	Navigating Distance & Disability		
	Travigating Distance & Disability		
	Legal and Fiduciary Approaches to Remote Caregiving		
1			
		1	
	Foundties to account of the		
	 Families increasingly live far apart 		
	 Care and decision-making often handled remotely 		
	Introduction • Disability adds complexity		
	to fiduciary roles		
	•Erosion of Medicaid Funded Service Systems		
	ABEPTWORKE CASE MANAGEMENT A ADDOCACY		
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		1	
	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. 		
1	se Study: • Lives alone in senior housing with 24/7 staff (~\$500K/year) • Relocated to more populated community for		
	Diane access to housing, homecare, and medical providers		
	Overview Diane: • 64, lives in Idaho, guardian and SNT trustee		
	 Relies on solo care consultant in NY Runs her own business; successor has limited capacity 		
	сиринту		
	adirradack CASE MANAGARINT		

• SNT (~\$4.2M): conflicting language re: Case Study: • Guardianship Estate (~\$7M): includes real estate, investments Assets and • Multiple accounts complicate compliance **Fiduciary** and reporting Challenges Fiduciary Issues: • SNT ambiguity about allowable distributions • High staffing costs threaten sustainability Diane oversees complex legal and financial matters remotely adirondack WILCENSKI PLEAT LAW

4

Dependent on one consultant with no backup \bullet 1:1 staffing being faded slowly to reduce cost • Staff turnover, cost, and oversight challenges Housing and Benefits: Case Study: • Independent senior housing not ideal for needs Long Term Care State Agency options limited and potentially lower quality and Succession Leonard ineligible for Medicaid; planning needed Considerations Succession and Sustainability: Diane aging and overwhelmed Successor unlikely to provide equivalent • Urgent need for sustainable plan and local WILCENSKI PLEAT LAW

Care Oversight:

5

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 Case Study: in liquid assets) The Corporate • Lives in group home in rural western Pennsylvania Trustee • Receives Medicaid waiver services, SSI, and SNAP Conundrum • Ampersand Trust is based in upstate New York; trust officer has never met James • No involved family members; relies on provider communication adirondack CASE MANAGEMENT & ADVOCACY WILCENSKI PLEAT LAW

	Lack of Firsthand Kn Frequent turnover of tr No direct contact with supports	ust officers
Case Study: The Corporate Trustee	Inconsistent Commun Vague or delayed distr Minimal documentation	ibution requests
Conundrum	3. Medicaid Substitution	Issues:
	 Requests for items pot Medicaid 	entially covered by
	 Ampersand lacks abilit coverage 	y to verify service
	adirondack CASE MANAGEMENT & ADVOCACY	WILCENSKI PLEAT LAW

4. Staffing Supplement Requests: • Group home wants SNT to pay for private staff • Uncertainty about Medicaid adequacy and impact Case Study: 5. Oversight of Disbursements: The Corporate • Preparing for judicial review • Incomplete records complicate Trustee justification Conundrum 6. Limits on Hiring Local Help: • Trust lacks express authority for care managers • Internal policy requires legal review for fiduciary roles adirondack CASE MANAGEMENT WILCENSKI PLEAT LAW



	Common tool for financial and legal decisions	
Durable Powers of Attorney	Must allow for remote/electronic access	
	May need to be accepted in multiple jurisdictions	
	•Address HIPAA	
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• Enables remote medical decision-making
 • Should be accessible in emergencies

Health Care Decision Making
 • Supplement with values statements when possible
 •Supported Decision Making



			_	
Guardianship	 Court-appointed authority 	ed legal	_	
	Understand scope and limitations under court order – Plenary vs. Least Restrictive Alternative		_	
	 Role in enrolling overseeing comm based services. 		_	
	adirondack CASE MANAGEMENT a ADVOCACY	WILCENSKI PLEAT LAW	_	

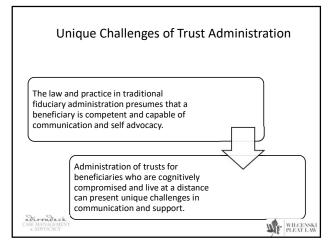
Supports autonomy in decision-making Supported DecisionMaking • Does not create agency authority • Works best when layered with legal tools like POAs, Health Care Directives, or non-plenary Guardianships **WORKS DESTRUCTION OF THE PORT OF

14

Supplemental Needs Trusts (SNTs) • Essential for maintaining means-tested benefit eligibility • Allows trustees to support quality of life • Must consider state-specific benefit rules

Use care managers or local professionals Remote Trust Administration Maintain clear records and rationale Ensure discretionary authority aligns with trust terms WILCENSE MANAGEMENT

16



17

Beneficiary communication beneficiary may be incapable of communication Documentation - family and informal supports may be Unique unreliable, conflicted or dishonest, and formal Challenges of supports (often through Trust Medicaid funded programs) may be overworked or inept Administration 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 WILCENSK PLEAT LAW adirondack

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





19

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.

CASE MANAGEMENT * ADVOCACY



20

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





• Should a trustee supplement or supplant an available good or service? Approving · Availability vs. adequacy and Distributions: appropriateness Adequacy of Before using trust assets to Alternatives 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 WILCENSKI PLEAT LAW adirondack

22

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





23

Impact of Distributions on Benefits

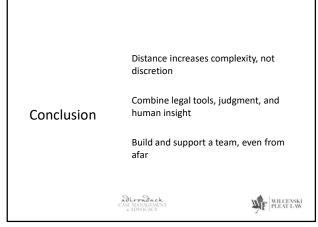
- Establish a process to verify financial benefits annually
- Establish a process to verify Medicaid funded and other available services on an annual basis
- Utilize a case manager or other professional to provide an annual assessment. These assessments serve as evidence that the trustee made an informed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





	True Link Cards
Practical Considerations	Technical Support
for Remote	Sibling/Natural Support
Caregivers & Fiduciaries	• Companions
	• Quality of life
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	 Weigh safety, services, and beneficiary goals
Housing	Watch for Medicaid implications of relocation
Transitions	 Always document decision rationale
	Trust owned Real Estate
	• Location considerations
	& ADVOCACY



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