

Beneficiaries with Disabilities are Among the Most Vulnerable-Once their Parents Die, Who's Looking Out for Them?

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About Amos Goodall

- Amos Goodall has been practicing law in State College since 1976. Before coming to Centre County, he was a judicial law clerk to Frederic S. Berman (NYC Criminal Judge and now NYS Supreme Court Justice), the late Gerard L. Goettel (SDNY Magistrate and later U.S. District Court Judge) and to the late Michael H. Sheridan, Chief Judge of the Middle U.S. District of Pennsylvania. He is certified as an elder law attorney (emeritus) by the National Elder Law Foundation (NELF), a Fellow of the National Academy of Elder Law Attorneys and is also a retired Fellow of the American College of Trust and Estate Counsel. He is immediate past president of the Board of the National Elder Law Foundation. He is a retired member of the Special Needs Alliance.
- Recognized as a Pre-Eminent attorney by Martindale Hubbell for over thirty years, he has been given status as a Super Lawyer in the area of Elder Law ever since that category was established. He was recognized as lawyer of the year for central Pennsylvania in Elder Law in 2016 and 2021 and Estate Planning in 2017. He received a lifetime achievement award by the Philadelphia Legal Intelligencer in 2021.
- He has received several professional awards, including the Powley Elder Law Award (for promoting in the minds of the general public a greater understanding of the rights and needs of the elderly and people with special needs) and the Theresa Alesandra Russo Foundation Award (for advocating for persons with special needs). In 2017, the Pennsylvania NAELA chapter named him as its attorney of the year. This year, he received an 2021 Achieva Award of Excellence for Legal Services for your extraordinary efforts on behalf of people with disabilities and their families.

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Disclosure

- Amos Goodall is one of the authors of Lexis Nexis Tax, Estate & Financial Planning for the Elderly, where his areas include Medicaid, SSI, Special Needs Trusts and VA chapters. He is also a co-author of Tax, Estate & Financial Planning for the Elderly: Forms & Practice.

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Goals of Course

- This session surveys strategies for “parents” to consider in order to provide the best destiny for their “children” with a disability.
- NOTE: Client may or may not actually be the “parent” of the person whose destiny is being addressed
- NOTE: The person whose destiny is being addressed may not actually be the “child” of the client.

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Clients' Expectations

As our clients leave the picture and their children continue to age, many want to assure that they have done everything possible to continue protection and nurture for their children.

This breakout session surveys a number of strategies, mainly based on State law, to facilitate this and to move it from a "hoping" goal to a "planning" goal.

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Why is This Important?

- Approximately 10% of persons over age 60 are the victims of elder abuse.
- Social isolation and mental impairment (such as dementia or Alzheimer's disease) are two factors. Recent studies show that nearly half of those with dementia experienced abuse or neglect. Interpersonal violence also occurs at disproportionately higher rates among adults with disabilities.
- *National Council on Aging, "Get the Facts on Elder Abuse" (2/23/21)*
<https://www.ncoa.org/article/get-the-facts-on-elder-abuse>.

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I Care A Lot/The Effective SNT—two cases



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Strategies

- Empowering the Child
 - Power of Attorney
 - Supported Decision-Making
 - Representative Payee/Advanced Designation of Representative Payee and Successor Representative Payee
 - Revocable Living Trust
 - Able Act
- Protecting the Child
 - Special Needs Trust: Creation
 - Special Needs Trust: Letter of Intent
 - Special Needs Trust: Trust Protector
 - Special Needs Trust: Trust Committee
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Empowering the Child (1)

- Capacity—
- Various standards (see written materials), generally determined under State law.
- Every person is presumed to be sui juris. Don't be afraid to be an advocate for the child.
- **Do Not Assume** any particular incapacitating condition absolutely bars a child from any participation determining his or her own future.
- Strategies need to be based on unique circumstances of each case in light of local standards.

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Empowering the Child (2)

“Caring for people with dementia requires respecting their autonomy and involving them in their care preferences as early as possible so their wishes can be known, while acknowledging their diminishing ability to make decisions,” said Orly Avitzur, MD, MBA, FAAN, President of the American Academy of Neurology. “This position statement offers guidance in accordance with core ethical principles, supporting the American Academy of Neurology’s mission to promote the highest quality patient-centered neurologic care.”

American Academy of Neurology, “AAN ISSUES ETHICAL GUIDANCE FOR DEMENTIA DIAGNOSIS AND CARE”, Press Release, July 12, 2021.
<https://www.aan.com/PressRoom/Home/PressRelease/4908>

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Power of Attorney

- Written Agreement. Comply with local statutes
- Powers
- Succession
- Supervision
- Note: Child Does Not Lose Power
- Supervision—POA Protector? Designate third party with power to enforce?

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Supported Decision-Making Arrangements

- Should be written agreement (if local law has statute, comply with that statute).
- Even without statute effective, de facto arrangement can be a defense to guardianship.
- “Supporter” someone designated to help child make and communicate decisions.
- “Monitor” someone designated to supervise supported in financial matters.
- Note: Child Does Not Lose Power

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Representative Payee Advance Designation of RP, Successor to RP

- Representative Payee—appointed by SSA to handle SS payments, generally by local office
 - Small, but cumulatively lucrative source of income for rapacious criminal
 - Child as beneficiary may designate persons in advance of need to be Representative Payee.
 - Must be a person, not organization
 - Can list and prioritize up to three persons in advance of need to be Representative Payee
 - Vacancy—if vacancy, no process.
- Strategy for Succession—parent writes and periodically updates annotated list of successors

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Revocable Living Trust

- Child probably does not have substantial assets, but even low value assets may be important to preserve
- Generally Court order creating guardianship does not affect previously created trust
- Consider “Sticky” Trust.
- Third party trustee can use Child’s EIN 26 CFR §301.6109-1(a)(2)(i)(B)
 - Must furnish tax information to Child (beneficiary)
 - Instruct Child that must be reported on child’s return
 - No other filing is necessary 26 CFR § 301.671-4(b)(2)(ii).

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ABLE Act Account

- Beneficiary (i.e., child) owns ABLE Act account
- Not a countable resource in PA and Child's deposits are not subject to fair consideration analysis—query whether Parents' deposits are allowed as transfers to child with a disability under 42 USC §1396p(c)(1)(J)(2)(A)(ii)?
- If Beneficiary lacks capacity, Fiduciary can open account and Fiduciary maintains control
- Do state rules allow owner to designate a third party to receive information?
- Remember, States by statute/regulation create ABLE Account system, but most States have contracted with financial houses (Fidelity, Vanguard, etc.) whose operations may not exactly reflect State's scheme.

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Special Needs Trust: Creation

- Provide funds to improve quality of life of Child—outside control of any guardian
- Engage fiduciary to be supportive of Child
- Identity of Fiduciary—professional or individual
- Favor current beneficiary
 - “Without limiting the Trustee's discretion, the Trustee may consider the needs of the Beneficiary as more important than the needs of any other beneficiary.”
- Provide encouragement and assistance to those helping Child.
 - Emily S. Unger et al., “Association Between New-Onset Medicaid Home Care and Family Caregivers' Health”, JAMA Health Forum. 2021;2(9):e212671. doi:10.1001/jamahealthforum.2021.2671 (9/17/2021); <https://jamanetwork.com/journals/jama-health-forum/fullarticle/2784386>

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Special Needs Trusts: Letter of Intent

- Precatory communication from trust creator to trustee
- Can be formal or informal
- Easily changed
- Available to Trustee to defend decisions
- SGY and LexisNexis forms attached to written materials
- Achieva-Personal Planning Guide Link in written materials

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Special Needs Trusts: Trust Protector

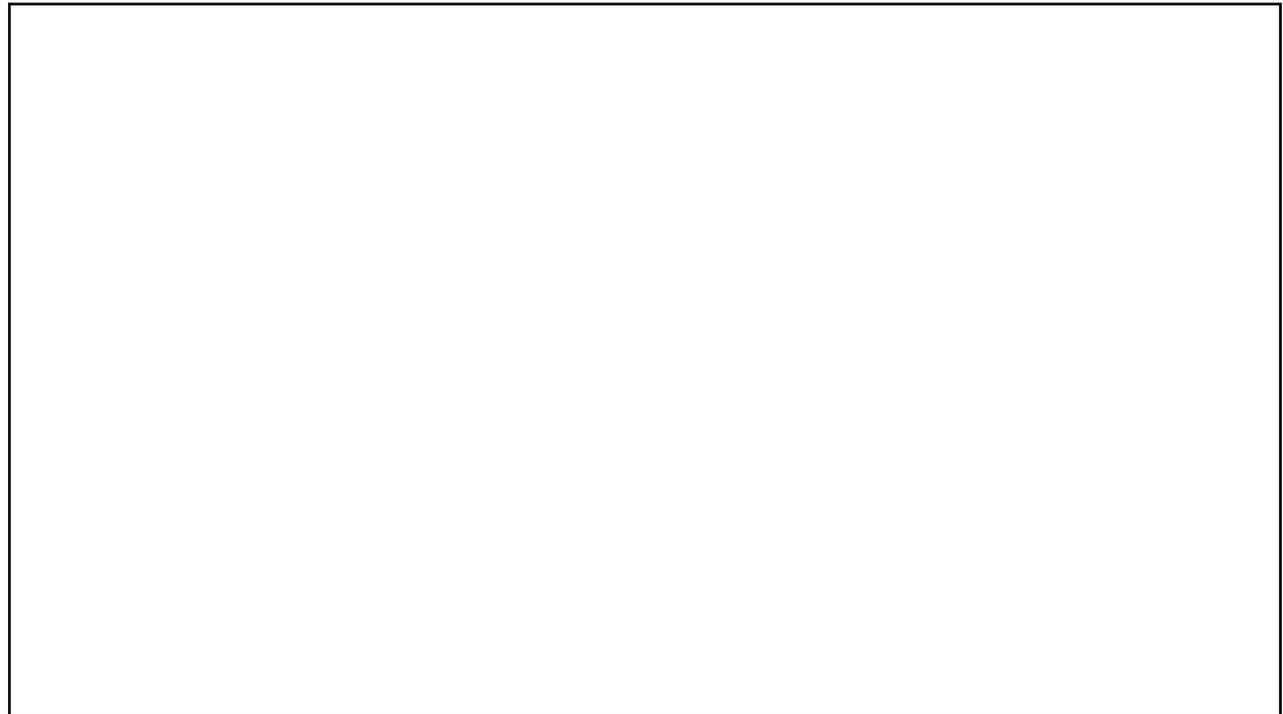
- Relatively new position, but a part of international law for many years
- Uniform Trust Act recognizes position but does not prescribe rights and duties
 - Fire and Hire Trustee
 - Consent to modifications
- Independent of Grantor/Beneficiary?
- Fiduciary/Non-fiduciary
 - Note: Under Uniform Directed Trust Act, power to hire and fire does not make trust protector a fiduciary

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Special Needs Trusts: Trust Committee

- Advocate for Beneficiary
- Right to Same Information as Child
- Can be informal role: Advise Trustee on Distributions

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