivors*

Medicare
You have enough credits to qualify for Medicare at age 65.
Medicare is the federal health insurance program for people:
- age 65 and older,
- under 65 with certain disabilities, and
- of any age with End-Stage Renal Disease (ESRD) (permanent kidney failure requiring dialysis or a kidney transplant).

Even if you do not retire at age 65, you may need to sign up for Medicare within 3 months of your 65th birthday to **avoid a lifetime late enrollment penalty**.
Special rules may apply if you are covered by certain group health plans through work.
For more information about Medicare, visit *medicare.gov* or *ssa.gov/medicare* or call **1-800-MEDICARE** (**1-800-633-4227**) (TTY **1-877-486-2048**).

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Medicaid Assets and Income

$2,901 Income Limit

$2,985 Deposit

At the passing of the parent, the child will receive $2,985 per month as Survivor Benefit, exceeding the Medicaid Monthly Income Limit.

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Special Needs Income Trust

A Special Needs Protection Income Trust

Is a Special Needs Trust designed to manage and provide for the needs of the DAC, while protecting the income from being counted against eligibility for government benefits, MEDICAID

There are many types of Special Needs Protection Income Trust

Social Security Survivor Income Trust
Military Pension Income Trust
Federal Employee's Retirement Income Trust (FERS Trust)
Railroad Retirement Income Trust (RRR Trust)
Teacher Retirement System Income Trust (TRS Trust)
Texas Retirement Employee Retirement Trust

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Medicaid Assets and Income

$2,901 Income Limit

$2,985 Deposit

A Special Needs Protection Income Trust, must be created by the parent or grandparent prior to the passing the in parent who's benefit is attached.

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Special Needs Income Trust

A Special Needs Protection Income Trust

Is a Special Needs Trust designed to manage and provide for the needs of the DAC, while protecting the income from being counted against eligibility for government benefits, MEDICAID

KEY POINTS

The need for an income trust must be identified prior to the passing of the parent, as they can only be created by

Grandparents
Parents
Court Ordered (bad timing as benefits may be lost)

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Changing Reimbursement Environment

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Unintended Consequences

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2024 SSI Rule Changes

SSI pays $967 per month

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2024 SSI Rule Changes

SSI = A disability payment intended to pay for Rent and Food and other items:

Rent	$322.33
Food	$322.33
Other	$322.33
Total	$967.00

REALLY!

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HCS Residential Transition

All Residential

- **Under financial stress and not stable.**
- The financial model at the provider level has change.
  - In 2019 the average cost of an HCS Residential home was $150,000 to $200,000.
  - In 2019, the finance rates were 2.50% to 3.50%
  - Food was affordable.
  - Providers could work with in the cost models of SSI
- Today
  - The average cost for a HCS residential home is $400,000
  - Finance rates are 6.00% to 9.00% or higher
  - Food is up 47%

Can't provide residential within the SSI benefit range

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HCS Residential

- ALL Residential
  - **Under financial stress and not stable.**
  - The financial model at the provider level has changed.
    - Attendant care reimbursement (2019) was $9.90 per hr. and minimum wage was $7.25 per hr.
    - State of Texas Legislature of 2025
      - Texas House budget proposed $17.50 per hr.
      - Texas Senate budget proposed $12.00 per hr.
      - Settled at $13.00 per hr. + benefits
    - Where do you find help at $13 per hr. in a $17+ labor market.

Can't pay market pricing for quality labor force.

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Medicaid Changes

Unintended Consequence or Not, Expect 1 of 4 things to occur

A. EXPECT HCS Residential and Companion providers to start to bill the parents for food costs, maintenance costs, entertainment costs and misc. costs in excess of the SSI benefit.

B. EXPECT HCS Residential and Companion provider to leave the industry. Many Local Authorities (LA) have already left.

C. EXPECT HCS Residential and Companion provider to start 501c3 Charitable Foundations to obtain charitable Gifts

D. EXPECT HCS Residential and Companion provider to request the guardians or representative payee's to obtain SNAP benefits.

Maybe a combo of all 4 to some degree

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Changing Regulations

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SSI Rule Change Summary

SSI Rule Change:

No Longer does SSI Require the Disability check to pay for Food and Maintenance when claiming disability.

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SSI Changes effective 9/30/2025

In reality, it's the Inflationary effect.

Simply put, Rent averages $800 - $900 or more per month.

The Average Texas Apartment is over $1,200 - $1,500 for a one bedroom.

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Medicaid Changes

Changes to HCS provider language

OLD: The provider's monthly charges cannot exceed the actual costs of the provider AND the charges could not exceed the available resources (benefits) of the ward.

NEW: The provider's monthly charges cannot exceed the actual costs of the provider.

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Medicaid Changes

Unintended Consequence or Not, It's no longer a FREE MEAL

Therefore, HCS Residential and Companion providers can now bill the parents for food and maintenance costs in excess of the SSI benefit.

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Medicaid Changes

WHY?

- **Medicaid was a program for All, Not a program for wealthy.**
  - **Medicaid Residential will pay for Rent, Care and Wellbeing, Day Programming, Therapies.**
  - **Parents must pay for Supplemental Needs – Food, Maintenance, Entertainment, Electronics, Misc, etc.**
    - **Home Maintenance (lawn care or repair maintenance)**
    - **Alarm and other monitoring systems**
    - **Preferred Personal Items**
    - **Furniture, TV or Appliance rental**
    - **Phone, Internet and/or Cable**
    - **Netflix, HBO, Prime, Max, Hula, Peacock….**
    - **Entertainment – Eating Out, Movies, Putt-Putt, Sporting or Leisure Activities, Gym Memberships**

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Financial Impact to the Family

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SSI Changes effective 9/30/2025

Reality,

Most SSI benefit recipients will need to use the majority of their maximum SSI benefit of $967 towards rent, leaving an unsustainable amount for food, maintenance and misc. item if the home was acquired in the past 2 year at inflated prices.

Benefit recipients may need support from their parents, family or third parties on a monthly basis for food & misc. support.

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Supplemental Security Income
In-Kind Support and Maintenance(ISM) Rules

Parents Responsibilities

What items that ARE considered In-Kind Support and Maintenance and are not therefore deductible from an SSI benefit.

FOOD
STREAMING – NETFLIX
ENTERTAINMENT
Maintenance Personnel
Carpet Cleaning
Security System
Pest Control
Lawn Care
Pre-Paid Burial / Funeral Arrangements
Tuition or Books
Tutoring
Travel or Entertainment
Taxes
Legal Fees or Trust Fees
Loans
INTERNET / WIFI
FIRE ALARMS or SYSTEMS
OUTINGS
Phone or Cell Phone
Linen or Bedding
Cable or Internet Services
Household Furnishing
Furniture
Television
Computers or Electronics
Medical Equipment
Care Management
Therapies outside the system
Guardianship Fees
Home Maintenance or Additions

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SSI Changes effective 9/30/2025

Benefit recipients may need support from their parents, family, third party support to Special Needs Trust or SNAP benefits TO PROVIDE FOOD GOING FORWARD.

Provider gave a choice, pay for Food Costs or Apply for SNAP

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SSI Changes effective 9/30/2025

SNAP Benefits

- **The Supplemental Nutrition Assistance Program (SNAP) helps people buy the food they need for good health.**
- **SNAP food benefits are put on a Lone Star Card and can be used just like a credit card at any store that accepts SNAP.**
- **Individuals receiving SSI benefits and those receiving less than $2005 are eligible for SNAP benefits to assist with their food expenses.**
- **The current SNAP benefit average is $220 for an individual.**
- **Apply at www.yourtexasbenefits.com**

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Medicaid Changes

Unintended Consequence or Not

ALL Special Needs Trust modeling done prior to these changes are no longer valid assumptions.

All Special Needs Trust modeling need to be reviewed.

Don't assume you have the appropriate amount dedicated to your Special Needs Trust

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Medicaid Changes

Change Your Mind Set

You are asking for change of the reimbursement rate.

Show them how to pay for the programs you need.

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Conclusion

- Understand the impact of Work Rules?
- Set up Income Trust for Survivor Benefits
- Check Residential Family Estate Plans.
- Stay Connected to the Parents

SESSION SURVEY

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