

Legal & Future Planning

for children & adults with special needs...

**HOW TO PRESERVE ASSETS AND
NOT LOSE SSI & MEDICAID**

BENJI RUBIN
Attorney & Sibling

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Special Needs Legal & Future Planning

Buffalo Grove • Chicago • Old Orchard
www.rubinlaw.com • email@rubinlaw.com
847-279-7999 • Toll Free 866.To.Rubin

It is

TIME

to start

**We will begin in
2 minutes...**

1st ...

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& Future Planning**

Your speaker

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WWW.RUBINLAWCORP.COM

Benji Rubin

An attorney, “little/big” brother of Mitchell, who has Autism, & a partner in Rubin Law, a firm whose practice is limited to future planning for his fellow families of individuals with special needs. Having Mitchell as a brother profoundly shaped who Benji is today, & thus the area of law he chose to practice. His personal experiences as a sibling offer a unique perspective into the responsibilities that come with caring for a sibling with special needs, a concern that he shares with all brothers & sisters of individuals with special needs.

Benji Rubin

- **Treasurer, The Arc of Illinois**
- **President, S.I.B.S., Illinois Chapter of Sibling Leadership Network (National Sibling Association)**
- **Member of the Special Needs Alliance, the national, non-profit, membership by invitation, organization of special needs planning attorneys**
- **Member of the Academy of Special Needs Planners**
- **Clearbrook Associate Board of Directors, an agency serving over 8,000 individuals with intellectual and/or developmental disabilities, including Benji's brother, Mitchell**

Benji Rubin

- **Chairman, American Bar Association Special Needs Planning Committee**
- **Faculty Member of IICLE, The Illinois Institute for Continuing Legal Education, on the topic of special needs trusts, and special needs legal & future planning**
- **Director, The SEDOL (Special Education District of Lake County) Foundation**
- **Director, DayOne Pact, Former ISC for DuPage County, Kane and Kendall Counties, also serve as Guardian and Trustee for individuals with Disabilities)**
- **Member, Encompass Advisory Council** (a joint venture of Jewish Children & Family Services, Jewish United Fund, Jewish Vocational Services Chicago, Jewish Community Centers Chicago, The Center for Enriched Living, The Center for Independent Futures, & Keshet, developing a sustainable, community integrated future for people with developmental &/or intellectual disabilities)

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**WHO ARE
YOU ?**

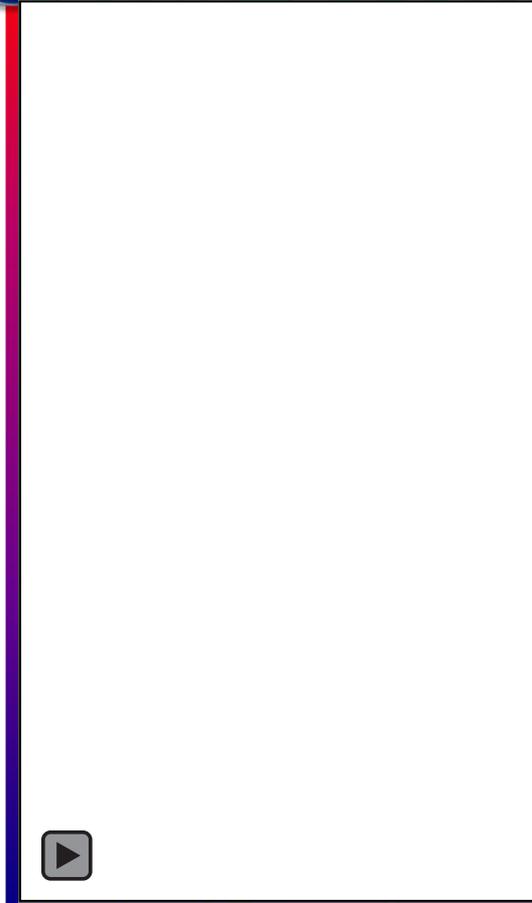
January 27, 1981



MITCH



Special Olympics



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Growing up as a “Sibling”...

- **Helps put things in perspective in life**
 - **Different than parents...**
 - **Vacations...**
 - **Trips to the Store...**
- **Understanding our future responsibilities**

Benji Rubin

President

S.I.B.S.

Supporting Illinois Brothers & Sisters
Illinois Chapter of the national **Sibling
Leadership Network**



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S.I.B.S. www.sibsnetwork.org

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Illinois Chapter of the national
Sibling Leadership Network**

Sibli
[www](http://www.siblingsupport.org)

The Siblings Support Network is a non-profit organization that provides emotional support and information to siblings of children with special needs. We provide support to siblings of children with special needs through our website, support groups, and one-on-one counseling.

Join the network today!
Visit us at www.siblingsupport.org



www.siblingleadership.org

What YOU,
or "OTHERS", do
IMPACTS

Government Benefits

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How much ?



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WHERE FROM ?

- ★ Working ?
- ★ Parent(s) ?
- ★ Siblings ?



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The
"GREAT" STATE OF
ILLINOIS
NOT!

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WORK

REQUIRES
SPECIAL
NEEDS
TRUSTS

FAMILY
INHERITANCES

GOVERNMENT



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1/3 les

- Don't
- or
- Don't
- NOT
- over S
- \$ 771

BEWARE...
SSI/SSDI
If living
"residential" then
only keep
\$60 @ month
for personal use...

BEWARE:
If turned down for Medicaid on application or lose Medicaid on redetermination, the State doesn't automatically then try one of the other "types".

- Int
- Adapt or Manage Oneself (new for 2017)
- Inability to Use Two Limbs

SSDI

Medicare

TWO YEARS

- IF DATE
- Dece
 - On S
 - Retir

Quarters – own record:
 2019 \$1,360
 Before 24 – 6 quarters

record II

JUST
Income Test



MEDICAID is a **MUST**?

Especially post school years...

- **HBSS:**
 - (18-21): 2019 2 x SSI = \$1,542 @ month
 - (22 &): 2019 3 x SSI = \$2,313 @ month
(could be almost \$28,000 income tax free...)
- **CILA \$55,000+**
- **ICFDD \$125,000+... SODC even more...**
- **Supported Employment**
- **Sheltered Employment (Workshops/"Regular Work")**
- **Day Programs ("Community Day Services")**

• **PLUS MEDICAL**

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PARENTS'



HEALTH INSURANCE!

- ↳ Dependent children NOT subject to “limiting age” provisions!
- ↳ Even if living “residentially”!
- ↳ Even if can’t claim as dependent for IRS Income Tax purposes!
- ↳ since 1969, amended 1997 & 2007.

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“the attainment of the **limiting age** does not operate to terminate the hospital and medical coverage of a person who, because of a handicapped condition that occurred before attainment of the limiting age, is **incapable of self-sustaining employment & is dependent on his or her parents, or other care providers for lifetime care & supervision.**”

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**WRONG
WAY**



**WRONG
WAY**

- **“Directly”**
- **No Will**
- **“Disinherit” & leave to others (“moral Obligation”)**
- **“Traditional Trust”**

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Special Needs Trusts

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Special Needs Trusts



3rd Party

Private & Pooled Versions



Self Settled

aka, OBRA, 1st Party, Pay Back...

Private (d4A) & Pooled (d4C)

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2 Versions, both...

- ✓ Reserve
- ✓ Supplemental Fund
- ✓ Over & Above
- Government Benefits
- ✓ No \$ limit
- ✓ Federal
- ✓ State



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3RD PARTY

TRUST

1st Version

WILLS

& GIFTS



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3RD PARTY TRUSTS

ORIGINAL - GOOD



by Court Decisions 1982



by Statute (760 ILCS 5/15.1) 1991

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3RD PARTY TRUST

INHERITANCE

GIFT

INSURANCE
IRA
401K

 Beneficiary's own assets
including child support (divorce)



SPECIAL
NEEDS
TRUST 

THEN
UPON
BENEFICIARY
PASSING...
PARENT(S)
DECIDE:

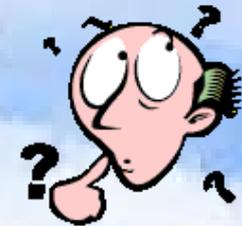
FAMILY
CHARITY
GUARDIANS

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OK... SO
INSIDE WILL
OR LIVING
TRUST ?

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**WRONG
WAY**

**WRONG
WAY**

NO! NO! NOT!

“DON’T DO IT!”

YOU WILL

OPENING

TRUST!

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**Won't
exist
until...**

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#1 So NO “Piggy Backing”

#2 NO “Grand Fathering”

#3 NO Nursing Home
Im impoverishment

#4 NO Place for gifts to go

#5 NO Need to share entire
Will/Living Trust with
SSA and HFS

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BUT I STILL DON'T GET IT ?



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Just what IS a Trust?



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**Just another way
of holding “title”
to, or “ownership”
of, assets,
investments or
accounts...**

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3rd PARTY SPECIAL NEEDS TRUST

REMEMBER

3rd PARTY

SPECIAL NEEDS
TRUST

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How to put in the Trust? From your & others' Wills & Trusts

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EXTENDED FAMILY & FRIENDS



- **Instruction letter**
- **Form Codicil**
- **Form Trust Amendment**
- **Trust Certification**
- **Consult with their Attorneys/Advisors**

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But...



Beware of

absentee



parents &

grandparents

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EX-SPOUSE

LETTER

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So...



1st *set up SNT*

2nd *reference in*

Wills/Trusts

3rd *extended family*

too

But...

But...

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Change

Beneficiaries

- ✓ **Life Insurance**
- ✓ **IRA**
- ✓ **401k**
- ✓ **Profit Sharing**
- ✓ **Etc.**

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WHAT ABOUT GIFTS ?

- ❌ NOT Directly
- ❌ NOT ABLE (stay tuned!)
- ❌ NOT UTMA



3rd Party SNT

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So far just

3rd Party

But

what if...

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BENEFICIARY



HAS ASSETS

Savings Bonds

UTMA Accounts AT 21



Large Gift

Law Suit Settlement

IRA - 401k

Excess SSI/SSDI

Inheritance

WILL/TRUST/BENEFICIARY

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If “not that much”

...consider spending it down on allowed expenditures, such as:

- ✓ COMPUTER, TV, DVD PLAYER...
- ✓ VACATION
- ✓ PRE-PAID FUNERAL
- ✓ PAY OFF DEBTS... EVEN TO PARENTS...
- ✓ CLOTHES
- ✓ BUT MUST BE FOR HIS/HER
- ✓ SOLE BENEFIT...

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If “not that much”

When to consider ABLE?

1. Excess SSI/SSDI/Earnings to avoid \$2,000 issue? But if SSD not SSI... & working, consider HBWD 1st!
2. Short term savings
3. For beneficiary to be in control of “some” spending money
4. Avoid 1/3 reduction for housing if on SSI
5. Small inheritances not correctly left to 3rd party trust
6. Small law suit settlements
7. NEW 2018 - Convert traditional 529 Account... up to \$15,000 limit...
8. NEW 2018 - Additional contribution of the lesser of earned income from employment for year & \$12,060, if no contribution by or for to an employer retirement saving plan. However, the earned income will still be counted for purposes of eligibility.

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ABLE SIDE NOTE

- **New Illinois Statute...**
- **Not as advertised...**
- **No Pay Back is being “advertised”
BUT**
 - 1. Doesn’t apply to all 9 Illinois
Medicaid Waivers including
DDD and DRS, and specifically
CILA/ICFDD, SODC, HBSS**
 - 2. Doesn’t apply to even medical
Medicaid post age 55**
- **Tax Deduction... so what**
- **Child Support... Feds say NO!**

Otherwise 1st Party Special Needs Trust

Federal Law 8/10/93
Illinois Law 1/1/96

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1st Party SNT

Called... “Self Settled”... or

- ☑ “OBRA 93 Trust”...
- ☑ “(d)(4)(A) or (C) Trust”
- ☑ “PAY BACK Trust” (like an ABLE account...
- ☑ because...

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1st Party Special Needs Trust



1st Party SNT...

“NOT” SO GOOD...

- ↳ Only if NOT 65
- ↳ Only by Parents, grandparents, Courts, guardians & self (new)... NOT others
- ↳ SSA Position...
- ↳ Courts often require...
- ↳ Pay Back to day 1...

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1ST PARTY SNTS
ARE THE VERSIONS
REQUIRED



FOR CHILD SUPPORT
NOT



3RD PARTY SNTS!
& AS OF NOW
NOT ABLE!





- ✓ **So NOT directly**
- ✓ **All to 3rd Party SNT**
- ✓ **IF no alternative then,
& only then,**
- ✓ **to a 1st Party SNT...**

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Spread the word...

NURSING HOME EXCEPTION

BUT BEWARE..

- **Power of Attorney/Living Trust**
 - **3rd party or 1st party SNT ?**

**AGAIN, ANOTHER REASON FOR
SNT NOT INSIDE YOUR
WILL OR YOUR LIVING TRUST!**

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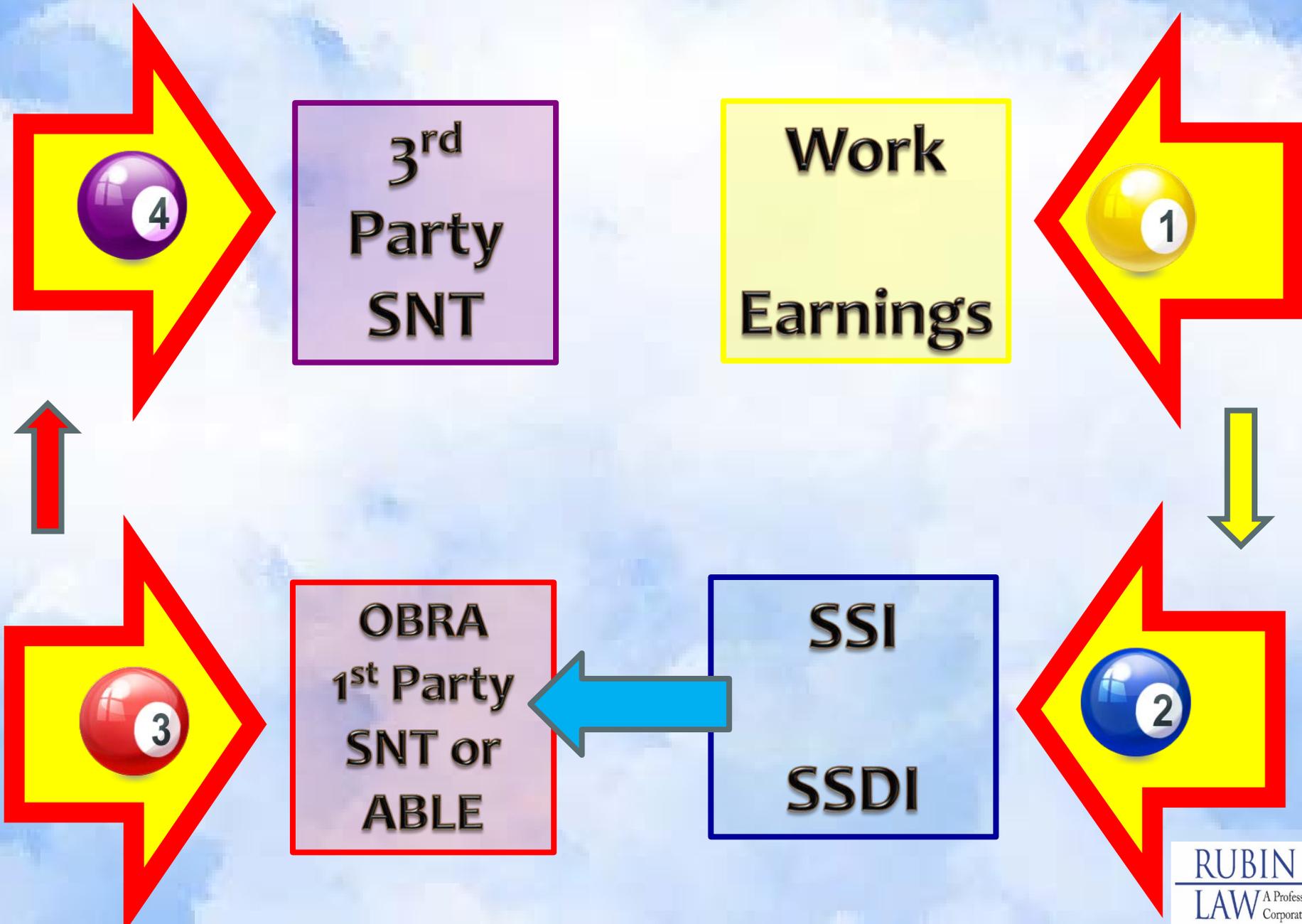


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WHICH "BUCKET" FIRST?



★ You say you **already have** a special needs trust?

★ Does it **qualify**?

★ Was it **approved** by SSA & HFS (Illinois Medicaid Agency)? AG?
Will it be approved when it is submitted (It **must** be submitted to SSA & HFS)?

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COMMON ATTORNEY MISTAKES!

**Calling it an
SNT doesn't
make it an SNT!**

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COMMON ATTORNEY MISTAKES!

**No Grand-
Fathering
Required
Language!**

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COMMON ATTORNEY MISTAKES!

NO prohibition
of 1st Party
money in 3rd
Party Trust!

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COMMON ATTORNEY MISTAKES!

NO requirement
to use 1st Party
Trust money or
ABLE money prior
to 3rd Party Trust
money!

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Not

100%

Discretionary

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Permitting Pay TO...

***So SHOULD provide ability
to distribute to ABLE!***

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Over Restrictive Language...

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COMMON ATTORNEY MISTAKES!

“No Trustee
Powers to
Correct” or
terms not
“broad” enough

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COMMON ATTORNEY MISTAKES!

No
“Band Aid”
or retro
Language



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No “Next
Generation”
Trustees...

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No “Contribution”
or
Gift Language
3rd Party

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No
Termination
Provision...

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COMMON ATTORNEY MISTAKES!

No
“Contingent”
SNT for others

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NO
Nursing Home
Sub Trust for 50
States

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COMMON ATTORNEY MISTAKES!

NO
TRS/SURS/Military &
other “public”
Pensions Sub Trust

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COMMON ATTORNEY MISTAKES!

NO Grantor(s)'
power to change
contingent
beneficiaries...

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COMMON ATTORNEY MISTAKES!

NO Trustee(s)'
power to change
contingent
corporate trustee...

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COMMON ATTORNEY MISTAKES!

NO Change of
State
Provision...

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Other Documents

- ✱ Wills need special language!
- ✱ Living Trusts too
- ✱ Insurance Trusts too
- ✱ Powers of Attorney too
- ✱ Beneficiary Designations too

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COMMON ATTORNEY MISTAKES!

**...and these are
just a few of the
attorney mistakes
that we see...**

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How to locate an experienced Special Needs Planning Attorney

1. SNA: The Special Needs Alliance - **Attorneys**

➤ <https://www.specialneedsalliance.org/find-an-attorney/illinois/>

2. ASNP: The Academy of Special Needs Planners – **Not all attorneys**

➤ <https://specialneedsanswers.com/illinois-special-needs-planners>

3. NAELA: The National Academy of Elder Law Attorneys – **Some...**

NOT all...

➤ <https://www.naela.org/findlawyer>

4. Agencies, Support Groups...

REMEMBER

SPECIAL NEEDS PLANNING IS

NOT

JUST A SPECIAL NEEDS TRUST,

NOT

JUST DOCUMENTS, BUT, RATHER,

SHOULD BE A

RELATIONSHIP.

An experienced special needs planning attorney should be able to answer, without additional fee:

- ✓ **Questions on government benefits (SSI, SSDI, CDB/DAC, Medicaid, Medicare)**
- ✓ **Questions on SSA, HFS, ISC /PAS correspondence, including defending the trusts they drafted**
- ✓ **Questions on impact of divorce**
- ✓ **Questions on impact on law suit settlements**
- ✓ **Guardianship and alternatives to guardianship**
- ✓ **Probate avoidance on death and/or disability**
- ✓ **Educate the extended family and friends**
- ✓ **Assist with beneficiary changes**
- ✓ **Navigating the maze of State services/programs**
- ✓ **Estate tax minimization if not elimination**

INFORMATION REQUEST FORM

DOCUMENTS WILL BE SENT BY EMAIL (select boxes below)

1. Special Needs Alliance "Special Needs Trust Handbook"
2. Letters of Intent ("Guidance & Information Form" for "future team")
3. Impact on Divorce & Child Support on SSI & Medicaid
4. Keeping your Child on YOUR Health Insurance (past 26)
5. Guardianship & Alternatives (Powers of Attorney)
6. Special Needs Trusts & Special Needs Future Planning
7. Adult Sibling Group & Sib Shop information for younger siblings
8. Impact of Guardianship on Driver's License
9. Taxes & Special Needs Trusts
10. Taxes & Adult HBSS Waiver
11. ABLE Accounts
12. Military Pension Benefit (SBP)
13. Pre-Paid Funeral Arrangements Rules
14. Please add me/us to your list to receive your newsletters by email

Check appropriate box and complete the needed information.

1. Do not contact me/us, just please send by email the information requested above.

Email address is: _____

2. Please contact me (us) to schedule an "Initial Consultation".

Day time phone number: (____) _____ Email: _____

Name(s): _____

3. Please contact me (us) to schedule a presentation to a group, organization, school, or agency.

Day time phone number: (____) _____ Email: _____

Name(s): _____



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Brian Rubin — Mitchell Rubin — Benjamin Rubin

“Legal and future planning for our fellow Illinois families of individuals with special needs, including intellectual disabilities, developmental disabilities, physical disabilities, and/or mental illness, is not one thing we do, it’s the only thing we do; it’s not one area of our practice, it’s our only area of practice.”

Brian N. Rubin, Parent

Benjamin A. Rubin, Sibling