CARE MANAGERS IN SPECIAL NEEDS TRUSTS
HOW TO PROVIDE LIFE LONG ADVOCACY

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WORKING WITH FAMILIES WITH DISABLED LOVED ONES

- Benefits are important – but not often the benefits are not the top priority
- Create a flexible plan
- A successful plan will focus on collaboration

THE BIG QUESTION

- Does my disabled child needs a Special Needs Trust?
  + Could manage funds without great assistance?
  + Build flexibility to deal with changed circumstances
  + Focus on advocacy and asset protection
  + Could keeping qualification for SSI or Medicaid be a tool to assist my disabled loved one?
BROADEN THE SCOPE OF YOUR SPECIAL NEEDS TRUST

- All too many practitioners focus exclusively on preservation of public benefits in their Special Needs Trusts and miss the big picture.
- Special Needs Trust can serve as an advocacy tool with instructions about how you wish you directives to be carried out.
- The issue is – where are you going to find someone to carry out your wishes?

CARE MANAGERS FINDING PEACE OF MIND

- Professional care management has given peace of mind to many of my families.
- I have seen my beneficiaries clinically improve by incorporating a care manager into their estate plan.

CARE MANAGERS

- Professional Geriatric Care Managers are health and human services specialists who typically help families care for older relatives.
- Many Care Managers and agencies also have experience with the needs of persons with physical and psychiatric disabilities.
- The Care Manager acts as a guide and advocate – identifying problems and offering solutions, while encouraging as much independence as possible.
ED ROBERTS

Anyone can join our group at any point in life. In this way, the Disability Rights Movement doesn't discriminate.

DEFINITION OF ESTATE PLANNING

- I want to provide for myself and my loved ones during my lifetime, and upon my incapacity or death give what I have to who I want, the way I want, when I want, and if I can save every last fee, tax or court cost possible.
- From Loving Trust

EXAMPLE – MARTHA’S STORY

- Martha is 85 years old and lives with her 55 year old daughter Helen.
- Helen has a psychiatric disability and has been living with her mother for the last 30 years.
EXAMPLE – MARTHA’S STORY

• Helen is very dependent upon her mother and the her mother recently spent a week in the local hospital.
• Both mother and daughter are concerned about what would happen upon Martha’s death or incapacity.

ENGAGING CARE MANAGERS BEFORE A SPECIAL NEEDS TRUST MATURES

• All too often Special Needs Trusts are seen as death planning – but what if the parent/advocate can no longer be there?
• Have the care manager do an assessment before the trust matures
• Often identify needs
• Lets the beneficiary meet the care manager before a crisis
• Allows the parent peace of mind to see the plan in action

PUTTING A VALUE ON PUBLIC BENEFITS

• Put a value on the benefits
• Families are seeking quality of life
• Spending thousands of dollars to preserve hundreds of dollars worth of benefits doesn’t make sense.
• Many families are opting to provide services privately, rather than rely on what they consider an unstable social service system.
HIRING THE CARE MANAGER TO ASSIST WITH COMPLIANCE

- Often times it is difficult for family members to set limits or boundaries
- A care manager can work with the disabled family member and work within defined boundaries

THE MORGANS

- Robert and Mary have a 21 year old son named Larry with bipolar disorder
- Larry does well when he sees his therapist and takes his medications, but he has periods when he stops taking meds and seeing his therapist.
- When Larry stops his treatment he becomes verbally and physically abusive to his parents.

THE MORGANS

- Robert and Mary are paying Larry’s rent, but they have been unable to encourage Larry to comply with his treatment.
- Robert and Mary set up a Special Needs Trust and fund it now.
THE MORGANS

They make Fred the care manager with guidelines that
+ if Robert can demonstrate he is complying with his treatment then the trust will be liberal in distributions, and
+ if he refuses to comply the trust will pay only basic expenses.

THE MORGANS

- Initially Larry tests Fred, does not take his meds, makes abusive calls to his parents.
- Robert and Mary with great difficulty are empathetic – but tell Larry that any future expenditures must be made by Fred.
- Larry begins taking his meds and seeing his therapist.
- He is now in school and looks forward to getting a job.

WHAT ELSE CAN CARE MANAGERS DO?

SAMPLE LANGUAGE

Article Four
Advocate for John Smith

Section 4.51 Enforcement of Advocate
My Trust may employ a qualified care manager as an Advocate for the benefit of John Smith. The Advocate shall provide comprehensive care management services, including, but not limited to, medical, social, and emotional services. If John Smith is not contacted by the Advocate at least 3 times a month, then the Trustee is required to employ an Advocate. If John Smith has been institutionalized for a time greater than 30 days, then the Trustee is required to employ an Advocate.

Section 4.52 Requirements for Advocate
The Advocate shall be a Licensed Clinical Social Worker, Care Management Agency, Registered Nurse or similarly qualified professional who is familiar with the needs of people with disabilities similar to John Smith’s.

The Advocate shall be responsible for making recommendations on what extraordinary distributions should be made for needs not covered by public benefits, as well as recommendations concerning distributions otherwise covered by public benefits.
WHAT ELSE CAN CARE MANAGERS DO?  
SAMPLE LANGUAGE

WHAT ELSE CAN CARE MANAGERS DO?  
SAMPLE LANGUAGE

MODEL 1 – THE TRUSTEE DIRECTED BY A TRUST ADVISORY COMMITTEE.

- The Trustee manages funds*, makes distributions, does taxes, keeps records
- Funds invested by financial advisor
- The Trustee directed by a Trust Advisory Committee which directs distributions, can amend the trust or replace the Trustee
- Can include care manager

Special Needs Alliance
www.specialneedsalliance.com
MODEL 2 – THE TRUSTEE DIRECTED BY A CARE MANAGER.

- The Trustee manages the funds
- The Trustee can be directed by a Care Manager.
- The Care Manager interacts with the beneficiary
- The Trust Protector oversees the Trustee and Care Manager from a distance and can replace either for any reason

MODEL 3 – CO-TRUSTEES

- For smaller trusts, or trusts where the beneficiary can advocate for herself, Co-trustees with the power to seek assistance from benefit, tax and financial advisors may be adequate.

TRUST PROTECTOR

- A Trust Protector oversees how the trust is managed, without day to day involvement
- The Trust Protector reviews accountings and assessments from the care manager
- The Trust Protector may hire and fire the trustee or care manager without cause
- A Trust Protector can be a professional, family or friends.
WHERE TO FIND A CARE MANAGER

- Many Special Needs Alliance Members have Care Managers on staff
- Two websites that are very useful for finding a care manager are National Association of Professional Geriatric Care Managers (NAPGCM) at http://www.caremanager.org/ and the National Guardianship Association (NGA) at http://www.guardianship.org/.
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<th>Special Needs, Special Attorneys</th>
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<tr>
<td>Welcome to the Special Needs Alliance</td>
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<tr>
<td>The Special Needs Alliance assists individuals with disabilities and their families and the professionals who serve them by providing education, advocacy, and resources to ensure public policies and systems promote basic rights and quality of life. The Alliance is dedicated to educating, advocating, and supporting individuals with disabilities and their families.</td>
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<td><strong>Members and Services</strong></td>
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<td>SPECIAL NEEDS ALLIANCE</td>
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**The Self Helps**

Members and programs are available to support individuals with disabilities in the community.

**The Self Helps**

For Special Needs, for individuals with disabilities and their families, to improve the quality of life.

**The Self Helps**

For Special Needs, to improve the quality of life.