STETSON UNIVERSITY

2026 National Conference on Special Needs Planning and Special Needs Trusts

My Cloudy Crystal Ball

Planning for Special Needs Beneficiaries Throughout Their Lifetime in an Era of Change

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One Big Beautiful Bill Act of 2025 (H.R. 1)

- Introduced sweeping changes to Medicaid
  - Work requirements (mainly ACA Medicaid)
- More frequent eligibility checks
- Less retroactive coverage
- Large federal funding cuts and new state limits
  - Projected $793B to $1.02T in cuts over next ten years
- Narrower immigrant eligibility
- Potential losses for dual-eligible beneficiaries

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Change Is Inevitable

- Benefit laws ~~may~~ will change
- Social service systems will change
- Housing models, health care, technology, etc. will change
- Trustees and advisors and advocates will change
- Kathy's condition may change
- Kathy's preferences, needs, abilities and relationships will change
- State and federal administration attitudes may change
- The amount of resources Kathy needs may change

The goal is not to predict the future. The goal is to build a plan that can adapt when initial predictions are incorrect.

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Kathy

- 17 years old, significant developmental disability
- Physically healthy - could live into her 70s
  - Trust may be operating into the 2080s
- Will need decision-making support, advocacy, and coordinated services for decades
- Social service systems will change
- Her condition may change
- Her advocacy system may change
- Attitudes may change
- The amount of resources she needs may change
- A 17 year old today may live into the 2090s

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Looking Back: 70 Years of Disability Policy

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19th- and early 20th- century origins

In the mid-1800s, social reformers advocated for the creation of public hospitals for people with mental illness and developmental disabilities.

The idea was to provide a **humane alternative** to jails and almshouses, where many people with mental illness were previously confined.

States built large institutions on rural campuses — these were often self-contained communities, including farms, workshops, and living quarters.

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Results

- Reliance on:
  - sustained funding
  - adequate staffing
  - manageable populations
  - meaningful oversight
- Admissions increased
- Resources failed to keep pace
- Overcrowding
- Understaffed
- Therapeutic aspirations -> custodial care

Reformers didn't lack compassion - service model deteriorated when operating conditions changed.



Burton Blatt & Fred Kaplan, Christmas in Purgatory: A Photographic Essay on Mental Retardation (1966)

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Deinstitutionalization & Federal Expansion

Community Health Act of 1963

- Brought about through advocacy from investigative reporting, family advocacy litigation and disability-rights organizations
- Signed by President Kennedy
- Shift from institutions to community care
- Federal grants to Community Mental Health Centers (CMHCs)
- Planned for 1,500 - 2,000 CMHCs nationwide - fewer than half were built
- Funded construction but not staffing
- State hospital populations dropped and many people gained more independence
- May have led to more homelessness and incarceration of people with disabilities

Mental Health Systems Act of 1980

- Brought about through the President's Commission on Mental Health (1977-78), chaired by First Lady Rosalynn Carter
- Signed by President Carter
- Aimed to fixed gaps of 1963 Act:
  - Focus on ongoing services
  - Gave states a larger role in planning and coordinating care
- Prioritized chronic, serious mental illness and underserved populations
- Recommended a "bill of rights" for people receiving mental health care
  - Confidentiality
  - Informed consent
  - Freedom from unnecessary restraint
  - Treatment in the least restrictive setting
- Largely repealed within a year

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The 1981 Retrenchment

Omnibus Budget Reconciliation Act of 1981 (OBRA '81)

- Repealed major portions of the Mental Health Systems Act of 1980
- Signed by President Reagan
- Created Medicaid Home and Community-Based Services (HCBS) waivers
- Made continued Medicaid eligibility the centerpiece of many disability plans
- Shifted funding to block grants, thus giving states more discretion
- Allowed states to disregard family income
  - Allowed states to apply institutional eligibility rules, eliminating some "deeming"
- Introduced waiting lists for services as waivers had to be cost-neutral when compared to institutional care
  - Note: impact on planning if a beneficiary moves states
- Created Medicaid "freedom of choice" waivers

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State Issues

Texas

- According to The Arc of Texas Harris County and related provider data, over 158,000 Texans with disabilities are waiting for HCBS waiver slots
- Corpus Christi State School "fight clubs"
- State Supported Living Centers (SSLCs)
  - U.S. Department of Justice and state of Texas entered into a settlement agreement in 2009 addressing conditions and practices at 13 state facilities (protection from harm, health care, discharge planning, etc.)
- System relies heavily on discretionary funding and constrained capacity

Virginia

- 2012 U.S Department of Justice vs. Virginia settlement
- DOJ concluded that VA violated the Americans with Disabilities Act by unnecessarily institutionalizing people with IDD
  - Cited insufficient community services, unreasonably long Medicaid waiting list and inadequate discharge planning
- Settlement expanded HCBS waiver slots, family support programs, and integrated employment and housing options
- VA agreed to phase out 4 of 5 "training centers" and spend $2.1B over the next decade to expand community-based care
- Case is still listed as "ongoing"

New Hampshire

- 2013 U.S Department of Justice vs. New Hampshire settlement
- DOJ concluded that NH violated the Americans with Disabilities Act by failing to provide enough community services for people with mental illness in the most integrated setting
- Settlement established the Community Mental Health Agreement
  - NH expanded Assertive Community Treatment to cover at least 1,500 people statewide
  - Added hundreds of supported housing units
  - Reformed transition planning for people leaving two state institutions
- NH received notice of noncompliance in 2021 - with a court approved plan in 2023
- Case and oversight remain ongoing

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Adaptation Can Work

California

- Short-Doyle Act of 1957
  - Supported locally administered county community mental-health programs well before federal initiatives - initially matching funding 50/50
  - Strengthened by the Lanternman-Petris-Short Act of 1967
    - Limited involuntary commitment and pushing care into community hands
  - Faced state financing formulas, deinstitutionalization, Medi-Cal changes, administration priority shifts, etc.
    - Funding shifted to sales tax and vehicle license fees
  - Still the backbone of CA's public mental health system

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H.R. 1

- Does **not** eliminate Medicaid
  - Important exclusions apply to many people with disabilities and caregivers
- Risk = **not** substantive eligibility; rather, procedural failure
  - Increased reporting obligations
  - Shortened eligibility windows
  - Heightened verification requirements
- Temporary lapses in compliance may result in:
  - Benefit suspension
  - Service disruption
  - Loss of provider relationships
  - Wait lists
- Medicaid Community-Engagement requirement
  - CMS interim final rule (June, 2026)
    - Applies to specified non-pregnant adults (ages 19-64) eligible for Medicaid adult group or comparable coverage
    - Recognizes statutory exclusions and exceptions
    - I.e., does **not** apply to every Medicaid beneficiary with a disability

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Over the past 70 years

- Since the 1950s, the U.S. has experienced more than a dozen significant policy reforms affecting disability services,
- at least seven major economic recessions,
- multiple periods of high inflation and economic growth,
- over a dozen foreign conflicts or military operations, dramatic increase in climate-related natural disasters and
- At least 5–10 major social or global crises (pandemics, civil unrest, large-scale disasters)

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Static Special Needs Planning Is Fragile

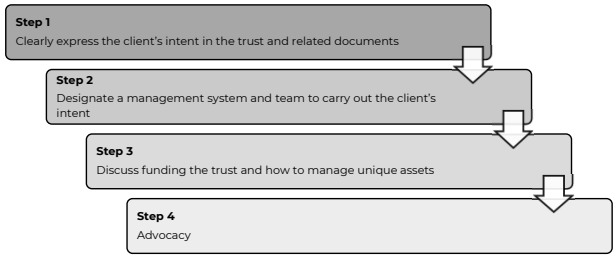
- SNTs
  - Must be drafted with careful attention to current eligibility requirements and technical compliance
    - May overvalue present-day benefit structures
    - May underestimate human turnover
      - Trustees, advisors, care providers, advocates, family
      - Needs to contemplate preservation of knowledge of beneficiary
    - May underestimate cumulative change
      - Service reductions, administrative requirements, housing issues, provider closures, benefit gaps

A long-term plan should be designed to remain useful after the assumptions that produced it are no longer valid.

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4 Step Process



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Step 1: Grantor Intent

- One of the trustee's fundamental duties is to administer the trust in accordance with the **grantor's intent**.
- A bare bones trust that only focuses on preserving eligibility for SSI and Medi-Cal will lack the proper directions needed for a trustee to carry out their duties.
- Proper documentation of the grantor's intent, will allow the trustee to understand the grantor's values and objectives
- **The SNT should have broad information** for overall guidance to the trustee and advocate.
- The letter of intent should give more detailed information.
- Think of the letter of intent as a journal of ongoing documentation of the beneficiaries needs.

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Step 2: Choice of Trustee

- Family
- Private Fiduciary
- Corporate Trustee
- Pooled Trust

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Step 2: Family and Friends as Trustee

- There is always an inclination to appoint family members as successor-trustees of Special Needs Trusts.
- Many family member trustees fail because they are not adequately prepared to navigate the complexities of benefits eligibility and the coordination of necessary services.
- This does not mean that family should not be included. This means only that they play more of a supervisory role.

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Step 2: PSNTs

Pooled Special Needs Trusts (PSNTs)

- Provides continuity beyond parents, siblings, trustees, advisors, service providers
- Robust knowledge of public benefits
- Person-centered approach
- 3rd Party standalone SNT administration
  - Successor trustee
  - Test run during settlor lifetime
  - Periodic funding
  - Spend-down/consolidation
  - Distribution advisor

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Step 2: Model

The Trustee Directed by a Trust Advisory Committee

Trustee Duties:
Manage assets, make distributions, file taxes, and maintain records.

Oversight:
Trust Advisory Committee or trust protector advises distributions, may amend terms, or replace the trustee.

Care Management:
Care manager assesses beneficiary needs and supports the management team.

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Step 2: Trust Advisory Committee

- Promotes settlor intent and beneficiary involvement
- May weigh in on discretionary distributions
- May be tasked with development of distribution plan
- Supporters may act as part of Committee
  - Best Practice: identify any conflicts of interest (e.g., remainderperson, housemate, etc.)

From Wealth Counsel:

"The Trust Advisory Committee shall consist of a minimum of 3 members, but no more than 5 members to be determined by the chairperson(s) then serving. If any member of the Trust Advisory Committee is unwilling or unable, for any reason, to act or continue to act as a committee member, the chairperson(s) then serving may decide whether or not to fill the vacancy. However, there shall be at least three (3) members serving at all times. If there are fewer than 3 members serving and the chairperson(s) then serving are unable or unwilling to appoint a successor committee member, the Trustee may appoint the successors."

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Sample Language

Distribution Advisement

The Trust Advisory Committee will advise the Trustee regarding distributions believed to be in Tommy Trojan's best interests, including, but not limited to, distributions for supportive services and major purchases as outlined in this Section. Before the Trustee distributes trust property as authorized by this agreement, the Trustee may first seek the Trust Advisory Committee's advice and recommendations, but is not required to do so, and may make a distribution without contacting or soliciting the advice of the Trust Advisory Committee. This Section in no way affects the sole and absolute discretion of the Trustee under this agreement.

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Step 2: Trust Protector

- Promotes settlor intent and beneficiary involvement
- May remove trustee
- May amend trust document for changes in law, public benefits, etc.
- May weigh in on discretionary distributions
- Supporters may act Trust Protector
  - Best Practice: identify any conflicts of interest (e.g., remainderperson, housemate, etc.)

From Bradley J. Frigon, JD, LL.M (tax), CELA, CAP:

"The Trust Protector may amend any provision of this Agreement, as it applies to any Trust for which the Trust Protector is serving, pursuant to [subsequent restrictions]. Notwithstanding the foregoing, the Trust Protector may not amend this Agreement in any manner that would make Trust corpus or income available to the Beneficiary for Medicaid eligibility. Further, the Trust Protector may not limit or alter the rights of the Beneficiary in any Trust assets held by the Trust before the amendment, nor may the Trust Protector remove or add any individual or entity as a beneficiary of any Trust asset."

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Step 3: Funding

How Much Should a Parent Set Aside for the Needs of their Child with a Disability

- "This is nearly impossible to answer — much like asking how many angels with disabilities could fit on the head of a pin."
- Even so – it may be time to rethink funding and probably dig deeper.

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Step 3: Funding

Distribution Plan/Tax

- Third-party Special Needs Trusts are treated as complex trusts under the Internal Revenue Code—making them tax-sensitive vehicles.
- A detailed distribution plan allows the attorney, CPA or tax preparer to align strategy with execution, identify deductible expenses, and structure income allocation effectively.
- The plan ensures advisors are working from the same set of priorities, timelines, and financial realities.

The tax advisor can:

- Optimize income distribution between trust and beneficiary
- Leverage deductions (e.g., care management, medical costs)
- Reduce tax drag over time
- Third-party SNTs operate similarly to bypass trusts:
  - they accumulate income,
  - face compressed tax brackets, and
  - require strategic income management.
- The distribution plan makes that strategy possible.

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Step 3: Funding

Distribution Plan/Financial Advisor

- Annual Distribution Planning: The trust required yearly reviews of living needs, health care, and long-term financial sustainability.
- Actuarial Projections: Financial advisors used actuarial modeling to assess whether trust assets could support projected distributions over time.
- Fiduciary Discipline: Projections guided the trustee and management team, preventing overextension and supporting prudent, budget-like decision-making.
- Aligned Investment Strategy: A clear distribution plan enabled asset allocation to be structured around real-world needs rather than guesswork.

The Distribution Plan and Sustainable Services

- The distribution plan also serves a critical role in determining which services are appropriate and sustainable for someone like Kathy.
- During planning discussions, it is not unusual to identify potential distributions that may be beneficial in theory—such as private housing upgrades, intensive therapies, or luxury recreational opportunities—but that may not be actuarially sound over the lifetime of the trust.
- Public benefits are a tool, not the ultimate objective.
- Plans may be dependent upon funding
- Consider prioritizing expenditures that promote long-term independence or prevent larger future costs

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Step 3: Funding (Budget)

Cost/Benefit Analysis: Identify those expenses that may be covered by public benefits. Consider 1/3rd ISM reduction

Transportation: Own vs. Lease?

Housing: Own vs. Rent?
- "Hidden" costs (insurance, utilities, taxes, maintenance, etc.)

Trust Longevity simulation:
- **TIP: adjust for inflation (not just CPE, but also food and medical)**

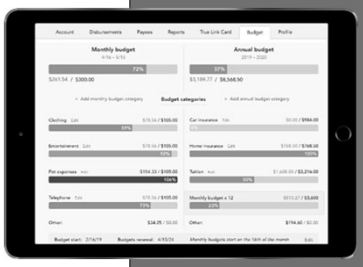
Budget for professional costs and fees

Optimal Outcomes:
- Start a business, attend college, travel, retirement
- Remainder person considerations
- **TIP: record all for future use**

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Step 3: Funding (Budget)



For illustrative purposes only.
Trust Administration Software provided by True Link Financial, Inc.

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Step 3: Funding (Qualified Plans)

Qualified Plans

A **qualified plan** is an employer-sponsored retirement plan that satisfies the requirements of the Internal Revenue Code Section 401(a) and ERISA, allowing it to receive favorable tax treatment for both employers and employees.

Examples include:

- 401(k) plans
- Defined benefit (pension) plans
- Profit-sharing plans
- Money purchase pension plans

Unique Assets

- **Real Estate**
  - Planning for Appropriate Housing can be difficult.
  - Funding the SNT with real estate pros and cons.
- **Qualified Plans**
  - Should consider the tax implications of SECURE and SECURE 2.0
  - SNT is an Eligible Designated Beneficiary

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Designing an Adaptive System

- ✔ **Design trusts to be flexible**—not just to preserve benefits, but to replace them if they disappear or the quality is unacceptable
- ✔ **Build in private care support** options: care managers, professional fiduciaries, pooled trusts, and advisors.
- ✔ **Create sustainable distribution plans** that anticipate surges in care costs and reductions in service availability.
- ✔ **Consider allocating more to the SNT** in anticipation that services may not be available or lack quality

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Step 4: Advocacy

- Long Medicaid HCBS waiver waitlists leave families providing care for years
- Many states heavily on unpaid family caregivers due to capped community services
- Caregiving responsibilities increasingly include medical and behavioral support
- Workforce shortages and service gaps intensify family strain
- Preservation of beneficiary's history, communication style, health, warning signs, preferences, relationships, etc.
- Assets transfer to a trust - advocacy does not

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Advocacy

Planning issue	Adaptive design response team
Change in public benefits or services	Trustee or pooled-trust administrator discretion to supplement or temporarily replace supports; periodic reassessment of available benefits and services.
Parent or sibling can no longer advocate	Care-manager role, advisory committee, designated advocates, and documented beneficiary preferences, history, and communication needs.
Trustee turnover or administrator succession	Successor-fiduciary process, organized records, written annual plans, and a governance mechanism capable of replacing a poorly performing fiduciary.
Service or provider failure	Authority to change providers, fund interim supports, and obtain independent assessment or care management.
Change in beneficiary needs or preferences	Recurring review that includes the beneficiary to the greatest extent practicable and revisits goals rather than merely prior spending patterns.
Geographic move	Reassess state-specific benefit rules, waiver or interest-list access, providers, housing, and the local support network.
Funding pressure	Multi-year cash-flow review, reserves where appropriate, and an explicit process for prioritizing quality-of-life expenditures.

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Step 4: Advocacy

Care Management

- In many cases, utilization of a care manager can assist in coordinating services for the beneficiary.
- Can often identify issues such as over medication, safety issues, or care giving issues.
- Some are skilled in analyzing benefits and services that may be available.

Supported Decision-Making

- Least restrictive alternative
- Person-centered planning opportunities
- Beneficiary empowerment
- Support system

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Ethical and Professional Considerations

- **Policy volatility heightens demand** for planners to counsel about long-term risk, trade-offs, limits of predictability
- **Fear based planning** creates pressure to draft around latest media coverage or perceived threats
- **Counsel should help families** understand that preservation of benefits may conflict with other objectives: safety, autonomy, housing stability, quality of life
- **Advising a family that private resources may be needed** is not pessimism - it's candid long-term planning.
- **Ethical planning must assume humility** as no planner can predict future legislation, technology, family circumstances, social conditions or beneficiary preferences and needs

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Designing an Adaptive System

- **Process over prediction**
- **Design trusts to be flexible**—not just to preserve benefits, but to replace them if they disappear or the quality is unacceptable
- **Future systems may offer** better supports, technologies, housing models, and forms of independence
- **Build in private care support** options: care managers, professional fiduciaries, pooled trusts, and advisors.
- **Create sustainable distribution plans** that anticipate surges in care costs and reductions in service availability.
- **Consider allocating more to the SNT** in anticipation that services may not be available or lack quality
- **Planning for change is not an exercise in pessimism** - it is a recognition of reality

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Thank You!

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