

# Special Needs Legal & Future Planning



**WWW.RUBINLAW.COM**  
**EMAIL@RUBINLAW.COM**  
**866.TO.RUBIN**



**"Legal and future planning for our fellow families of individuals with special needs, including intellectual disabilities, developmental 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."**

# HANDOUTS

## 3 easy steps

**#1 Go to [www.rubinlaw.com](http://www.rubinlaw.com)**

**#2 Select “Calendar of Events”**

**#3 Under “In2Great” event, select “Learn More”**

- ✓ **Power Point Slides**
- ✓ **More Information Request Form**
- ✓ **and more...**



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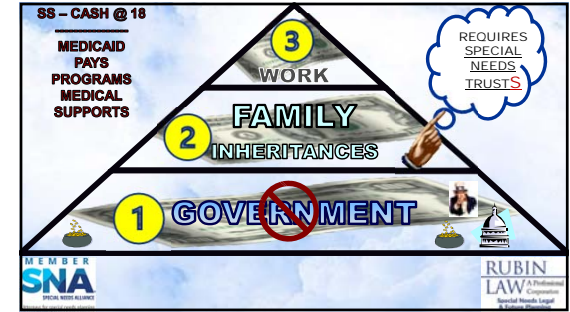
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What **YOU**,  
or "**OTHERS**", do  
**IMPACTS**  
Government Benefits

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MEMBERSHIP 101 - SSI - SSDI - MEDICAID - MEDICARE - SNA - ETC.

**BEWARE...**  
SSI/SSDI  
If living "residentially" 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".

Parents' income counts if  
• IRS Dependent  
• Under 65  
• Not on Medicare

**SSDI**  
Quarters - own record:  
2022 \$1,510  
2023 \$1,640  
Before 24 - 6 quarters

**TWO YEARS**  
Income Test

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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 **condition** that occurred before the attainment of the limiting age, is **incapable of sustaining employment & dependent on his or her parents, or other care providers for lifetime care & supervision.**"

**Request  
Form  
# 4**

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**State of Illinois**  
**Department of Human Services**

#1  
**DDD**

#2  
**DMH**

#3  
**DRS**

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STATE OF ILLINOIS DHS DDD DEFINITION OF DD FOR WAIVER

NOT  
SAME  
AS  
SSA

- Before 18 BUT NOT BEFORE 17 (Adult Test)
- IQ 70 or below
- Before 22 3 or more of 6 major life activities

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**ADULTS - if not "DD"**  
(or can "try" even if...)

**DHS - DRS  
HOME SERVICES  
WAIVER**

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**PUNS for DDD**

PRIORITIZATION OF URGENCY  
OF NEED FOR SERVICES

**REQUIRED**

Children (2½ - 17) & adults (18+) with I/DD,  
since February 2008.

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**PUNS + Medicaid**  
**Required** for:

- ▶ All Medicaid Waiver Programs... For DD
- ▶ Children's Waiver
- ▶ Adult Waiver
  - CILA - Group Homes
  - HBSS
  - In-Home CILA
  - Supported Employment Services
  - Community Day Services (DT)
  - Regular Work (Workshop)

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**WHERE DO YOU BEGIN?**

• The ISC (Independent Service Coordination) Agents (*used to be "Pre-Admission Screening" Agents, name change, but same organizations*) are **THE** point of **ENTRY** to access state & federally funded services for persons with developmental disabilities, over the age of three, & their families.

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Illinois Department of Human Services Division of Developmental Disabilities  
Independent Service Coordination Agents (ISC) - Effective July 1, 2018

**ISC AGENT PHONE NUMBERS**

Region	ISC Agent	Phone Number
Area 1	ASDM - Access Services of Northern Illinois	815-282-8824
Area 2	CISA - Central Illinois Service Access	217-732-4791
Area 3	CCRPC - Champaign County Regional Planning Commission	217-328-3313
Area 4	CAI - Community Alternatives Unlimited	773-867-4000
Area 5	CSO - Community Service Options	773-471-4700
Area 6	CSO/IRM - Developmental Disability Services	309-279-0020
Area 7	DayOne Pact (Kane & Kendall Counties)	630-479-0277
Area 8	DayOne Pact (Du Page County)	630-460-9700
Area 9	DDIME - Developmental Disabilities Services Metro East	618-236-7957
Area 10	GRSC - Great Rivers Service Coordination	217-243-0300
Area 11	LCRMB - Livingston County Mental Health Board	815-644-7708
Area 12	OMAC - Options & Advocacy McHenry County	815-477-4700
Area 13	PSO - Peoria Area Service Coordination	217-362-8128
Area 14	Service, Inc.	815-741-1678
Area 15	SCCSB - Southern Illinois Case Coordination Services	618-532-4346
Area 16	SA, INC. - Suburban Access, Inc.	708-798-0190
Area 17	WCSC - West Central Service Coordination	217-285-0227
Area 18	WISC - Western Illinois Service Coordination	309-433-1621

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**FYI as of November 2018**

The State has changed to just 2 categories if not in Crisis:

- In Crisis – Must be served within 72 hours
- If not in Crisis then:
  1. Seeking – desire services within one year:
    - ✓ under 18 – Seeking Children's Waiver
    - ✓ 18+ Seeking HBSS/Residential Waiver
  2. Planning – future will need

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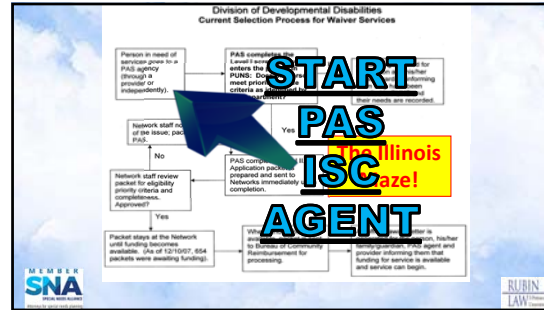
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**CHILDREN'S DD WAIVER(S)**

**Parents assets & income do not count!**

**ADULT DD WAIVER(S)**

**ADULT ICFDD ?**

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**CHILDREN WAIVER**

**NOT part of LIGAS**  
Class action lawsuit!

**2011 – 2022 only if in crisis**

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**18+ crisis**

\* **Definition of Crisis - Adults (4/6/2021)**

- Homeless
- Abuse
- Neglect

\* **Those in Crisis are to receive services**  
**“expeditiously” (72 hours?)**

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**“WAITING LIST” CLASS MEMBERS NOT IN CRISIS**

1. Class member residing at home **not in crisis** will be placed on PUNS waiting list.
2. **Prior to Ligas, 80 to 100 @ year**
3. **Since Ligas, 500 @ year minimum, many years - 2X to 3X**
4. **2019: PUNS selections “will be tailored such that by the Fiscal Year 2025 selection, no individual will wait on PUNS for more than 60 months (5 years).”** Also, fiscal years 2021 through 2025: minimum of 630 @ year, but, again, State has done much more.
5. Note that for individuals on the PUNS before age 18, the 60-month period begins on the 18th birthday.

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**FOR DRS, NOT PUNS – RATHER**  
**DETERMINATION OF NEED - “DON” SCORE**  
 LOCAL DRS OFFICE or call 1-800-843-6154

- Personal Assistant
- Homemaker Services
- Home Health Services
- Electronic Home Response
- Home Delivered Meals
- Adult Day Care
- Assistive Equipment
- Environmental Modifications
- Respite Services
- Brain Injury (Behavior; Habilitation;  
Pre-Vocational; Supported Employment)
- Community Reintegration

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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**

→ **3<sup>rd</sup> Party**

→ **Self Settled**

aka, OBRA, 1<sup>st</sup> Party, Pay Back...

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SNTs.. 2 Versions, both...

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

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**3<sup>RD</sup> PARTY TRUSTS**

**ORIGINAL - GOOD**

→ by Court Decisions **1982**

→ by Statute 760 ILCS 3/509 (1/1/20)  
Original statute 760 ILCS 5/15.1 **1991**

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GIFTS  
INHERITANCES  
**NOT**  
OWN  
1<sup>st</sup> Party!

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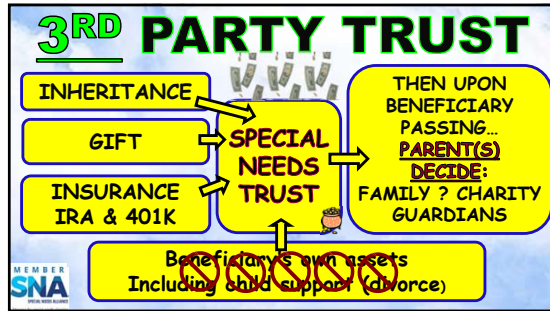
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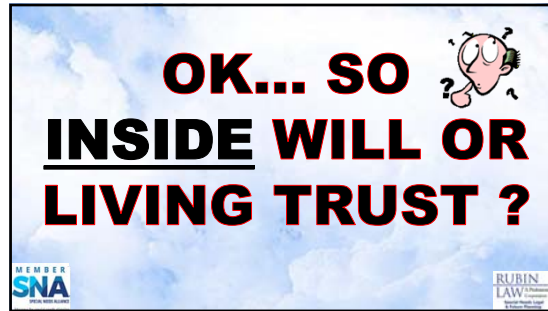
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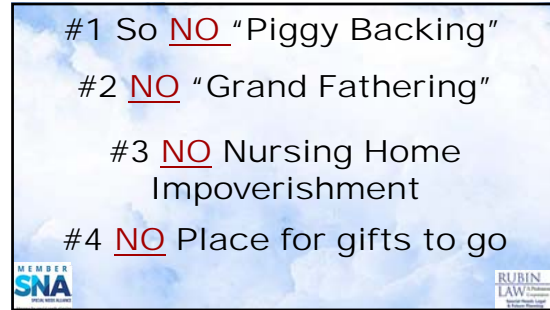
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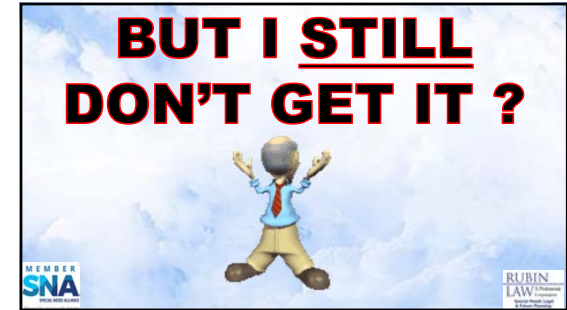
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What **YOU**,  
**AND** what "**OTHERS**", do, even  
**UNintentionally, IMPACTS**  
 Government Benefits

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**EXTENDED FAMILY & FRIENDS**

- **Instruction letter**
- **Form Codicil**
- **Form Trust Amendment**
- **Trust Certification**

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**But...**  
**Beware of**  
**absentee**  
**parents &**  
**grandparents**

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**EX-SPOUSE  
LETTER**

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**So...**  
1<sup>st</sup> set up SNT  
2<sup>nd</sup> reference in Wills/Trusts  
3<sup>rd</sup> 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

**YES** 3<sup>rd</sup> Party SNT

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So far just  
3<sup>rd</sup> Party  
**But what if...**

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BENEFICIARY **HAS ASSETS**

Savings Bonds 529? **NOT!** UTMA Accounts **at 21** Large Gift  
IRA - 401k Excess SSI/SSDI Inheritance WILL/TRUST/BENEFICIARY Law Suit Settlement

**CHILD SUPPORT - DIVORCE**

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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 3<sup>rd</sup> party trust
6. Small lawsuit settlements
7. Court ordered divorce child support not to exceed \$16,000 in a year (\$17,000 in 2023) (stay tuned)
8. 2018 - Convert traditional 529 Account... up to \$16,000 (\$17,000 IN 2023) limit...
9. 2018 - Additional contribution by BENEFICIARY of the lesser of earned income from employment for year & federal poverty level amount. 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

- Illinois Statutes - Not as advertised...
- “No Pay Back” is being “~~advertised~~”

**HOWEVER BEWARE REQUEST FORM # 11**

1. Per Feds (CMS) “No Pay Back” doesn’t apply to all 9 Illinois states including DDD and DRS, and VIFCDD, SODC, & HBSS.
2. Also, per Feds (CMS) the “No Pay Back” doesn’t apply to any medical Medicaid post age 55.
- Tax Deduction... so what

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# Otherwise 1<sup>st</sup> Party Special Needs Trust

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

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# 1<sup>st</sup> 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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✓ **So NOT directly**

✓ **ALL to 3<sup>rd</sup> Party SNT**

✓ **IF no alternative then, & only then, to a 1<sup>st</sup> Party SNT or ABLE...**

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**Spread the word...**

**NURSING HOME EXCEPTION**

**BUT BEWARE...**

- Power of Attorney/Living Trust
- 3<sup>rd</sup> party or 1<sup>st</sup> party SNT ?

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



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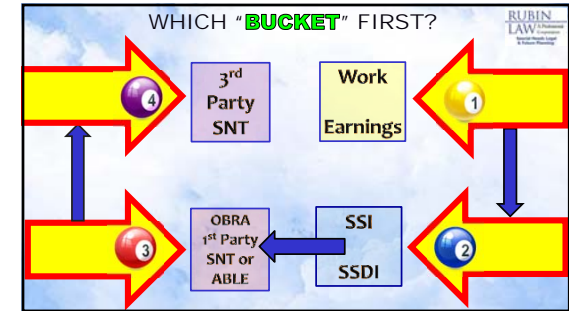
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- ★ You say you **already have** a special needs trust?
- ★ Does it **qualify**?
- ★ Was it **approved** by SSA & State Medicaid Agency
- ★ Will it be approved when it is submitted (It **must** be submitted to SSA & State)? – 10 day rule...

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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 1<sup>st</sup> Party  
money in 3<sup>rd</sup>  
Party Trust!**

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**NO requirement  
to use 1<sup>st</sup> Party  
Trust money or  
ABLE money prior  
to 3<sup>rd</sup> Party Trust  
money!**

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**Not  
100%  
Discretionary**

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COMMON ATTORNEY MISTAKES!

**Permitting  
Pay TO...**  
**{So... SHOULD  
provide ability to  
distribute to ABLE!}**

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COMMON ATTORNEY MISTAKES!

**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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**COMMON ATTORNEY MISTAKES!**

**No “Next  
Generation”  
Trustees...**

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**COMMON ATTORNEY MISTAKES!**

**No “Contribution”  
or  
Gift Language  
3<sup>rd</sup> Party**

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**COMMON ATTORNEY MISTAKES!**

**No  
Termination  
Provision...**

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**COMMON ATTORNEY MISTAKES!**

**No  
“Contingent”  
SNT for others**

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**COMMON ATTORNEY MISTAKES!**

**NO  
Nursing Home  
IMPOVERISHMENT  
PROVISION**

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**COMMON ATTORNEY MISTAKES!**

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

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**COMMON ATTORNEY MISTAKES!**

**NO Trustee(s)’**  
**or Guardian**  
**Power to change**  
**corporate trustee...**

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**COMMON ATTORNEY MISTAKES!**

**NO Change**  
**of State**  
**Provision...**

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COMMON ATTORNEY MISTAKES!

**1/1/2020**  
**Trust Code**  
**BEWARE!**

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COMMON ATTORNEY MISTAKES!

**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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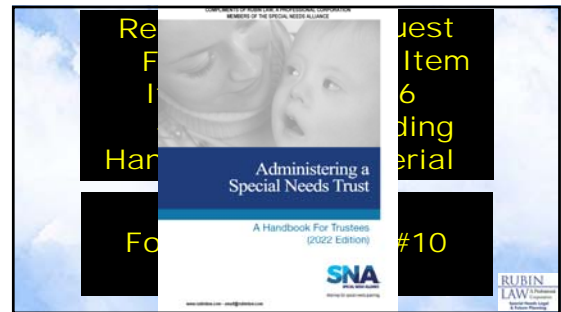
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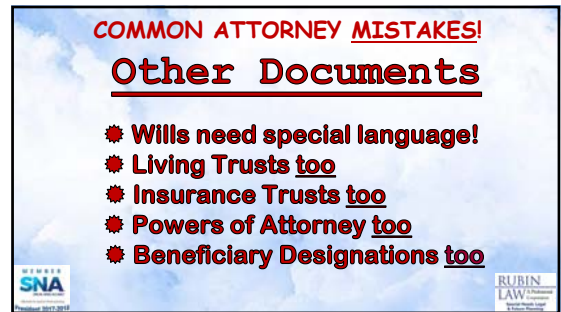
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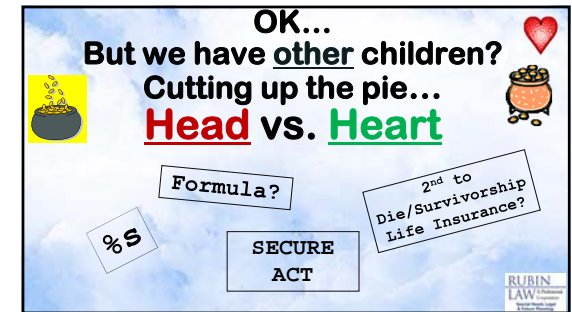
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When someone is an adult, 18 in Illinois, that person is **presumed fully legally competent...**  
**...and only IF** a court (Judge) determines otherwise, is that person **NOT** deemed competent...

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- Schools?
- Doctors/Hospitals
- Insurance Claims?
- Signing documents/Contracts
- Dealing with SSA /State
- Residential/Living arrangements
- Employment/Day Programs
- Agencies
- Marriage
- Driving
- Arrests – DD/ID/MI is NOT Diplomatic Immunity...

**STOP!**  
This means YOU.

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SO... the questions to ask...

- Can he/she **fully manage** his/her personal, medical, education & financial **decisions**?

Even **IF** can...

- Could he/she be **vulnerable** to, or be **taken advantage** of by others?

**IF SO, THEN...**

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**Before** considering  
"Guardianship",  
**ALWAYS**  
first consider the  
**ALTERNATIVES**

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**What are  
the  
ALTERNATIVES?**

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**OPTION #1**  
**Do nothing?**  
Actually...  
If **NO** "CAPACITY"  
FOR *MEDICAL DECISIONS...*  
**THEN** ➡

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(755 B.C.S. 450) Health Care Surrogate Act.

(755 B.C.S. 450): Sec. 1. Short title. This Act may be cited as the Health Care Surrogate Act. (Source: P.A. 87-286.)

(755 B.C.S. 450): Sec. 2. Legislative findings and purposes.

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1. **LACKS** decisional capacity AND  
2. **NO** health care agent, **THEN**  
3. In order (a) Guardian of Person... (b) spouse... (c) any adult children... (d) any parent... (e) any sibling

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But just **MEDICAL/HEALTH!**

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[illegible]

OPTION #2

IF DO HAVE

“Decisional Capacity”

then... ➡

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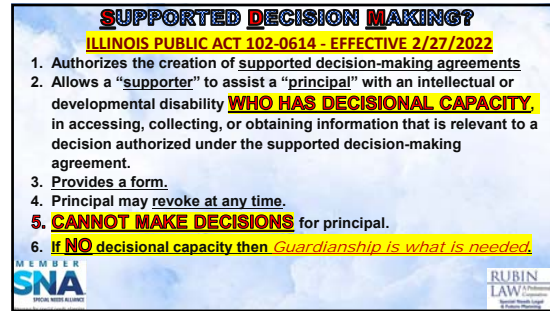
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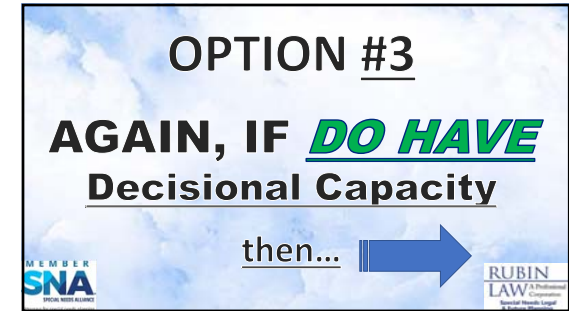
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# PowerS of Attorney

(IF decisional capacity)

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(IF decisional capacity)

- Financial
- Medical
- Education
- Mental Health
  - SSA
  - State




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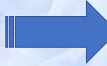


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## OPTION #4

Limited or  
Plenary (Full)  
Guardianship

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**What if** he/she:

- **DOES HAVE CAPACITY** to "sign" **BUT** refuses to "sign"?
- **DOESN'T HAVE CAPACITY** to "sign"?
- **HAS CAPACITY, HOWEVER**, just can't help **getting** himself/herself into trouble; maybe legal, maybe criminal, maybe financial, maybe personal, maybe medical/health related?
- **HAS CAPACITY, HOWEVER**, is a danger to himself/herself or others?

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**AND WHAT IF** he/she **DOES HAVE CAPACITY** to "sign" **BUT**

- **He/She** terminates/voids the PA as soon as... when...?
- **AND...**
  - Doesn't **prohibit** him/her from...
  - Remains vulnerable?

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**That is, *will Powers be enough?***

- What if he/she is on computer buying things with mom's credit card.
- What if he/she refuses to have parents at IEP/504/ISP meeting, or is "tricked".
- What if he/she is being asked to sign \_\_\_?

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If he/she can't, or won't "sign" DPAs...  
**AND/OR** if you determined that SDM, DPAs, or HCSA,  
 are simply **NOT ENOUGH** to assist and/or protect  
 him/her...  
**THEN, MAYBE... JUST MAYBE**, "some form" of  
**GUARDIANSHIP** would be appropriate to help, and to  
 protect him/her, from himself/herself, and from  
 others...

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**The Guardianship Law!**  
**755 ILCS 5/11a**  
**Going to court to take away**  
**someone's rights...**

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**A 60 to 75 minute presentation by itself...**

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 SPECIAL NEEDS LEGAL & FINANCIAL PLANNING  
 1000 N. LAKE STREET, SUITE 200  
 CHICAGO, IL 60610  
 TEL: 312.786.1000 FAX: 312.786.1001  
 WWW.RUBINLAW.COM

**DOCUMENTS WILL BE SENT BY EMAIL, (unless I advise below)**

- ☐ Special Needs Alliance "Special Needs Trust Handbook"
- ☐ Letter of Intent ("Guidance & Information Form" for "Future Trust")
- ☐ Report on Trusts & Other Assets as SD & Medicaid
- ☐ Drafting your SD as 755 ILCS Health Savings Plan (HSA)
- ☐ Guardianship & Alternatives (Review of Attorney, Reportorial Decision Making)
- ☐ Special Needs Trusts & Special Needs Planning
- ☐ ADAT (Living Group & SD) (Step information for younger siblings)
- ☐ Report of Guardianship on Client's Consent
- ☐ Trusts & Special Needs Trusts
- ☐ Taxes & ADAT (HSA) Waiver
- ☐ ADAT Summary
- ☐ Military Pension Benefits (SDP)
- ☐ Any Asset Transfer/Assignment Notice
- ☐ Please add notes to your list to receive your materials by email

Check appropriate box and complete the relevant information.

☐ I do not prefer email and please send by email the information requested above.

Email address to: \_\_\_\_\_

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

Day time phone number: (\_\_\_\_) \_\_\_\_\_ Email: \_\_\_\_\_

Name: \_\_\_\_\_

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**Guardians  
are  
nominated  
in parents  
Wills!**

CONSIDER  
even if  
don't  
think  
"ever"!

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(755 ILCS 5/11a-16)  
Testamentary guardian

A parent of a disabled person **may designate by will** a person, corporation or public agency qualified to act... to be appointed as... successor guardian of the person or of the estate or both of that person...

**If** the court finds that the appointment of the one so designated will serve the best interests and welfare of the ward, it shall appoint the one so designated...

(Source: P.A. 81-795.)

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**Who will be Guardian?**

- Who will make all of the necessary decisions?
  - Medical?
- Government Benefits?
  - School Issues?
- Recreation & Social?
  - Employment?
  - Day Programs?
  - Residential?

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**Who will be Guardian?** 



**Who is going to fill our shoes?**

- Can they understand?
- Job will outlast them!
- Other Children? Siblings? Grandparents? Friends?
- School District of Guardian?
- Married Couples?
- Same as Trustees?

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**Short Term Guardian Declaration?**

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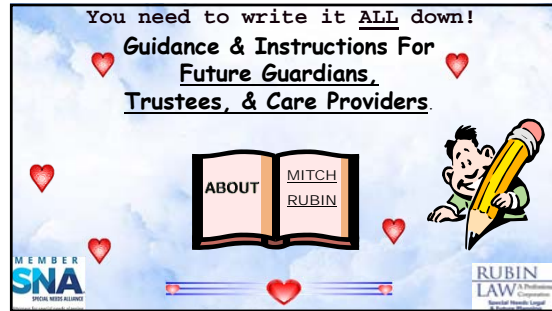
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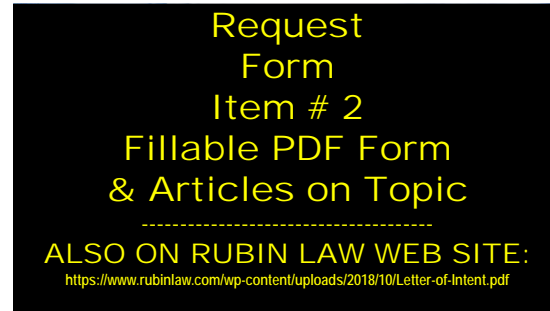
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### INFORMATION REQUEST FORM

**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, Supported Decision Making)
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): \_\_\_\_\_