



# Planning for Loved Ones with Disabilities

## Protecting Benefits & Securing Their Future

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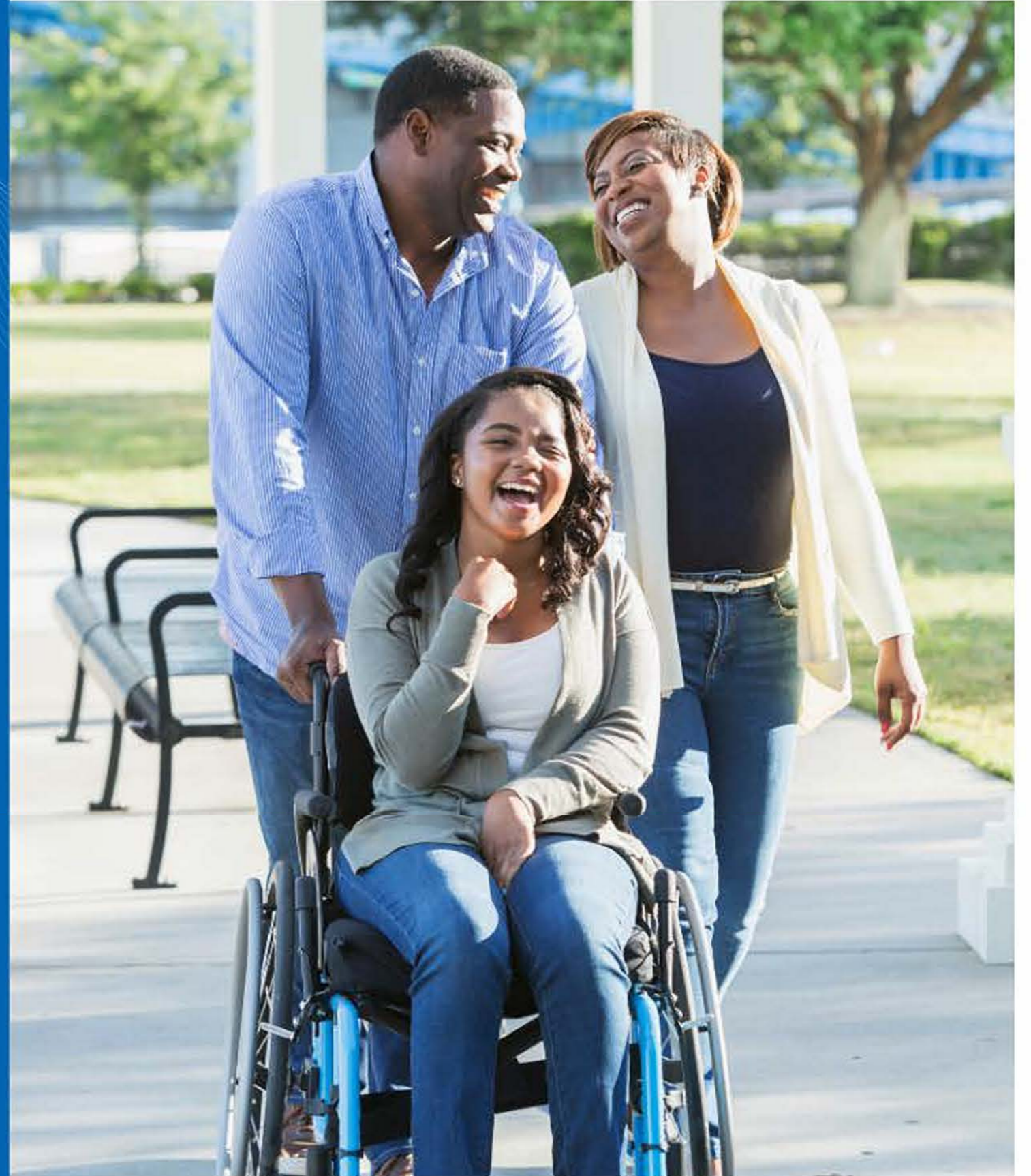
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Presented by:

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# About Jonathan Gudema, Esq.

- Jonathan Gudema is an estate and elder planning attorney with more than 30 years of experience helping individuals and families plan for the future with clarity, confidence, and compassion.
- Jonathan serves as **Legacy Giving Advisor to Kessler Foundation**, where he works with individuals and families to incorporate charitable giving into their estate and retirement plans in meaningful and tax-efficient ways. He also advises nonprofit organizations on planned giving strategy, legacy program development, as well as estate planning for individuals.

# Agenda

- Landscape of benefits/challenges for disability planning
- Planning Techniques
- QIT Miller Trusts
- ABLE accounts
- Special Needs trust
- General spend-down issues

# Snapshot: Income & Asset Rules (2026)

| Program         | Asset Limit                      | Income Limit                      | Key Point                 |
|-----------------|----------------------------------|-----------------------------------|---------------------------|
| <b>SSI</b>      | \$2,000 (ind.)                   | ~\$994/mo<br>base (phases<br>out) | Strict needs-<br>based    |
| <b>Medicaid</b> | ~\$2,000<br>(varies by<br>state) | Varies by<br>state/program        | Covers care &<br>services |
| <b>SSDI</b>     | ✘ No asset<br>limit              | ~\$1,550/mo<br>(SGA, approx.)     | Work-based<br>benefit     |

# Why Planning Matters

| Issue             | Result                    |
|-------------------|---------------------------|
| Too many assets   | Loss of SSI / Medicaid    |
| Too much income   | Reduced or lost benefits  |
| Improper spending | Disruption of eligibility |

# Planning Techniques

## **Income (Monthly Cash Flow Problem)**

**Challenge:** Income too high for Medicaid (in some states)

### **Solutions:**

- Income Cap States → **Miller Trust (QIT)**
- Spend-Down States (NY/NJ) → **Pooled SNT**

**Goal: Redirect income without losing eligibility**

# Planning Techniques

## **Assets (Inheritance / Savings Problem)**

**Challenge:** Assets disqualify benefits

### **Solutions:**

- Family assets → **Third-Party SNT**
- Individual's assets → **First-Party or Pooled SNT**

**Goal: Protect assets while maintaining benefits**

# Planning Techniques

## **Flexibility (Daily Living & Independence)**

**Challenge:** Need accessible funds for everyday life

**Solution:**

- **ABLE Account**

**Goal:** Allow flexible, independent spending

# How People Qualify for Medicaid (Income Cap States)

- Income limit (often ~300% of SSI, roughly \$2,800–\$3,000/month range in 2026)
- If income exceeds the cap by even \$1 you're out
- Use a **Qualified Income Trust (QIT) / Miller Trust** to qualify
- Excess income deposited into trust, funds used for approved expenses, not freely accessible, subject to Medicaid payback
- FL, TX, GA, AZ, TN, AL, MS, OK, NV, and CO

# QIT/Miller Trust

## Common Approved Expenses

### **Patient Responsibility / Cost of Care (Primary use)**

- Nursing home costs, assisted living (in some programs), home and community-based services (HCBS)

### **Personal Needs Allowance (PNA)**

- Small monthly amount typically ~\$50–\$150/month (varies by state)
- Can be used for: clothing, toiletries, personal items, small discretionary spending

# QIT/Miller Trust

## Common Approved Expenses

### **Health Insurance Premiums**

- Medicare Part B & D, Supplemental insurance (Medigap)

### **Medical Expenses Not Covered by Medicaid**

- Prescription drugs (if not covered), therapy services, dental care, vision care

# QIT/Miller Trust

## Common Approved Expenses

### Spousal Allowance (If Married)

With a **community spouse**, funds may go toward:

- Minimum Monthly Maintenance Needs Allowance (MMMNA)
- Supporting spouse living at home

### Typical MMMNA Amounts (2026 Range)

**Federal Minimum – Approx. \$2,550/month**

**Federal Maximum – Approx. \$3,850/month**

# How QIT/Miller Trusts Work

- Medicaid/disabled spouse income: \$3,500/month
- Community spouse income: \$1,500/month
- MMMNA: \$3,800

## What happens?

- Community spouse is “entitled” to: \$3,800
- Currently has: \$1,500
- Shortfall: \$2,300

That \$2,300 can be diverted to community spouse

# How QIT/Miller Trusts Work

After passing of Medicaid/disabled spouse:

- Medicaid payback is satisfied
- Any remaining funds in a QIT/Miller Trust distributed according to the terms of the trust
- Can include the estate or named beneficiaries, individuals, charitable institutions

# What is an ABLE Account?

An **ABLE account** (Achieving a Better Life Experience account) is:

- A **tax-advantaged savings account** for individuals with disabilities
- Designed to allow them to **save money without losing SSI or Medicaid**
- **Up to \$100,000 protected for SSI**
- **For Medicaid, there is generally no \$100,000 cap—the entire ABLE account is disregarded.**
- Like a 529 college plan—but for disability-related expenses

# Who qualifies for an ABLE account?

- Disability must have begun before **age 46**
- Receive SSI/SSDI **OR** meet Social Security's disability criteria

## **Social Security Disability Definition:**

- Unable to engage in substantial work
- Due to a medically determinable impairment
- Expected to last at least 12 months or result in death

# What Must Be Shown to Qualify for an Able Account?

## **Medical Documentation**

- Diagnosis (ie...autism spectrum disorder)
- Evidence from doctors, psychologists, etc.

## **Functional Limitations** - Significant limitations in areas like:

- Communication
- Social interaction
- Concentration / focus
- Adapting to changes
- Managing daily life

# More on ABLE Accounts

**Someone who didn't qualify because their disability began after age 26 may now qualify—if disability started before age 46**

## **Annual Contribution Limit:**

- **\$20,000 per year**
- Family, friends and the individual
- If the individual is working, they may contribute **more** (ABLE to Work rules – earning up to \$15k+)

# More on ABLE Accounts

## Maximum Account Size

- Based on state 529 limits
- Typically \$300,000–\$500,000+
- Medicaid generally unaffected by total balance (state of ABLE participant important)
- If SSI no longer a factor, more family assets can find their way into the ABLE account

# How are ABLE funds spent?

- ABLE funds must be used for **Qualified Disability Expenses (QDEs)**
- A QDE is any expense that:
  - Relates to the individual's disability **OR**
  - Helps maintain or improve health, independence, or quality of life
- If it helps the person live better with their disability, it likely qualifies.

# How are ABLE funds spent?

**Basic Living Expenses:** Rent, utilities, food, mortgage, property, taxes

**Transportation:** Car purchase, gas, public transit, rideshare

**Health & Wellness:** Medical care, therapy, mental health services, medications

**Assistive Technology & Support:** Wheelchairs, Devices, Home modifications, Personal aides

# How are ABLE funds spent?

**Education & Employment:** Tuition, job training, career support

**Legal & Financial:** Attorney fees, financial planning

**Recreation & Quality of Life:** Travel, hobbies, fitness, entertainment

# How are ABLE funds NOT spent?

## What Are the Limits?

- There is **no strict list of “approved” vs “not approved” expenses**
- The test is **purpose-based (why not what)**
- IRS “expects” reasonable connection to the disability

## What You **CAN'T** Do (Practically Speaking)

- ❌ Use funds for clearly unrelated purposes
- ❌ Abuse the account as a general investment vehicle
- ❌ Take distributions with no documentation or rationale

# Caution regarding ABLE accounts

## **Money used to pay a non-qualified expense?**

- Earnings portion of withdrawal treated as income, taxed at beneficiary's tax rate, and subject to a 10% federal tax penalty.
- Any state tax deductions or credits taken in previous years related to contributions may need to be recaptured.
- Check your state tax department for more information on recapture requirements.
- Strongly recommended to keep records and receipts on how money was spent.

# Finding the right ABLE account

- Should you find one in your state (like NJABLE) or would an out-of-state option like Fidelity (MA) or ABLENow (VA)?
- How are funds invested? Fees?
- Ease of use? Debit card?
- Home state may offer:
  - State income tax deduction
  - Matching contributions/other incentives

# Remainder of ABLE account?

- State has a right to recover Medicaid payments after the account was established
- States with large Medicaid systems tend to have:
- More formal recovery programs/estate recovery units (ie..NJ, NY, CA)
- This does **not mean automatic or maximum recovery in every case**
- **If funds remain after death, go either to estate or designated beneficiary on account**

# What Is a Special Needs Trust (SNT)?

A special trust that allows assets to be used for a person with a disability **without disqualifying them from SSI or Medicaid**

Without an SNT:

- Inheritance → **X** Loss of SSI
- Loss of SSI → **X** Loss of Medicaid
- Result → Forced spend-down + disruption of care

With an SNT: Assets protected, benefits preserved, quality of life enhanced

# Third-Party Special Needs Trust

Funded by **someone else's money**

- Parents
- Grandparents
- Family members

## **Key Features:**

- Not counted for SSI/Medicaid
- No Medicaid payback
- **Can pass to other beneficiaries at death**

# First-Party Special Needs Trust

Funded with the **individual's own assets**

- **Personal injury settlement**
- Inheritance received outright
- Savings in their name
- One month to get funds into SNT or risk loss of benefits
- Preserves eligibility
- **Requires Medicaid payback at death**

# First-Party Special Needs Trust

Transfers are **NOT penalized** if:

- Properly drafted and administered
- Trust meets federal requirements:
  - (d)(4)(A) or (d)(4)(C)
- Includes Medicaid payback provision
- Beneficiary under 65 (applies to pooled SNTs too)

# What Is a Pooled Special Needs Trust?

- A type of **first-party Special Needs Trust**
- Managed by a **nonprofit organization**
- Funds **pooled for investment purposes**, but tracked in **separate accounts**
- **Remaining funds after death:**
  - **First Medicaid payback**
  - **Rest usually remains with nonprofit org**
- Usually offer case manager associated with nonprofit

# Examples of SNT Resources

- **PLAN|NJ** offers Pooled SNT Trust as well as serves as trustee of 1<sup>st</sup> & 3<sup>rd</sup> Party trusts
- **NYSARC Trust Services:** Offers Community Trust I (for assets), II (for income/surplus), III (for large assets), and Third-Party Trusts
- **UJA-Federation of New York Community Trust** (often in partnership with **FEGS** provides Pooled Special Needs Trusts)

# What can an SNT pay for?

**Supplemental (Not Basic Support) - SNTs are designed to supplement—not replace benefits.**

## **Common Uses:**

- Therapies not covered, Caregivers / aides, Travel
- Education, Technology, Recreation

 **Caution:** Direct payments for food or housing could reduce SSI

The trust enhances life—it doesn't replace government support

# What SNTs can't pay for

## Restricted / Sensitive:

### **Food & Housing**

- Paying directly for rent or groceries can reduce SSI

### **Cash to Beneficiary**

- Generally avoided, counts as income

## **ABLE account can cover these items**

- Must be done carefully (QDEs only)
- Cash withdrawals must be spent within Calendar Month!

# Oversight over Trustees of SNTs?

## **Fiduciary Liability:**

- Can be sued for mismanagement, self-dealing, negligence

## **Beneficiaries & Family Oversight**

- Family members can monitor activity, raise concerns, request accountings

## **Court Oversight (If Needed)**

- Courts can remove a trustee, review actions, enforce duties

# Oversight over Trustees of SNTs?

## **Accounting Requirements**

- Trustees typically must keep records, track distributions, provide periodic reports

## **Trust Protectors/Advisors**

- Trust protector or distribution advisor
- Override or guide trustee decisions
- Replace trustee if needed

# Choosing the right SNT trustee

## **Probably the most difficult decision:**

- Family member
- Professional trustee
- Corporate trustee
- Pooled trust nonprofit

# How are SNTs Taxed?

| Type of SNT     | Tax Treatment         | Who Pays the Tax?    |
|-----------------|-----------------------|----------------------|
| Third-Party SNT | Complex trust         | Trust or beneficiary |
| First-Party SNT | Usually grantor trust | Beneficiary          |
| Pooled Trust    | Usually grantor trust | Beneficiary          |

# Forced Spend-downs

| Transfer Type          | Result                    |
|------------------------|---------------------------|
| Gift to family         | ✗ Penalized (Medicaid)    |
| Transfer to proper SNT | ✓ Allowed                 |
| Transfer to ABLE       | ✓ Allowed (within limits) |
| Allowable spending     | ✓ Allowed                 |

# Medicaid-Approved Spend-Down Expenses

## **1. Paying Off Debt**

- Credit cards, medical bills, personal loans
- Mortgages

## **2. Home Improvements (Primary Residence)**

- Roof repairs, Bathroom renovations
- Accessibility modifications (ramps, rails)
- HVAC, plumbing, electrical

# Medicaid-Approved Spend-Down Expenses

## **3. Purchasing or Replacing a Vehicle**

- One vehicle is typically **exempt**
- Can upgrade or replace

## **4. Prepaid Funeral & Burial Arrangements**

- Irrevocable burial contracts
- Funeral plans

# Medicaid-Approved Spend-Down Expenses

## 5. Medical and Care Expenses

- Private caregivers, therapy, medical equipment, dental and vision care

## 6. Personal Property & Household Items

- Furniture, appliances, clothing, electronics
- Must be **reasonable (not excessive luxury)**

# Medicaid-Approved Spend-Down Expenses

## **7. Assistive Technology & Accessibility**

- Wheelchairs, hearing aids, Home modifications, Communication devices

## **8. Legal and Professional Fees**

- Attorney fees (estate planning, Medicaid planning), Financial planning

## **9. Education, Training, and Support Services**

- Job training, skill development, support programs

# What you CAN'T do in a Spend-down

## Disqualifying Transfers (subject to 5-year look-back!)

- Gifts to family
- Selling assets below market value
- Transferring money to others “for safekeeping”

These trigger **Medicaid penalty periods**

# How Does This All Impact Us?

- All very big decisions
- On top of getting or staying qualified for assistance that is needed
- Options are good – consider multiple buckets
- Let us know what topics or questions you have!
- Feel free to set up a time to speak with me!

# Thank you for participating!

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