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

Kate Devine Schye

"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

- What steps do I need to take to prepare for transition to adulthood?
- How can I continue to help my child make decisions and access services?
- How will I protect the assets and benefits that I have established for my child?
- How do I identify the right people/team to manage my child's care when I am gone?
- How do I build a secure financial and life 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?

My Goal for this Presentation:

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

In this Presentation:

- Decision Making Tools
- Government Benefits Review
- Importance of a Special Needs Trust
- Letter of Intent
- Action Items
- Questions

Decision Making Tools

755 ILCS 9/15

Sec. 15. Presumption of capability.

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

How can I still help my child make decisions when he or she turns 18? What tools are available?

Decision Making Considerations: First Step

- 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
  - Vulnerable to exploitation/Protective

Decision Making: Available Tools

Least parental involvement ↔ ***Most oversight possible***

Supported Decision-Making

- Consists of a "Principal" and "Trusted Supporter"
- Not well recognized with healthcare and financial institutions
- Difficulty implementing; mixed results

Powers of Attorney

- Health Care
- Property
- Person retains decision making ability
- Revocable
- Capacity preserved
- Well recognized; statutory

Guardianship

- Plenary or Limited
- Person and/or Estate
- "Permanent"
- Guardian becomes sole decision maker
- Can – and should- include ward in decisions; but guardian has final say
- Granted by Court

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/routine and emergency
    - Financial consequences and undue influence
    - Ease of interacting with agencies like SSA, DHS, DRS

Decision Making Considerations: POA and Guardianship Timing and Process

- **Supported Decision Making – when decided by person with disability**
  - https://gac.illinois.gov/supported-decision-making.html
- **POAs – 1 week before 18th birthday**
  - Decision making capacity
  - Verbalize continuation of parental involvement
  - Requires proper notarization and witnessing
- **Guardianship – 2-3 months**
  - Court process; county/Judge specific; timeline

Government Benefits Review

Government Benefits:
What Benefits are Available?

Generally, eligibility for benefits begins at age 18.

- **Supplemental Security Income ("SSI")**
  - Monthly Cash Benefit (2026, $994/month)
  - Must have "disability" and financially needy (assets less than $2,000)
  - Lengthy application process; plus 14-18 month average approval
  - 3 year look back period
- **Medicaid**
  - Health Insurance, Prescription Drugs
  - Home Based Waiver OR CILA Residential programs (PUNS List)
  - Long term supports
- **Social Security Disability Income (SSDI)**
  - Benefit for those who are working, even minimally, or have a parent who receives social security or has died ("CDB benefit")
- **Medicare**
  - Health Insurance, Hospital and Medical Coverage; Prescription Drugs
  - Automatic eligibility after 2 years of SSDI

*These are not guaranteed benefits!

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 = $20,280 ($1,690 / month, 2026)

B. Financially:

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

OBSTACLES

- Not enough *recent* evidence
- Assessments Outdated or Nonexistent; IEP Team doesn't suggest repeat testing; parents didn't authorize testing;
- Assessments Nonexistent; Parents didn't seek or authorize
- "Diagnosis doesn't matter" philosophy
- Where IQ score needed, must be after age 17 (timing issue)
- IEPs strength-based; paint inaccurate picture to outsiders
- IEP respectfully silent on key issues
- No trial work experiences

B. Financially:

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

Consider – all bank accounts, savings bonds, UTMA accounts, some life insurance, accounts opened by grandparents/family members. (accounts co-owned with another <u>do</u> count!). 529 Plans <u>do not</u> 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

- Protect Benefits
  - $2,000 asset threshold in SSI
  - Child can receive inheritance
  - 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.**
- Develop a Life Plan
  - Identify people or professionals to step in
  - Organize care and support for your child
- An important solution: **The Special Needs Trust**

The Special Needs Trust

- Federal laws allow individuals to transfer money into a Trust and hold it aside for a beneficiary
- Can hold unlimited funds which are not counted toward the $2,000 limit.
- Required for various IL pensions (example: Teachers Retirement System)
- Funds can be used for services and items needed by your child. Just one aspect of the Trust.

The Special Needs Trust

- Should include a life plan for your child
  - Who will manage the funds, care and advocacy?
  - Trust Advisory Committee will provide support and guidance to Trustee and your child
- Appoint a group of trusted family and friends to participate in different roles in the SNT.
- SNT is the Roadmap for your child's future.

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 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 personal non-legal 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
- Clancy & Associates does a Legal of Intent Clinic on Zoom in January every year

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

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? This depends on the age of your child.
- ✓ Consult with attorney to establish Special Needs Trust and Estate Plan
- ✓ Organize and keep track of all individualized education plans (IEPs), diagnostic reports, and professional reports.
- ✓ Identify which decision-making tool is most appropriate when your child turns 18.
- ✓ Write your child's care plan (Letter of Intent) – this can be used now!
- ✓ Begin asset planning now – ensure that your child does not have more than $2,000 in his or her name.
- ✓ What tasks are not time sensitive and can be done in "down" time?

Parent Timeline: Action Items Based on Age of Child

EARLY CHILDHOOD (0-12 years)

• Register your child on the PUNS list.
• Keep complete records of individualized education plans (IEP), diagnostic reports, and professional reports.
• Do not open financial accounts or purchase savings bonds in your child's name.
• Establish a relationship with a qualified Special Needs Planning Attorney.
• Focus on therapies, services, and a well-developed IEP.

THE TEEN YEARS (13-16 years)

• Verify your child's PUNS registration is current.
• Encourage and incorporate "work" experiences at school via the IEP.
• Consult with a Special Needs Planning Attorney to evaluate government benefit eligibility.
• Collect documents and diagnostic reports to prepare for SSI Application.
• Ensure your child does not have assets exceeding $2,000.
• Begin Transition Planning with IEP Team when your child is 14 ½.
• Prepare a Special Needs Trust and your own Estate Plan.

ADULTHOOD — REACHING AGE 18

• Confirm your child's assets do not exceed $2,000.
• Confirm your child's registration on the PUNS list is current; consider changing category to "seeking services."
• Meet with your Special Needs Attorney to review the following Transition topics:
- Determine if Guardianship or Powers of Attorney is appropriate.
- Evaluate the IEP/Transition Program for alignment with your goals and future plans for your child.
- Enroll in Medicaid (approval is automatic if SSI approved).
- Prepare for SSI application.

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
  - Coaching you through evidence gathering, deadlines, and connecting you with resources

Take a Deep Breath

We know thinking about this planning is overwhelming.
We will help you through it!

QUESTIONS?

Ready to Act?

Schedule a Consultation

Sign Up For Our Newsletter

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