



CLANCY & ASSOCIATES

Guiding Families with Unique Needs

Legal Planning for the Special Needs Family

Presented by
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About the Speaker & Our Mission



Jennifer Sabourin



"Our mission is to eliminate the confusion and stress families feel when planning their child's future."

We do this by serving as your guide through the legal system."



Common Parent Questions

- How can I continue to help my child make decisions and access treatments/information?
- What government benefits is my child eligible for?
- How can I save for my child's future care?
- How do I build a secure plan for my child's care once I am gone?
- I am so overwhelmed and don't know where to start. What are my next steps?

The Goal for this Presentation:

Empower you with information so you have peace of mind and focus on your next steps.



Special Needs Planning Overview

- Legal and Financial planning are *different* for the special needs family.
- Typical parents raise their children for 18-22 years. The adult child should then be independent and supporting themselves. These parents are also planning for their own retirement needs, managing both financial and health.
- As Special Needs Parents, we have many additional and greater responsibilities. Our children may never fully live independently, requiring multiple forms of support from us. Most importantly, we must plan for their lives beyond us. This planning is essential and critical, and should not be delayed.



Special Needs Planning: Your Plans Coming Together

Financial Planning:
determines a strategy
to fund the Trust

Care Planning:
create a vision for your
child's care and goals
to guide others in
charge of his or her
care, living, support
and direction

Legal Planning:
to protect person's eligibility
for public benefits, protect
the assets in trust from
misuse, identify roles and
responsibilities



In this Presentation:

- Decision Making Tools / POAs vs. Guardianship
- Government Benefits Overview
- Special Needs Trusts and Estate Plans
- Action Items
- Questions



Decision Making Tools



755 ILCS 9/15

Sec. 15. Presumption of capability.

(a) All adults are presumed to be capable of making decisions regarding daily living and to have capacity unless otherwise determined by a court.



1. Decision Making Considerations Available Tools

Least parental involvement

Most parental involvement



Supported Decision-Making

- Consists of a "Principal" and "Trusted Supporter"
- Not well recognized with healthcare and financial institutions
- We do not recommend, good option for self-advocates

Powers of Attorney

- Health Care
- Property
- Person retains decision-making authority
- Revocable
- Capacity
- For everyone!

Guardianship

- Plenary or Limited
- Person and/or Estate
- "Permanent"
- Guardian becomes sole decision maker
- Can always include child in decisions, but guardian has final say



1. Decision Making Considerations

- Identify your child's strengths and limitations
 - Managing and spending money
 - Medical decisions and treatment options
 - Medication management
 - Knowing what to do in an emergency
 - Understanding impactful choices and consequences
 - Driving (either now, or in the future)
 - Vulnerable to exploitation



1. Decision Making Considerations: Timing

- When to Decide?
 - 17 and younger
 - Wait and see
 - 17 and older
 - Recommend making a decision by 17 ½
 - No decision - consequences
 - Lack of healthcare access
 - Financial consequences and undue influence
 - Ease of interacting with agencies like SSA, DHS, DRS



1. Decision Making Considerations: POA and Guardianship Timing and Process

- POAs – 1 week before 18th birthday
 - Decision making capacity
 - Verbalize continuation of parental involvement
 - Good first step
 - Requires proper notarization and witnessing
- Guardianship – 2-3 months
 - Physician's Report
 - Preparation of documents
 - Service and hearing
 - Final documents
 - Court process; county/Judge specific; timeline



Government Benefits Overview



2. Government Benefits

What Benefits are Available?

- Supplemental Security Income (SSI)
- Medicaid
- Social Security Disability Income (SSDI)
- Medicare

*These are not guaranteed benefits!



2. Government Benefits

What Benefits are Available?

Supplemental Security Income (SSI):

- Can be eligible at age 18
- Monthly Cash Benefit (2025, \$967)
- Must qualify as "disabled"
- \$2,000 asset limitation
- Benefits are paid retroactively to date of application (but not date of eligibility)
- Application process can take 10-12 months
- High denial rate; be prepared to be persistent and appeal a denied application
- 3-year look back period
- Can own car and house

Medicaid:

- Health Insurance, Prescription Drugs
- Day programs, vocational training, job coach, home-based waiver programs, personal service workers, technology, equipment, modifications, service coordination ("Home Based Waiver")
OR
Residential programs/CILA
- PUNS = waiting list - registration required
- \$2,000 asset limitation (AABD= \$17,500)
- If SSI approved, Medicaid approval automatic in IL
- Can apply separately from SSI, especially if SSI approval not expected immediately
- 5-year look back period



Medicaid – The Waiver and CILA

- "PUNS LIST" is defined as "Priority of Urgency of Needs System".
- Illinois does not have enough funding to provide services to all who need them. The "PUNS List" is a database of people who have Developmental Disability (DD) and are waiting to receive services.
- Services include in-home support, residential living, job coach, respite services, day programs, transportation, therapies, equipment, and much more.
- Register now, when records documenting DD are current and available.
- It is a waiting list; there is no guarantee services will be provided.



2. Government Benefits

What Benefits are Available? Cont.

Social Security Disability Insurance (SSDI):

Two ways to qualify:

- (1) Earn In on Own Record
 - Earn 6 credits before age 24. After age 24, credit requirement increases.
 - Medicare Eligibility after 2 years
 - Credit = \$1,810 earnings (2025)
- (2) Qualify As Disabled Person on Parent Record
 - If Disability began before age 22
 - Auxiliary benefits are based on a parent's SS benefits ("CDB benefits")
 - CDB Benefits – 50% SS Retired Parent; 75% SS Deceased Parent
 - Medicare Eligibility after 2 years
 - No asset limitation
 - Must never have exceeded SGA (\$19,440 annually – 2025 or \$1,620/month).

Medicare:

- Health Insurance, Hospital + Medical Coverage, Prescription Drugs
- Automatic eligibility after receiving SSDI benefits for 2 years
- Does not provide residential/nursing home benefits
- Does not provide Medicaid waiver services
- Qualified individuals should enroll in both Medicaid and Medicare (referred to as "dual eligibility")
- Critical for individuals turning 26 and losing eligibility under parent's plan



Supplemental Security Income (SSI)

A. Disability – (Category or 'diminished work capacity')

- Do you have evidence to meet SSA's and DHS's definition of "disability"?
- Disability: An impairment that severely limits ability to engage in Substantial Gainful Activity ("SGA"). SGA = \$19,440 (\$1,620/month, 2025)

B. Financially:

- Confirm your child does not own more than \$2,000 in assets in his/her name and will not in the future.
 - Establish a Special Needs Trust for future inheritance



2. Government Benefits

Obstacles Parents Face in Providing Evidence of Impact of Impairment on Ability to Work

OBSTACLES

- Not enough *recent* evidence
- Assessments Outdated or Nonexistent
- “Diagnosis doesn’t matter” philosophy
- Where IQ score needed, must be after age 17 (timing issue)
- IEPs strength-based; paint inaccurate picture to outsiders
- No trial work experiences



2. Government Benefits

Generate 'Evidence of Impact of Impairment on Ability to Work'

Collaborate with your IEP Team

- Request adult-measure IQ testing where ID suspected
- "Accurately reflect support (aide, peer, when needed, consequence of absent support)
- Ask that IEPs include a description of challenges; strength-based IEPs paint inaccurate picture to outsiders
- Describe internships or practical scenarios as if to an outsider
- Brainstorm and implement trial work scenarios; detailed report on outcome (accuracy, time spent, success rate, support used, cooperation with others, interaction, obstacles, etc.) Examples of tasks - sorting mail, delivering items to teachers, "assisting" in other classes, library help, making copies, café)



2. Government Benefits Providers - Evidence of Impact of Impairment on Ability to Work

Collaborating with your Medical/Therapeutic Team

- Medical Report; Records
- Consider vocational assessment (targeted to SSA)
- Ask outside professionals to include recommendations in reports
 - Assistance with activities of daily living, "substantial" support needs, support managing medication, "structure" needs, detailed accommodations needed at home, school and community
- Share outside reports with IEP Team and integrate/cross reference reports results in IEP.



B. Financially:

Confirm your child does not own more than \$2,000 in assets in his/her name and will not in the future.



Consider – all bank accounts, savings bonds, UTMA accounts, some life insurance, accounts opened by grandparents/family members. (accounts co-owned with another do count!). 529 Plans do not count; parent is considered the owner.



1. Make a list of your child's accounts.
2. List all savings or other bonds.
3. Include UTMA accounts and life insurance.

Importance of a Special Needs Trust



The Special Needs Trust

- Remember, in order to qualify and maintain your child's eligibility for government benefits, your child cannot own more than \$2,000 in his/her name **and will not in the future.**
 - *How can I leave money to my child when I die?*
 - *How can I organize care and support for my child?*
 - *How can I plan around the \$2,000 asset limit?*
- An important solution: **The Special Needs Trust**



The Special Needs Trust

- Can hold unlimited funds which are not counted toward the \$2,000 limit.
- Required for various IL pensions (example: TRS).
- Allow parents to protect eligibility for government benefits.
- Funds can be used for services and items needed by your child.
 - Just one aspect of the Trust!
- Is a life plan for your child: Who will manage the funds? Who will provide guidance and care for your child after you are gone? Who will be involved in your child's plan?
 - Memorialize your vision for your child in this critical document.
- SNT is the governing document/plan after your death.
 - Roadmap for child's life.



Roles in the Special Needs Trust

- Trustee: Manages the SNT for the benefit of the beneficiary
- Trust Advisory Committee: Supports the Trustee in making the best possible decisions for the beneficiary's well-being
- Advocate: Ensures the beneficiary's needs are met; advocates for services
- Care Manager: Coordinates and evaluates the beneficiary's care; ensures healthcare and care plan is appropriate
- Trust Protector: May amend SNT if needed due to changes in the law



Role of Trustee in the Special Needs Trust

- Inquire into and manage needs and welfare of the beneficiary
- Spend assets on the beneficiary's needs; make expenditure decisions
- Maintain eligibility for government benefits
- Report to agencies administering benefits
- Work with family members, professionals, and others to support beneficiary
- Invest trust property
- Account for expenses
- Tax reporting



Consider employing a professional Trustee!



Role of Trust Advisory Committee in the Special Needs Trust

- "Circle of Support" around your child and the Trustee
- One Trustee and an Advisory Committee
 - Usually 3+ members
- Weigh in on significant decisions and can contribute knowledge and expertise
 - Serve as a sounding board
 - Trusted individuals who know the beneficiary and your family
- Can review the "books" and review all expenditures
- Provides Trustee with support and help; preserves longevity
- Committee can be family, friends, professionals



Role of Trust Protector in the Special Needs Trust

- Person to serve as another pair of eyes for the beneficiary
- Can be given power to fire Trustee if he/she not performing
- Has access to records and accountings
- Make technical changes to Trust so it stays in compliance if laws change
- Helpful feature as Special Needs Trust becomes irrevocable upon Grantors' passing



Role of Care Manager/Advocate in the Special Needs Trust

- Another tool that can be used to support the Trustee in ensuring the Beneficiary's needs are being met
- Create detailed "care plan" for Beneficiary
- Coordinate and evaluate the Beneficiary's existing care to make sure it is appropriate, efficient, and thorough
- Determine if the Beneficiary is receiving all available services and public benefits
- Advocate for services the Beneficiary requires
- Visit the Beneficiary to inspect and review home care
- Speak with the Beneficiary's medical personnel to make sure health care is appropriate and care plans are being followed; medication management
- A great solution if family members do not live in the same area



Letter of Intent

- A document written by you to help others learn important information about your child
- Serves as a guide for future caregivers, guardians, and trustees when making decisions for your child
- Gives direction for your child's care, living arrangements, goals, and quality of life
- Highlights personality traits, allergies, routines, calming strategies, hobbies, medical care plans
- A critical part of your special needs plan and trust



Aligning your Plans

- The Special Needs Trust, alone, will do nothing unless it is a part of a cohesive estate plan.
 - A comprehensive estate plan generally consists of wills and trusts. The Will and Trust then direct inheritance to the child's Special Needs Trust.
 - Without a Special Needs Trust, your child will inherit directly and exceed your child's \$2,000 limitation!
 - Exceeding \$2,000 limitation will cause interruption and/or termination of your child's benefits.
- Ensure that the Special Needs Trust is set up to be funded:
 - Beneficiary Designations
 - By Will
 - Financial Planning (IRAs, Insurance)



Action Items



Action Items

High Priority:

1. Register your child on the PUNS list.
2. Review current and most recent IEPs for "evidence".
 - 2a. Identify whether additional testing is necessary and schedule or docket for IEP team; next annual meeting; raise issue now.
3. Gather most recent assessments and professional reports.
4. Audit your assets- plan for resources and in the future.
5. This planning can be difficult and time-consuming for "catching up". In some cases, omissions can cause irreversible damage to a child's eligibility for some benefits.



4. Transition Planning: Action Items



- ✓ Take stock of your current plan and your child's age to best determine the priority of your next steps. What needs to be done?
- ✓ Identify your goal and work backwards to prepare a timeline.
- ✓ What tasks can you assign to others / take off your plate?
- ✓ What tasks are not time sensitive and can be done in "down" time?
- ✓ Don't delay. It will take time to put together a plan, complete necessary tasks, visit with providers or conduct testing, and work with an attorney.



Take a Deep Breath

Thinking about this planning is overwhelming. (We know, we've been there.) We will help you through the steps!

- We will guide you with an overall process, one piece at a time.
- We will help you keep the pace and accomplish each step of the plan.
- Having a solidified plan will bring you comfort and assurance that you are taking control of your child's future and resources.



Our Team

Our Special Needs Planning Law Practice

- Estate Planning for Parents
 - Wills/Trusts
- Designing a Special Needs Trusts and Life Plans
- Guardianship/POA
- Benefits Consulting
 - SSI/SSDI
 - Medicaid/Medicare
- Life Planning
- Consulting Services
 - Impact of Divorce
 - Probate & Trust Administration
 - Life Planning/CILA/Independent Living



Ready to Act?

Schedule a
Consultation



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Bonus- ABLE Accounts



ABLE Accounts

- Achieving a Better Life Experience
- Bank account for a person with a disability
 - Owner and beneficiary
 - Anyone can contribute
- Disability onset before age 46*
- Can be used for qualified disability expenses



Health



Education



Housing



Transportation



Legal Fees



Financial
Management



Employment Training
& Support



Assistive Technology
& Personal Support
Services



Oversight &
Monitoring



Funeral &
Burial



Other Approved by
Treasury Regulations



ABLE Accounts

- Up to \$100,000 does not count as assets for SSI purposes
- Up to \$19,000 in contributions per year
 - Earnings of an employed individual with a disability can also be deposited up to \$15,060

<https://www.illinoisable.com/>



Does my child need an ABLE account?

- Is your child receiving public benefits?
- Is your child working?
- Does your child need to access funds?
 - Pay for day-to-day expenses
- Does your child use a debit card?
- Does your child currently have money in his/her name?

