Legal & Future Planning
for children & adults with special needs...

HOW TO PRESERVE ASSETS AND
NOT LOSE SSI & MEDICAID

BENJI RUBIN
Attorney & Sibling
It is TIME to start
We will begin in 2 minutes...
1st...
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)
WHO ARE YOU?
January 27, 1981

MITCH

Best Worker at Rubin Law

Rubin Law

Best Man 8/9/15
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
S.I.B.S. www.sibsnetwork.org
Supporting Illinois Brothers & Sisters
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www.siblingleadership.org
What **YOU**, or “**OTHERS**”, do impacts Government Benefits
WHERE FROM?

*- Working ?
*- Parent(s) ?
*- Siblings ?
1/3 reduction to $449.34

Medicare Income & Asset Test

JUST Income Test

More than medical...

TWO YEARS Assets

$ 2,000

Rx - Co Pays - Deductibles

RESIDENTIAL CDB (DAC) on parent's record IF Income & Asset Test 2019 = $ 771

Disabled? A two part test:
- Listing level impairment
- Diagnosis
- Current Medical Information
- Functional limitations – Why can’t work?
- Documentation from “Professionals”
- IEPs, School Records
- Concentration, Pace, Persistence
- Appropriate Social Functioning
- Activities of Daily Living
- Understand, Remember, Apply Information (new for 2017)
- Interact with Others (new for 2017)
- Adapt or Manage Oneself (new for 2017)
- Inability to Use Two Limbs IF DATE OF ONSET BEFORE 22 & PARENT: - Deceased - On SSDI - Retires and receiving SSA

Income:
- 2019 $ 1,220
- Earned Income - after $85 @ month, lose 50 cents on the dollar
- Student
- 2019 $ 1,870 @ mo. $ 7,550 @ yr.

CO-PAYS (non-residential)

Generic $2, Brand Name $3.90 (4/1/13)

M.D. $3.90 @ visit (4/1/13)

Hospital $3.90 @ day (4/1/13)

1/3 less if:
- Don’t charge rent (Taxable Income)
- Don’t charge “fair share” (NOT Taxable Income but won’t work if over SSI amount)

$ 771 reduced to $ 514 (2019)

2nd of 3 - Traditional Medicaid

1. Feds match 50%
2. $2,000 of non-exempt assets
3. Income under $1.065 ($1,040 plus $25) (spend down)

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

1st of 3 - ACA/Obama Care Medicaid

1. Feds match 100% - the current Illinois default...
2. No asset test
3. Income under $1,436 @ month (March 2019)
4. But:
- Income over $1,436 @ month (March 2019)
- Parents' income counts if IRS Dependent
- Under 65
- Not on Medicare

3rd of 3 - HBWD Medicaid (Health Benefits for Workers with Disabilities)

1. Feds match 50% like traditional Medicaid
2. Must be employed and FICA being withheld
3. Non-exempt assets under $25,000
4. Qualified Plans (IRAs/401ks) fully exempt
5. Income under $3,643 @ month (March 2019)
6. Previously on SSI or SSDI as “disabled”
7. Doesn’t work for “residential” only "community"

BEWARE...

SSI/SSDI

"residential" then only keep $60 @ month for personal use...

“non-residential” living it if turn down for Medicaid on application or lose Medicaid on redetermination, the State doesn’t automatically then try one of the other "types".

BEWARE...

RUBIN LAW Corporation

LAW

A Professional

Special needs require special attorneys
MEDICAID is a MUST?

Especially post school years…

- HBSS:
- (18-21): 2019 \( \underline{2} \times \text{SSI} = \$1,542 \ @ \text{month} \)
- (22 &): 2019 \( \underline{3} \times \text{SSI} = \$2,313 \ @ \text{month} \)
  (could be almost \$28,000 \text{ 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
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!
“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.”
• “Directly”

• No Will

• “Disinherit” & leave to others (“moral Obligation”)

• “Traditional Trust”
Special Needs Trusts
Special Needs Trusts

3rd Party
Private & Pooled Versions

Self Settled
aka, OBRA, 1st Party, Pay Back...
Private (d4A) & Pooled (d4C)
2 Versions, both...

✓ Reserve
✓ Supplemental Fund
✓ Over & Above Government Benefits
✓ No $ limit
✓ Federal
✓ State
3rd Party
Trusts
Original - Good

by Court Decisions 1982

by Statute (760 ILCS 5/15.1) 1991
INHERITANCE
GIFT
INSURANCE
IRA
401K

SPECIAL NEEDS TRUST

Beneficiary's own assets
Including child support (divorce)

THEN UPON BENEFICIARY PASSING...
PARENT(S) DECIDE:
FAMILY CHARITY GUARDIANS

3RD PARTY TRUST
OK... SO
INSIDE WILL
OR LIVING
TRUST?
NO! NO! NOT!

"I PLUS"

YOU WILL OPENING

TRUST!
Won’t exist until...
#1 So NO “Piggy Backing”

#2 NO “Grand Fathering”

#3 NO Nursing Home Impoverishment

#4 NO Place for gifts to go

#5 NO Need to share entire Will/Living Trust with SSA and HFS
BUT I STILL DON'T GET IT?
Just what IS a Trust?
Just another way of holding “title” to, or “ownership” of, assets, investments or accounts...
So what's all for?

- Instruction Manual
- “Rules of the Road”

Who can use it?

- Parents
- Siblings
- Grandparents
- Anyone...

Remember - 3rd Party Parents & Family as Trustees...
How to put in the Trust?
From your & others’ Wills & Trusts
EXTENDED FAMILY & FRIENDS

• Instruction letter
• Form Codicil
• Form Trust Amendment
• Trust Certification
• Consult with their Attorneys/Advisors
But...
Beware of absentee parents & grandparents
So...

1st set up SNT
2nd reference in Wills/Trusts
3rd extended family too

But... But...
Change Beneficiaries

- Life Insurance
- IRA
- 401k
- Profit Sharing
- Etc.
WHAT ABOUT GIFTS?

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

YES 3rd Party SNT
So far just 3rd Party

But what if...
BENEFICIARY HAS ASSETS

- Savings
- Bonds
- UTMA Accounts at 21
- IRA - 401k
- Excess SSI/SSDI
- Large Gift
- Law Suit Settlement
- Inheritance

WILL/TRUST/BENEFICIARY

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Special needs require special attorneys.

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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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President 2017-2018

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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.
• 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
1st Party SNT Called... “Self Settled”... or

☑ “OBRA 93 Trust”...

☑ “(d)(4)(A) or (C) Trust”

☑ “PAY BACK Trust” (like an ABLE account... because...
Party Special Needs Trust

Medical Malpractice

Personal Injury

Inheritances & Gifts NOT to 3rd party SNT

Special Needs Trust

His/Her own assets, such as savings bonds, & Child Support

Then upon passing...

The State, even before FUNERAL bill... any left only then: FAMILY CHARITY GUARDIANS
1st Party SNT... "NOT" SO GOOD...

- Only if NOT 65
- Only by Parents, grandparents, Courts, guardians & self (new)...
  Others... NOT

- SSA Position...
- Courts often require...
- Pay Back to day 1...
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...
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!
WHICH “BUCKET” FIRST?

1. Work Earnings
2. SSI SSDI
3. OBRA 1st Party SNT or ABLE
4. 3rd Party SNT
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)?
COMMON ATTORNEY MISTAKES!

Calling it an SNT doesn’t make it an SNT!
COMMON ATTORNEY MISTAKES!

No Grand-Fathering Required Language!
NO prohibition of 1st Party money in 3rd Party Trust!
COMMON ATTORNEY MISTAKES!

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

Not 100% Discretionary
COMMON ATTORNEY MISTAKES!

Permitting Pay TO...

So SHOULD provide ability to distribute to ABLE!
COMMON ATTORNEY MISTAKES!

Over Restrictive Language...
"No Trustee Powers to Correct" or terms not "broad" enough
COMMON ATTORNEY MISTAKES!

No “Band Aid” or retro Language
COMMON ATTORNEY MISTAKES!

No “Next Generation” Trustees...
COMMON ATTORNEY MISTAKES!

No “Contribution”
or
Gift Language
3rd Party
COMMON ATTORNEY MISTAKES!

No Termination Provision...
COMMON ATTORNEY MISTAKES!

No "Contingent" SNT for others
COMMON ATTORNEY MISTAKES!

NO Nursing Home Sub Trust for 50 States
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...
COMMON ATTORNEY MISTAKES!

**NO** Trustee(s)’ power to change contingent corporate trustee...
COMMON ATTORNEY MISTAKES!

NO Change of State Provision...
COMMON ATTORNEY MISTAKES!

Other Documents

- Wills need special language!
- Living Trusts too
- Insurance Trusts too
- Powers of Attorney too
- Beneficiary Designations too
COMMON ATTORNEY MISTAKES!

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

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 HBCS 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): ____________________________
“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