

## Navigating Distance & Disability

Legal and Fiduciary Approaches to Remote Caregiving

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## Introduction

- Families increasingly live far apart
- Care and decision-making often handled remotely
- Disability adds complexity to fiduciary roles
- Erosion of Medicaid Funded Service Systems

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## Case Study: Leonard & Diane Overview

### Leonard:

- 56 years old with lifelong intellectual disability
- No prior Medicaid/State Agency Support; cared for by parents at their home in rural community until their passing.
- Lives alone in senior housing with 24/7 staff (~\$500K/year)
- Relocated to more populated community for access to housing, homecare, and medical providers

### Diane:

- 64, lives in Idaho, guardian and SNT trustee
- Relies on solo care consultant in NY
- Runs her own business; successor has limited capacity

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## Case Study: Assets and Fiduciary Challenges

### Assets:

- SNT (~\$4.2M): conflicting language re: 'primary needs'
- Guardianship Estate (~\$7M): includes real estate, investments
- Multiple accounts complicate compliance and reporting

### Fiduciary Issues:

- SNT ambiguity about allowable distributions
- High staffing costs threaten sustainability
- Diane oversees complex legal and financial matters remotely

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## Case Study: Long Term Care and Succession Considerations

### Care Oversight:

- Dependent on one consultant with no backup
- 1:1 staffing being faded slowly to reduce cost
- Staff turnover, cost, and oversight challenges persist

### Housing and Benefits:

- Independent senior housing not ideal for needs
- State Agency options limited and potentially lower quality
- Leonard ineligible for Medicaid; planning needed

### Succession and Sustainability:

- Diane aging and overwhelmed
- Successor unlikely to provide equivalent involvement
- Urgent need for sustainable plan and local supports

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## Case Study: The Corporate Trustee Conundrum

Ampersand Trust Services is corporate trustee of a First-Party SNT

- Beneficiary: James, 37, with schizoaffective disorder and TBI
- SNT funded by PI settlement (~\$500K in liquid assets)
- Lives in group home in rural western Pennsylvania
- Receives Medicaid waiver services, SSI, and SNAP
- Ampersand Trust is based in upstate New York; trust officer has never met James
- No involved family members; relies on provider communication

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### Case Study: The Corporate Trustee Conundrum

1. Lack of Firsthand Knowledge:
  - Frequent turnover of trust officers
  - No direct contact with James or family supports
2. Inconsistent Communication:
  - Vague or delayed distribution requests
  - Minimal documentation from provider staff
3. Medicaid Substitution Issues:
  - Requests for items potentially covered by Medicaid
  - Ampersand lacks ability to verify service coverage

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### Case Study: The Corporate Trustee Conundrum

4. Staffing Supplement Requests:
  - Group home wants SNT to pay for private staff
  - Uncertainty about Medicaid adequacy and impact
5. Oversight of Disbursements:
  - Preparing for judicial review
  - Incomplete records complicate justification
6. Limits on Hiring Local Help:
  - Trust lacks express authority for care managers
  - Internal policy requires legal review for fiduciary roles

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### Legal Framework for Remote Caregiving

- Powers of Attorney
- Health Care Proxies
- HIPAA Authorizations
- Guardianship
- Supplemental Needs Trusts (SNTs)

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## Durable Powers of Attorney

- Common tool for financial and legal decisions
- Must allow for remote/electronic access
- May need to be accepted in multiple jurisdictions
- Address HIPAA

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## Health Care Decision Making

- Enables remote medical decision-making
- Should be accessible in emergencies
- Supplement with values statements when possible
- Supported Decision Making

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## HIPAA Authorizations

- Allows sharing of protected health info
- Critical for communication with providers
- Must be standalone, broad, and current
- Confirm if your state agencies have their own forms

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## Guardianship

- Court-appointed legal authority
- Understand scope and limitations under court order – Plenary vs. Least Restrictive Alternative
- Role in enrolling in and overseeing community-based services.

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## Supported Decision-Making

- Supports autonomy in decision-making
- Does not create agency authority
- Works best when layered with legal tools like POAs, Health Care Directives, or non-plenary Guardianships

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## Supplemental Needs Trusts (SNTs)

- Essential for maintaining means-tested benefit eligibility
- Allows trustees to support quality of life
- Must consider state-specific benefit rules

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## Remote Trust Administration

- Use care managers or local professionals
- Maintain clear records and rationale
- Ensure discretionary authority aligns with trust terms

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## Unique Challenges of Trust Administration

The law and practice in traditional fiduciary administration presumes that a beneficiary is competent and capable of communication and self advocacy.



Administration of trusts for beneficiaries who are cognitively compromised and live at a distance can present unique challenges in communication and support.

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## Unique Challenges of Trust Administration

- Beneficiary communication - beneficiary may be incapable of communication
- Documentation - family and informal supports may be unreliable, conflicted or dishonest, and formal supports (often through Medicaid funded programs) may be overworked or inept
- Distribution decisions must take into consideration rules and programs that are not within the traditional expertise of most fiduciaries, leaving a trustee unable to document the basis for its decision

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## Establishing a Protocol for Communication

- Establish a communication protocol that includes:
  - (1) the beneficiary if capable
  - (2) guardian/agent if available
  - (3) concerned family member/friend if appropriate
  - (4) educators/program staff if available

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## Establishing a Protocol for Communication

If there are no credible family supports, no court appointed guardian, no agent under power of attorney and no reliable Medicaid funded staff, the trustee should consider retaining a private case manager, social worker, or advocate to serve as its objective “boots on the ground” to obtain information the trustee can consider when making a distribution decision and otherwise support the beneficiary.

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## Approving Distributions: Determining Whether a Program Pays

- What it really means when a beneficiary is Medicaid eligible
- Availability of goods and services, availability of staff - consider staffing shortages around the country
- Ensuring available public services are adequately utilized

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## Approving Distributions: Adequacy of Alternatives

- Should a trustee supplement or supplant an available good or service?
- Availability vs. adequacy and appropriateness
- Before using trust assets to supplement or supplant a government funded good or service, trustees should have a process in place to confirm what the program is providing and a means to document the beneficiary would benefit from something better

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## Approving Distributions: Adequacy of Alternatives

Establish a validation process.

- Assess whether family or other informal supports are reliable
- Determine whether Medicaid funded staff can provide answers and support
- Retain a private case manager or other paid advocate to provide objective assessment of program eligibility, use, and adequacy and who can make credible recommendations

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## Impact of Distributions on Benefits

- Establish a process to verify financial benefits annually
- Establish a process to verify Medicaid funded and other available services on an annual basis
- Utilize a case manager or other professional to provide an annual assessment. These assessments serve as evidence that the trustee made an informed decision to supplement Medicaid funded supports and other publicly funded supports with private dollars and is relying on an objective source

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## Practical Considerations for Remote Caregivers & Fiduciaries

- True Link Cards
- Technical Support
- Sibling/Natural Support
- Companions
- Quality of life

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## Housing Transitions

- Weigh safety, services, and beneficiary goals
- Watch for Medicaid implications of relocation
- Always document decision rationale
- Trust owned Real Estate
- Location considerations

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## Conclusion

Distance increases complexity, not discretion

Combine legal tools, judgment, and human insight

Build and support a team, even from afar

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Thank you!

Tara Anne Pleat, Esq.  
Wilcenski Pleat Law  
[www.WPLawNY.com](http://www.WPLawNY.com)



Michael Cognito, MS. Ed & MBA  
Adirondack Case Management &  
Advocacy  
[www.ADKCMA.com](http://www.ADKCMA.com)



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