

# Managing Excess Income and Assets with Receipt of Needs-Based Government Benefits

Presented to:   
***The Arc***  
*Illinois*

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SPAIN, SPAIN & VARNET P.C. *has joined*

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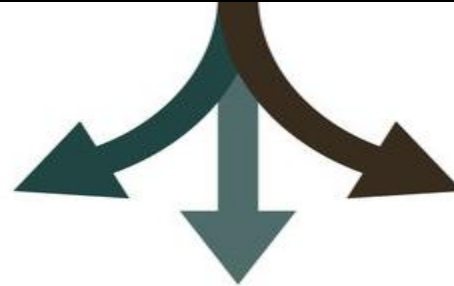
1.

# Government Benefits Overview

# Knowing Beneficiary's Public Benefits

## Government Benefits

Medicaid



Medicare



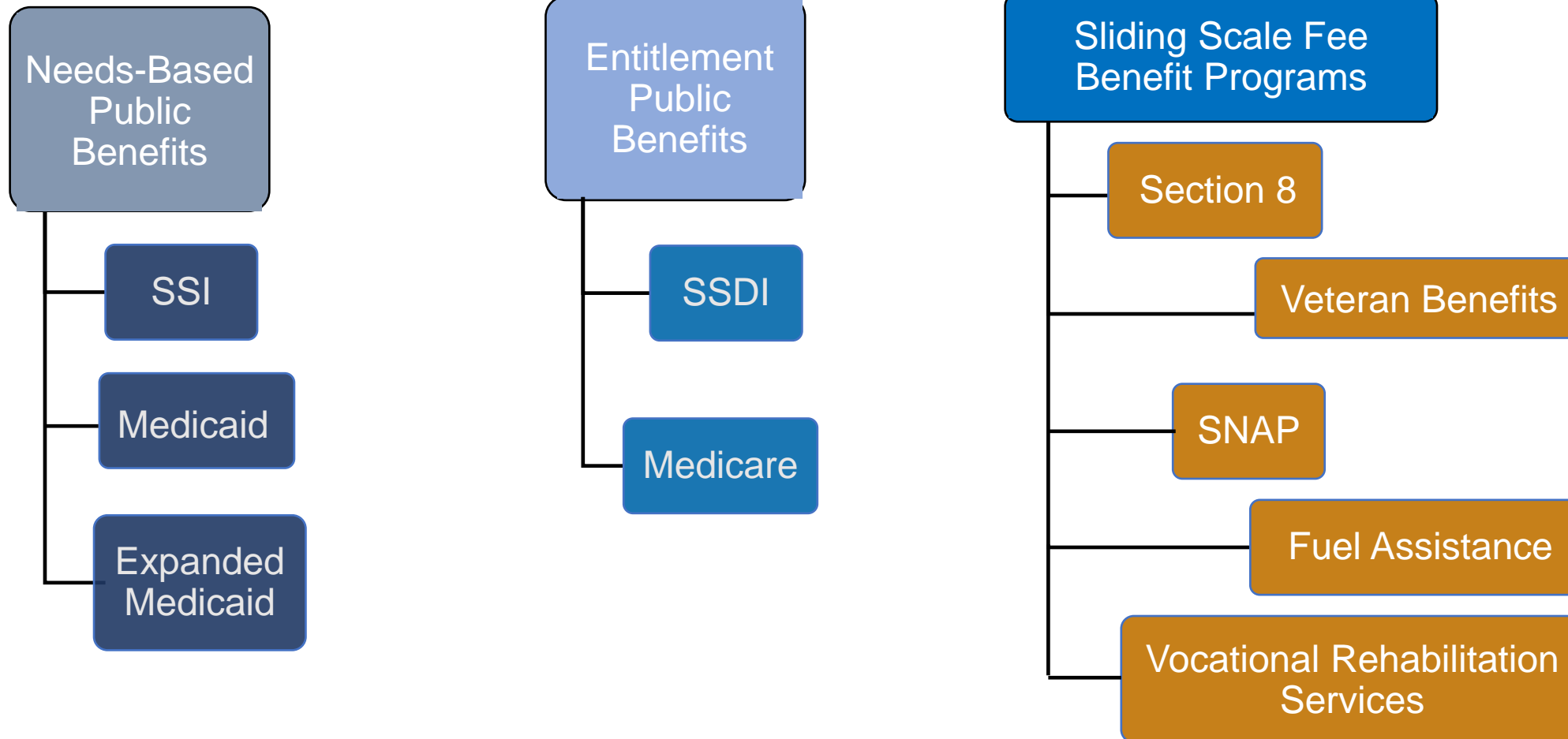
# Navigating Government Benefits

- Needs-Based Benefits
- Entitlement Benefits
- Sliding Scale Fee Benefits





# Types of Public Benefit Programs





# Eligibility Criteria Under Current Laws



- Social Security “Disability”
  - Same for SSI, SSDI, Medicaid
  - Inability to engage in substantial gainful activity and earn \$1,620/month (non-blind) \$2,700 (blind) (known as SGA)



# Supplemental Security Income (SSI)- Federal Benefit

- Needs-Based
- U.S. Resident
- Countable vs. Non-Countable Assets
- Less than \$2,000 in non-exempt assets
- \$967 Monthly in 2025
  - With 1/3 reduction for in-kind support: \$644.66

# Exempt Assets for SSI

- Less than \$2,000 in cash or equivalent
- A house or condo that individual resides in
- One car of reasonable value if used for transportation of SSI recipient or member of household
- Life insurance with a face value of up to \$1,500
- Medicaid eligible irrevocable prepaid funeral/burial plan
- Equipment needed for work
- ABLE account up to \$100,000



# Types of Income for SSI Rules

Unearned Income	Earned Income	In-Kind Support & Maintenance
<p>Gifts, annuities &amp; pensions, alimony &amp; support, dividends, interest, rents, awards and payment from other benefit programs</p>	<p>Consists of wages, royalties, net earnings from self-employment, and any honoraria received for services rendered</p>	<p>Actual receipt of shelter expenses</p>
<p>Reduces benefits dollar for dollar after the first \$20</p>	<p>Reduces benefit \$1 for every \$2 after the \$20 disregard, first \$65 earned monthly and IRWE</p>	<p>Reduces SSI dollar for dollar up to a max. of 1/3rd of full SSI</p>



# Important Change

- Food was eliminated in calculation of In-Kind Support and Maintenance (ISM)
- Intended to make SSI determination more streamlined
- **Elimination of food in calculation took effect on 9/30/24**
- Shelter expenses need to be paid to eliminate ISM (*i.e.*, rent, mortgage payments, real property taxes, heating fuel, gas, electricity, water, sewerage, and garbage collection services)= \$342.33 in 2025

# SSDI- Federal Benefit

- Social Security Disability Income (SSDI)
- Benefit based on contributions paid to SSA
- NOT needs based



# Eligibility Criteria



## Childhood Disability Benefits (CDB)\*

- Eligibility:

- Person with a disability,
- Onset prior to age 22 and
- Parent covered by Social Security who has died, retired, or become disabled
- To convert from SSI to SSDI, call SSA to apply (currently cannot apply online)
- Per law, a switch from SSI to CDB does not cause ineligibility for Medicaid or a spenddown for Medicaid

- NOT need-based

\*Also known as Disabled Adult Child (DAC) Benefits

# SSDI or CDB

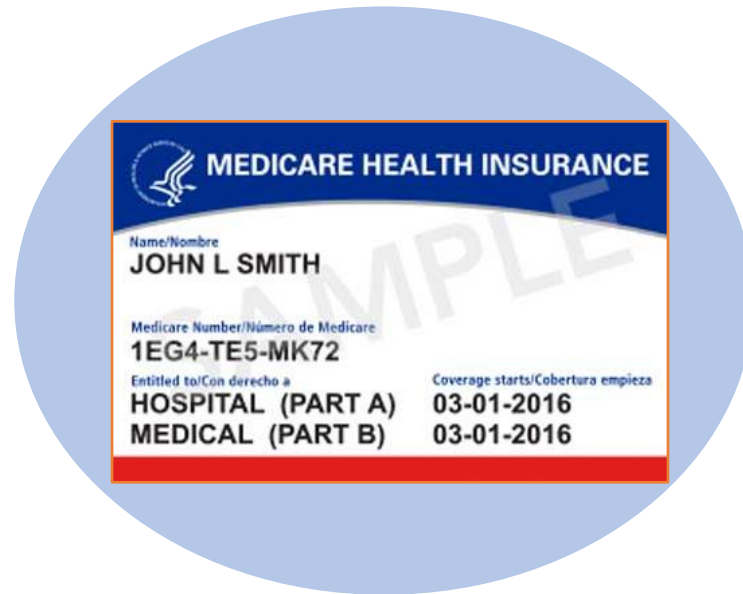
## Monthly cash benefit

- Amount based on the amount of contribution by individual (for his own SSDI) or by parent if the child is on CDB
- $\frac{1}{2}$  of the amount of the parent's benefit if parent is retired or disabled
- $\frac{3}{4}$  of the amount the parent's benefit if parent is deceased.



# Medicare with SSDI and CDB

- Medicare premiums for “Dual Eligibles” (individuals eligible for both Medicare and Medicaid) may be paid by Medicaid
- Medicaid may also pay for Medicare co-pays and reduce prescription costs.



# SSDI and CDB

- Individual on SSDI or CDB is entitled to Medicare after 2 years
- Medicare eligibility does not have asset limits
- Medicare premiums (if due) are deducted from SSDI or CDB
- MEDICARE DOES NOT PAY FOR CILA OR RESIDENTIAL CARE

MEDICARE DOES NOT PAY FOR CILA OR RESIDENTIAL CARE –  
MEDICAID DOES

# Aid to Aged Blind and Disabled (AABD) Medicaid-Combination of Federal and State Benefits



- Disability standard (incapable of performing SGA)
- Asset limits now different in Illinois for SSI and for AABD Medicaid:
  - \$17,500 for medical benefits
  - \$2,000 for AABD cash

## Medicaid Benefits

- Medical Assistance
  - Doctors
  - Hospitals
  - In-home care
  - Respite care
  - Residential costs at CILA
  - Group home
  - Nursing home
  - Prescriptions

# Medicaid Benefits

## Medicaid



- Pays for residential and day programs after aging out of high school
- Waiver program pays for in-home caregiver (often a family member)
- Coordinates with Medicare to pay Medicare premiums and copays



# Options for Excess Funds

- Spend Down
- ABLE Account
- Supplemental Needs Trust



# Spend Down

- Spend down excess assets on valid goods and services – don't give them away for less than fair market value, lookback is 36 months for SSI and 60 months for Medicaid long term care
- Examples:
  - Pre-paid funeral and burial plan which includes burial plot, casket, headstone, liner, services to open and close grave, urn
  - Glasses, dentures, clothing, shoes
  - Cell phone, computer, tablet, adaptive equipment
  - Vacation
  - Furniture and furnishings
  - Personal grooming needs and services

2.

# ABLE Act

# Achieving a Better Life Experience (ABLE) Act of 2014

- Disability prior to 26 currently; prior to 46 beginning 2026
- One account per person
- Annual Contribution Limit: \$19,000\*(2025)
- SSI eligibility temporarily suspended at \$100k until ABLE account depletes to under \$100k- don't have to reapply
- Medicaid eligibility at 529 limit (\$500k IL)
- *\*Additional earned income contributions allowed through ABLE to Work Act, but this is set to expire in 2025; max \$15,060 in 2025*





# Eligible Individual

## **Under 18 years of age**

- Establish disability under SSA definition or Act criteria

## **Over 18 years of age**

- Establish disability under SSA definition before 26 years old\*

One ABLE Act account with maximum of \$19,000 gifted per year

*\*This increases to age 46 on 1/1/2026*

# Contributions to ABLE Account

## Any “Person” can contribute

- “Person” includes trust or corporation
- Contributions must be “cash” or “in-kind”

## Beneficiary’s own income is countable for SSI

- But can be contributed to ABLE Account
- *Important:* Child support will be deemed unearned income even if assigned to ABLE Account (\*unearned income reduces SSI) by Court Order



# Eligible Expenses Are Called “Qualified Disability Expenses” or QDEs

- Basic Living Expenses
- Education
- Housing
- Transportation
- Employment Training & Support
- Assistive Technology & Related Services
- Personal Support Services
- Health
- Prevention & Wellness
- Financial Management & Administrative Services
- Legal Fees
- Expenses for ABLE Account Oversight & Monitoring
- Funeral/Burial Expenses



# ABLE Account Mechanics

- Contribution Rules
  - Cash **OR** in-kind rollover
- Annual Contribution
  - Limit of \$19k
  - ABLE to Work Act- A beneficiary who works and does NOT participate in an employer sponsored retirement may contribute up to an additional \$15,060 from their earnings into their ABLE account\*
- Tax deduction for Illinois ABLE
  - For contribution (gift)
- Not a resource for SNAP benefits eligibility
- Growth is tax free
- Unpermitted distribution
- Income taxable and 10% penalty if unpermitted distribution

*\*ABLE to Work Act is set to expire in 2025*



# Medicaid Payback

- Costs of medical assistance since start of ABLE Account
- 15 ILCS 505/16.6 implies that Illinois may not seek payback reimbursements from ABLE Accounts
  - *But* Federal law and the National ABLE Alliance Plan Disclosure Statement reminds us that state Medicaid agencies must seek recovery from those who received Medicaid at the age of 55 or older and who received coverage for certain Long-Term Services and Supports (LTSS) and were subject to post eligibility treatment of income (PETI) rules which include Medicaid waiver enrollees.





# Distributions for Basic Living Expenses



- Housing is a Qualified Disability Expense (QDE) = **NOT** “ISM,” so NO 1/3 Loss of SSI
- Income from Account **NOT** treated as Income
  - Does not reduce SSI

# Tax Cuts & Jobs Act 2017

- Allows rollover of 529 Plan up to \$19,000
  - Rollover plus any other contribution cannot exceed \$19,000 in one year\*
- Beneficiary can add the lesser of earned income or federal poverty line for family of 1 = \$15,060 (2025)\*
  - This is in addition to the \$19,000, **IF** not contributing to an employer retirement plan



*\*Sunsets in 2025*

# ABLE – Countable Assets for SSI Purposes

- ABLE distributions to the beneficiary which are qualified QDEs are not counted as income for SSI purposes
- Try to pay landlord directly. Distribution to the beneficiary on the last of the month to use for rent as of the first of the next month will count as an asset even if used to pay rent on the first day of the next month so if a distribution to the ABLE account owner is necessary, pay out immediately in the same month

# Planning Strategies

- Can help eliminate unnecessary expenses (trust administration, tax return for the trust)
- Permits transfers from UTMA and 529 plans
- Can be used to address issue of staying below \$2,000 in representative payee account
- Strategies for housing-related expenses and avoidance of 1/3<sup>rd</sup> reduction rule for ISM



# ABLE Accounts and SSI 1/3 Reduction

- Do payments from an ABLE Account for shelter cause an ISM reduction for SSI recipients?
  - No, housing is a qualified disability expense
- The Social Security Administration has directed that distributions from an ABLE Account do not count as income regardless of whether the distributions are for non-housing QDEs, housing QDEs, or non-qualified expenses.
  - If not QDE, IRS says: taxable income plus 10% penalty, but in reality, interest earned on the item purchased must be added as income to the individual's federal tax return in the year that the non-QDE occurred, and for many people, the penalty is next to zero.



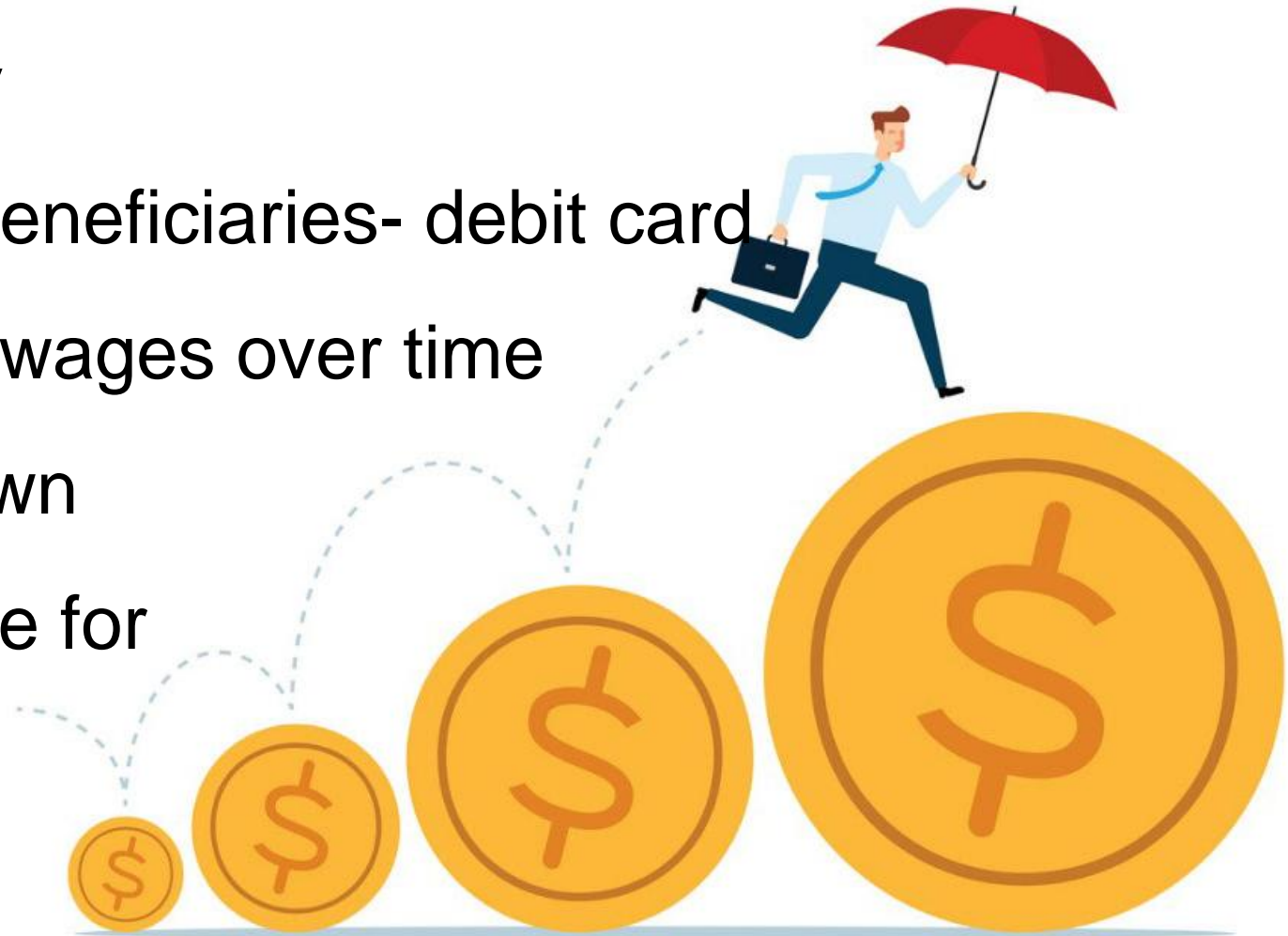


# Information for Enrollment in an Illinois ABLER Account

1. Illinois ABLER sign-up: IL ABLER Accounts for Individuals with Disabilities | IL ABLER ([illinoisable.com](http://illinoisable.com))
2. ABLER National Resource Center: <http://www.ablenrc.org>
3. National ABLER Alliance:  
<https://savewithable.com/il/home.html>

# Potential Uses of an ABLE Account

- Small amount of money
- Control for competent beneficiaries- debit card
- Allows accumulation of wages over time
- Alternative to spend down
- Avoids 1/3 reduction rule for housing expenses



# Practical Concerns of ABLE Accounts

- Payback requirement\*
- Only one account
- Potential for overfunding
- Should not be used for receipt of child support payments
- Reportable to FAFSA
- Payments for qualified expenses
- Authorized Representative Allows Protection from:
  - Fraud
  - Undue Influence
  - Exploitation

*\* For some Medicaid services in Illinois*



# Who can be an ABLE account Authorized Representative:

- 1. Authorized Agent under Power of Attorney (person or entity)
- 2. Legal Guardian (person or entity)
- 3. Spouse
- 4. Parent
- 5. Sibling
- 6. Grandparent
- 7. Representative payee appointed by the Social Security Administration (person or entity)

# ABLE accounts and SNTs

- An ABLE account can be funded from the assets of a first party or third-party trust. We have added a provision in our supplemental needs trusts specifically authorizing the trustee to make transfers to an ABLE.
  - Originally, there was a question whether an ABLE account could be funded if there is a guardian of the person but not of the estate. The Illinois probate act added authority for the guardian of the person to open an ABLE account. 755 ILCS 5/11a-17 (a-3)







# 3.

## Supplemental Needs Trust

“SNT” for Short / Third Party / First Party / Pooled Trust



## Special or Supplemental Needs Trusts

All three types are intended to preserve “government benefits” which provide financial support, services or medical assistance



# Supplemental Needs Trust (SNT)

\*also called Special Needs Trust



- Can be part of the Will
- Standalone SNT
- Can be established and managed by a person or non-profit corporation
- Can be funded now or later



# First Party SNT; OBRA '93 Payback Trust

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Created and/or funded by a disabled beneficiary which requires payback to the state for Medicaid monies

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For unexpected assets stemming from an inheritance, lawsuit, retroactive SSA payment, earned income

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Can be private with family member as Trustee or professional corporation

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Can be a pooled income trust managed by a not-for-profit organization



# First Party Trusts 42 USC 1396p(d)(4)(A) Omnibus Reconciliation Act of 1993 or “OBRA 93 Trust”

- Irrevocable
- Beneficiary meets federal definition of disability
- Created by a parent, grandparent, guardian, by the beneficiary or by the court
- Assets held for the **sole (primary) benefit** of the beneficiary
- Beneficiary is under 65 years old when created and funded
- Payback provisions – upon death of the beneficiary, reimbursement to State Medicaid agency for benefits provided to the beneficiary



# Pooled Income Trust 42 USC 1396p(d)(4)(C) or Pooled OBRA '93 Trust



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Managed by a non-profit corporation

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Funds are pooled in a single investment fund

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Sub-accounts held for the benefit of individual beneficiary

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Some pooled income trusts have both 3<sup>rd</sup> party and 1<sup>st</sup> party trusts

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Upon death of beneficiary, sometimes a portion of trust assets retained by non-profit

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For 1<sup>st</sup> party trusts, Medicaid pay-back upon the death of the beneficiary



# Payback and Termination of OBRA '93 Trust

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NO Distributions After Death Without Consulting Attorney

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REMINDER – NO Funeral Bills Paid After Death

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Medicaid monies must be paid back, and DHS Will Seek Reimbursement

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Request Medicaid Payback Statement

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Fees for Guardian of the person cannot be paid after death (keep current)

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# Payback and Termination of OBRA '93 Trust - *continued*

- Trustee **MUST** be able to Account for Expenditures Made during the life of the trust
- Fees for Trustee and Attorneys for “wrapping up” are ok
- If Funds Exist, Medicaid and DHS Will Seek Full Reimbursement



# Third Party SNT

Created and funded by third parties, often parents

- **CANNOT** be funded by disabled beneficiary

Created in advance

For families – parents, grandparents, siblings, aunts, uncles

Can be private and managed by family member or professional trustee

Can be a pooled trust and managed by a not-for-profit organization

# Third Party SNT - *continued*

Discretionary power  
vested in Trustee

Grantor's intention is  
to *supplement*  
available government  
benefits, not support  
beneficiary

Revocable if left  
unfunded

Irrevocable upon the  
death of parent(s) or  
upon funding

No payback provision  
– remainder  
beneficiaries

Successor Trustees



# Typical Benefits Paid by Supplemental Needs Trust



Medicaid, dental, and diagnostic work for which there is no funding



Medical procedures deemed desirable by the trustee but not deemed “medically necessary”



Differentials in cost between housing in a shared and private room



Travel and transportation expenses

# Typical Benefits Paid by Supplemental Needs Trust - *continued*



Companionship, entertainment, cultural and educational experience



Case manager, service providers, and advocacy services



Birthday, holiday and special event gifts from third-party trusts



Exercise, health club, and physical therapy



Vacation related expenses



# Medicaid Payback for Various Financial Vehicles

Estate	ABLE Account	3 <sup>rd</sup> Party SNT	D4A Trust
Medicaid used for medical purposes after age 55 or in a long term care facility	The amount of any such Medicaid payback is calculated based on amounts paid by Medicaid after the creation of the ABLE Account*  <i>*Payback may be required for certain Medicaid services for ABLE in IL</i>	No Lien	All Medicaid paid during lifetime

# True Link Card- use with special needs trusts

## Different from:

- Credit Cards
- Debit Cards
- Gift Cards

## SSA has approved its use

- POMS: SI 01120.201.I.1.e

Administrator-managed prepaid cards



# True Link Card

- Parent/Trustee can be “Card Administrator”
- Receive alerts
- Receive monthly statements

The screenshot displays a web application interface. At the top, there is a 'Clients' table with columns for Name, Status, Statement, and Latest Transfer. Below the table, a modal window titled 'Alex Smith's Card' is open, showing details for a specific card and three action buttons: 'Freeze card', 'Replace card', and 'Permanently close'.

Name	Status	Statement	Latest Transfer
Alex S.	\$50.00		\$150 on May 1 >
Ben J.	\$0.98		
Carrie D.	Activate		
Jane M.	\$1280.52		
James L.	\$103.77		

Alex Smith's Card		
Status	Balance	Ends in
Active	\$50.00	...5555

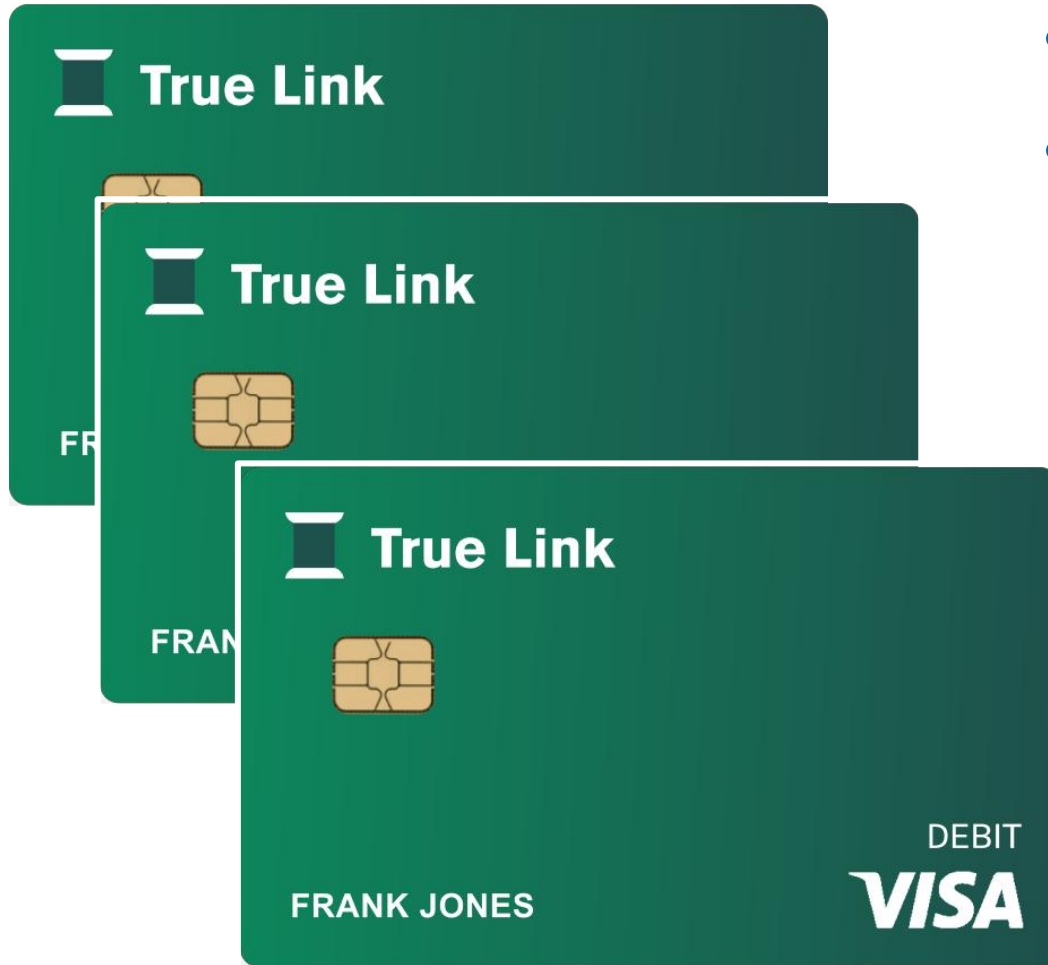
[Freeze card](#)

[Replace card](#)

[Permanently close](#)



# True Link Card



- Reloadable VISA card
- Customizable:
  - Block/limit-cash
  - Specific Vendors
  - Non-transferrable

Questions? Comments? Concerns?



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